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The Views of Children and Young People with Learning Disabilities about the Support they Receive from Social Services: A Review of Consultations and Methods

Report of a review prepared for the DfES

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Summary

This report is intended to act as a resource for local authorities and others, to assist them in consulting young people with learning disabilities about the services they receive. It identifies some of the ethical and practical issues involved, and provides practical examples of how consultations have been carried out. It also includes a list of useful resources and websites, and an overview of findings from recent UK studies focusing on the views of disabled children and young people (including those with learning disabilities) about social services provision.

The report was commissioned by the Department for Education and Skills to complement a national survey in 2005 of children and young people aged 10-17 who were in contact with social services. It is based on a comprehensive electronic and paper literature review and discussions with key experts. This review identified a relatively small number of studies which have focused on the views of children with learning and other disabilities about social services provision. Consultation has usually centred on a particular service children were attending or receiving, such as respite care or short breaks, being looked after, transitions to adult services, and play and out-of-school experiences. Issues identified by the children and young people in these studies included:

- the importance of trusted adults who communicated directly with them;
- access to friends; and
- choice, both in day-to-day matters and in more major decision-making such as at times of transition.

The report includes detailed examples of four studies chosen to illustrate aspects of consultation. From these, it draws out key messages about the consultation process, such as:

- the importance of gaining knowledge and competence in the young person's preferred ways of communicating, and
- the need for clarity about the purpose of any consultation, and about whether it will benefit young people including those directly involved.

No single method is advocated, but a range of consultation and research tools are identified which may enable children and young people with a range of disabilities, including those who do not communicate through speech, to express their views and experiences. Resources described and referenced include those focusing on communication in general, and those designed specifically for carrying out consultations.

1. Introduction

Background to the report

During 2005, local authorities in England carried out a survey on behalf of the Department for Education and Skills (DfES) of children and young people aged 10-17 who were in contact with social services, which asked them about the care and support they received[1]. The survey did not include children with moderate or severe learning disabilities, because of the additional resources that local authorities would have had to find to include these children. The DfES recognised, however, that the views of these children are very important and that authorities should be taking them into account. The Department therefore commissioned researchers at the Thomas Coram Research Unit, Institute of Education, University of London to undertake a short study with the following objectives:

- to review the sorts of consultations that have been carried out so far with learning disabled young people, particularly about the support they receive from social services;

- to consider ethical and practical issues relating to consulting with young people with learning disabilities;

- to study the variety of methods which have been used in such consultations and to consider what has worked well and how any problems could be addressed;

- to produce practical guidelines to assist those carrying out consultations with learning disabled young people about the services they receive.

The basis of the report is a comprehensive electronic and paper literature review and consultation with key experts. The review covered UK-based research and consultations involving children with disabilities, including learning disabilities, from 1995. Keywords used in the search for relevant sources were: consultation, listening, talking, researching, children, young people, disabled or disabilities, learning difficulties and disabilities, intellectual and communication impairments. The databases searched were British Education Index, Education Resources Information Center, Economic and Social Research Council database of research reports, International Bibliography of the Social Sciences and Social Services Abstracts, together with hand searches at the libraries of Institute of Education, University of London Senate House and the National Children's Bureau. It is acknowledged that some schools and organisations working with young people with learning disabilities carry out their own consultations. It has not been possible to include the resulting grey (unpublished) literature from such work in the review. The review was, however, supplemented by telephone conversations with twelve academics and practitioners, all experienced in communicating and working with disabled people. A list of the individuals and organisations consulted for the purpose of this report is given in Appendix C.

Defining key terms

In using the term 'disability', we refer to 'the following aspects of functioning: mobility, hand function, personal care, continence, communication, learning, hearing, vision, behaviour and consciousness'[2]. Children and young people with disability are a very diverse group, including some who are multiply disabled.

The term 'children and young people with learning disabilities' is used here to include children and young people with moderate or severe learning disabilities, some of whom use forms of communication other than speech.

We have used the terms 'learning disabilities' and 'learning disabled' rather than 'learning difficulties' because of their familiarity to those working in social services settings. The latter term

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[1] DfES, 2005
[2] DfES, 2003 p7

frequently refers to children who have some problem in learning in the classroom, which may not extend to their out-of-school lives.

Throughout this report, we use the terms consultation and research interchangeably, and refer to the person involved in face-to-face consultation with children as 'the researcher'. We also use the expressions 'young people' and 'children' interchangeably. The age range covered by this review is from ten to eighteen years-old.

Why consult young people with learning disabilities?
The last two decades have witnessed greater recognition, by government, of the importance of consulting children and young people, including disabled young people, about their views. Examples of this include the Gillick ruling of 1984 advocating that children should be consulted about decisions which affect their lives, the United Nations Convention on the Rights of the Child[3] and the Children Act 1989[4], and more recently the Every Child Matters programme[5] and the National Service Framework for Children[6]. All stress the importance of seeking and taking into account children's views.

Consulting disabled children about service use and support is important because this diverse group are more often subject to assessments and medical interventions than other children[7]. Disabled children are also significantly more vulnerable to abuse than non-disabled children[8]. Some commentators emphasise in particular the 'double jeopardy' of disabled children living away from home[9]. It is for this reason that Government guidelines on planning services in partnership with parents and children stress that:

> Even children with severe learning disabilities or very limited expressive language can communicate preference if they are asked in the right way by people who understand their needs and have the relevant skills to listen.[10]

Yet, there is evidence that within social services departments, the participation of disabled young people is still patchy and their involvement at a higher strategic level remains rare[11].

The 'questionable' reliability and validity of information obtained from learning disabled young people, and the competence of children and young people in general is sometimes cited as a reason for failing to consult them[12]. However, research indicates that an important starting point in consulting with young people is to assume that all children and young people, regardless of their level of communication and/or cognitive impairment, have their own perspective to communicate. The responsibility rests with those carrying out consultations to find appropriate methods of understanding their views and experiences[13].

There is now a considerable number of examples of consultations with young people with learning disabilities about the support or services they are receiving. We draw on these for our consideration of ethical and practical issues and for the more detailed illustrations of consultations and research which then follow.

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[3] United Nations, 1989
[4] DH, 1989
[5] HM Treasury, 2003
[6] DH, 2004
[7] Dickens, 2004.
[8] Marchant and Page, 1993; NSPCC, 2003.
[9] Morris, 1995, 1998a, 1998b; Marchant and Page, 1993; Westcott, 1993.
[10] DH, 1991, p.14
[11] Franklin and Sloper, 2004; Cavet and Sloper, 2004; Morris, 2003, p. 346.
[12] Beresford, 1997
[13] Morris, 2003; Ware, 2004.

2. Ethical and practical considerations

Consultation and research always give rise to ethical considerations. These should be borne in mind throughout the consultation process. A record should be kept of these matters and how they have been addressed. Guidance on ethical issues can be obtained from a large body of literature that discusses issues to be aware of in consulting children and young people, including those with learning disabilities[14]. We summarise some of the main concerns below.

Research should be of clear benefit to children and young people
It is important to be clear about the aims and objectives of a consultation with young people and of its value. Before embarking on a consultation with disabled children and young people, those responsible should establish its potential value. They should be clear as to how the consultation's findings may be used for the direct or indirect benefit of the young people concerned, or for others in similar circumstances. They should be equally clear that the process and the outcomes of the consultation could not harm the child in any way and involve no greater than minimal risk.[15]

Informed consent
It is very important that those involved in consulting children obtain the children's own informed consent to their participation in the research. Those carrying out research and consultations need to identify the most appropriate methods for informing children and young people about what is involved in the research. This is a prerequisite for requesting their consent to participate. Information about the research should be of a type that the young person understands, whether communicated by word of mouth, by signing, and/or by producing age-appropriate printed or Braille leaflets. Many children use symbol packages such as Makaton and Boardmaker at school. It is important for those carrying out the consultation to ask the child's parent, teacher or carer to advise on how the child best communicates. The parent, teacher or carer may also be turned to for any clarification needed and for assistance in interpreting how the child feels about being consulted[16]. In such cases, it should be explained to the parent, teacher or carer that the child should not be 'over-persuaded' to take part: the consent given must be genuinely that of the child.

The researcher needs to get to know the young person, spending time with them and just 'being there'.[17] This is necessary not only as a basis for the consultation process itself, but also in order to ascertain if the child is willing to participate in the research. Obtaining consent should be seen as on-going throughout the consultation process.[18] A young person may change their mind although they may not say so, explicitly. Sometimes children begin a consultation activity by being quite happy to participate but later become restless or disturbed. Many children will feel reluctant to tell the adult they do not want to answer a question or to continue participating. One way to help them do this is to rehearse stopping the session before the consultation or interview starts. A 'traffic light' system can also be used, whereby a child will give the researcher a yellow card if s/he does not want to answer a question or a red one if s/he wants to end the session altogether. In addition, the person conducting the research needs to get to know how the young person expresses themselves (for example, through body language and behaviour), and, therefore, whether they are willing to continue with a session, whether there should be a short break or if the researcher should return on another occasion.

Being able to give informed consent to research participation is a potentially problematic issue when consulting young people with severe learning disabilities and/or communication impairments[19]. Despite the complexities, young people should be included in research or

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[14] For example: Beresford, 1997; Ward, 1997; Morris, 1998a; Alderson, 1995; Morrow and Richards, 1996; Stalker, 1998; Detheridge, 2000; Lewis, 2002; Alderson and Morrow, 2004; Lewis and Porter, 2004; Lewis and Kellett, 2004; Ware, 2004

[15] Lewis and Porter, 2004

[16] Lewis, 2002

[17] Morris, 2003

[18] Marchant et al, 1999a; Lewis and Porter, 2004

[19] Dye et al, 2004; Detheridge, 2000

consultation only with their express agreement. The consent of a parent or carer, while necessary, should not be seen as a sufficient basis for including a young person in a consultation.

Empowering young people
In carrying out a consultation, the researcher should be aware of inequalities and power relations between the disabled young person and the person carrying out the consultation. Steps should be taken to minimise the possibility of the consultation exploiting the young people, and to allow young people to have 'ownership' of the consultation activity.

Those planning and conducting the consultation should do everything possible to make it into a positive experience for the participants. Any questions asked should be meaningful for the children and young people. The researcher should adopt an encouraging and supportive style.[20] Many disabled children and young people are not used to being asked for their views, and may not think that their views are important.[21] Some people with learning disabilities may have a tendency to acquiesce to the suggestions of others, because they are so used to being controlled by others.[22]

One way of empowering young people within the consultation process it to involve them in the design of a consultation, individually or as a member of an advisory group (see below). Another is to ensure there is appropriate feedback to children of the results of a consultation, including any outcomes. Even if no outcomes result from the consultation, children should be told this and why this should be so[23]. Children who have been consulted should be told something about what other children have said. Because timescales for change may be lengthy, it is important that researchers give timely feedback about the consultation, rather than waiting for any changes to be achieved. It is important to identify, in advance, such ways of helping young people feel empowered and valued by a consultation, and with some sense of ownership of it.

Confidentiality
Privacy, anonymity and confidentiality are crucial but can be problematic in consultation work, since they need to be balanced with child protection concerns. Disclosures of allegations need to be acted upon appropriately.

Issues of confidentiality and data protection apply equally when consulting disabled children as when consulting with adults. A child and their parent/carer should be assured that what is communicated in the course of research will remain confidential to the researcher and their immediate colleagues. But, because children and young people with learning disabilities may be more vulnerable to abuse,[24] the need for confidentiality and privacy sometimes has to be weighed against child protection issues.[25] Researchers need to have strict procedures in place to ensure that if a young person makes any allegations of abuse by carers or others, these are acted upon appropriately. [26] [27]

Gaining access
Gaining access to disabled children for the purposes of research often involves approaching and gaining permission from one or more third parties, such as a parent, a carer, a teacher or a social worker. These third parties are often referred to as 'gatekeepers'. They can either facilitate, or in some cases block, preliminary access to a child, prior to gaining the child's consent.

Researchers should emphasise to gatekeepers the desirability of including in a consultation all those young people who have been identified as potential participants. This applies particularly to those with severe and profound disabilities, to whom a gatekeeper may be more reluctant to allow

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[20] Lewis and Porter, 2004

[21] Lewis and Porter, 2004

[22] Stalker, 1998

[23] Lightfoot and Sloper, 2003

[24] Marchant and Page, 1993; Morris, 1998b

[25] Lewis, 2002; Lewis and Porter, 2004

[26] Smith, 1999

[27] Jones, 2003

the researcher access[28]. Gatekeepers should be fully informed about the consultation and be assured that young people can make a worthwhile contribution to it, and methods should be adapted accordingly.

A variety of factors can lead to gatekeepers being reluctant for children to participate in research. These may include a lack of understanding of its purpose and what is involved, a wish to protect the child and perhaps most commonly, an attitude that young people with severe learning disabilities and communication impairments cannot, validly, be consulted.[29] Where such young people are to be included, there should be a specific focus on them in the consultation. The researcher should be aware of why it is important to include them and be prepared to adapt consultation methods to suit the requirements of individual children.[30] These matters should be covered in information provided about the project. The researcher should inform gatekeepers as fully as possible about the consultation and its potential value, in writing, but also in conversation. They should also allow sufficient time to discuss any concerns the gatekeeper might raise.

Awareness of physical needs and environment
It is important for the researcher to remain alert to the physical needs of the children or young people engaged in the consultation. This may include making refreshments available during the activity (having checked with parents or carers about any special dietary requirements). Similarly, arrangements for toilet breaks need to be considered. The physical environment should be one in which the children feel comfortable, and one in which the adults have paid attention to noise levels and temperature.

3. Some methods and resources for consulting young people

Consulting children and young people about their lives can be a complex task. Difficulties may be magnified if the children and young people concerned have a learning disability and particularly if they also have a communication impairment. Recognition of the differences between disabled children suggests that small-scale interpretative approaches are likely to be of particular value.[31]

There is no single method which will 'work' with all children. It is more a question of equipping practitioners with a range of tools which may be adapted to support communication with individual children or groups of children. Before beginning a consultation with a child, it is crucially important for the researcher to get to know about the child's behaviour and preferred methods of communication. This usually entails spending time with them[32] and speaking to people who know them well.[33] Because of this, it may be better to think of consultation as an ongoing process, rather than as a one-off event [34].

Involving a third party
It may also be valuable to involve people such as carers, teachers or parents in interpreting a child's responses during the consultation process, although this may pose problems[35]. For example, some writers advise that consultations should not be carried out in the presence of parents or other interested parties (such as staff directly involved with the services that may be being evaluated)[36]. This is because such people may have a vested interest in offering certain types of information. Also, young people may be inhibited in their presence, or feel pressurised into giving answers of which they would approve.

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[28] Stalker,1998, p. 8
[29] Davis et al, 2000 p.209
[30] Morris, 2003
[31] Detheridge, 2000
[32] See, for example, Davis, Watson and Cunningham Burley, 2000
[33] Stalker, 1998
[34] Brewster 2004, p. 169
[35] Beresford, 1997; Ward, 1997; Russell, 1998
[36] Marchant et al, 1999a

Using everyday communication
Methods for consulting with children with learning disabilities need to take into account, at an individual level, the modes of communication the children are most familiar with in daily life. This may include speech as well as Augmentative and Alternative Communication (AAC), ranging from the use of sign language to high technology communication aids. This may mean, for example, that some children may be more able to express their views and experiences through a computer programme than through a traditional interview.

We consider next a number of specific methods and strategies which have been used to gather the views and experiences of children with learning disabilities about the services they receive. In some cases this has included social services provision.

In My Shoes
This package takes the form of a computer-assisted interview[37]. It has been developed to help children communicate about their lives, including about distressing circumstances. The purpose may include interviewing children where there are child protection concerns but is not limited to this application. The interviews use images, sound, speech and video. Three-way interaction is established between the child, the computer and the supporting adult. The exact format of the interviews can be tailored to the individual interests and priorities of the children concerned. The package allows detailed records of individual sessions to be kept. Current work includes developing this approach with children with autism. *In my Shoes* has also been adapted to be used with adults with learning disabilities. It has been used by a range of professionals including social workers, psychologists, health workers and those from forensic services (for further details of training see Appendix B).

Talking Mats
This research tool was devised to enable people with cerebral palsy and communication difficulties to express their views and choices.[38] Participants position graphic symbols around a 'mat' or board and participants' own photographs may be used.[39] [40] The activity is intended to facilitate 'conversation' and participants can dictate the pace of the exchanges.[41] Talking mats have also been used in a variety of contexts including with young adults with learning and/or communication disabilities[42] (see Appendix A for an example). Two of the contexts covered have been life transitions,[43] and out-of-school activities.[44]

Mosaic approach
This multi-method strength-based approach was originally developed to enable young children under five years-old to express their views about their nurseries.[45] The underlying principle is that children are 'experts in their own lives'. [46] The approach has been used in a study involving children with autistic spectrum disorders about social care and support services[47] and in an evaluation of a holiday scheme with children with disabilities.[48] A range of visual and verbal methods are brought together to enable children to take an active role in expressing their views and experiences about their everyday lives. This includes the use of photographs taken by the

[37] Calam, Cox, Glasgow, Jimmieson, Groth Larsen, 2000

[38] Murphy, 1998
[39] Germain, 2004
[40] Brewster, 2004
[41] Cameron and Murphy, 2002, p. 111
[42] Rabiee, Sloper and Beresford, 2005
[43] Cameron and Murphy, 2002
[44] Germain, 2004
[45] Clark and Moss, 2001; Clark and Moss, 2005; Clark, 2004
[46] Langsted, 1994
[47] Beresford, Tozer, Rabiee and Sloper, 2004
[48] Bryson, 2004

children (a technique also reported in a study of mothers with learning disabilities[49]). Other tools used in the Mosaic approach include a child-led tour of the provision, map making and informal interviews. These activities are used as the basis for conversations between children and adults, based on the new understandings revealed.

Consultative groups

Consultative groups offer an alternative strategy for listening to the views and experiences of children with disabilities. Three such groups have been developed with children with disabilities including severely learning disabled children by the independent organisation Triangle.[50] These consultative groups involve children and young people aged from three to twenty four years-old, who communicate through spoken language, sign, symbol, or more directly through their behaviour. There are usually about fourteen children at each session with six adults to facilitate the process. Methods used include discussion and play, art-based activities and voting. Some sessions include visits to other settings. Recent issues discussed include 'what makes a good social worker?' and 'how should doctors tell children about painful procedures?'.

Facilitated communication

Consultation with children with learning disabilities needs to remain sensitive to children's existing methods of communication. This may include 'facilitated communication', an alternative communication technique which relies on the role of a facilitator.[51] Using this approach, the facilitator places her hand over the hand of the child and supports the child's hand, arm or wrist above a keyboard or board displaying words, letters or images. The intention is to assist the child in the physical act of making a selection without influencing the selection. This method of communication has attracted considerable controversy[52] because of the difficulty of establishing if the child is being supported or led to making a choice.[52] Despite divided professional opinion about this means of communication, it may enable children to take a direct part in a consultation in which they would otherwise only be able to play a passive role.[53]

4. Examples of consultations and research about the support that disabled young people receive from social services

There have been relatively few studies which have reported the views of disabled children or young people (particularly those with learning disabilities) about social services provision. Those identified for this review address either social care services in general or, more commonly, a particular service such as respite care/short breaks, the experience of being looked after, transitions to adult services or play and out-of-school experiences.

Social care services

Several consultations have been carried out with disabled children about social care services in general. The Audit Commission's 2003 review of services for disabled children and their families, for example, included consultations with disabled children and young people carried out by the independent organisation, Triangle, and the Thomas Coram Research Unit at the Institute of Education, University of London[54]. Methods included using a variety of 'trigger' materials (such as poster and 'graffiti' sessions, or providing a disposable camera to photograph favourite and least favourite activities) to stimulate both group discussion and conversation with individuals.

More recently, researchers at the Norah Fry Research Centre at the University of Bristol have consulted 18 disabled children and young people with complex care needs to assess the impact of

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[49] Booth and Booth, 2003
[50] See Appendix B for contact details for Triangle
[51] Biklen and Schubert, 1991
[52] Mostert, 2001
[53] For example see Connors and Stalker, 2003
[54] Audit Commission, 2003

multi-agency working on the children's lives, their families and professionals[55] (see Appendix A Example 1 for details).

The Sharing Value Project [56] conducted by researchers at the Social Policy Research Unit of the University of York in collaboration with Barnados and the Family Fund Trust, consulted disabled children for their views about the quality of services that they are in contact with. Meetings with disabled children and young people made good use of a variety of methods, such as children posting positive service attributes into a gold box decorated with a smiley face, and negative attributes into a dull brown box with a picture of a sad face.

A consultation of disabled children about social care services in general, was carried out in Wales by Barnardos, Children First and NCH[57]. This consultation involved 105 disabled children and young people aged 5 to 25 including some who had multiple disabilities and complex needs. A variety of both traditional and more creative and flexible methods were used to consult the children and young people, including individual and group interviews, ranking exercises and 'draw-and-write' methods. The main messages from the consultation centred on the following: the attitudes and behaviour of staff; the availability of information about children's disabilities and about services; access to and availability of services (including the availability of transport and other support); and the levels of participation of disabled young people in decision-making.

Respite care or short breaks

There have been a number of consultations carried out with disabled children and young people about their experiences of short breaks (respite care), including short-term residential care.[58] The independent organisation, Triangle, has carried out a number of these consultations, such as a study of 30 learning disabled young people using three different residential care services in Kent [59] and a consultation with 26 disabled young people about a residential respite care service run by East Sussex[60]. Young people generally said they wanted more choices about what they did while they were staying at the residential unit. Other studies carried out with disabled children and young people about short breaks have included an investigation of six residential respite care services involving interviews with 77 disabled children and young people [61] and a study of children on the autistic spectrum about their experience of short-term residential care [62] (see Appendix A Example 3 for details).

Experiences of living away from home

The views of disabled young people who are being looked after by social services in settings such as residential units and schools and foster care have been elicited in a number of studies[63]. These consultations have included finding out about young people's general experience of being away from home, their relationships with their families, peers and professionals, and levels of involvement in decision-making in matters affecting their everyday lives.

Experiences of the transition to adult services

One of the themes covered in consultations with disabled young people concerns their experiences of the transition process to adult services.[64] Overall, findings from these studies suggest that provision that is specifically geared to transition to adulthood is rather patchy. One study which involved 27 young people with learning disabilities and their parents, as well as a wider survey of 283 families, showed that the quality of transition planning varied widely. In some cases it was ad hoc and uncoordinated. Almost half of the young people had little or no

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[55] Townsley et al, 2004; Abbott et al, 2005
[56] See Mitchell and Sloper, 2001.
[57] Turner 2003.
[58] Minkes et al, 1994; Marchant et al, 1999a; Marchant et al, 1999b; Crisp et al, 2000; Preece, 2002; Prewett, 1999
[59] Crisp et al 2000
[60] Marchant et al., 1999b
[61] Minkes et al., 1994
[62] Preece, 2002
[63] Morris, 1995, 1998b,1998c; Knight, 1998
[64] eg. see Morris, 1999a, 1999b, 2002; Heslop et al., 2002; Ward et al.,2003 reviewed by Beresford, 2004

involvement in planning for their future, and lack of planning led to uncertainty and stress for some families[65].

Experiences of play and other out-of-school services
An evaluation of the Hadrian School Play Scheme was carried out in 2004 by the Children's Society.[66] Using the Mosaic Approach,[67] six children and young people between the ages of six and 15 were consulted. The children emphasised the importance of having access to the outdoors in all weathers and the ability to choose which members of staff to work with. Some studies focusing on out-of-school services for children have included disabled children. In one such study,[68] ethnographic methods were used to help the researchers understand the perspectives of children with more severe learning disabilities. This involved getting to know the children at home and in their play schemes, observing their behaviour and their expressions of emotion. It appeared that the play services were appreciated by the children. In another study, conversational interviews with disabled and non-disabled children explored their appreciation of inclusive play services.[69] A more recent study asked nearly 100 children and young people, many of whom had learning disabilities, about their experiences of the school holidays and any out-of-school services which they use. Again a variety of methods were used.[70]

Common issues identified by disabled children and young people in many of the studies described above include: the importance of trusted adults who communicate directly with them; access to friends; and choice, both in day-to-day matters and in more major decision-making such as at times of transition.

5. Conclusions

This review has outlined a number of methods and strategies for gathering the views and experiences of children with learning disabilities. Work in this area is still at an exploratory stage and more research and evaluation to establish which methods are most effective is needed. The review has pointed to some of the ethical considerations involved and the principles that need to underpin such consultations. It has stressed that the process of consulting young people should be positive and empowering not exploitative, and noted the importance of clarity about the purpose of any consultation and about whether it will benefit young people.

Common themes identified in the review include the need to prepare thoroughly for the consultation process, to be flexible and sensitive to different age groups, the individual strengths and needs of the children involved and to make the best use of children's preferred ways of communicating and the contexts in which they are most comfortable.

Above all, consulting children about their views and experiences must be based on effective communication skills. These include demonstrating interest and attentiveness, respect and patience. There are methods and technical resources which can facilitate consultations but there are few substitutes for spending time with children and finding out how they choose to express themselves.

We conclude with the following message from a disabled child with a communication impairment, which highlights how experience, time and commitment are required in order to consult disabled children and young people.

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[65] Heslop et al., 2002
[66] Bryson, 2004
[67] Clark and Moss, 2001
[68] Petrie et al.,2000
[69] Petrie et al, 2002
[70] Petrie et al., in preparation

We are used to people saying we cannot communicate, but of course, they are wrong. In fact we have powerful and effective ways of communicating and we usually have many ways to let you know what it is we have in mind. Yes we have communication difficulties, and some of those are linked with impairments. But by far the greater part of our difficulty is caused by 'speaking people' not having the experience, time or commitment to try to understand us or include us in everyday life[71].

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[71] Disabled People using Scope Services (2002:1-2 quoted in Rabiee, Sloper and Beresford, 2005)

Appendix A: Four examples of consultation with children with learning disabilities

The following examples have been chosen to illustrate different aspects of the process of consultation with children and young people across a range of disabilities including learning disabilities. The descriptions highlight issues of ethics and methods, and draw attention to lessons learned about effective consultation.

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1. The impact of multi-agency working on disabled children with complex health care needs, their families and the professionals who support them. [72]

The Consultation
This three year research study was carried out by a team of researchers from the Norah Fry Research Centre, University of Bristol and the Family Fund. The study investigated the impact of multi-agency working from the perspectives of the professionals involved, the families and the children and young people. Eighteen children from two to fifteen years-old were visited, each with complex health care needs including communication impairments. Ten of the children and young people had no verbal communication, some of whom used signs, three had limited verbal communication supported by signs and five used limited verbal communication. All of the children were dependent on medical technology, including seventeen who were tube-fed.

Methods
The study used a mixed-methods approach tailored to the communication strengths of the individual child. A detailed picture was assembled of the children involved including their views and experiences of having many different professionals involved in their lives. Visits took place in the children's homes and lasted about an hour. The visits were informal.
Researchers used a topic guide as a basis for the conversations. The guide covered: things I like, things I don't like; who lives at home with me; school; friends; adults who help me; short breaks; things that are difficult to do and general happiness.
Drawing was used as a tool to support the conversations in some cases, either by the child drawing on large sheets of paper or the researcher documenting the conversation.

Ethics
Children and young people were sent a pictorial leaflet/consent form to explain about the research and to seek consent. This contained a photograph of the researcher who would visit. A parent or carer was also present during most interviews to act as an interpreter or proxy during the session (2004: 61).

Main findings
The children reported how they coped well, in general, with relating to the many professionals in their lives. These relationships were stronger with those professionals who made an effort to communicate directly with the children. Several of the children did not know who their key worker was. The children's aspirations were similar to other children of their own age: the desire for friends, opportunities to interact with their contemporaries and to be treated with respect and dignity.

Lessons learned about the consultation process
The leaflet and consent form proved to be a successful way of recruiting children and young people to the project. It was valuable to talk to parents and key workers in order to find out about each child's communication needs in preparation for the visit. Researchers needed to be flexible and sensitive to each child's feelings, reactions and preferred ways of communicating.

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[72] Townsley, Abbot and Watson, 2004

2. Outcomes of social care and support services study: children with communication impairments.[73] [74]

The study
A team of researchers at the Social Policy Research Unit, University of York undertook a four-year research and development study, funded by the Department of Health, to identify the priorities and perceptions of disabled children and young people (birth to 18 years) and their families about outcomes of social care and support services. The study worked with four groups of children with disabilities who were described as 'difficult to reach' by service providers. They included children with complex health care needs, communication impairment, autistic spectrum disorders or degenerative conditions.

Methods
The methods described here relate to the research methods used with children who did not use speech to communicate, some of whom had cognitive impairments. Eighteen children took part in the interviews, eleven of whom had complex health needs and seven who did not use speech to communicate. This second group of children were aged between six and eighteen. The majority of children had a number of different impairments including cognitive and physical impairments. This study developed a research tool based on the principles of Talking Mats. This tool was used with the seven children who did not use speech. Each child was given a mat with their name on it. The children were asked to choose from three options which statement they agreed with (reflecting positive, negative or ambivalent views). These statements could then be stuck onto their mat to build up a picture of their lives. The interviews took between forty five minutes and one hour and fifteen minutes. Children used a combination of methods to communicate their views using the tool together with their preferred ways of communication including signing and communication aids.

Ethics
The researchers aimed to ensure that the consultation was a non-threatening and enjoyable experience for the children and, in keeping with the principle of inclusivity, used a flexible approach which could be adapted to the different cognitive and communication abilities of the children. The children were interviewed on their own unless it was considered useful to have someone present who knew the child well to facilitate communication or to provide support. The child's assent was always obtained in those cases. Interviews took place at venues recommended as most appropriate by the parent or carer. These were the home, in a school or a respite care setting.

Main findings
The children in the study conveyed similar aspirations to non-disabled children including the desire to have friends, interests and future independence. This raises questions about how services including social services define and measure outcomes for children with disabilities and the role services can play in helping them to achieve these outcomes.

Lessons learned about the consultation process
The statements which formed the basis of the interaction with the children needed careful preparation. A preliminary task was to identify what areas of the children's lives needed to be covered in the statements. This fine-tuning of the themes to the children's experiences helped to make the subject of 'outcomes' less abstract. There were times when despite the researchers efforts to ease communication, children were reluctant to take part. This was responded to by

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[73] Parvaneh, Sloper and Beresford, 2005
[74] Rabiee, Sloper and Beresford, 2005

providing the children with frequent breaks, staying for a longer time with the child or where possible repeating visits.

3. Consultation with children with autistic spectrum disorders about their experience of short-term residential care. [75]

The study
The consultation was carried out with three children who attended a six-bed, short-term care unit for children with autistic spectrum disorders.

Methods
Teachers carried out the consultation as they were not directly involved in the services, but knew the children well. Two of the children had some speech but also used other communication methods, such as photographs, picture symbols and objects of reference. One child had no speech and found interaction very stressful. His communication was very restricted, mostly comprising motoric gestures. The structured consultation process was individually designed for each child in the classroom. For the child with no speech, described above, the most appropriate method was 'being there' and using observations. The children were observed in the classroom and short-term settings before the consultation. Two of the children participated in structured interviews. The other was only observed under the headings: 'consultation and involvement', 'activities', 'quality of care' and 'enjoyment'. Semi-structured interviews were also carried out with teachers, residential staff and documentary evidence such as the children's files were examined. The information gathered using the different methods was brought together and compared, a research technique known as 'triangulation.'

Ethics
Consent was obtained from parents and agencies to consult the children. The children's willingness to participate was ascertained before each session by the teacher. Consent was seen as a continuous process and not a one-off agreement. It was accepted that a session would stop when the children wanted it to or if it was clear that the process was causing distress.

Main findings
Although the size of the sample was small, the consultation provided an insight into the children's experience. The consultation illustrated the importance of consistency for the children of the approach provided across environments, which enabled them to have a more positive experience of short-term care. Observations of one child showed that the staff's knowledge of the child, the staffing levels and the demands of other children were critical to his experience of the service.

Lessons learned about the consultation process
The characteristics of autism impacted on the consultation process, such as the children's social anxiety and poor memory. The children were calmer and more secure with known adults; they found open questions and choice difficult. Using visual methods, such as photographs and symbols, strengthened the communication. Carrying out the consultations shortly after the child had attended the residential unit was helpful in minimising the effects of poor memory, and having prior knowledge of the children was important. This made it easier to understand the children's individual ways of communicating and minimised social discomfort. The process highlighted the importance of using a mixed methods approach to data collection, and the triangulation of information from different sources. It was also important that consultation addressed and was relevant to the children's direct experience. For example, questions about playmates and friends proved particularly problematic due to the children's social anxiety, as did questions about similarities and differences between the short-term unit and their own homes. It was necessary and important to individualise the consultation process and to use a range of consultation methods suitable for each individual child.

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[75] Preece, 2002

4. Consultation with a group of learning disabled young people about a residential respite care service, 'Dorset Road', by an independent organisation [76]

The study
A consultation was commissioned by East Sussex Social Services Department to focus on the views of learning disabled children and young people about their use of a residential respite care service. An independent organisation, Triangle, was commissioned to carry out this consultation. Twenty six young people between nine and nineteen years-old took part each with moderate or severe learning disabilities. The young people communicated their views about the residential services of Dorset Road in a variety of ways. Eleven of the participants used little or no speech during the consultation although some used one or more Makaton signs during the visit. Two used neither speech nor Makaton. The consultation took place within a tight timescale of three weeks.

Methods
Triangle selected a consultation team of 'visitors' chosen for their skills in communication and their commitment to children's rights. Each attended a training and orientation session. There were two components to the consultation: individual 'visits', conversations held in the young person's own home or, occasionally, during trips to a local café or youth club. Each of the young people was visited up to three times. A handbook was provided for the visitors to provide guidelines for the visits. Parents were present during at least part of most visits.

Twelve of the young people were then invited to take part in two group sessions. The location was selected by the young people and their families in consultation with the visitor. The aim of the group sessions was to give the young people more opportunities to express their views about Dorset Road. After introductory games, the young people took part in group and paired activities to reflect on their experiences. Some activities used visual prompts such as photographs taken of staff members, rooms and objects within the building.

Ethics
Parents first gave consent for the young people to be involved. This was followed by seeking informed consent from the young people themselves. A leaflet was designed to help in this process, but this was only part of an ongoing process of seeking consent at each stage of the consultation. The research findings were presented to the young people in a specially-designed report[77]. This was seen as essential to the ethical underpinnings of the consultation.

Main findings
The young people indicated that being with friends was one of the important features of staying at 'Dorset Road'. There were positive comments about most of the staff, but not all. Night time routines were discussed including suggestions from the young people as to how improvements could be made. The young people described how they would like more independence during their stay. Other suggestions included changes to the building and to the transport used to take them to the setting.

Lessons learned about the consultation process
The consultation benefited from the shared experience of the team of visitors who had previous knowledge of involving learning disabled young people. The importance of using an independent organisation to carry out the consultation was commented on by some parents and young people. The combination of visits and groupwork produced a more detailed impression of the young people's lives at Dorset Road than if consultations with individuals or groupwork had been the sole method involved. This suggests there are advantages to adopting a mixed method approach for such consultations even when the time available is limited.

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[76] Marchant et al.,,1999a.
[77] Marchant et al., 1999b.

Appendix B: Some useful resources and websites

There are several important web sites with lists of resources for communicating with children with disabilities, including learning disabilities, together with specific resources for carrying out consultations. Essential reading is the information concerning involving children available from the Integrated Children's System website at the link below. This includes a section on involving disabled children which was compiled by the Council for Disabled Children and Triangle in1992:

http://www.everychildmatters.gov.uk/socialcare/integratedchildrenssystem/resources/

The information below provides examples of the range of support which is available. This includes resources which focus on supporting communication in general, and others which have been developed specificallyn to use in consultations.

A Lot to Say
Jenny Morris (2002) London: Scope. ISBN: 094682842360
This booklet offers guidance on how to communicate with young people with communication impairments. It is written for those without specialist training in this area such as social workers and personal advisors. The insights given are informed by interviews with young people.
Available online from Scope: **http://www.scope.org.uk/publications**

I'll go First
Lucy Kirkbride (1999) London: Children's Society. ISBN: 189978313X
This is a planning and review tool kit, published by the Children's Society. It is designed for use in decision-making with children with disabilities in a range of contexts including short-term foster care, family-based short-term care, residential children's centres and educational settings. The pack includes guidelines for involving children with learning disabilities. There are a series of boards and stickers to promote communication about children's feelings about their experiences.
Available from The Children's Society, Edward Rudolf House, Margery Street, LondonWC1X 0JL. Tel. 0845 300 1128 **http://www.the-childrens-society.org.uk**

Communication Passports
Communication Passports are designed to give a concise overview of individuals with sensory and communication disabilities who do not use speech. The information could be used as a starting point for introducing a new practitioner to the necessary details to aid communication with a young person or adult with learning disabilities. Further details from the CALL centre, University of Edinburgh, Paterson's Land, Holyrood Road, Edinburgh EH8 8AQ Tel.: 0131 651 6236 **http://www.callcentrescotland.org.uk**

Communicating with vulnerable children
David Jones (2003).London: Gaskell Publishing. ISBN: 1901242919
This book, commissioned by the Department of Health, sets the subject of communicating with children with disabilities within a broader context of vulnerable children. It is designed as a practical resource book for practitioners across a range of disciplines including social work and health. Chapter Five focuses on the influence of diversity and difference on communication, and includes specific advice for communicating with children with a range of physical and cognitive disabilities.

In My Shoes
This computer-assisted interview package is referred to in section three of this report on methods. Three-way interaction is established between the child, the computer and the supporting adult. The exact format of the interviews can be tailored to the individual interests and priorities of the children concerned. It has been used by a range of professionals including social workers, psychologists, health workers and those from forensic services Further details of this package and training opportunities are available by contacting Liza Bingley Miller, email **liza.miller@ntlworld.com** or write to: Child and Family Training Services, PO Box 4205, London W1A 6YD. Tel.: 01904 634417

SEN Tool Kit
This set of guidelines produced by DfES (2003) is designed primarily for schools and LEAs to implement the Special Educational Needs Code of Practice. The section on children's participation includes an examination of the principles of involving children in decision-making and suggests steps for including children with disabilities, including those with learning disabilities. The Tool kit is available to download from the Teachernet website:
http://www.teachernet.gov.uk/wholeschool/sen/teacherlearningassistant/

'How to Ask Us' learning pack
Bill Badham (2005) London: Children's Society.
This is the third in a series of CD-Roms based on multi-media methods for consulting children and young people with disabilities, including those who do not use speech. The accessible format is adaptable for using with practitioners and young people. The third CD-Rom includes a learning pack which explains the process of consulting children during the making of these consultation materials.
Available from The Children's Society, Edward Rudolf House, Margery Street, London WC1X 0JL. Tel. 0845 300 1128 **http://www.the-childrens-society.org.uk**

All Join In
This video/DVD looks at inclusion and difference. The participants are members of one of the Triangle consultative groups, a diverse group of children who at the time of filming were between three and seven. The video was made in conjunction with NSPCC in 2004. This, together with a range of publications about consultations and communication, can be purchased from Triangle.
Triangle, Unit E1, The Knoll Business Centre, Hove BN3 7GS. Tel.01273 413141.
http://www.triangle-services.co.uk

Appendix C: Table of participants in telephone interviews

Ann Lewis	Professor of Special Education and Educational Psychology, School of Education, University of Birmingham
John Davis	Lecturer/Co-ordinator BA Childhood Studies, University of Edinburgh
Linda Ward	Director, Norah Fry Research Centre, University of Bristol
Ruth Townsley	Senior Research Fellow, Norah Fry Research Centre, University of Bristol
David Abbott	Research Fellow, Norah Fry Research Centre, University of Bristol
Bryony Beresford	Senior Research Fellow, Social Policy Research Unit, University of York
Ruth Marchant	Co-Director, Triangle, Sussex
Jenny Morris	Independent Consultant, London
Liza Bingley-Miller	National Training Coordinator, Child & Family Training, Making Research Count, University of York
Jean Whyte	Senior Research Fellow, Children's Research Centre, Trinity College, Dublin
Sheila Groth Larsen	Educational Psychologist, Barnados
Kirsten Stalker	Reader, Social Work Research Centre, University of Stirling

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