Independent Reviewing Officers' Communicating with Children with Complex Communication Needs.
An investigation for DCSF.
The Children's Society is a leading children's charity committed to making childhood better for all children in the UK. We take action to prevent, rescue and support children facing life trapped in a vicious circle of fear and harm; a vicious circle driven by violence, neglect, poverty and discrimination, which destroys childhood and wrecks community living. We give children the hope and confidence they need to face the future with optimism. We never turn away.
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1 Introduction

The DCSF commissioned The Children’s Society to undertake an investigation to identify;

- the skills needed by Independent Reviewing Officers [IROs] to communicate with children with complex communication needs,
- the extent to which they have these skills,
- how IROs can be up-skilled and/or supported by advocacy or other support services to ensure that children’s views are heard.

The investigation was undertaken to inform the development of new guidance for IROs following the Children and Young Persons Act 2008, and to inform the guidance, *Get it Sorted: Providing Effective Advocacy Services for Children and Young People Making a Complaint under the Children Act 1989*. The investigation had a very short deadline (June – end of July 2009) and hence its scope was limited. Such a tight time scale was imposed so that the investigation would tie in with the progression of the new guidance, which the DCSF envisaged would be circulated for consultation in September 2009.

It was hoped that this investigation will lead to a better understanding, and a clear set of recommendations, of how best to implement the commitment made in the Care Matters White Paper that IROs will elicit the views of children with communication needs directly, or indirectly through specialist services such as advocacy. Ultimately it is hoped that this work will lead to children with complex communication needs having the same opportunities as other children to engage in their care plan reviews and decision making about their lives.
2 Background

2.1 Policy
All looked after children, including those with complex communication needs, have the right to communicate and to have their wishes and feelings understood and given due consideration. The right for all children to communicate is underpinned by The Human Rights Act 1998 and should be enshrined into the core values of all agencies working with children. Legislation requires that the wishes and feelings of children are ascertained and given due consideration when making decisions about providing services to meet a child’s needs under sections 17, 20 and 47 of the Children Act 1989 as amended by section 53 in the Children Act 2004. The Children Act 2008 goes further and requires IROs to ensure that the local authority gives due consideration to any views expressed by the child. This means that assessments, care plans and review processes must take into account the preferences and views of all looked after children including those with complex communication needs. Children with complex communication needs are likely to require additional action by IRO’s to ensure that their individual means of communication is facilitated and understood so that their views can be presented, and taken into account during the reviewing process.

2.2 Definition of children with complex communication needs
The term complex communication needs is an umbrella term, which covers a wide group of children described as having speech, language and communication needs (SLCN). In order for there to be a common understanding of what this term might mean, the following definition was used throughout this investigation. This definition is taken from guidance published by The Communication Trust (2009).
(www.thecommunicationtrust.org.uk).

Definition of children with complex communication needs

Children with complex communication needs includes those who use non-verbal means of communication as well as a wider group of children who have difficulties in communicating with others. It may be that they cannot express themselves effectively or they may have difficulties in understanding what is being said to them. Equally those who support them may not understand their way of communicating. Many children communicate successfully using non-verbal means such as signing, gestures, communication books or electronic communication equipment.

[This is drawn from The Communication Trust publication Explaining Speech, Language and Communication Needs, 2009]
The Communication Trust guidance explains how communication needs can often be a “hidden disability”, not always recognised and some children can become proficient at hiding the nature of their difficulties. Communication needs can be minor and temporary or they may be complex and long-term. Many participants in this investigation stressed that “communication needs must be seen as a continuum” and encompass, for example, children in distress who may have temporary communication needs, in addition to those who may have long-term persistent complex communication needs associated with an impairment.

Children with complex communication needs may use a range of communication methods and these can change and develop over time. A child might use a formal communication system or develop a unique method, such as using body language, gestures, facial expressions and behaviour. Some children might communicate with a sign, word or movement that indicates yes or no. All communication methods should be equally valued and children have the right to freedom of expression through the media of their choice under Article 13 of the United Nations Convention on the Rights of the Child (1989). Useful fact sheets and information on the most commonly used communication methods can be found on www.communicationmatters.org.uk and within The Two-Way Street Handbook (Marchant and Gordon, 2001). This investigation also required the production of an appendix which contains a collation of resources, offers advice on communication and a list of available training courses. See www.childrenssociety.org.uk/research.

2.3 Skills needed to communicate effectively with children with complex communication needs

The Speech, Language and Communication Framework (SLCF) published by The Communication Trust (2009) sets out the skills and knowledge needed by all practitioners to promote and support children’s speech, language and communication development and identify those children who are experiencing difficulties. The SLCF consists of four stages, it might be expected that IROs as a minimum should consider the “universal stage” (for those who need a general awareness of speech, language and communication skills and need to identify features of SLCN). However, IROs also might benefit from examination of the “enhanced stage” (for those who need a more detailed understanding and who are likely to work with children and young people whose SLCN has been identified). The stages set out competencies such as;

“You will be aware of some of the features that promote a positive communication environment”, “You will be aware of the different professionals who may be involved in supporting children and young people with particular SLCN” and “You will be aware of the range of SLCN that children and young people may have”.

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The SLCF is also available as an interactive tool so that practitioners and managers can evaluate their own skills and knowledge, and link to training and resources (www.communicationhelppoint.org.uk).

Research evidence illustrates communicating with disabled children and those with complex communication needs is often little different from communicating with any child. It mostly requires some basic skills, a willingness to be adaptable and a positive attitude (Stalker and Connors, 2003; Mitchell et al, 2009). However, in some cases children and young people with complex communication needs may require additional support, more time, access to people who understand their communication method and/or materials made accessible for them. There have been a number of publications providing advice and recommendations to improve communicating and consulting with disabled children (see for example, Ward, 1997; Morris, 1998; Murphy, 1998; The Children’s Society, 2001; Knight et al, 2006; Mitchell et al, 2009). As already mentioned, as part of this investigation a resource was also created which offers advice on communication, a list of resources and available training courses. See www.childrenssociety.org.uk/research.

2.4 Numbers of children and young people with communication needs

The Communication Trust, quoting Tomblin et al, 1997, report that an estimated 5-7% of children starting school have speech, language and communication needs (SLCN) in the absence of any other difficulty including general learning difficulties, or any sensory or physical impairment. Significantly more children have SLCN as part of another condition (for example, learning disabilities, Autistic Spectrum Disorders, Downs Syndrome, Cerebral Palsy, Sensory Impairment, Attention Deficit Hyperactivity Disorder (ADHD), Attention Deficit Disorder (ADD) and Dyslexia) and SLCN represent the most prevalent type of special educational need (SEN) amongst pupils with statements of SEN.

Based on the broad Disability Discrimination Act definition of disability it is estimated that there are 770,000 disabled children in the UK. Aiming High for Disabled Children: Better Support for Families (HM Treasury and DfES, 2007) suggested this equates to 570,000 disabled children in England, 7% of the child population. For the purposes of the Aiming High for Disabled Children Programme, the numbers of severely disabled children in England have been estimated at around 100,000, about 17% of the total disabled children population; 1.2% of the whole child population (HM Treasury and DfES, 2007). It might be expected that the vast majority of these children will have a communication need, although data of this nature is not collected.

In 2007, it was estimated that there were 2,300 children looked after whose principal category of need was disability; 4% of the looked after population (DCSF, 2007b). However, a significantly higher number of looked after children have communication needs, but their principle category of need
would not necessarily be a disability. In addition, the figure of 4% does not include children who are looked after as a result of having a series of short breaks.

Other related statistics include the outcome indicators for looked after children in England. In the twelve months to 30 September 2006, 28% of looked after children had a statement of special educational need. These figures are based on children who have been looked after for a continuous period of 12 months (DCSF, 2007a). Once again, it is important to note that not all looked after children with a statement of SEN will have a communication need, although, as already indicated it is the most common type of special educational need amongst pupils with statements of SEN.

Statistical data is not collated on the numbers of looked after children who have a complex communication need and thus it is difficult to establish the prevalence rate or level of need amongst these children and young people.

2.5 Research evidence
Although the investigation only required an examination of literature concerning communication skills required by IROs to facilitate the involvement of children with complex communication needs, the literature search was widened to incorporate evidence on levels of, and facilitators and barriers to, involvement. An examination of this was deemed necessary, as it is apparent that skills in communication alone may not always be sufficient to eliminate all barriers to the involvement of this group of children, although of course up-skilling in this area is vital. It is hoped that by placing this investigation within the wider available research literature a more holistic understanding of this area can be deemed.

2.5.1 Levels of involvement
There is a severe shortage of rigorous research exploring the participation of disabled children and young people, and even less available specifically on the involvement of children with complex communication needs. Despite an increase in the participation of children and young people, disabled children are still much less likely to be engaged in decision-making, and their involvement needs considerable development (Morris, 1998; 1999; Sinclair and Franklin, 2000; DH/DfES, 2004; Sinclair, 2004; Cavet and Sloper, 2004; Franklin and Sloper, 2007; 2008). There is limited systematic gathering of evidence of good practice, and disabled children with complex needs, including complex communication needs, or those from black and minority ethnic backgrounds are even less likely to participate (Marchant and Jones, 2003; Knight et al, 2006). This is despite the fact that disabled children and young people are more likely to become looked after in the care system and are generally more vulnerable to abuse and neglect, both at home and in care (Marchant and Page, 1993; Morris, 1995; Russell, 1995).

2.5.2 Barriers to involvement
The research evidence highlights that a combination of practical and attitudinal barriers exist which adversely affects the involvement of disabled
children and those with complex communication needs. For some children their involvement is hampered by a lack of availability of the communication aids on which they rely (Morris, 1998; Rabiee et al, 2001; Stone, 2001) or a lack of access to advocacy services (Oliver et al, 2006, Knight and Oliver, 2008). Whilst a study by Franklin and Sloper (2007, 2008) highlighted the following; a lack of commitment to valuing participation at whatever level is appropriate for a child, a lack of a culture of participation for disabled children and reliance on a few individuals to facilitate involvement, a lack of understanding of how to facilitate involvement of children with complex needs, few resources and limited time dedicated to participation, a lack of shared information about a child’s communication method and little joint working to facilitate a child’s involvement in decision-making.

2.5.3 Accessibility and availability of advocacy
Advocacy can be considered to be one way to facilitate disabled children’s participation in decision-making (Rabiee et al, 2001; Knight, 1997; Morris, 1999). Advocacy assists children and young people to communicate their views and opinions and helps them to have their views taken into account (Oliver, 2003; Oliver et al, 2006). Government guidance defines advocacy for children as;

…”speaking up for children.. empowering children and young people to make sure that their rights are respected and that their views and wishes are heard at all times. Advocacy is about representing the views, wishes and needs of children.... to decision-makers and helping them to navigate the system (DH, 2002, p1).

There is very limited data on the accessibility and use of advocacy for disabled children and young people, and none which examines advocacy specifically for children and young people with complex communication needs. Oliver et al (2006) and previously Atkinson (1999) noted the accessibility difficulties for children with communication needs, however, in depth studies of advocacy for this group are lacking, and the views and opinions of children using or needing this service remain unheard. Knight and Oliver (2008) report on the lack of skills and knowledge amongst advocates to communicate effectively with young people with severe learning disabilities and/or those with complex communication needs, in addition to a lack of time to develop and undertake advocacy with this group of children.

In 2007, The Children’s Society undertook a survey of advocacy services in England. This report illustrated that the vast majority of advocacy services have strict service criteria often age related or restricted to those ‘at risk’, who want to make a complaint or those children and young people in, or leaving care. The results of this survey suggest that the number of disabled children and young people receiving advocacy was small. Approximately 877 disabled children and young people across England received advocacy during a nine-month period (April 2006-December 2006). Two-fifths of survey respondents specifically stated that they could not provide advocacy for children and young people with complex communication needs and over
a third could not meet the needs of children with autism. Advocacy services reported on a lack of awareness of advocacy and its potential by professionals, parents and young people, a lack of commitment amongst some professionals to ensure that children’s views are heard, and a lack of understanding that children with communication needs can communicate. Barriers were also reported to be limited or restricted access to children and young people to raise awareness of advocacy and their rights.

2.6 Children and young people’s views on reviews and involvement

Although there is an increasing amount of literature detailing, from children’s perspectives, the benefits of participation and suggested methods, the views of disabled children and young people do not feature highly within this, and those children with complex communication needs remain almost invisible. Much can be learnt from the evidence gathered from the general population of children and young people, however, it is important to not treat all children homogenously. Children with complex communication needs may have very different experiences and opinions than that of their peers.

Knight and Oliver (2007, 2008) gathered data from 12 disabled young people who have an advocate. These young people were positive about the service and expressed value at being listened to and having their views taken seriously. Other positive outcomes of advocacy and of participation in general, reported by disabled children are feeling included, valued and empowered, increased confidence and skills, and services changing to better meet their needs, including for example, personal care in residential settings (Franklin and Sloper, 2007, 2008; CDC 2008, The Children’s Society, 2001).

Disabled children and young people also have many suggestions about how participation should be facilitated.

- For participation to be effective the methods of involvement should be determined by the needs of disabled children and young people (Beresford, 1997; Morris, 1998; The Children’s Society, 2001).
- Multiple visits may be required to get to know a young person and their means of communication (Beresford and Sloper, 1999; Morris, 1998; Cavet and Sloper, 2004).
- Disabled children and young people want an informal, flexible, ongoing approach to involvement, in addition to formal structures and isolated events (Beresford and Sloper, 1999; Lightfoot and Sloper, 2003).
- Creative, multi-method, flexible approaches are important (Marchant et al, 1999a, 1999b; Stone, 2001; Ward, 1997; Morris, 2002).

For some young people, the starting point for any involvement has to be the availability of suitable communication aids (Morris, 1998; Rabiee et al, 2001; Stone, 2001).

The Children’s Rights Director in England undertook a consultation on advocacy with a group of young people in care (n=138) and almost 20%
defined themselves as having a disability. Half of those consulted had not heard of advocacy despite the fact that all children in care have the right to help from an advocate if they want to make a complaint. Participants reported that

“advocates need to be good listeners and speakers, understand children’s issues, have the right personal qualities and be reliable” (p10).

Personal qualities included honesty, reliability, respect, a sense of humour, confidence and non-judgemental. Although the sample was small, 6 out of 10 young people stated that advocacy had made a difference to their lives (Morgan, 2008). The Children’s Rights Director also undertook a consultation on children’s views of placements, decisions and reviews in 2006. Eighty-six children and young people participated, but whether they consider themselves disabled is not recorded. When questioned what are the best ways to ask young people for their views when making important decisions in their lives, the overwhelming answer was;

“simply ask children what they think and feel and really listen to what they say” (p9).

Also of importance was that a young person feels comfortable talking to the person asking for their views and having a choice of who to talk to. Young people reported that personalities, their own and that of the adults, are important. Participants in this consultation also expressed that;

“children will only share personal views and concerns when they feel safe” – confidentiality is crucial to this (p9).

Children and young people’s priority messages to practitioners on how to involve them in decision-making included:
- Asking children what they think and feel.
- Allowing children to write or draw their views or use a computer package such as Viewpoint.
- Better designed, more interesting and age appropriate review forms,
- Hold reviews in less worrying/frightening places and have less people attending.
- Having an advocate.
- Explain things in words they can understand.
- Keep children informed of what is happening (even at times when nothing is happening so that they do not feel forgotten or fear the worst).
- Genuinely take what children say in to account.
- Feedback on what has been decided and why.
- Explain who makes the final decision in a review meeting and explain what a young person can do if they are unhappy with a decision.

Specifically on the review process, ¾ of children and young people in this consultation had attended their review. The principle reason for attending
was reported to be to find out what is going on, having a say in what happens to you and finding out reasons for decisions made about you. Reasons for not attending were not being able to get their views across, the meetings are boring, and it is difficult to talk about personal issues in front of a large number of strangers/adults, and hearing negative or untrue things about yourself. This consultation revealed children and young people’s views on adults’ behaviour during review meetings. Children reported that adults butt in when they spoke, did not look at them when they are talking, and spent all the time writing notes and using difficult language.

Respondents also revealed how reviews are particularly difficult if you lack confidence and are not used to speaking in front of large numbers of people. These messages of exclusion and lack of any control from the decision-making process is a recurring theme throughout the research literature on involvement in decision-making across social care (see for example, Shemmings, 1996; Sinclair, 1998; Thomas and O’Kane, 1999; Munro, 2001; Danson et al, 2003; Boylan and Ing, 2005; Voice, 2005; Boylan and Braye, 2006; Leeson, 2007). Throughout children and young people report little confidence that their views will be listened to and inform decisions made about them. As Timms and Thoburn (2006) highlight;

“given the importance placed in self-efficacy as a key component of resilience (Gilligan, 2004; Rutter, 1985), to fail to listen to, or to over-rule, children’s wishes on matters about which they feel so deeply must be considered highly likely to damage their long-term well-being” (p167).

As already mentioned, the available research evidence has in the main explored the barriers to involvement faced by children who use speech to communicate, it can be assumed that these difficulties would only be exacerbated if a child has a complex communication need.
3 Methodology

There were a number of related components undertaken to inform this investigation:

- An examination of existing research evidence concerning the skills needed to communicate effectively with children with complex communication needs, including the views of children and young people.
- Collating existing guidance, tools and information on training to support the involvement of children with complex communication needs.
- A series of 3 national stakeholder consultation events with Independent Reviewing Officers and Managers, Independent Advocates and other interested parties.

The aims of the survey and stakeholder consultation events were to gather information on:
- current levels and gaps in terms of communication skills,
- IROs’ capacity to involve children with complex communication needs within their reviews,
- knowledge and accessibility of specialist services such as advocacy to support communication,
- knowledge and accessibility of appropriate training,
- particular groups of children currently not being involved and barriers to their involvement.

3.1 Involving children and young people in the investigation

Although it would have been preferential to have sought the views of children and young people in developing the guidance, a decision was made to consult with children and young people with complex communication needs on the new IRO guidance when it is published in draft form in September 2009.

This decision was made because of the tight deadlines and the need for adequate time to properly undertake such a task. Considerable time would have been needed to have gained the relevant access and consent to interview children, and to develop appropriate, accessible and often individualised methods. Thus it was considered more appropriate to involve them in commenting on the published draft guidance. Consideration was also given to the fact that there is already existing evidence of what children
and young people in general have expressed about their involvement in decision-making arenas.

3.2 Drafting of IRO guidance
Following the investigation, a draft section of the new IRO guidance was submitted to DCSF. This section related to how IROs can involve children with complex communication needs within the reviewing process, and in what circumstances they may need to call upon advocacy and other specialist services to support children in planning and review meetings.

An appendix of further information was also submitted with the view that this be made available alongside the IRO guidance. This included summary information on different forms of communication, barriers to communication and participation experienced by children and actions to enable and support communication. A list of resources and training courses was also included.

3.3 Samples

3.3.1 Survey
In the absence of a register or database of IROs, and the short time scale for the investigation, a snowball approach to sampling was used to undertake the survey and recruit stakeholders to attend the consultation events. Known IRO and advocacy contacts were approached and relevant organisations such as The National Association of Independent Reviewing Officers kindly offered their support. The survey was emailed and respondents were encouraged to forward the survey to other IROs and IRO managers. There was little control over this process and it is not known, for example, whether the survey reached all local authority IRO teams, but given the time scale a more systematic, rigorous approach would not have been possible.

Although the sample cannot purport to be representative, a wide geographical spread of responses was achieved, and representation from both IROs and IRO managers. In total 66 completed surveys were received, from across 44 local authorities (one missing data). Forty-nine IROs and 15 IRO managers responded (1 other and 1 missing data).

3.3.2 Stakeholder consultation events
Three half-day stakeholder events were held across England, again known contacts were approached and encouraged to circulate invitations to colleagues. There were 44 attendees across the three events; this included a cross-section of IROs, IRO managers, advocates and representatives from across a variety of voluntary organisations.

Although these samples may not necessarily be representative, there was considerable consistency across the survey and stakeholder events in terms of suggested guidance. Across responses the same barriers to communication and involvement were identifiable, and the same suggestions for improving practice.
4 Findings

The research evidence, survey responses and data collected at the stakeholder events was collated and analysed thematically. The findings are organised to firstly describe and capture the wide variety of current practice across local authorities in England and then a series of themed recommendations to improve practice are presented. Within each recommendation, the barriers faced by IROs are described to provide context.

4.1 Current practice across local authorities

From the data collected it is evident that the involvement of children and young people with complex communication needs varies considerably across local authorities. A number of authorities had made attempts to improve practice through measures such as employing specialist disability IROs, one reported employing disability consultation workers attached to their IRO team and another authority reported that they had undertaken a pilot project in order to address this gap in their reviewing processes. Others reported on their use of advocacy services, although access to specialist advocacy to support children with complex communication needs was reported to be limited. However, the consistent message was that much needed to be done to improve the involvement of this group of children.

“As an IRO… I am more than aware of my lack of knowledge and skills in communicating with children with complex communication difficulties. I do feel that there is a certain amount of lip service when encouraging communication to take place and these young people are not particularly valued, which is of concern.”

The number of challenges facing IROs to involve children with complex communication needs in the review process is presented throughout this report. However, a question on the survey specifically enquired whether they currently faced any challenges to involving children and young people with particular complex communication needs. Children on the autistic spectrum and those children who have additional needs such as a severe learning disability and/or sensory impairment, in addition to a communication need presented particular challenges. The challenge for many IROs was a lack of knowledge, training and experience of working with children with these needs, a lack of understanding of, and access to, appropriate methods to facilitate involvement and not having time to spend with these children observing and learning how they communicate – as many noted communication could be individual to the child.

4.1.1 Examples of current practice

Survey respondents were asked to comment on three vignettes of children with complex communication needs and describe the most probable
approach that would be undertaken in their authority to elicit the views of the child. Respondents were also asked to describe how they thought practice could be improved.

**Vignette One: A child is 8 years old, he lacks confidence and finds it hard to communicate with strangers, he can express his views using symbols.**

Fifty-eight respondents shared a multitude of different approaches to involving this child in their review process. The responses can be divided into those who would make some arrangements to facilitate the involvement of the child, either directly or indirectly (n = 45 (78%)) and those who stated that no attempt would be made to engage with the child. In these cases the parents/carers or others such as the child’s school would be consulted instead (n = 13 (22%)). Some specifically stated that the IRO would not necessarily meet this child. Approaches to involvement included;

- Identifying a trusted professional to consult with the child.
- Appointing an independent advocate.
- Encouraging the child to create a booklet of pictures and symbols expressing their views.
- The IRO observing the child directly or via video.
- The IRO meeting the child prior to the review and reflecting on any consultation exercise they may have undertaken.
- The IRO seeking whether the child wants to attend their review.
- The IRO considering whether the review meeting should be adapted to better meet the child’s needs.

One IRO presented a very thorough approach to meeting this child’s communication needs;

*He would be invited to take part in keywork sessions with the worker/carer or TA who he is most confident with. He could be encouraged to choose from a range of symbols/PECs so that he can express his likes and dislikes about his care plan and placement i.e. whether or not his care needs are well met, is he happy about the activities that he is encouraged to take part in and does the plan make him feel happy or sad and is there anything that he would like to change if it can be changed. The sessions could build into a booklet that he can paste in the symbols he has chosen and which can incorporate photographs of activities etc that he would like to tell people about. He would be invited to attend the meeting with the support of someone he feels more confident with or asked if that person can present his views in the review. If he does not want to attend I would ask if he would like to meet me so that he can show me his booklet (or chosen method of presenting his views - I have had children providing me with a wide range of examples including mobiles made up of special symbols).*

A number of authorities reported that they would send the child their standard consultation documentation and would attempt to adapt this with
the use of symbols. Whilst others mentioned that they use a Viewpoint questionnaire which would be adapted to the child’s needs.

An IRO in one authority noted that although the child’s social worker would spend time with him to elicit his view;

“I would also try to engage with him on the basis that I might be reviewing him for several years, and he might find it easier to trust me with each successive review”. Another respondent reported that within their authority they also adopt this approach, “We give each child a named IRO so over a period of time the IRO will be seen by the child as a friendly face”.

Suggestions for improved practice were obviously dependent on the current levels of involvement and as already mentioned some respondents were starting from a position of “no involvement”. However, a number of common themes for improvement emerged:

- Improved knowledge of consultation tools and methods which could be used.
- More and improved training for IROs.
- More time for the IRO to be able to build a relationship with the child.
- More skills and knowledge of how to explain the reviewing process to the child.
- More time available for the review meeting and more suitable, accessible venues in which to hold reviews.
- Professionals to be more open-minded and committed to children’s involvement and seeing children as key partners in decision-making.
- More access to advocacy services.
- Social workers and others to have more time to consult with children.

However, it should be noted that suggestions for improved practice in a small minority of cases, still illustrated a lack of understanding or commitment to trying to elicit this child’s view. The vignette states that the child can communicate using symbols, however, some respondents when describing how practice could be improved still demonstrated a reliance on seeking the views of others, rather than looking at methods to involve the child directly.

Vignette Two: A young person is 14 years old. She communicates through eye-pointing and has cognitive abilities.

Fifty-seven respondents supplied information with regard to this vignette. Fewer responses than in the previous vignette indicated that some arrangements would be made to involve this young person in their review (n=38 (67%)), in 19 cases no attempt would have been made to seek this young person’s view.
“Parents, carers and IV (independent visitor) would be asked to share their views”

It is also interesting to note that even amongst those who would facilitate some level of involvement, very few responses indicated that this young person would be invited to attend their review even though the young person has cognitive abilities which might suggest that they are competent and capable of participating.

As with the first vignette, similar methods of involvement would reportedly be undertaken, predominantly the IRO would seek the support of someone able to facilitate communication with this young person. Others stated that they would undertake observations and in a few cases that the young person would be given access to an independent advocate.

Also worth noting, a proportion of respondents indicated in their answer that they do not know what eye pointing is, or how to communicate with someone who uses this method to communicate.

“I do not know what eye-pointing is and I would be reliant on someone else to communicate information to me”

Again this demonstrates a lack of training and understanding in the variety of communication methods. In some cases a complete lack of understanding, and what might be considered inappropriate practice, can be demonstrated. For example, one respondent stated that current practice would be;

“A written form can be completed and the young person can also phone or email the reviewing officer”

Suggestions for improved practice were the same as with the first vignette.

Vignette Three: A child is 10 years old. He is in an out-of-authority specialist school on a 52-week placement. He has autism and uses just one or two word sentences often on a repetitive basis.

Information from 56 respondents was received for the final vignette. In 39 cases (70%) some form of involvement would be undertaken with this child, although predominantly the IRO would be reliant on others to facilitate this or sometimes the use of videos and a Powerpoint presentation would be harnessed. In a number of cases, IROs indicated that they would want to seek some verification, if possible, that the child’s views had been presented objectively, as one indicated,
Reliant on others to give me information and would briefly talk to young person to confirm what I have been told hoping that I can convey myself in a way the young person understands. I would also use observation skills.

Although improvements in practice followed similar lines to those mentioned above, a higher proportion of respondents also mentioned the need for more time to undertake observations, and more access to independent advocacy in this case. One respondent, a specialist disability IRO shared their current practice which would involve an advocate;

Ensuring that an advocate is involved who has a good understanding of ASD and that there is an allocated social worker who has been able to visit on a regular basis to observe the young person so that they (social worker and advocate) can observe and interpret their behaviour and presentation.

They also went on to describe the specific arrangements they would make to try to include this child within the review meeting;

I would ensure that the review is held in an environment at the school that is comfortable for the child and that strategies are used to support him to attend some or all of the review. This could perhaps be using music, social stories or even using a sensory room. I would want to ensure that there are breaks in the meeting and that the child has a support worker(s) who can go with him if he leaves the review. There needs to be consideration of which professionals need to actually attend the review.

Seventeen respondents indicated that the views of others would be sought, such as parents/carers or school staff and that no attempt would be made to seek independently the views of this child.

The independent representation of the views of children with complex communication needs was raised as an issue throughout the investigation. The lack of training, time and access to resources and people who understand their communication method often limits the opportunities for children with complex communication needs to participate independently. Subsequently they are usually dependent on carers, parents or others to translate or communicate on their behalf. This is not necessary a problem if the translator can be objective and interpret without bias. However, this is not always the case (see for example, Beresford, 1997; Mitchell and Sloper, 2001). As Mitchell and Sloper's research indicated, disabled children and their parents/carers often want different things from services and define quality of services in different ways (2001). Thus it becomes important not to treat all parents/carers or others as proxies for children, in some cases it is imperative that some independent validation is sought.
Interestingly, what is also worth noting is that a number of respondents gave the same answer to each vignette, despite the very different ways in which the children communicated and their varying levels of cognitive abilities.

This section has illustrated the wide variety of practice in operation across local authorities and has also shown that there is much to improve if the participation of children with complex communication needs is to become a reality. Despite guidance, policy and legislation to support involvement of this group of children, this limited investigation has highlighted widespread non-participation, in addition to a lack of understanding, training and knowledge about how best to involve children with complex communication needs within the reviewing process. The respondents to this investigation have also demonstrated that there is a dedicated group of IROs and advocates who are committed to improving practice and urging for support to undertake this work.
Recommendations for the involvement of children with complex communication needs in the reviewing process

This investigation has highlighted both challenges and recommendations for practice, rather than present a series of barriers and then recommendations, the following section collates this information. Recommendations are placed within the context of the current challenges faced by IROs, both on an attitudinal and practical level, without a thorough understanding and examination of these barriers, implementation of recommendations will remain difficult.

5.1 A change in attitudes towards the involvement of children with complex communication needs

The views of those who contributed to this investigation echoed earlier research findings, indicating that there is still a need for a change in attitudes across the workforce towards the participation of disabled children and those with complex communication needs, although some respondents felt that things were improving gradually (See for example; Franklin and Sloper, 2008).

Many IROs and advocates described a lack of a culture of involvement and little prioritisation of children’s views and opinions, especially for those with communication needs and those children living away from home. Respondents described that it is “not seen as a priority to see children and involve them but seen as a luxury”.

Many had witnessed attitudes from professionals/practitioners, as well as from parents/carers and foster carers, that children with more complex communication needs cannot communicate and cannot contribute to decision-making arenas. One IRO described the challenges she faced in ensuring a child’s wishes and feelings are considered when those around him/her do not believe they can have a view.

Participants in the investigation spoke of the “need to foster a cultural expectation that children with communication needs can/should/will be...”
included” and a commitment to making the child central to the planning process.

One IRO survey respondent wrote:

“Sometimes residential establishments are reluctant to assist in gathering the views of children although this is changing. Often they are worried that if a child attends a review with their parents present they will become upset and not understand the process fully and think that they are going to go home. However, this is not my experience.”

Another IRO wrote:

“Carers and residential staff also need training in methods and encouragement to elicit views from children in more imaginative ways”.

Creating a participatory inclusive culture was identified as being key to enabling children with complex communication needs to participate. To create such a culture requires commitment at all levels and a shared understanding and sense of responsibility (Kirby et al, 2003). Research evidence illustrates that successful participation can only be achieved if barriers to involvement are identified and eliminated, and processes and procedures adapted rather than expecting children to try to adapt or fit into decision-making arenas which can alienate or confuse them.

A number of IROs raised the issue that participation in decision-making is a right under the United Nations Convention on the Rights of the Child, and that in many cases a child’s involvement is not facilitated because their basic human rights are not being met. Examples included a lack of accessible meeting places, lack of access to a signer/interpreter, inaccessible paperwork, and denying the child their right to participate through not holding reviews in a suitable venue or at a time when a child could attend. There appeared to be little choice given to children about when and where reviews were held, and some respondents described how children in some circumstances were not allowed to be accompanied by a friend when they had wanted to be.

5.2 An improved and wider understanding of the meaning of participation

Once again, there are consistent messages from research evidence and from this investigation that there needs to be an improved and wider understanding of what participation should entail and what can constitute participation. It appears that there still needs to be an acceptance of a continuum of participation, where children’s involvement can be at whatever level is appropriate to their ability and wishes (Franklin and Sloper, 2007, 2008). Discussions at the stakeholder consultation events illustrated that there still exists amongst professionals and practitioners an assumption that because some children and young people do not have the cognitive abilities
to participate in decisions concerning the “bigger” questions, then these children should not or cannot be involved in the reviewing process. As IROs described people thus forget to ask about the “smaller questions”. For example, because it might be impossible to ask whether a child would like to change their placement, questions are not asked about day-to-day issues that might be important such as meals, staff or activities, which would help to inform the more complex decision-making. Those who shared their practice illustrated how, although it may be difficult to obtain quick answers to specific questions for a review meeting, taking a holistic approach to participation and building a picture of a child’s life; their likes and dislikes or what makes them happy or sad, helps to inform these “big” decisions.

In addition, some IROs and advocates pointed out there is a lack of understanding of, and attention paid to issues of importance for children, such as food or the cleanliness of the toilet. Often the focus of the review is on the statutory requirements or adult led agenda and does not take into consideration the issues, which may be causing most anxiety to children.

Respondents also stressed that there needed to be a better understanding that there are multiple ways of being involved and that the method(s) of participation should be seen flexibly. Thus involvement can, and should, be facilitated in a number of ways to make it meaningful and accessible to children and young people. Thus “alternative”, innovative and creative methods should/could be used to enable children to contribute to their reviews. Methods might include eg: Picture books including a child’s achievements, likes/dislikes, a Talking Mat™, DVD, diary, or photographs. (Although some participants were keen to add that there needs to be a balanced presentation of photographs which showed the child happy and sad, because it is unnatural to take photographs when children are unhappy or distressed, without checks, photographs alone may present a biased picture).

For children and young people with very complex and multiple needs and very limited cognitive abilities, observations over time and in a number of settings should also be seen as a legitimate way to ensure that their best interests are represented. As IROs and advocates attending the stakeholder events described, a child’s behaviour can speak volumes.

5.3 Involvement should be seen as a process not an event or meeting

Existing literature, young people’s recommendations and the views of those taking part in this investigation all conclude that positive, non-tokenistic involvement should be an ongoing two-way process, built on trust and relationships and not just undertaken at a review meeting (Sinclair, 1998; Thomas and O’Kane, 1999; Voice, 2005; Franklin and Sloper, 2008).

Many IROs and advocates attending the stakeholder events highlighted how for some young people with complex communication needs the context and content of a review meeting might be meaningless and it would be disrespectful to expect a child to attend. Although most IROs subscribed to
the fact that children should be given a choice about whether they attend their review and encouraged to attend, they also highlighted how trying to facilitate some children’s attendance at a meeting might be a waste of time, and that time might be better spent on gathering a child’s views outside of the meeting. Respondents were keen to point out that the reviewing system is not child friendly and requires children to fit into an adult agenda. As one attendee stated “meetings are not a natural environment for children”. Hence, the evidence suggests the importance of seeing participation as an on-going process and not an on-off event. Many IROs pointed out the danger that the focus often becomes the meeting and not about a child’s views.

5.4 Involvement should be holistic and individualised
All of the evidence collated indicates that the methods of involvement for children with complex communication needs should be individualised and a holistic approach be taken to gathering their views. Many respondents spoke of the importance of getting to know a child and the need to develop a relationship with them, especially if they have complex communication needs, understanding a child’s communication method may take time. As one IRO stated “why should they express their views to stranger(s)?”

Pointers of good practice were identified as;
- Explaining the reviewing process and thus preparing the child for the review. Some IROs and advocates described how they produced a letter in Widgit, which introduced themselves and explained what was going to happen and the importance of the review, and reassuring the child of their independence. Some included a photograph of themselves.
- Preparing the child by increasing their confidence to express their views.
- Providing feedback to children and young people following a review. Many participants highlighted that young people should be entitled to have feedback following review meetings and some reminder of what was said and the decisions made. Good practice was described as sending the child an accessible note of the actions and identifying a named person e.g. social worker or advocate to explain this to a child and answer any questions they might have.

5.5 An improved and wider understanding of the variety of communication methods and the range of ways in which children communicate
The survey of IROs and IRO Managers illustrated that more can be done to improve their understanding and knowledge of communication methods, discussion at the stakeholder events supported this. As Table One illustrates, less than half of survey respondents described their knowledge of the preferred communication methods of all children and young people on their caseloads as excellent or good, with 12% stating that it was poor. Over a third (35%) of survey respondents stated that their knowledge of specialist support available to facilitate involvement of this group of children was poor or very poor. Similarly, knowledge of specialist communication methods was equally low, with 43% describing their levels as poor or very poor. Finally,
over 60% reported poor or very poor levels of knowledge of available training to support them in communicating with children with complex communication needs. Lack of knowledge of communication methods has been highlighted within the published literature (see for example, Beresford and Sloper 1999; Morris, 2002; Franklin and Sloper, 2008).

**Table One: How IROs rate their knowledge regarding children with complex communication needs**

<table>
<thead>
<tr>
<th>Knowledge of the preferred communication methods of all children and young people on your caseload (n=57)</th>
<th>Excellent %</th>
<th>Good %</th>
<th>Ok %</th>
<th>Poor %</th>
<th>Very Poor %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>3</td>
<td>46</td>
<td>39</td>
<td>12</td>
<td>0</td>
</tr>
<tr>
<td>Knowledge of specialist support available to facilitate involvement of children with complex communication needs, e.g. advocacy services (n=57)</td>
<td>5</td>
<td>39</td>
<td>21</td>
<td>32</td>
<td>3</td>
</tr>
<tr>
<td>Knowledge of specialist communication methods e.g. Makaton, PECS (n=58)</td>
<td>0</td>
<td>29</td>
<td>28</td>
<td>34</td>
<td>9</td>
</tr>
<tr>
<td>Knowledge of available training to support you in communicating with children with complex communication needs (n=58)</td>
<td>0</td>
<td>14</td>
<td>24</td>
<td>52</td>
<td>10</td>
</tr>
</tbody>
</table>

One IRO reported on their survey that they face a particular challenge, “I have two young people with complex needs who are unable to talk”. Without more detail it is difficult to comment, however, unable to talk is not the same as unable to communicate. One might conclude that this indicates a lack of awareness that communication takes many forms not just the spoken word.

The research literature and discussions in the stakeholder events illustrates that there exists certain assumptions or expectation of what communication is – often based on the notion that communication can only take place through speech. In addition, there was a concern about the lack of knowledge generally on the variety of communication methods which children might use, a number of survey respondents also highlighted that they felt levels of knowledge were not high amongst social care staff, including social workers in disability teams. As one IRO Manager described,

*The social workers who are involved in the lives of the children I review have rather limited ability in terms of communicating with disabled children who have communication difficulties.*
5.6 **A child’s preferred communication method should be identified and recorded on their care plan**

It appeared from the investigation that quite often IROs did not always know that a child had a complex communication need until the first or even second review. Such a finding is not new, similarly Franklin and Sloper (2007, 2008) identified that social workers were not always recording a child’s preferred communication method on the case file.

Because of the wide variety of practice there was much debate during the stakeholder consultation events about when should be the most appropriate (and achievable) point at which IROs should be expected to know whether a child has a complex communication need and their preferred method of communication identified. Most thought that a complex communication need should be identified at the 72 hour planning/placement meeting, that an IRO should be informed at this point and that it should be recorded on their care plan, in the same way that a child’s first language is recorded.

IROs indicated that this information should be regularly updated and that any additional resources required should also be noted. Some IROs stated that realistically at the first review meeting at 28 days, there may not have been enough time in all cases to organise consultation with a child with complex communication needs, but at the first review, note should be taken to ensure that involvement is facilitated before the next review.

It was noted that review forms do not contain details of a child’s preferred communication method and this was seen as an omission.

5.7 **A child’s involvement in their review process should be recorded and reviewed regularly**

Currently IROs are required to record levels of involvement, for example, does not attend, or attended did not contribute. However, many respondents expressed that this gives some indication of quantity but not quality. IROs at the stakeholder events called for evidence of participation to be recorded on case notes as well as a child’s preferred communication method. It was felt that involvement and preferred communication method should be reviewed regularly as a child’s communication needs and preferred methods of participation may change and indeed develop with more experience of being involved.

There was some debate at the stakeholder events about whether it is an IRO’s role to identify the person to communicate with the child and seek their views for the reviewing process, and to action this, or whether this should be the Care Manager. Most felt it was the responsibility of the IRO to review if this was happening satisfactorily, if they were not able to facilitate involvement themselves.
5.8 Consideration should be given to identifying a specialist IRO within the team

The survey asked respondents to indicate whether their authority employed specialist disability IROs to undertake the reviews of this group of children. Responses from eleven authorities indicated that they employ specialist disability IROs. Although it is interesting to note that in two authorities, two IROs respondents answered this differently, possibly indicating that the term “specialist disability IRO” may be being interpreted and understood in a number of ways.

Throughout the investigation the advantages of this role were reported to be improved involvement of children because IROs are able to develop a wider skills base, more knowledge and experience both in terms of specific communication methods and any other specific needs of this group of children.

Other benefits were identified as being the development of more positive relationships with schools, residential units and specialist foster carers, promoting more direct work with children with communication needs and providing training and advice to others. A few respondents stated that through having this specialist role, and the subsequent improved participation of children with communication needs, there are improved outcomes and better care plans developed for these young people.

A respondent in an authority who employs a specialist IRO reported, that the advantages are;

*Knowledge and skills relating to the task, in particular knowledge of medical issues, different types of disabilities, syndromes and conditions. Develops expertise on resources in the field, particular sensitivity and approach to the families and carers which can need to be different at different times; his expertise is then available to the rest of the team; families feedback that they appreciate the consistencies and approach of a specialist worker.*

The identified disadvantages to this role mainly centred on the fact that many respondents felt that “all IROs should be skilled in communicating with children who have complex communication difficulties” and “children with severe communication difficulties are the responsibility of all of us”. One respondent also highlighted that the vast range of communication needs and methods of communication would make it impossible even for a specialist to fully grasp.

Another concern centred on the de-skilling of other IROs who might subsequently have limited contact with this group of children, and concern around what would happen if the specialist left their post or was on long-term sick leave. This might create a skills gap amongst those remaining IROs.
One respondent felt that this specialist role would “marginalise this group further”. Another issue raised by a small number of respondents concerned whether a specialist IRO would become “complacent and find it hard to challenge bad practice if they become part of the furniture”. A couple of respondents described how the development of such a specialism might “narrow the overall view of the IRO about young people’s needs beyond their disability” or loose touch with wider issues. One respondent, whose authority does not employ specialist IRO posts, thought the role unnecessary providing there are sufficient numbers of people able to elicit the views of children with communication needs.

Overall, however, respondents reported more advantages to this specialist role than disadvantages, and thus consideration might be given to the development of this role, particularly for children who use specialist communication methods and who might benefit from an IRO skilled in this method. At the least, IROs agreed that wherever possible children with complex communication needs should be matched to the IRO with most skill, experience or understanding of the child’s communication method, and that wherever possible, this IRO should retain this case for continuity.

5.9 There should be continuity of an IRO for children with complex communication needs
IROs indicated that wherever possible IROs should retain the same cases for continuity. This was seen as important for two reasons, firstly, because this enabled the IRO to get to know the child better, develop a more trusting relationship and thus help the IRO to understand the child’s preferred communication method and in turn their views and opinions. It was also seen as important, because IROs are often in post for long periods so they can provide long-term consistency for a child. As IROs indicated they can often be more consistent than social workers because of the turn over of social work staff. As one IRO stated a child on their caseload had 3 social workers in an eight-month period. Another stated;

Many of the children do not have an allocated social worker and it is therefore difficult for such children to develop feelings of trust in those social workers who may be present at their review

However IROs indicated concerns about the resource implications and the significant gap in skills if this was to be achieved satisfactorily.

5.10 IROs caseloads need to be adjusted to reflect the longer time it takes to involve children with complex communication needs
Survey respondents were asked to indicate how many children and young people they currently have on their caseloads. From our small sample of 38 full-time IROs, the average caseload was 88, although the range was from 40 to 137. However, care should be taken when interpreting these figures as, for example, some IROs were possibly specialist disability IROs whose caseload had been adjusted to reflect the extra time needed to support
children with complex needs, some also mentioned that they also chair child protection conferences and thus further examination is required in order to gain a true indication. Similarly, caseload figures of children with complex communication needs also requires careful reporting, caseloads ranged from 0 – 73. The average is difficult to report as without full knowledge of whether an IRO is in a specialist disability role, the figures are likely to be skewed. However, this wide range illustrates the variability of IROs experiences of working with children with complex communication needs.

Throughout the investigation, IROs and their managers expressed the need for caseloads to be reduced in order to accommodate the extra time required to facilitate the involvement of children with complex communication needs within the reviewing process. Some IROs estimated that it could take three times as long to conduct a review when using an interpreter.

*The main thing is to have time to get to know the young people… as each individual communicates in their own way… Even Makaton symbols are adapted by young people*” (IRO)

A specific question on the survey asked respondents to state approximately how much time they are able to spend with each child prior to their review. Of the 46 IROs who responded with a quantifiable time, the majority (18) stated that they had 15 minutes with each child (39%), a further 11 had less time, of these 3 IROs stated they spent no time at all and a further 8 spent five to ten minutes with a child. Only five IROs indicated that they could spend longer than 30 minutes with a child prior to their review. A number of respondents did not state a time, rather reporting that it varied depending on the child. It is hoped that in these cases variation is determined by the needs of the child and thus adjusted to adequately meet the child’s communication needs. However, what the figures have shown are IROs opportunities to really get to know a child and their communication method are limited. As one IRO remarked, *15 minutes prior to a meeting is fine to remind the child of the meeting process if you have a relationship with a child and the child has a good level of communication but it is not sufficient to gather their views.*

5.11 Children should be given choice about participating and who helps them to express their views
It was evident from the data gathered that most agreed that children and young people should be encouraged to be involved in their reviewing process, however, as some pointed out children should also be allowed to choose not to be involved.

Similarly, respondents in the main agreed that children should have choice about who might help them to express their views and support them in this process. As one IRO pointed out, it is important to also see that for some children they may not want a cross-over of roles of, for example, their teacher or support worker into their advocate.
5.12 Independent advocacy should be made available to children

The survey asked respondents to indicate whether they had access to independent advocacy services within their local authority. Respondents from 22 authorities indicated that they did have such services, but only 12 of these stated that they had sufficient services available to meet demand, and further analysis of responses also reveals that in many authorities access to advocacy is limited to certain age bands and for specific issues. Some respondents identified that if the criteria for referral was expanded, then demand would certainly outstrip capacity.

Respondents also reported that advocacy was not always available for young people with complex communication needs and gaps in service were identified to be for the “most severe cases”, or advocates with specialist skills in Makaton or British Sign Language. Advocates attending the stakeholder events themselves reported a lack of training in working with children with complex communication needs.

“We have an advocacy service but they do not provide a service with workers who have specialist communication skills.” (IRO Manager)

“The current advocacy service will attempt to represent these children but has no access to specialised training”

A number of respondents also indicated that their service was newly developed and in some cases staff were not yet in post. Two respondents also indicated that their advocacy service no longer existed.

Interestingly, a number of IROs reported that they did not know about advocacy services in their authority, the referral criteria and they reported a lack of information about advocacy in general. As two IROs stated:

“There is insufficient advertising of these services because in my four years as a chair, I am aware that services are there but don’t have any further information”

“I am not sure if a service is available. I have never been informed in supervision that it is.”

Despite limited availability and some lack of awareness, a significant number of respondents to the survey and attendees at the stakeholder events reported on the need for more availability of advocacy, and repeatedly expressed that this should be seen as a right for children with complex communication needs. As one IRO wrote;
“I think all young people, especially with communication difficulties, who are subject to any reviewing process, including children in need should have access to advocacy services as a right”

There was overwhelming support across participants for the use of independent advocacy for this group of children and young people. Many IROs argued that children and young people should have access to independent advocacy from as early as possible or at a bare minimum wanted children with complex communication needs to have access to an independent advocate where there was a conflict of rights or they were placed in an out-of-authority placement. As IROs and advocates alike described, an advocate can often provide long-term consistency for a child. During the stakeholder events, IROs shared examples of social workers visiting out of authority schools and not seeing the child. Issues of concern were also raised in respect of safeguarding children with complex communication needs, particularly as in some cases these children might have only a handful of people who understand their communication method, and these same people are asked to present their views.

It was concluded across the stakeholder events that where specialist expertise is not available within the IRO team, the allocated IRO should ensure that from the outset the child has access to specialist support such as independent advocacy so that their wishes and feelings can be elicited effectively. It was also considered important to provide a definition of an advocate as this may not necessarily be a formal service but could be a supporter as in a Natural Ally (someone known to the child, for example, an aunt, uncle or a teacher).

The independent role of advocacy was seen as very important to many IROs. Many had concerns about whose views were being presented at review meetings, as some stated, people come with their own agendas, or parents/carers often complete the consultation form on behalf of the child (possibly because in some areas consultation forms are sent to all children regardless of whether they are accessible to them). There were issues of concern particularly around short breaks and a possible desire for parents to report that their child viewed this more positively than the reality, possibly because parents were desperate for the break and were worried that this service might be withdrawn on the basis of their child’s view (Also a finding reported in Franklin and Sloper, 2007).

Some discussion within the stakeholder groups centred on the need for wider recognition of non-instructed advocacy as a legitimate way to ensure that the wishes and feelings of children and young people with very complex communication needs and limited cognitive abilities are taken account of. (See Knight and Oliver (2007) for a useful discussion of this area).

Another important issue highlighted by some participants was that often children do not know what an advocate is and what advocacy can offer them. Thus being offered an advocate, without this information means they cannot make an informed decision – as one person described, “choice
needs to be a real choice”. Therefore improved and more accessible information for children is required. A number of participants highlighted the important role of visiting advocacy services who visit units for children with complex communication needs and inform the children attending of advocacy services, work with the children to empower them, inform them of their rights and also represent them in some cases.

The lack of knowledge of the accessibility and availability of advocacy services was also a problem for IROs. There was some call for a register of advocates and a national referral service for advocates, particularly for advocates skilled in communication methods.

5.13 Attention should be placed on the independence of those who support children to express their views

As already mentioned, one issue which caused some concern for IROs was reported to be the independence of people tasked with seeking a child’s view, and how some people can promote (deliberately or subconsciously) their own agendas, and thus not objectively present the child’s view. Again the need for independent advocacy was highlighted as a solution to this and the need to wherever possible, find someone independent of a service the child receives, or identify more than one person, to facilitate a child’s involvement.

IROs at the stakeholder events reported that standard consultation documents sent to children are often completed by a child with the foster carer or parent standing over them, or completed by the adult themselves. IROs wanted to feel confident that the information brought to the review is that of the child, without misinterpretation and bias.

In many cases, IROs reported that they rely solely on others to obtain a child’s view if that child has complex communication needs. Discussion in the stakeholder events explored the difficulties this can sometimes present in terms of the objectivity of the person seeking the child’s view and how it was sometimes difficult to untangle whose view was being presented in a review. An understanding of this issue amongst all those involved was seen as important if practice was to improve. The need to be sure that the views being presented were actually the child’s views was important to IROs, but often they had limited recourse to challenge.

My own limited knowledge means I have to take the views and interpretations of others with limited additional independent methods to support and reinforce these.

In addition, general levels of expertise and training amongst those tasked with undertaking the consultation were also reported to be limited and in need of development, alongside any up-skilling of IROs themselves. For example, as we have already established this includes residential staff and advocates as well as social workers.
Some IROs expressed that if they have the lead role in supporting the child
to express their views this can cause difficulties in terms of the IRO
maintaining independence and the need to balance all views and draw
conclusions based on the best interests and wishes of the child. Some IROs
felt that consultation should be the social workers role because there might
be safeguarding issues, but that an IRO should be involved to some degree,
know the child and act as an “addition”. Many felt that an independent
advocate should undertake consultation, so that an objective view would be
presented. Most thought it should be the responsibility of the IRO to ensure
that the child’s view has been obtained, rather than they themselves
undertaking such consultation in every case.

5.14 Multi-agency working should be promoted to facilitate
involvement
Throughout the investigation participants called for more multi-agency
working to promote the participation of children with complex communication
needs, particularly closer links with disability social work teams, and
improved liaison and relationships with schools. IROs wanted to better
understand the communication methods used in schools and resources
available. As a minimum, some described that it would be helpful to have
more knowledge of some of the most common communication methods
supported across the local authority. Some IROs were able to share good
experiences of close collaboration with schools, where education staff had
taught them how a child communicates and undertaken good quality
consultations with children to inform their reviews.

“Some of the best reviews I have been to are the ones that take place
jointly with Educational Reviews – they are more child friendly”.

However, good relationships with schools were described to be “not always
easy to secure as education also have their own priorities around
reviewing”.

5.15 There needs to be improved training and development
opportunities for IROs in communication skills and
methods
The survey asked for details on any training IROs had undertaken with
regard to involving children and young people with complex communication
needs within their reviews. The findings from the survey echoed the
discussions across the stakeholder events; there is a lack of training
undertaken by IROs in this area. As Table Two indicates there was not a
single IRO who rated their skills and training levels with regard to children
with complex communication needs as excellent. Conversely, 39% rated
their skills as poor or very poor in terms of identifying the best methods to
involve children with complex communication needs and 48% again rated
poor or very poor their skill levels in eliciting the views of this group of
children. Training levels were particularly low, 76% had poor or very poor
training levels in specialist communication methods (17% very poor) and the
same figure of 76% for poor and very poor training levels in communicating
with children with complex communication needs. Although the sample of IROs may be small, nearly 8 in 10 stated poor or very poor levels of training in communicating with children with complex communication needs.

Table Two: How IROs rate their skills and training levels regarding children with complex communication needs

<table>
<thead>
<tr>
<th>Skill</th>
<th>Excellent %</th>
<th>Good %</th>
<th>Ok %</th>
<th>Poor %</th>
<th>Very Poor %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skills in identifying the best methods to involve children</td>
<td>0</td>
<td>30</td>
<td>31</td>
<td>37</td>
<td>2</td>
</tr>
<tr>
<td>with complex communication needs (n=57)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skills in eliciting the views of children with complex communication</td>
<td>0</td>
<td>23</td>
<td>29</td>
<td>41</td>
<td>7</td>
</tr>
<tr>
<td>needs (n=58)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Training levels in specialist communication methods</td>
<td>0</td>
<td>9</td>
<td>15</td>
<td>59</td>
<td>17</td>
</tr>
<tr>
<td>(n=58)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Training levels in communicating with children with complex</td>
<td>0</td>
<td>10</td>
<td>14</td>
<td>62</td>
<td>14</td>
</tr>
<tr>
<td>communication needs (n=58)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

There is a need for more training and development opportunities for IROs and IRO Managers, in addition to an up-skilling across the workforce in terms of communication methods. As some IROs indicated they cannot be trained in all communication methods but should have a basic understanding and knowledge of good practice, and access to specialist training, such as Makaton, if required. Many respondents were at odds to highlight that you need the same skills as you would need to work with all children and young people but in addition an awareness and understanding of additional support that a child might need if they have complex communication needs.

5.16 There needs to be improved access to information and resources that facilitate communication

Throughout the survey and stakeholder events, participants reported the need to share information and resources across their authority and become knowledgeable about the range of consultation tools and methods available. Reasons for this included so that they can challenge social workers and others to use the resources. Improved knowledge of accessibility and availability of advocacy services and interpreters as well as more information on training opportunities was also highlighted as necessary.

As already mentioned, IROs and advocates also indicated that children and young people need to have access to communication aids, PCs and
resources so that they can express their views, and for such equipment to be made available at review meetings.

5.17 There needs to be more opportunities available for IROs to share and learn from good practice
IROs reported at the stakeholder events that they lack opportunities to share good practice. Many mentioned that they had valued the opportunities to share knowledge and views as part of this consultation process. More opportunities to share ideas and experiences will help to develop practice in this area, and support those with less experience.

5.18 There needs to be more research on the processes and outcomes of involvement of children with complex communication needs
Although this investigation has provided some evidence, the lack of rigorous research in this area is noticeable, and in particular a lack of evidence on the processes and outcomes of involvement of children with complex communication needs within the reviewing process. The sharing of ‘what works’ will help to improve practice. Most alarming is the absence of the views of children with complex communication needs about how to improve their involvement; more research with children in this area is vital.
6 Informing the guidance

In addition to the findings and recommendations presented, attendees at the stakeholder events were asked specifically what they would want to see in the new IRO guidance. The following points were taken into consideration and underpinned the submission of the draft guidance to DCSF. Stakeholders suggested that the guidance includes:

- A recognition of the need to communicate with ALL children and that this equally applies to children with complex communication needs.
- Examples of how a child could be involved and illustrations of good practice so that local authorities can benchmark their practice and push for improved standards. Case studies and a range of approaches should be illustrated.
- A clear step-by-step approach that IROs should take.
- A national requirement for IROs to facilitate involvement because it is a rights issue.
- A prescription about how an independent advocate or other support person is identified.
- A recognition that the involvement of children with complex communication needs requires a unique/individual approach.
- A reinforcement that the IRO role remains independent and achievable.
7 Conclusion

This investigation sought to gather information in order to inform new IRO guidance. Specifically, it sought evidence on the extent to which IROs were able to facilitate the involvement of children with complex communication needs within the reviewing process, and what more needed to be done to improve practice in this area. Although this investigation is small, and therefore limited in scope, the messages from this, in collaboration with the limited research evidence available, points to the following findings and recommendations.

Children with complex communication needs are still not being adequately involved within the reviewing process, especially children with additional support needs such as autism, learning disabilities and sensory impairments. There also appears to be a lack of knowledge, understanding and training concerning this area of practice.

In order to improve the involvement of children with complex communication needs within the reviewing process, there requires a commitment to, and expectation of, participation of this group of children. In addition, an improved understanding that participation can be facilitated in multiple ways and at multiple levels. Similarly, there needs to be a better understanding of communication and the multiple forms this can take. Training across all levels of the workforce appears to be required. Training and skills development for IROs is vital, however, IROs cannot be skilled in all methods of communication, and thus cannot work in isolation. They need access to resources, more time and specialist services such as advocacy to support children to express their views.

The following recommendations to improve practice were identified:

- A change in attitudes towards the involvement of children with complex communication needs.
- An improved and wider understanding of the meaning of participation.
- An improved and wider understanding of the variety of ways and methods in which children communicate.
- Involvement should be seen as a process not an event or meeting.
- Involvement should be holistic and individualised.
- A child’s preferred communication method should be identified and recorded on their care plan.
- A child’s involvement in their review process should be recorded and reviewed regularly.
• There should be continuity of an IRO for children with complex communication needs.
• IROs caseloads should be adjusted to reflect the longer time it takes to involve children with complex communication needs.
• Multi-agency working should be promoted to facilitate involvement.
• Independent advocacy should be made available to children.
• Children should be given a choice about participating and who helps them to express their views.
• Attention should be placed on the independence of those who support children to express their views.
• There needs to be improved training and skills development for IROs.
• Consideration should be given to identifying a specialist IRO within the team.
• There needs to be improved access to information and resources that facilitate communication.
• There needs to be more opportunities for IROs to share and learn from good practice.
• There needs to be more research on the processes and outcomes of the involvement of children with complex communication needs.
Appendix One: Attendees at stakeholder consultation events

London:
Louise Boxer Action for Children, 
Celia Brockhurst, Independent IRO Essex, 
Liz Gosling LAC Islington, 
Sue Hearne IRO Lambeth, 
Nadine Ibbotson Action for Children 
Jennifer Johnson IRO Stoke 
Rachel Larking, IRO West Sussex 
Sarah Mepham Mencap 
Hayley Nicholls TCS London DAP 
Paula Perryman National Autistic Society 
Maggie Siviter IRO Bath 
Daphne Smewing IRO Stoke 
Chris Stewart LAC Islington 
Julie Tadd IRO Luton 
Amandeep Thind TCS London DAP 
Amanda Wright IRO Herts 
Nicola Wyld Voice

York:
Sue Burns IRO Manager North Tyneside 
Peter Cobb IRO Newcastle 
Dan Horne IRO Hull 
Nicky Linacre IRO Leeds 
Robin Logan IRO Suffolk 
Marie McCallum IRO Stockton 
Edna Murray IRO Leeds 
Derek Ruddick IRO Bradford 
David Webster, NYAS 
Rebecca Wall IRO Durham

Birmingham:
Agnes Gault IRO Swindon 
Linda Green IRO Birmingham 
Carolann James IRO Manager Milton Keynes 
Balwinder Jandu IRO Sandwell 
Barbara Lee IRO Oxfordshire 
Maggie Levans-Harris IRO Wolverhampton 
Karen Mitchell IRO Conrnwall 
Jerry Ogdon IRO Sandwell 
Pauline Robbins Voice 
Paul Russell IRO Sandwell 
Claire Sayer Action for Children N Somerset 
Alyson Sefton NYAS 
Marie Shaw, IRO Derbyshire 
Ray Tait NSPCC Childrens Rights Officer 
Morvette Williams IRO Nottingham 
Celia Winter IRO Hertfordshire 
Kay Vincent IRO Worcestershire
Appendix Two: References


The Communication Trust (2009) *Explaining speech, language and communication needs* (SLCN). London, The Communication Trust. [www.thecommunicationtrust.org.uk](http://www.thecommunicationtrust.org.uk)


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