research in practice







Communicating with children and young people with speech, language and communication needs and/or developmental delay

Dartington

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Introduction

This briefing is aimed at professionals who work directly with children and young people who have speech, language and communication needs and/or developmental delay. It may also be helpful for people working in child advocacy roles.

The importance and principles of involving children and young people in decisions and processes that affect them are highlighted in several key pieces of policy and legislation, including The Children's Act 1989 and 2004, the NHS Act 2006 and, most recently, the Children and Families Act 2014 and the Care Act 2014. These place duties on local authorities to ensure that the views, wishes and opinions of children and young people are ascertained and given due weight. It is paramount that practitioners prioritise the voice of the child and develop skills and confidence to ensure their voice is heard.

Speech, language and communication needs (SLCN) is a term used to describe a difficulty with some form of communication. This can be where speech or language does not develop at the expected or average pattern, or at the expected or average rate. It can also describe difficulties with expressive language (making themselves understood) or receptive language (understanding what is being communicated) (The Communication Trust, 2011).

Developmental delay is a generic description used when a child does not reach certain developmental milestones by a certain point in their development. Developmental delay can include speech, language and communication skills; but also motor, cognitive, and social and emotional skills (Contact a Family, 2015).

Some children and young people with SLCN will also have another form of developmental delay, or be disabled. However, others have SLCN without any other physical or learning disabilities or developmental delay. Moreover, whilst some of these children and young people may be defined as disabled in service terms, they may or may not personally identify as being disabled or having a disability. For the purposes of this briefing, the term 'disabled children and young people' includes children and young people with SLCN and/or developmental delay.

Some of the specific barriers for young people with SLCN and/or developmental delay include:

- > misconceptions about a child or young person's capacity
- misconceptions about a child or young person's ability to communicate
- non-verbal or other means of communication not being recognised or valued in the same way as verbal communication
- > not allowing enough time during assessments
- > availability of independent interpreters or facilitators.

(Participation Works, 2008; VIPER, 2013)

The price of not listening

Disabled children have the right to receive a comprehensive child-focused assessment of their needs in which their views and expectations are central, with the full participation of all agencies involved so that the needs of the disabled child are not allowed to mask safeguarding and child protection concerns. (Ofsted, 2011)

Disabled children and young people are three times more likely to be abused or neglected than other children and young people. Children who are at particular risk include those with learning difficulties/disabilities, speech and language difficulties, health-related conditions and deaf children (NSPCC, 2014).

Several factors contribute to the challenges to safeguarding disabled children and young people, these include:

- Disclosures of abuse not being taken seriously or downplayed.
- Lack of identification of the signs and indicators of abuse or attributing these to a child's impairment or condition.
- Lack of understanding of impairment specific behaviour and communication needs, particularly where children and young people exhibit behaviour that challenges.
- > Social isolation.
- Children and young people being reliant on parents, carers or other professionals to meet care and support needs.
- Reluctance by practitioners to challenge parents, carers or other professionals.
- Lack of awareness from children and young people that abuse is happening and/or a lack of awareness of how to seek help.
- > The infantilisation of disabled children and young people.
- The lack of their voice, needs, wishes and views being heard and responded to (NSPCC, 2014; Franklin, 2015).

"You do tend to get parents spoke to instead of you, or you don't get involved as much because you just get overlooked."

Young person

Recent research by Ofsted into serious case review judgements highlights the importance of the voice of the child in safeguarding and child protection (Ofsted, 2011). The report outlines five themes which contribute to ensuring the voice of the child is adequately represented:

- 1. Children and young people should be seen and observed frequently by practitioners on their own and/or in an environment that is appropriate to their needs and allows the children to express themselves. Practitioners should also prioritise the use of appropriate communication methods when working with disabled children and young people.
- 2. Practitioners should balance the risk that exists where the voice of the parent is over relied on, with the risk where the voice of a parent is not listened to when they had important information to contribute.
- Safeguarding children and young people should be the main concern and priority and not be overlooked to protect family privacy.
- 4. Practitioners should primarily focus
 on the needs of the child, not on
 meeting the needs of the parents

 particularly where parents are
 vulnerable themselves.
- Practitioners should not only listen to the voice of children and young people, but respond to it by developing actions that ensure the child or young person is protected.

However, children and young people continue to report that they are not listened to and views are often sought from families rather than them.

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Questions for practice

- How are we safeguarding children and young people with speech and language impairments and developmental delay?
- Are we routinely listening to the voice of these children and young people in a setting that is appropriate to their needs?
- How are we eliciting the voice of the child in situations where parents, carers and other professionals are very vocal about their needs?
- How are we responding to what the child or young person tells us? For example, are we developing an action plan which ensures the child or young person is adequately protected?

Beyond the spoken voice

When we talk about voice, it's important to recognise that we're talking about all communication. There is a danger that we only listen to those children and young people who can easily tell us their views. Subsequently, we don't deliver services that meet the needs of children and young people who have a range of differing support needs.

This means:

- starting from the assumption that all children and young people can and do communicate
- getting to know the children and young people we are working with and the communication systems they use
- giving children and young people enough time to communicate
- being willing to learn from the child or young person about how they prefer to communicate
- taking time to understand what we as practitioners can do to support that child and the barriers to that child's communication (What helps? What gets in the way?)
- giving children and young people clear, simple and accessible information in a format that best works for them - no jargon
- not making assumptions about what a child or young person is saying; check that you have understood.

(The Communication Trust, 2011; Participation Works, 2008)

Every child has a way to make their wishes, views, likes and dislikes known. Many young people with communication needs will communicate through a specific system or method. For example:

- Gestures including body language, facial expressions and eyepointing.
- > Formal signing systems such as Makaton and British Sign Language.
- Symbol support, including paperbased communication tools such as Talking Mats or communication passports and boards.
- > Written messages.
- > Voice output communication aids.

(The Communication Trust, 2011)

However, other, more informal, methods can be used to facilitate communication with young people with communication needs. Practitioners may consider using methods such as questionnaires, visual aids, kinaesthetic strategies (using movement and touch), video clips or diaries, observations and creative methods such as drawing, role-play, storytelling, or the use of 'third objects' (Mitchell, 1981) such as toys, games or hobbies to focus on and help establish a connection with the child (Atkinson et al, 2015).



Questions for practice

- How confident are we (as individuals and as a team) in communicating with children and young people with speech, language and communication impairments and developmental delay?
- Are there any opportunities to learn from colleagues or other health and social care professionals about using alternative communication methods in practice?

Building a listening culture

Having high expectations of how children and young people can and do communicate is fundamental to building a listening culture.

In order to build a listening culture we must:

- start from a place of assuming capacity
- understand the potential impacts of not listening on children and young people's outcomes
- view children and young people's involvement in decisions from a rights-based perspective
- embed the principles of co-production and person-centred approaches in our day-to-day working practices.

Although individual and strategic decision-making are often seen as different entities, the two are not mutually exclusive. Children and young people must be supported to develop the skills and confidence to be involved. in decision-making from a young age. Person-centred approaches are key in effectively supporting decision-making, for example using person-centred annual reviews to recognise what is and isn't working in an individual's care and support plan or personal budget. Having autonomy over decisions which affect individuals support and care will, in turn, develop their skills and confidence to be involved in decisions about service design and development or, indeed, strategic level decisions about local area provision.

"We can make our own decisions. We have our own ideas about what we'd like to achieve."

Young person

Practitioners should be able to link strategically with the right people to ensure that the views, wishes and experiences of children and young people can influence and impact on local authority practice and processes. This approach requires a culture change, shifting from children and young people being 'done to' towards a culture of collaborative engagement, which challenges traditional professional/client relationships (Selwyn, 2016).

Attitudes, understanding and skills

Effective communication, having empathy and being flexible to individuals' needs are crucial to the success of practitioners' relationships with children and young people. More specifically, this includes:

- having a positive attitude about children and young people's abilities
- demonstrating a 'can-do' attitude to problem-solving
- being willing to try something new or different if a tried and tested approach hasn't worked
- understanding children and young people as individuals
- seeing children and young people as experts in their own lives
- > being reflective.



Questions for practice

- Are we being person-centred in our practice? For example, giving children and young people choice and making sure they can lead where appropriate?
- Are we supporting and facilitating children and young people to communicate, as opposed to assuming we know what they want, or speaking for them?
- Are we demonstrating and communicating evidence of impact to children, young people, parents and other professionals, to ensure they can see where their involvement has made a difference, both in their own lives and in wider policy development? (VIPER, 2013)

Inclusive and accessible processes, systems and structures

The Social Model of Disability describes the identification and removal of barriers (Oliver, 2012). This includes barriers to participation and communication. Using the model's principles, practitioners should frame conversations with children and young people in terms of what they need to take part, not on what they can't do, or unnecessary details about their impairment or condition. Additionally, people's needs change over time, so it's important not to assume that needs are the same as before.

Methods to support inclusion include:

- > Framing conversations with children and young people in terms of what's working and what's not working ensures that practitioners can understand what needs to change to improve services or processes that a child or young person uses.
- Person-centred tools such as creating action plans ensure that practitioners can evidence how change has happened (Helen Sanderson).
- Providing children and young people with choice over the decisions and processes they are involved in. It is the child's choice not to take part, but practitioners should ensure that all possible efforts have been made to support their rights to involvement; explain the purpose of involvement; make clear how their contributions will be used.
- Producing appropriate, accessible information in a format that is preferred by the child or young person.

By gathering feedback from children and young people about their experiences of assessment, practitioners can continue to develop systems, structures and processes that are proactive and not reactive.

A range of methods and approaches

All children and young people should be supported to contribute to assessments and other decision-making processes that affect their care and support. It's important to recognise that this means different things to different young people and is not a 'one-size fits all' approach. Practitioners should consider a range of approaches to gather children and young people's views. This requires a planned and proactive approach and consideration of how children and young people can have their say before a formal needs assessment process starts.

Alison Clark and Peter Moss first described the 'Mosaic Approach' for working with children under five (Clark, 2001). This approach gathers the views and experiences of children using a range of different methods which complement each other and build a holistic view of children's experiences. It starts from the principle that children are 'experts in their own lives' and puts them at the centre of the process of gathering information using a variety of different approaches and techniques. These may include drawing, mapmaking, role play and photographs taken by the child; alongside observations of the child in situ and interviews with people close to the child (for example parents, key workers, etc).

The principles of the 'Mosaic Approach' can easily be adapted to working with children and young people with speech, language or communication needs, or developmental delay, or for children and young people with English as an additional language. The second edition published in 2011 includes new examples of how the Mosaic approach has been adapted, and offers case studies that will encourage practitioners to use the framework in their own setting (Clark and Moss, 2011).

Person-centred approaches and outcomes

Person-centred planning describes the approach taken to plan the support that enables a child or young person to increase their independence and control in their life (loseph Rowntree Foundation, 2006). A wealth of resources and person-centred planning tools exist to support practitioners in using this approach during assessments (Social Care Institute for Excellence; Helen Sanderson Associates; TLAP, 2015; Dimensions). However, it is important to highlight that this is not just about assessment, practitioners must give consideration to the development of outcomes as well as the identification of support needs.

Crucially, this is backed up by evidence through the 'CHUMs' study (Peninsula Medical School, 2014), which highlights the difference between the health outcomes that children and young people set for themselves, and those identified as important or priorities to professionals. Outcomes identified by young people as most important had more focus on emotional wellbeing and social and community life, as opposed to being about a specific function.

Historically, a service-led approach has meant that services are provided based on standardised approaches to assessment, linking needs to eligibility criteria and what services are currently available. In contrast, a person-centred approach requires practitioners to put the views of the child or young person at the centre of the process. It requires identifying what works for the individual, focusing on strengths and goals, identifying and setting outcomes and priorities with them, and identifying a range of different ways to meet outcomes (Cook, 2009).

Evaluation and impact

Demonstrating that children and young people's contributions are valued by others and make a difference is important to ensure they don't feel assessments or decision-making processes are a 'tick-box' exercise. Practitioners should regularly feedback to children and young people the outcome of decisions, even when they are not what the young person wants. Children and young people have reported that it's important they're told what is happening, otherwise they feel they have not been listened to.

The Communication Trust recently produced a practice development resource for staff working in education settings on how to involve children and young people with SLCN in decisions, with a key focus on using personcentred approaches within the context of developing and delivering outcomes for children and young people with speech, language and communication needs (The Communication Trust, 2016).

Accessible assessment approaches

Children and young people with SLCN or developmental delay may not be used to being asked about what they need, so additional support and time should be built in to the assessment process for them to consider and reflect on identifying their needs; and respond. It's important that practitioners and children and young people have a shared understanding that information is used to facilitate inclusion, not evidence exclusion. Conversations should be framed in terms of "How can we help?" and "What can we do?", and should begin with a discussion about why information is needed and being asked for.

Interviews with young people in Bromley highlight that many young people did not know about the process of assessment or that they were taking part in an assessment (Council for Disabled Children, 2016). They felt that the assessment process was 'a tick box' exercise and, moreover, the lack of information about, or understanding of, the process left them feeling anxious before the assessment had started. Using a range of different, creative methods and approaches may be more successful than traditional conversations or interview style processes as they provide opportunities for practitioners to ask more open questions and reduce leading questioning. Using visual aids and methods supports language processing, reduces memory demands and improves focus.

The Department for Education (DfE)
Children's Social Care Innovation
Programme aims to understand more
effective ways of supporting children
and families who use children's social
care services. As part of this programme,
the Council for Disabled Children is
researching how local areas co-produce
assessment processes with children,
young people and families.

Transforming culture and practice in children's social care assessments has so far highlighted accessible methods and approaches to involving children, young people and families in assessment processes. For example, self-assessment questionnaires and surveys for carrying out early help assessments; involving a wide range of professionals through multi-disciplinary assessments; observations; and carrying out assessments within the community (Council for Disabled Children, 2016). The full report, including examples of these tools, is due to be published in September 2016.

"I believe that disabled young people should be involved in decisions that could really affect them because they are the ones that are going to be affected and they know what helps them in life and what doesn't."

Young person

Practitioners should begin by breaking down the needs assessment process into distinct phases, considering what is involved and how to involve children and young people at each stage of the process. For example:

Pre-meeting:

- Provide children and young people with some personal information about yourself. 'All About Me' forms are a widely used tool to help children and young people get to know the professionals in their lives.
- Provide clear, accessible information about the process to children and young people in the format that is most suitable to them. What does it mean, what will happen and when, how they can be involved, how will decisions be made and how will those decisions affect them?
- Provide a list of questions about what will be asked to help the young person think about what they want to say beforehand; for example likes, dislikes, who or what is important in your life, daily routines, how do you spend leisure time, what things do you need help with?
- Consider confidentiality and consent for the young person's views to be recorded. Young people may want to know who sees the information they give and how it is used.

Assessment or review meeting:

- Meetings should be arranged at a time and in a location that works for young people - such as at home, or in community settings, and not during school time.
- Meetings should be held in a relaxed or informal setting, perhaps utilising activities the child or young person enjoys.
- Children and young people should be offered to invite (where appropriate) someone they feel can best support them to input their views.
- Meetings should focus solely on the child or young person or, where that is not possible, part of the meeting should be dedicated to the child or young person.
- Children and young people should be given an equal chance to express themselves.
- Time is important. Children and young people will need adequate time to contribute; however, meetings should not be overly lengthy.

Should, for whatever reason, a child or young person be unable or unwilling to take part in a meeting, practitioners should seek alternative ways to ensure they have an opportunity to input their views. This could include:

- Using young people profiles, photo diaries, video clips.
- Story telling or creating visual maps of what children and young people want, and/or their experiences.
- Observations from services or settings that children use and enjoy can be fed in.
- > Emotive user journeys to map how assessment feels for the child or voung person (Department for Education, 2016).
- Completing a self-assessment or supported self-assessment with professionals or other individuals. For example Surrey, Somerset and Northamptonshire:

tinyurl.com/z87dwod tinyurl.com/hxa8ue4 tinyurl.com/hcfmqqt

Post-meeting:

- Reiterate what will be done with the information.
- Provide clear and honest next steps and timescales (when can they expect a decision or a review meeting)?
- Where possible, provide feedback to the child or young person about how their views impacted on decisions and/or the process.

Involving family and carers

Children and young people often do not know they have the right to participate in decisions and processes that affect them and may defer to parents to tell professionals about their needs because they lack the skills and confidence to do so themselves. Similarly, professionals will often be used to discussing processes or aspects of care or support with parents or other family members, particularly where a child or young person is under 18 or has been assessed as lacking capacity. In these cases it is the practitioner's responsibility to ensure children and young people have adequate information to understand they can have their say, and what difference their voice will make to the process.

One of the key issues raised by practitioners is what we can do when parents and children and young people disagree. Best interests and wellbeing principles from the *Mental Capacity* Act 2005 and the Care Act 2014 can be applied to support practitioners to navigate some of these issues and, of course, consideration must be given to the age and capacity of the child or young person.

Families, personal assistants and other professionals play an important role in gathering information about young people's needs. They are often the most experienced in their child or young person's preferred communication method and hold much of the information practitioners will need to develop plans to include young people. Crucially, it's about building a relationship of trust with the child or young person, their family and the people who work closely with them, and recognising that doesn't happen overnight.

We might not always get it right first time but, as young people have told us, it's important for them to see that we are trying and want to work with them to understand them.

Using advocates

Where working with families and guardians is not possible or appropriate, advocates may provide additional support to children and young people with SLCN and/or developmental delay in assessment processes. Advocacy is described as supporting individuals to have their say and making sure their views and wishes are taken into consideration on decisions and matters that affect them. It is also about ensuring that rights are upheld.

The Care Act 2014 introduced new duties for local authorities to commission advocacy services for those who require additional support to take part in 'care and support processes' (Department of Health, 2015). The Mental Capacity Act 2005 establishes the role of an Independent Mental Capacity Advocate, which supports people who lack capacity to participate in decisions, and Working Together 2015 highlights the potential use of advocates in assessment and safeguarding procedures.

Furthermore, other legislation and associated regulations provide guidance on the right to access and the provision of advocacy services that are relevant to working with children and young people with SLCN and/or development delay. These include (but are not restricted to) the Children Act 1989, Getting the Best from Complaints guidance (Department for Education, 2006) and Planning Transition to Adulthood for Care Leavers (Department for Education, 2010); as well as the National Standards for the Provision of Children's Advocacy Services (Department of Health, 2002).

Advocates can either be directed or nondirected (where the advocate gathers information through observation and other methods to act on someone's behalf) but, either way, act specifically with and for the child or young person to support them to express their views, choices and decisions; even if they don't agree that the decision is in the child's best interests. Most advocacy is time limited and single issue based. Types of decisions that advocates could support children and young people with include:

- reviews and safeguarding meetings
- planning for transition to adult services
- moving from mainstream to special school and/or vice versa
- contact with parents
- ensuring that children and young people are able to access and use appropriate services.

In particular, advocates for children and young people with SLCN and/or developmental delay often act as an objective facilitator to communication for those children and young people who are reliant on others to support them, and consequently provide a key safeguarding role for children and young people who are more likely to be vulnerable to abuse (The Children's Society, 2011).

Working with adolescents with communication needs

The purpose of risk assessment remains the same for adolescents with SLCN and/or developmental delay, as it does for any other young person; namely to identify, analyse and determine how to manage or, where possible, eliminate risk and reduce any necessary risks to a level that is 'reasonably practicable' without undermining the benefits of that activity to the young person. Central to this process needs to be identifying what good long-term outcomes are for the young person and how we are engaging them in developing their own outcomes.

Disabled young people are at greater risk of forced marriage, gang activity and peer pressure to engage in anti-social behaviour, bullying and intimidation, and sexual exploitation (NSPCC, 2014). However, a balance needs to be struck between overly assessing for things that are simple (such as risk aversion to inclusion in mainstream activities) and under-assessing or not focusing enough on potential safeguarding issues because they are hard to identify and because the needs of the young person have not been given due consideration.



Questions for practice

- What do practitioners think about a young person with a learning disability drinking alcohol?
- What are practitioners' views about sex and relationships education for disabled young people?
- Should young people with SLCN and/or developmental delay be afforded the same consent and confidentiality arrangements as other young people?
- How do professionals identify, assess and manage children and young people's behaviour, particularly when it is behaviour that challenges?

The Mental Capacity Act is a useful legislative tool to support practitioners to manage risk with young people. It applies to young people over the age of 16, specifically in regards to decision-making; and sets out what should happen when people are unable to make one or more decisions for themselves, and is based on a single decision at a single time.

The *Mental Capacity Act* sets out five key principles when assessing capacity to be involved in decisions:

- We should always assume capacity unless and until it can be proven otherwise, so practitioners should not assume that a young person cannot make a decision because they are disabled or have a Special Educational Need.
- 2. All practicable help and support should be provided in order for a person to understand and communicate their decision.
- 3. Once a child has turned 16 they have the right to take risks. It should not be presumed that someone doesn't have capacity just because they have made an unwise decision; if they understand the consequences of their decision, it is their decision to make.
- 4. If it has been assumed that a person doesn't have capacity, all decisions that are taken on their behalf must be done in their best interests.
- 5. When decisions are being made on behalf of someone who lacks capacity, it should limit their right to freedom as little as possible.

(Department for Constitutional Affairs, 2005)

The Mental Capacity Act and accompanying Code of Practice also set out clear guidelines about the 'best interest' process that should be applied if it is assessed that a person does not have capacity to make a decision for themselves. While the legislative power only applies to young people over 16, the Mental Capacity Act principles are a useful guide for practitioners navigating the tricky questions of how to support young people with communication needs and developmental delay to understand and manage risk.

The legal context

A number of existing statutory duties, policy drivers and practice guidance promote children and young people's voice in decision-making. Many of these, such as the UNCRC, the UNCRPD, the Children Act 1989 and the Children Act 2004 are well known to frontline practitioners and have been discussed in other literature (Atkinson et al, 2015).

The Equalities Act 2010 puts a duty on local areas and public services to actively promote disability equality and make reasonable adjustments. This extends to adjustments to services or practice which will allow children and young people to participate in decision-making about their own support and care, as well as service design and development.

A number of recent pieces of legislation include duties on local authorities relevant to practitioners working with children and young people with speech, language and communication needs, and developmental delay. These are the Children and Families Act 2014, the Mental Capacity Act 2005, the Care Act 2014 and Working Together to Safeguard Children guidance 2015.

Section 19 of the *Children and Families* Act states that the local authority must have regard to the views, wishes and feelings of the child or young person and, crucially, that the child or young person must be provided with the information and support necessary to enable them to participate in decisions. These relate to decisions about their individual care and support, and not necessarily collective or strategic level decision-making. It also extends the right to appeal to the Special **Educational Needs and Disability Tribunal** (SENDIST), which will have implications for how children and young people are supported to participate and have their views heard in these decision-making processes.

The Care Act 2014 places a general duty on local authorities to promote individual wellbeing, which is relevant to young people with care and support needs post-16. Much like the Children and Families Act, and Mental Capacity Act, the wellbeing principle highlights that professionals should ascertain the wishes, views, feelings and beliefs of those who have care and support needs; and highlights the importance of people being supported to be involved as much as possible in decisions about their support and care. The Care Act 2014 will be of particular relevance to young people with communication needs going through transition assessments and where they are moving into adult care services.

Definitions

Disabled children and young people

The Equality Act 2010 states that a person is disabled if they have 'a physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.' Substantial is defined as 'being more than minor or trivial' and long-term as 'a year or more.'

This definition can be applied to children and young people with speech, language and communication needs. However, as highlighted earlier, children and young people with SLCN may or may not identify as 'disabled'.

Participation

Participation is the active process by which individuals or groups can influence decision-making and bring about change (Sloper, 2007).

This applies equally to changes in service provision and delivery to changes in how young people experience receiving their individual support and care.

Co-production

'Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours.' (New Economics Foundation, 2009)

Social Model of Disability

The Social Model of Disability was developed by disabled people and states that it's society's reaction to impairments that disables people rather than impairments themselves. Taking a Social Model approach means focusing on what people can do and how everyone can be included, not making assumptions, and working with young people to identify potential barriers and find solutions together (Oliver, 2012).

Inclusion

Inclusion and participation are distinct terminologies that have a reciprocal relationship. Inclusion is the identification and removal of barriers that prevent children and young people with additional support needs accessing the same opportunities as their peers. Participation is when children and young people are involved in decisions and issues that affect them. The voices and experiences of children and young people in decision-making is one of the key principles of inclusion and is key to developing processes, systems and services that work for those who use them. Similarly, systems and processes for children and young people to express their views, wishes and feelings must be accessible and inclusive before they can participate.

(Council for Disabled Children, 2008; 2009)

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