

Working with Disabled Children

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Revised Edition 2

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DIVERSITY ISSUES IN THE TRAINING SETTING

People who present courses for Reconstruct make some assumptions, even though we're supposed not to, about participants.

These are that the group will contain people from a diverse range of backgrounds, some visible some less visible, some personal some professional. This diversity will cover gender, race, sexual orientation, disability and a lot more including personal experiences, class and religious persuasion.

So this means that the course will:

- Be presented using variety because people have different learning styles.
- Describe concepts using a variety of examples.

The presenters will:

- Avoid jargon (or at least explain it).
- Be aware of individual differences within the group and respect these.
- Avoid the stereotyping of particular groups in society.
- Be aware of the effect of language.
- Accept that everyone has the right and the responsibility to challenge.

Additionally the facilitators hope that participants will:

- Arrive punctually and stay (but explain unavoidable absences).
- Respect each other.
- Maintain the confidentiality of sensitive information.
- Recognise and value difference.
- Share experiences.
- Ask questions.
- Challenge views constructively.

We hope that this will provide a useful framework within which learning and development can take place.

The 'Working with Disabled Children' Resource Book

The resource book is provided to compliment the training. It should be used in the context of an ongoing learning process. This resource book will be used for the following courses:

- Protecting Children with Disabilities
- Communicating with Disabled Children
- Transitional Planning for Disabled Children

Every attempt has been made to ensure that all information and quotes have been accurately referenced.



WHEN YOU LOOK AT MY CHILD

What do you see
When you look at my child?
How does he make you feel?

Yours words confirm what I see in your eyes
Confident words, so secure
In the assumptions that you make.

Which child are you speaking about?.....

When did I tell you I wanted him changed
Than I would prefer him different
From as he is?
When did I tell you I wanted your help
To change him?
I longed for my child for such a long time
I met him and chose him
And held my breath for a while.
I was very lucky.
He decided I belonged to him too.

Why would I change him?
Don't you realise that I can feel
Your need to change him
Your need for him to be other than as he is
To be "improved"
To be more or less or whatever
You are disturbed by?

Don't you understand that
The comments you make about my child
Tell more about yourself
And not about him?

And the needs we discuss
Are yours
And not his.
When you look at my child.

Jill Penman
Let our Children Be

Cited in 'All Our Children Belong'⁴⁶



STATISTICS AND TRENDS

Collecting concise information on disabled children and outcomes is difficult due to a lack of an agreed definition of a 'disabled child' and of agreed methods of collating information. This can impact on the planning, design and delivery of services. The Families Resources Survey¹ estimates that:

- There are 700,000 (approx.) disabled children under the age of 16 years in Great Britain.
- Up to 6,000 children living at home that are dependent on assistive technology.
- The number of children diagnosed with autistic spectrum disorders has increased in the last ten years.
- An estimated 1.2 million school-age children have special educational needs (14% of school-aged population).
- 250,000 pupils have statements of special educational need (3% of all pupils).

The 'Every Child Matters' website² states: "disabled children and young people currently face multiple barriers which make it more difficult for them to achieve their potential, to achieve the outcomes their peers expect and to succeed in education." The following figures are provided:

- "Approximately 770,000 (7%) of children in the UK are disabled.
- 29% of children live in poverty.
- Educational attainment of disabled children is unacceptably lower than that of non-disabled children and less than 50% of schools have accessibility plans.
- Disabled young people aged 16-24 years are less satisfied with their lives than their peers and there is a tendency for support to fall away at key transition points as young people move from child to adult services.
- Families with disabled children report particularly high levels of unmet needs, isolation and stress.
- Only 4% of disabled children are supported by social services.
- There is a lottery of provision, inadequate strategic planning, confusing eligibility criteria and families are subjected to long waits and had to jump through hoops to get services [from the Audit Commission, 2003].
- The prevalence of severe disability is increasing.
- Disabled children, especially those with learning difficulties, are more likely to experience behavioural and emotional difficulties than non-disabled children."

Furthermore, mothers of disabled children are less likely to be in paid employment compared to mothers of non-disabled children³. Families of disabled children who are most vulnerable are least likely to apply for DLA⁴ and families with disabled children are rarely in receipt of the childcare tax credit because they are less likely to be in paid employment due to caring responsibilities.

¹ Department for Work and Pensions (2004). Family Resources Survey 2002-3.

² www.everychildmatters.gov.uk/socialcare/disabledchildren/facts

³ Beresford, B., Sloper, P., Baldwin, S. & Newman, T. (1996). What works in services for families with disabled children? Barnardo's.

⁴ Chamba *et al* (1999) cited in Preston, G. (2005). Helter Skelter. Families, disabled children and the benefit system. Disability Alliance.



MODELS OF DISABILITY AND DEFINITIONS

“The needs of disabled children, young people and their families are unique. They are often complex and change over time. The challenge is to understand these needs and develop a whole system of services around them – a system that is flexible enough to meet the requirements of individuals and diverse populations.”⁵

The Medical Model

The medical model sees disabled people as ill or sick and as patients. Under this model disabled people must be ‘cured’ or ‘made better’. The only true experts are medical professionals who explain, in general terms, how disability “limits” disabled people. Disabled people therefore have things done to and for them, which ultimately leads to disempowerment by those “who know best”.

This, as a model, holds significant power. This is exemplified, for example, in the medical evidence required in registering as disabled. Another example is the way in which society internalises the medicalisation of disability seeking and relying on ‘cures’.

The Charity Model

This model portrays disabled people as being worthy of pity. They are “brave”, “resilient people” who despite their misfortune survive and get on well. Disability is viewed as a personal disaster. Control and power rests with well meaning non-disabled people who strive to bring about change for the benefit of the “afflicted”. The language used is similar to that used in the medical model. People are “crippled” with polio, “afflicted” with arthritis, “suffering” from, a stroke etc. Disabled people are ultimately expected to be grateful for what they receive and are therefore required to be submissive.

In employment terms attention is focussed on whether people ‘are up to it’ or whether they can ‘cope’, ‘it wouldn’t be fair on them’ etc. Within this model, for example, non-disabled people may discuss disability amongst themselves during the recruitment process but would not enter into a direct dialogue with the disabled candidates.

The Social Model

The social model of disability is linked to the way in which society organises itself. Disabled people are seen as having wants, needs and aspirations. Passivity is replaced by a demand for equality. Disability is not seen as something invoking pity or in need of a cure. It may be viewed as a positive asset. Equality for disabled people is seen in the same light as equality for other under represented groups. In employment terms the social model looks at job modifications building adaptations, organisational restructuring etc. Changes are seen to be beneficial to all and disabled people are seen as assets and not problems.

⁵ Audit Commission (2003). Let Me Be Me: A handbook for managers and staff working with disabled children and their families.



“The social model uses the term ‘disability’ not to refer to impairment (functional limitations) but rather to describe the effects of prejudice and discrimination: the social factors which create barriers, deny opportunities, and thereby dis-able people.”⁶

When considering the models and their application, it is important to note that the models may not be as diametrically opposed as the above analysis suggests. It could be that the reality for disabled children is somewhere in-between. For practitioners, it is important to develop an understanding of the power differentials that exist between the models and of the experience of the service user/s with whom they are working.

In the paper, Improving Life Chances of Disabled People⁷, disability is defined as:

- “**Disadvantage** experienced by an individual...
- ...resulting from **barriers** to independent living or educational, employment or other opportunities
- ...that impact on people with **impairments** and/or ill health.”

This definition makes a clear distinction between disability, ill-health and impairment. The Report continues to state:

- “**Impairments** are long-term characteristics of an individual that affect their functioning and/or appearance.
- “**Ill health** is the short-term or long-term consequence of disease or sickness.”
- “Many people who have an impairment or ill health would not consider themselves to be disabled.”

The report summarises some of the types of barriers faced by disabled people:

- Attitudinal.
- Policy – policy design that doesn’t take disabled people into account.
- Physical – through design of environments, transport etc.
- Empowerment-linked – disabled people not listened to, consulted or involved.

Complex Needs

Marchant⁸ defines children with complex needs as:

- “Children who have major health care needs in addition to their impairments, including children with life-limiting conditions.
- Children who have more than one impairment affecting their communication or more than one impairment having other major impact on their lives.
- Children whose impairments have been caused by maltreatment, including those children whose disability is a consequence of the parent inducing or fabricating the child’s illness.
- Most children with complex needs will then, be disabled, but not all disabled children have complex needs.”

⁶ Morris, J.

⁷ DWP, DoH, DfES, OPMD (2005). Improving the Life Chances of Disabled People.

⁸ Marchant, R. (2003). ‘The Assessment of Children with Complex Needs’ in Howarth, J. (Ed) (2003) The Child’s World. Assessing Children in Need. Jessica Kingsley Publishers: London & New York.



LEGISLATIVE AND POLICY FRAMEWORK

The following are examples of some of the policies, initiatives and pieces of legislation that relate to work with disabled children, young people and their families and carers. The list is not exhaustive. Further information on the legislative framework can be found such as on the internet on the various Government websites.

Children Act 1989

The Act is concerned with all children but also specifically identifies the legal duty that Local Authorities have to provide services to children who are defined as 'in need'. Disabled children are automatically categorised as 'children in need'. The following definition is provided⁹:

"A child is disabled if he is blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed."

The language used within the Act is an old definition of disability taken from the National Assistance Act 1948 and the language used reflects its age. However, the Act does place in law, a clear duty on the Local Authority to provide services for disabled children in order to minimise the disabling effect of society and lead to equality of opportunity. Local Authorities are also required to maintain a register of disabled children in their area.

Section 17(1) defines children in need as including any child:

- who is unlikely to achieve or maintain, or to have the opportunity to achieve or maintain, a reasonable standard of health or development without the provision of services by a Local authority;
- whose health or development is likely to be significantly impaired, or further impaired, without the provision of such services; or
- who is disabled.

S17(3) states:

"Any service provided by an authority in the exercise of functions conferred on them by this section may be provided for the family of a particular child in need or for any member of his family, if it is provided with a view to safeguarding or promoting the child's welfare."

Schedule 2 requires Local Authorities to:

- Identify the extent to which there are children in need living in their area.
- Provide family support services with a view to safeguarding and promoting the child's welfare; and
- Encourage their upbringing by their own families as far as is consistent with the child's overall welfare.

⁹ Children Act 1989. HMSO.



Paragraph 3 of Schedule 2 states that :

“Where it appears to a Local Authority that a child within their area is in need, the Authority may assess his needs for the purposes of this Act at the same time as any assessment of his needs is made under:

- The Chronically Sick and Disabled Persons Act 1970;
- Part III of the Education Act 1993;
- The Disabled Persons (SCR) Act 1986; or
- Any other enactment.”

Children Act 2004

- Section 1 creates a children’s commissioner for England and strengthens the role for the United Kingdom,

England:

- Section 10 strengthens the duty to co-operate to promote well-being,
- Section 11 strengthens the duty to co-operate to safeguard and promote welfare,
- Section 12 allows for databases to be created nationally or locally to keep information about children,
- Section 13 changes Area Child protection Committees to Local Safeguarding Children’s Boards,
- Section 17 requires children’s services to produce a children and young people’s plan, this replaces the need for an area child protection plan,
- Section 18 ensures that there will be a Director of Children’s Services,
- Section 19 creates a lead member for children’s services in each local authority,
- Section 20 creates joint area reviews whereby children’s services in geographical areas will be inspected rather than each individual agency,

Wales:

- Section 25 strengthens the duty to co-operate to promote well-being,
- Section 26 requires children’s services to produce a children and young people’s plan, this replaces the need for an area child protection plan,
- Section 28 strengthens the duty to co-operate to safeguard and promote welfare,
- Section 29 allows for databases to be created nationally or locally to keep information about children,
- Section 31 changes Area Child protection Committees to Local Safeguarding Children’s Boards,
- Section 35 allows CAFCASS to be integrated into the Welsh Assembly and creates “Welsh family proceedings officers”,
- Section 39 makes the Welsh Assembly a “child care organisation” under the Protection of Children Act 1999.

Thus in Wales many of the same changes will apply as per England but there is no requirement to create children’s services therefore no need to separate children’s and adults social services nor create Director of Children’s Services or lead members. Joint area reviews will not apply to Wales.



- Section 44 widens the law on private fostering to include people who “will” as opposed to “are” privately fostering and are “concerned with” rather than “caring for” children. Local authorities must promote public awareness of private fostering,
- Section 53 strengthens the need to ascertain children’s wishes and feelings in terms of being looked after and being subject to child protection enquiries.

The Disability Discrimination Act 1995 (DDA)

This Act came into force in 1996 and gives rights to disabled people in the areas of employment, access to goods and services and in education.

- Part I: A disabled person is defined as someone “with a physical or mental impairment, which has a substantial and long-term effect on his or her ability to carry out day-to-day activities”. The Act therefore covers a vast range of disabilities including people who have previously been disabled. However, it doesn’t encompass all disabled people to the extent which is covered by the social definition of disability accepted by the Disability Movement.
- Part II: Relates to employment and protects disabled employees and jobseekers against discrimination.
- Part III: Relates to the provision of goods and services to the public and the requirement for those providing them not to discriminate against disabled people. Reasonable adjustments to physical features of premises are now required.
- Part IV: Relates to education. The Special Educational Needs and Disability Act 2001 amended the DDA to bring education into the scope of the Act. It came into force on 2nd September 2002.

The Disability Rights Commission

There are plans to merge this Commission which was set up in accordance with the DDA. The White Paper, ‘Fairness for All: A new Commission for Equality and Human Rights’ was issued in 2004 outlining the government’s proposals for a new commission: the Commission for Equality and Human Rights (CEHR).

The government believes that the new commission will bring together expertise in equality and act as a single point of reference and contact for information and advice. Through helping individuals, their families/carers, businesses and organisations, they can promote awareness and tackle discrimination on multiple levels thus acknowledging that some people may face more than one form of discrimination.

Race Relations (Amendment) Act 2000

This Act strengthened and extended the Race Relations Act 1976 by placing a new duty on public authorities to promote race equality and good race relations. The Amendment Act was a response to the McPherson Report following the murder of Stephen Lawrence on 22nd April 1993 which was described as “unequivocally motivated by racism”.



The McPherson Report identified fundamental errors and incompetence in the handling of the murder case and identified 70 recommendations for change, 30 of which related to Local Authorities. The scope of the Act prohibits discrimination in all functions of public service e.g. central and local government, Police, NHS. It applies to private or voluntary sector organisations carrying out public services and stipulates that all public service activities must be free of racial discrimination.

The Amendment Act¹⁰ introduced two new definitions:

- **Institutional Racism:** “The collective failure of an organisation to provide appropriate and professional service to people because of their colour, culture or ethnic origin. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping, which disadvantaged minority ethnic people”¹¹
- **A Racist Incident:** “A racist incident is any incident which is perceived to be racist by the victim or any other person.”

Disabled children and their families from black and other ethnic minority groups can face ‘double discrimination’ whereby they are discriminated against as a result of disability and race, ethnicity and/or culture. There is a shortage in the provision of culturally appropriate services (such as single-sex services, services that meet dietary needs etc.) and where services are provided, they can often be limited to certain cultural groups⁵.

Carers and Disabled Children Act 2000

Came into force 1st April 2001 and gives local councils the power to supply specific services to carers following assessment. Carer’s also have a right to an assessment even where the person for whom they are caring has refused an assessment themselves.

Direct payments also became available for carers. Direct payments are made to individuals to increase choice and control over the services that they can then ‘purchase’. The aim of Direct Payments is to improve the quality of life of people who would rather manage their own social services support. They can promote independence and aid social inclusion through offering further opportunities through leisure, education and employment. Direct payments can also be provided to 16 and 17 year old young people who are carers as well as for 16 and 17 year old young disabled people.

Valuing People 2001

The Department of Health produced a White Paper entitled, ‘Valuing People: A New Strategy for Learning Disability for the 21st Century’. This was the first White Paper produced for people with learning disabilities (in England) for 30 years. It is based on people having:

¹⁰ Race Relations (Amendment) Act 2000. HMSO.



- Rights as citizens;
- Inclusion into local communities;
- Choice in their daily lives;
- Real opportunities to be independent.

It was written in partnership with people with learning disabilities, families and carers and frontline workers from organisations and services that support people with learning disabilities.

SEN and Disability Act 2001

Introduced new special educational needs code of practice.

SEN: A Mainstream Issue 2002¹²

Identified the following issues:

- Too many children wait too long to have their needs met.
- Some children who should be taught in mainstream education are turned away.
- Many staff feel ill-equipped to meet the broad range of needs of children.
- There is uncertainty for special schools in relation to the future role.
- There are unacceptable variations in the support levels for families from schools, local authorities and their local health service.

Choice for Parents, the Best Start for Children: a Ten Year Strategy for Childcare 2004

Sets out the Government's vision to ensure that all children get the best start to live and to give more parental choice re work/family life balance. Focussed on four key areas:

- Choice and flexibility.
- Availability.
- Quality.
- Affordability.

Carers (Equal opportunities) Act 2004

Amongst other things, Local Authorities are required to have "a protocol, shared between adults and children's services, for identifying and assessing young carers."¹³

"Young carers are children and young people under 18 who provide, or intend to provide, personal care, assistance or support to another family member on a regular basis. They carry out significant or substantial caring tasks and assume a level of responsibility which is inappropriate to their age¹. Caring tasks can involve physical or emotional care, or taking responsibility for someone's safety or well being."

¹² The Audit Commission (2002). SEN: A Mainstream Issue.

¹³ Carers (Equal Opportunities) Act 2004. HMSO.



“Disability” is used in this protocol to include physical disability, disabling physical or mental illness, HIV/ AIDS and substance misuse.”

National Service Framework for Children, Young People and Maternity Services 2004

The framework, known as the NSF, is at the heart of the government’s ‘Change for Children programme. Its purpose is to:

“Set national standards for the first time for children’s health and social care, which promote high quality, women and child-centred services and personalised care that meets the needs of parents, children and their families.”¹⁴

The NSF comprises eleven standards and is divided into three parts:

- Part 1: applies to all children and young people and contains standards one to five;
- Part 2: applies to children and young people in particular circumstances (e.g. mental health problems; disabled) and contains standards six to ten;
- Part 3: applies to standard eleven for maternity services.

The standard that relates specifically to disabled children stipulates:

“Children and young people who are disabled or who have complex health needs receive co-ordinated, high-quality child and family centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to lead ordinary lives.”

Removing Barriers to Achievement: the Government’s Strategy for SEN 2004

This sets out the Government’s vision for the education of children with Special Educational Needs and disabled children. It is an ambitious programme of sustained action in four key areas:

- Early intervention.
- Removing barriers to learning.
- Raising expectations and action.
- Delivering improvements in partnership.

¹⁴ DfES and DoH (2004). National Service Framework for Children, Young People and Maternity Services: Core Standards. DoH.



Improving the Life Chances of Disabled People 2005

This report¹⁵ sets out a very ambitious programme of action, opportunity and change for disabled people by supporting disabled people to support themselves. The focus is on the participation and inclusion of disabled people:

“By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society.”

The strategy for change is identified through practical measures in four key areas:

1. Supporting disabled people to achieve independent living;
2. Improving support for families with young disabled children;
3. Facilitating a smooth transition into adulthood;
4. Improving support and incentives for getting and staying in employment.



COMMUNICATION

What is Communication?

- The sending and receiving of messages between people.
- Various forms of communication including verbal and non-verbal.
- Augmentative and alternative communication (AAC) can compliment or replace spoken communication.

Augmentative and Alternative Communication (AAC) - Definition

AAC “may range from any movement or behaviour that is observed and interpreted by another person as meaningful, to the use of a code agreed upon between people where items have specific meanings i.e. a language... It is appropriate for individuals who have difficulty with receptive and expressive language due to physical, sensory or learning disability. It provides an opportunity to attain emotional, social, educational and vocational goals.”¹⁶

Communicating with children who do not use verbal communication can pose particular difficulties for workers, parents and carers. There can be many barriers to communication for disabled children. There is a wide range of resources available to aid working with children with AAC. Observation is a key skill in working with children, particularly those who may use the slightest eye movement or movement of a finger to indicate a ‘yes’ or a ‘no’, for example.

There are two main types of AAC and most AAC users use both forms:

- **Aided Communication:** additional equipment is used such as picture books or computer aids. Aided communication can be either **low technology** (not powered e.g. a communication book with pictures and symbols) or **high technology** (more complex, electronic aids such as computers).
- **Unaided Communication:** no additional equipment is required e.g. body language, pointing with eyes and so forth.

Communication Bill of Rights

This Bill¹⁷, which was produced in USA in 1992, provides a sound basis for putting communication at the heart of all service planning, design, delivery and evaluation. It states:

“All persons, regardless of the extent or severity of their disabilities, have a basic right to affect, through communication, the conditions of their own existence. Beyond this general right, a number of specific communication rights should be ensured in all daily interactions and interventions involving persons who have severe disabilities. These basic communication rights are as follows:

¹⁶ ACE Centre Advisory Trust (2001).

¹⁷ National Joint Committee for the Communicative Needs of Persons with Severe Disabilities (1992). [Communication Bill of Rights](#).



- The right to request desired objects, actions, events, and persons, and to express personal preferences, or feelings.
- The right to be offered choices and alternatives.
- The right to reject or refuse undesired objects, events, or actions, including the right to decline or reject all proffered choices.
- The right to request, and be given, attention from and interaction with another person.
- The right to request feedback or information about a state, an object, a person, or an event of interest.
- The right to active treatment and intervention efforts to enable people with severe disabilities to communicate messages in whatever modes and as effectively and efficiently as their specific abilities will allow.
- The right to have communicative acts acknowledged and responded to, even when the intent of these acts cannot be fulfilled by the responder.
- The right to have access at all times to any needed augmentative and alternative communication devices and other assistive devices, to have those devices in good working order.
- The right to environmental contexts, interactions, and opportunities that expect and encourage persons with disabilities to participate as full communicative partners with other people, including peers.
- The right to be informed about the people, things, and events in one's immediate environment.
- The right to be communicated with in a manner that recognizes and acknowledges the inherent dignity of the person being addressed, including the right to be part of communication exchanges about individuals that are conducted in his or her presence.
- The right to be communicated with in ways that are meaningful, understandable, and culturally and linguistically appropriate.”

Total Communications

This is an approach to communication that recognises the individual needs of all people whilst ensuring that all agencies and others working with the person have the same, co-ordinated and coherent approach to communication. It is an approach that is defined as ‘cradle to grave’ meaning it is applicable for people of all ages.

Total Communication (TC) recognises:

- The value of a full and up to date assessment of need
- The benefits of adopting a common standard for tools and techniques
- The benefits of joint training initiatives to develop skills and promote consistency
- The benefits of pooling resources.

There are a number of projects (such as ‘Somerset Total Communications’ and the Isle of Wight ‘Total Communication Project’) that have successfully managed to ‘join up’ the way in which agencies work together to meet the needs of people in their area to promote inclusion and meet fundamental communication rights. It combines a range of communication through verbal, non-verbal and visual representation and is used in a wide range of settings for example, non-disabled children are taught to sign in school to staff in the local supermarket.



BARRIERS TO COMMUNICATION

There are a wide range of barriers to working with children and young people and these can be more profound where there are additional communication needs. Morris (2002) identifies that many children did not have the following:

- Access to a communication system that suited their needs.
- Routine access to people who understood the ways they communicated.
- Access to independent facilitators.

In addition to this, Morris¹⁸ identifies that:

- Children with communication impairments often experience low levels of interaction.
- When children are treated as though they have no communication, they sometimes 'switch off'.
- No response to a child's communication can sometimes lead to the child becoming angry and frustrated and giving up. This may in turn be labelled as 'challenging behaviour'.
- Communication impairments can impair opportunities to develop literacy.
- There is often a lack of important words, meanings or symbols in communication systems such as body parts.
- There is often a lack of up-to-date assessment.
- Assessments may lead to imposed communication systems.
- Communication aids don't travel with the child.
- There is often a lack of training of staff in use of communication systems.
- There is inappropriate equipment.
- There is a need for repeated explanation re using the communication system.
- Information is not passed on regarding a child's needs or an understanding of how the communication system is used to meet the child's individual needs.

Furthermore, it is important to consider 'double negatives'. For example, a child with autism may find it difficult to have too many choices and this may in itself act as a further barrier to communicating and exercising choice.

Morris highlights the importance of overcoming the barriers to communication:

"Unless channels of communication are opened up between these young people and those around them, it is difficult to see how they can experience ordinary human relationships. A denial of communication means a denial of so much of what it is to be human. It means being denied a say in what happens to you and creates a risk that your needs will not be recognised."

Jenny Morris¹⁹ provides checklists and guidance for good practice in relation to communication which are invaluable.

¹⁸ Morris, J. (2002). That Kind of Life. SCOPE.

¹⁹ Morris, J. (2002). A Lot to Say! A guide for social workers, personal advisors and others working with disabled children and young people with communication impairments. SCOPE.



BASIC TIPS FOR COMMUNICATING

The following list is taken from 'Two-Way Street'²⁰ and provides some guidance for consulting with a child or young person whose impairment affects their communication*:

Planning and Preparation

- Find out if possible how the child usually communicates, but keep a very open mind and remember that all children use a combination of communication methods;
- Give careful thought to your initial approach to children and young people.
- Develop a range of communication resources relevant to your role with children.
- Have a wide and open definition of communication.
- Make approaches to the young people responsive and individualised.
- Approach consent as a process rather than a single event.
- If parents or other adults are to be involved try to negotiate clear ground rules (e.g. perhaps that their role is to assist communication rather than to give their own views).
- A child or young person may be more relaxed and more able to communicate if engaged in other activities such as play, or art, or going for a walk or drive.
- Depending on the child or young person's age and understanding, take interesting things in a bag or folder for them to look through or play with.
- Show an interest in the young person's hobbies; find out about what they do in their spare time.

Communication Approaches

- Use language carefully to introduce yourself and why you are there.
- Be non-directive, reflect back to young people what they have told you.
- Give the young person time to expand a message before going on to ask open questions.
- Respond respectfully to young people's use of communication resources and methods, even if they are unfamiliar to you.
- It can be easy to get distracted by the method of communication, particularly with electronic communication aids, remember to focus on the content of the message being generated.
- Learn skills in repairing and recovering communication.
- Respond to young people's actions or statements in a neutral and careful way.
- Acknowledge if things aren't going well, say if you don't understand.
- Attend carefully to everything being communicated, especially where there is a discrepancy between verbal and non-verbal messages.
- Clarify boundaries for confidentiality.
- Be willing to go back to the beginning and start again.
- Don't assume, keep an open mind, check back.

²⁰ Triangle & NSPCC; supported by JRF (2001). Two-Way Street: Communicating With Disabled Children and Young People Handbook.



- Let it take time, go at the young person's pace, be willing to wait, sometimes for quite long periods.
- Keep an open mind; attend on all channels.
- Have lots of different ideas ready, and be prepared to abandon them.

Writing Up

- ensure a balance between what the child said/signed or communicated directly and what they did (expressions, gestures, behaviour etc.).
- use the child or young person's own words/signs/symbols or drawings wherever possible.
- Check what you have written with the young person if you can.

*** 'Basic Tips for Communicating' copied with kind consent from Triangle.
See 'Resources' section on page 37 for further details of 'Two Way Street'.**

And Finally...

Don't forget - be prepared for responses that challenge expectations. Disabled children can be extremely perceptive and construct their own realities to rationalise the world around them. The challenge for us is to engage with that world.



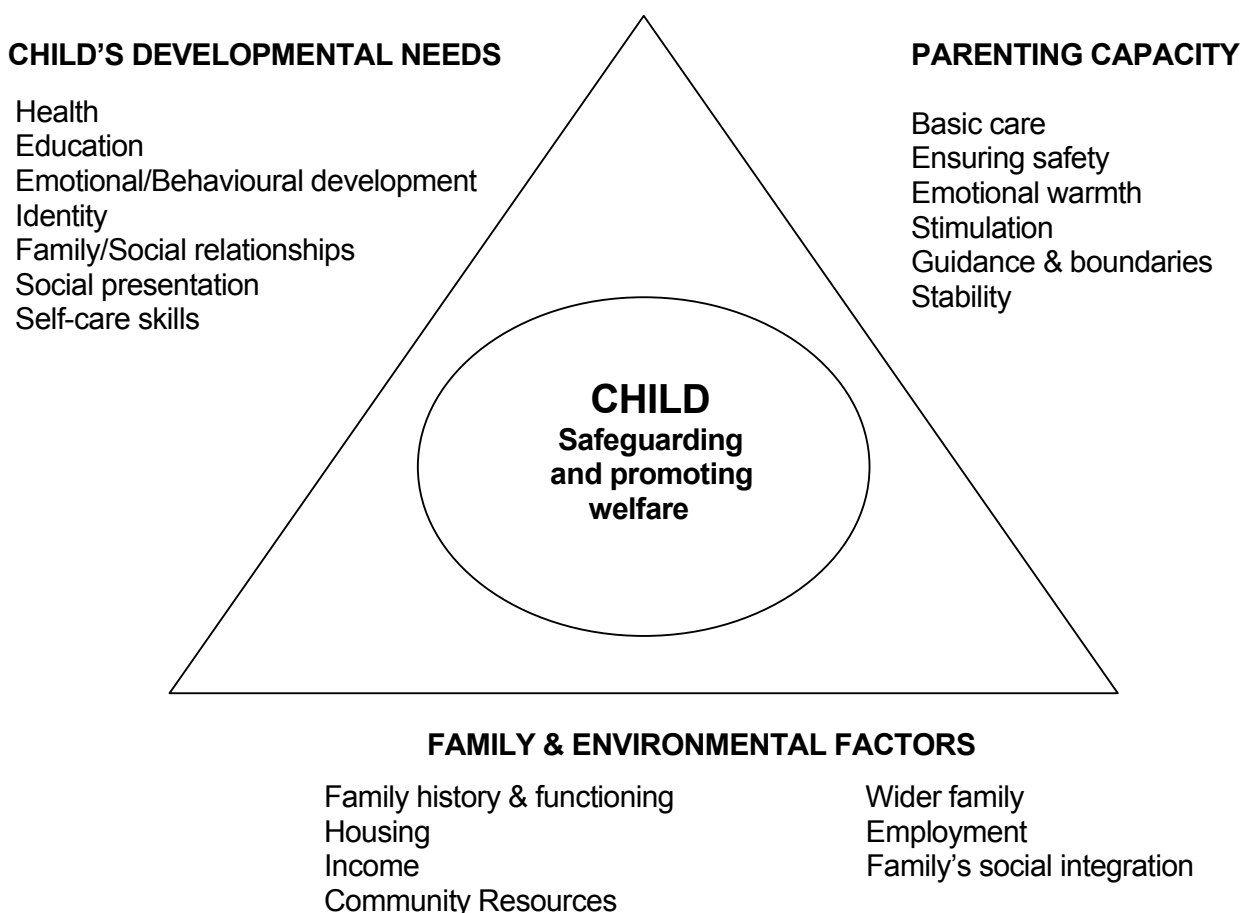
ASSESSMENT

The Framework for the Assessment of Children in Need and their Families²¹ is an inclusive model that stipulates:

“Ensuring equality of opportunity does not mean that all children are treated the same. It does mean understanding and working sensitively and knowledgeably with diversity to identify the particular issues for a child and his or her family, taking account of their experiences and their family context.”

A Framework for Assessment

“It is important that an approach to assessment, which is based on a full understanding of what is happening to the child in the context of his or her family and the wider community, examines carefully the nature of the interactions between the child, family and environmental factors and identifies both positive and negative influences.”



²¹ DoH, DfES, Home Office (2000). Framework for the Assessment of Children in Need and their Families. Department of Health.



Marchant⁸ argues that patterns of care for disabled children that are deemed unacceptable for non-disabled children are tolerated and this is influenced by our values that guide decision-making. When undertaking assessments, it is crucial that consideration is given to the way in which we view disability and our underpinning values. Marchant offers the example of a child who experiences regular overnight care in a number of different environments (family home, link family home, residential respite unit) as well as frequent admissions to hospital. In considering the need for stability and security, would this be seen as acceptable for a non-disabled child? Thus what is seen as acceptable or not is dependent on our value-base.

Marchant continues to identify the following as key factors when assessing children with complex needs:

- Think about your own understanding of disability.
- The use and limits of developmental milestones.
- The boundary between control, treatment and abuse.
- Involvement of children in the assessment process.
- Be clear about the position of your service.
- Take responsibility for communication.
- Try to take the child's perspective.

Common Assessment Framework (CAF)

The expectation is that the CAF will be implemented throughout children's services by the end of 2008. It shifts the focus from dealing with the consequences of difficulties to prevention and earlier identification. It is a nationalised, standardised approach to conducting an holistic assessment. The CAF has been designed so that it can be used by practitioners from all agencies to enable more effective communication and working in partnership.

When consent is provided, it will encourage increased sharing of information between agencies. The CAF should²²:

- "Promote earlier intervention where additional needs are observed
- Reduce the number and duration of different assessment processes that children and young people need to undergo
- Improve the quality and consistency of referrals between agencies by making them more evidence-based
- Help embed a common language about the needs of children
- Enable information to follow the child
- Promote the appropriate sharing of information
- Provide a single point of contact, who children, young people and families can trust, and who is able to support them in making choices and in navigating their way through the system
- Ensure that children and families get appropriate interventions when needed, which are well planned, regularly reviewed and effectively delivered
- Reduce overlap and inconsistency from other practitioners.
- Where the assessment indicates that the child has urgent or complex needs, requiring specialist assessment and intervention, the common assessment information will feed into the specialist assessment process."

²² www.everychildmatters.gov.uk



ABUSE AND DISABLED CHILDREN

Myths

The Chailey Heritage²³ identified the following myths that exist in relation to sexual abuse of disabled children:

1. Disabled children aren't vulnerable to abuse.
2. Sexual abuse of disabled children is ok or at least not so harmful as sexual abuse of other children.
3. Preventing the abuse of disabled children is impossible.
4. Disabled children are even more likely than other children to make false allegations of abuse.
5. If a disabled child has been abused, it's best to leave well alone once the child is safe.

Prevalence

- Disabled children are 3.4 times more likely to be abused or neglected than non-disabled children (USA)²⁴.
- In UK, 51% of Local Authorities state they record whether an abused child was disabled but only 14% could actually provide a figure²⁵.
- There is a lack of common definition and inconsistent recording resulting in information not being available⁶.
- Sample week data collated by the DOH in 2001 identified that 7% of 'looked after children' population were disabled in comparison with 3% of total population being disabled²⁶.
- 2% of disabled children in need are on the child protection registers in comparison with 8% of the general population of children²⁷.

Vulnerability

There is limited research into risk factors and protection. What has been identified fall into three main categories²⁸:

1. Attitudes and Assumptions

- Society devalues and disempowers disabled people – negative attitudes create vulnerability and disabled people are less likely to be listened to.
- There is a lack of awareness of vulnerability and indicators.
- Assumptions are sometimes made about the effects of the impairment which leads to mistakes regarding indicators.
- There is a common belief that disabled children aren't abused.

²³ The Chailey Heritage (1997). Myths and Facts About Sexual Abuse and Children with Disabilities.

²⁴ Sullivan, P and Knutson, J (2000). *Maltreatment and Disabilities: a population based epidemiological study* in *Child Abuse & Neglect* 24(10).

²⁵ Cooke, P. (2000). Final Report on Disabled Children and Abuse. The Ann Craft Trust

²⁶ DOH (2001). Children in Need Census.

²⁷ Personal social Services Research Unit (2002). *The Children Act Report 2002*.

²⁸ Miller, D. (2003). *Disabled Children and abuse* in National Working Group on Child Protection and Disability (2003). *It doesn't happen to disabled children*. NSPCC.



- There is a failure to recognise the impact of abuse on disabled children.
- Negative attitudes can lead to vulnerability of bullying and intimidation, especially by peers.

2. Inadequacies in Service Provision

- Barriers to participation which limits the capacity to contribute and to access.
- Isolation is a major risk factor.
- Organisational and skills gaps are barriers.
- There is a lack of comprehensive multi-agency assessments, planning and failure to identify early signs.
- There is a lack of access to communication systems and to a 'language'.
- There is failure to consult.
- Dependency on the abusing carer.
- There can be a learnt compliance or acceptance of not complaining.
- There is a lack of sex education or safety and awareness work.
- There is a fear of losing services.
- There is a lack of someone to turn to, privacy, receptiveness and independence.

3. Factors Associated with Impairment

- Intimate care needs can lead to a greater risk of exposure.
- There may be a reduced capacity to resist or avoid the abuser.
- It is more difficult to tell or disclose abuse if there are communication needs that are unmet.

The Criminal Justice System

The criminal justice system has not been effective in either deterring perpetrators of abuse or in securing convictions of those guilty of abuse²⁹. MENCAP and Respond³⁰ reported in 2001 that research indicated that out of 284 suspected cases of alleged sexual abuse against people with learning difficulties, Police only investigated 63 of the cases, less than a quarter of the cases; two resulted in a court case; and only one resulted in a conviction. The reason for this was because the witnesses were thought to be unreliable or unable to articulate what had happened to them.

In January 2002, the Home Office published guidance for implementing the 'Speaking up for Justice Report' (1998) called 'Achieving Best Evidence in Criminal Proceedings: Guidance for Vulnerable or Intimidated Witnesses, including Children'³¹. The guidance recognises the additional needs that children of all ages have as well as differing needs of disabled children that may affect giving evidence. The guidance states: "there is rarely any reason in principle why such children should not take part in a videotaped interview, provided the interview is tailored to the particular needs and circumstances of the child." However, it is important to reflect that many alleged cases of abuse never even get into the court arena as a result of the barriers in communication and attitude.

²⁹ Utting (2004). Safeguarding Disabled Children: A Review of Progress since the Utting Report into Children Living Away from Home. Joseph Rowntree Foundation

³⁰ MENCAP & respond (2001). From Behind Closed Doors: Report from Voice UK.

³¹ Home Office *et al* (2002). Achieving Best Evidence in Criminal Proceedings: Guidance for Vulnerable or Intimidated Witnesses, including Children.



SAFEGUARDING DISABLED CHILDREN – WHAT RESEARCH TELLS US

'People Like Us'³², the report produced by the Utting Review into the systematic child abuse in residential children's homes also explored provision and care for disabled children and young people, whom they identified as being another particularly vulnerable group to abuse. The report made a number of recommendations to address areas of concern. The report also identified that disabled children were more likely to live in a residential setting rather than a family one. In addition to risk factors for all children in residential settings, there was an increased risk for disabled children of particular forms of abuse including over-medication, poor feeding and toileting arrangements, issues around control and challenging behaviour, lack of stimulation, information and emotional support²⁸.

A further report was published, 'Progress on safeguards for children living away from home: A review of action since the People Like Us report'³³. This report identified that action had been taken on a number of the recommendations and there had been developments in the legislative and policy framework. However, the report concluded that there were still significant gaps between policy and practice and there was a lack of consistency across the country. A need for much more effective partnership working across agencies and progress within the criminal justice system were also identified.

The National Working Group on Child Protection and Disability³⁴ undertook a significant piece of work in collating and reviewing research and information relating to 'what works' in protecting disabled children from USA and the UK in its response to *Every Child Matters*³⁵. Whilst the group acknowledged the measures to improve support to vulnerable witnesses through 'Achieving Best Evidence'³¹, they argued that it does not go far enough to address the barriers experienced by disabled people. The Working Group identifies recommendations to improve disabled children's access to the criminal justice system.

The report also acknowledges the limited research that has been undertaken into the specific issues that relate to protecting disabled children²⁸. They state that an effective safeguarding strategy MUST address barriers at four levels:

³² Utting (1997). People like us: The report of the Review of Safeguards for Children Living Away from Home. HMSO.

³³ Stuart, M. & Baines, C. (2004). Progress on safeguards for children living away from home: A review of action since the People Like Us report. JRF.

³⁴ National Working Group on Child Protection and Disability (2003). It Doesn't Happen to Disabled Children. NSPCC.

³⁵ DfES (2004). Every Child Matters.



1. Society Level

- There needs to be a shift in values, attitudes and awareness.
- Disabled people need to be recognised and valued as equal citizens with equal rights.
- Recognition is required of responsibilities to remove barriers to participation.
- Safeguarding of disabled children has to be a priority.

2. Community Level

- Supportive and safe environments that empower disabled children need to be provided.
- There has to be a choice of safe and accessible community and leisure services.
- Flexible support needs to be provided that is responsive to individual needs, values and views of disabled children.
- Policies and practices need to be robust to safeguard, empower and respect disabled children.
- There needs to be effective child protection strategies and systems in place.

3. Carer Level

- There needs to be co-ordinated, interagency support in planned way.
- There should be an up-to-date, holistic assessment of needs that also addresses cultural and religious needs.
- Early and comprehensive multi-agency assessments need to be undertaken and any underlying causes for concern identified.
- Disabled children should be consulted on their own care needs and matters.
- Barriers to communicating with disabled children need to be addressed.
- Awareness-raising regarding vulnerability, indicators and carers' role in protecting and safeguarding disabled children should be provided to carers.
- Training, supervision and appraisal provided for all staff.

4. Individual Level

- Disabled children need to be empowered.
- Disabled children's wishes, views and feelings need to be sought.
- Choice and provision of opportunities should be ensured.
- Provision of sex education, safety and awareness work for disabled children is crucial.

In summary, taking a rights-based approach is the key to safeguarding disabled children and young people. There is a need to shift the focus away from a 'deficit' model of communication and disability and work within the social model of disability. This report called for a national strategy for safeguarding disabled children and further research.

Since production of this book, a new resource pack has been produced entitled: 'Safeguarding Disabled Children: A Resource for Local Safeguarding Children's Board' has been produced. It was commissioned by the DfES and written by Jenny Morris on behalf of the Council for Disabled Children. See www.everychildmatters.gov.uk for a copy.



PLANNING SERVICES TO MEET NEEDS

There is an ever-increasing gap between the level of breadth of services that disabled children and their families receive. There are tensions that exist in all organisations relating to budget and resource allocation. Within Social Services, there are a number of models that exist for service provision. Examples include 'looked after children' teams, 'children in need' teams, locality teams, disabled children teams or generic childcare teams.

By definition, 'children in need of protection' can demand a more immediate response thus placing a strain on resources (e.g. time) which can in turn create a tension for the provision of services to 'children in need', a category in which disabled children fall. This can sometimes contribute to unmet need for these children and families.

The Audit Commission⁵ reported that whilst some children and families were in contact with a large number of services, others received very little in the way of formal support. However, they were all in agreement that good, high-quality public service provision is crucial in improving and achieving a better quality of life. CSCI³⁶ state that in a typical week, 27,000 disabled children are provided with services from children's social services.

In addition to the difficulties that exist in relation to communication, the Audit Commission identified the following barriers to accessing specialist services:

- "Uncoordinated planning and provision, causing confusion and inconvenience;
- Poor multi-agency working around transitions (for example, from children's to adult services, or from hospital to community services);
- Eligibility criteria that were unclear, inconsistent between agencies, or so exclusive that families believe that they were intended to protect budgets rather than meet need; and
- High turnover in many staff groups (for example, learning support assistants, therapists, carers), leading to service gaps and poor continuity of care."

In planning services, it is essential to have a good understanding of local need. The Audit Commission Report identify that to have a good understanding of need, authorities need to resolve practical and cultural issues so that:

- Users and local people help to define their key needs;
- Agencies work together and demonstrate ownership and support for a multi-agency register;
- Agencies share relevant information, to understand the level of unidentified need;
- Services/agencies have a shared working understanding of client confidentiality to facilitate information sharing;

³⁶ CSCI (2005). [Making Every Child Matter: Messages from inspections of children's social services](#). CSCI.



- Compatible information systems allow transfer of data between partners and minimise data input time;
- Partners have shared working definitions of disability, agree how they record and have transparent eligibility criteria; and
- Partners agree clear accountability and resource for maintaining the register (in terms of database management, equipment and IT development).

There are a range of self-evaluation checklists within the Report that can be used by practitioners to audit knowledge, skills and services which Reconstruct highly-recommend training participants to read and consider their use for practice.

The study, 'Services for Disabled Children'³⁷ also undertaken by the Audit Commission identifies four critical components of effective services for disabled children:

- “Commissioning and delivery driven by a thorough understanding of what local families want and need;
- Specialist and mainstream services focussing on helping families participate in everyday activities;
- Recognition of the particular impact on children of waiting for support or treatment;
- Frontline staff who understand individual needs, and work with users in respectful partnership.”

The Audit Commission argue that on the basis of their research, service provision to disabled children does not need reform with new targets, new structures or wholly new approaches, rather, what is required is:

- “Better management of service, so that good practice is mainstreamed;
- Leadership that makes this possible;
- And a new attitude that sees the social exclusion of disabled children as unacceptable.”

CSCI³⁶ state that their “recent inspections confirm that whilst services to disabled children and their parents have improved in many areas, overall progress remains disappointing.” They have developed a checklist of what is required from councils and partner agencies to improve outcomes for children in need. One of the questions relates specifically to disabled children “Have you developed more integrated arrangements to assess and deliver services better to disabled children and their families?” This question arises from their finding that “cultural barriers, different eligibility criteria, priorities, referral systems and statutory requirements across health, education and social services continue to get in the way of single service models.”

³⁷ Audit Commission (2003). Services for Disabled Children.



Some tips for good practice:

- Allow adequate time for planning.
- Ensure adequate consideration of a young person's communication needs to empower participation.
- Ensure effective partnership working with all involved including the young person, their families and/or carers and colleagues in adult services.
- Consider advocacy support for the young person.
- Be creative in your approach to communication, engagement, participation and planning.
- Be SMART: ensure plans are Specific, Measurable, Achievable, Realistic and there are clear Timescales.

Person Centred Planning (PCP)

A person's wishes and views are central to all planning regarding their future and meeting their needs. It requires a lot of commitment and understanding from everyone involved with meeting the person's needs to listen to and learn from the person themselves. It is therefore an empowering approach to planning.

There are five features outlined by the Department of Health³⁸:

1. The person is central to the plan.
2. Family and friends are full members.
3. PCP reflects the person's capacities, what's important to them and specifies the support required for them to make a full contribution to their community.
4. Builds a shared commitment to action to uphold a person's rights.
5. Leads to continual listening, learning and action to help a person get what they want out of life.

³⁸ Department of Health (2001). Planning with people towards person centred approaches.



TRANSITIONAL PLANNING

Transitional Planning, by law, is required to start when a young person is 14 years of age, to help them plan for the transition to adult life.

The National Service Framework¹⁴ states that::

“Assessment and planning for transition from child to adult services is often unsatisfactory. For many, there is a lack of co-ordination between the relevant agencies and the little involvement from the young person. Some... are not transferred with adequate care plans, resulting in their exclusion from adult services. In addition, some disabled young people experience a decline in the services they receive. This can lead to a regression in their achievement and/or deterioration in their condition. Disabled people need high quality, multi-agency support to allow them to have choice and control over life decisions...to be aware of what opportunities are open to them and the range of support they may need to access services.”

Disabled young people leaving care also have entitlements under the Children (Leaving Care) Act 2000.

The Transitional Plan

The Transition Plan is an action plan identifying the young person's needs and how they will be met and should be updated each year; often this is done at the same time as the young person's Annual Review. The Transition Plan pulls together information from the range of professionals and the family but most importantly from the young person themselves. The Plan should be strengths-based as well as reflecting the young person's interests and aspirations and identify issues relating to:

- further education;
- health;
- housing;
- transport;
- work;
- relationships; and
- hobbies/interests.

The approach used in transitional planning should be person centred (see page 24).

There are a number of different projects that have developed tools to assist young people with transitional planning. See, for example, Trans-active (page 33).

CSCI³⁶ (2005) identified that there continues to be a lack of multi-agency future planning using the data obtainable from the Disabled Children's Register regarding the needs of cohorts.



DISABLED CHILDREN FROM BLACK & MINORITY ETHNIC GROUPS

Additional barriers exist for disabled children and young people from black and other minority groups who can experience multiple forms of oppression or 'double discrimination'. Ronny Flynn³⁹ identified that the take-up rate of 'short break' provision by black, disabled children and their families was low and there showed no signs of improvement. There was a higher incidence of Black families using more institutionally-based service provision rather than family-based than white families.

Hatton *et al*⁴¹ argue that the prevalence amongst South Asian communities of severe learning disabilities may be up to three times higher than the general population. Combining this with other data, they suggest that this will increase significantly over the next 20 years.

Chamba *et al*⁴⁰ state that the level of unmet need for services for black and minority ethnic (BME) disabled children and their families is higher than that for white children and families. There is also a lower take-up of benefits such as Disability Living allowance⁴⁰ and Direct Payments⁴¹ amongst black children and families. They also identified that the disadvantage experienced by BME families with a disabled child was even more than that of white families.

The PSSRU⁴² on the secondary analysis of the Children in Need Census 2000 state that there is a higher than average proportion of Asian children in need are disabled (22%). In contrast, the proportion of disabled children in need from Afro-Caribbean and mixed-race backgrounds are lower than average. When poverty and poor environmental circumstances compound the discrimination experienced by disabled children from minority ethnic families, there is a failure to access supportive services⁴³.

In considering the development of services for BME disabled children it is important to reflect on how services meet language, cultural and religious needs.

Henley & Schott⁴⁴ state that the impact of language barriers results in a "compromising and lowering of professional standards" (p.158). These barriers can be exacerbated as a result of the additional difficulties that may exist as a result of a communication impairment. Henley & Shott also argue that the consequences of a language barrier can result in "poor referrals, incomplete

³⁹ Flynn, R. (2002). Short breaks: Providing better access and more choice for Black disabled children and their parents. The Policy Press/Joseph Rowntree Foundation

⁴⁰ Chamba, R. *et al* (1999). On the edge: minority ethnic families caring for a severely disabled child. Joseph Rowntree Foundation.

⁴¹ Hatton, C. *et al* (2004). Supporting South Asian families with a child with severe disabilities. Jessica Kingsley Publishers: London.

⁴² PSSRU (2002). Children Act Report 2002. DfES

⁴³ Beresford, B., Sloper, P., Baldwin, S. & Newman, T. (1996). What works in services for families with a disabled child? Summary. Barnardo's.

⁴⁴ Henley, A. & Shott, J. (1999). Culture, Religion and Patient Care in a Multi-Ethnic Society cited in O'Hagan, K. (2001). Cultural Competence in the Caring Professions. Jessica Kingsley Publishers: London.



investigations, inappropriate interventions and treatments and inaccurate files” as well as significantly affect the relationship between the practitioner and service user/s. Others (such as Hatton *et al* and Chamba & Ahmad⁴⁵) also identify language barriers and a lack of information in an accessible format which then compromises basic rights such as access to information and access to benefits.

Furthermore, consideration needs to be given to meaning and interpretations attached to language. The concept of disability itself can be widely interpreted in different cultures alongside terms such as ‘learning disability’. There may also be a cultural stigma attached to disability which may in turn lead to a child or its parents being seen as ‘cursed’ or ostracised from the community.

The report, ‘All Our Children Belong’⁴⁶, states that there is a qualitative difference between the experiences of BME disabled children and their families from their white counterparts. The parents interviewed within the research state that within the “BME communities, many parents of disabled children go unsupported and their needs largely ignored. For certain sections of the BME community, ideals of self-reliance and the fear of being seen as not coping is very strong. As is a reluctance to seek assistance or support from those outside our communities. Thus service providers fail to be proactive and interpret these messages as a lack of need.”

A helpful model produced by McDonald⁴⁷ is the ‘Strengths and Weaknesses Model’ produced following the Children Act 1989 with a focus on race and disability. Its aim is to recognise and the build on strengths of families and work within a model of empowerment. It challenges practitioners to move away from a weakness model where pathological responses from social work agencies to BME families dominates. For example through assumptions and cultural stereotypes, professional superiority, power and cultural superiority.

Working within a strengths model (broadly) requires practitioners to:

- Recognise life experiences of BME;
- Develop an understanding of the black experience;
- Have sensitivity to cultural pride;
- Take a holistic approach and have knowledge of the family support system;
- Redress the power imbalance;
- Work against racism and discrimination.

⁴⁵ Chamba, R. & Ahmad, W.I.U. (2000). *Language, communication and information: the needs of parents caring for a severely disabled child* in Ahmad, W.I.U. (ed). *Ethnicity, Disability and Chronic Illness*. Open University Publications.

⁴⁶ Broomfield, Annette (ed), 2004. All our children belong. Exploring the experiences of black and minority ethnic parents of disabled children. A report brought together by Parents for Inclusion’s Black and Minority Ethnic Reference Group. Parents for Inclusion.

⁴⁷ McDonald, S. (1991). All Equal Under the Act. Race Quality Unit.



PARTICIPATION

Participation is “not simply to mean ‘taking part’ or ‘being present’ but as having some influence over decisions and action”⁴⁸

Article 12 of the United Nations Convention on the Rights of the Child⁴⁹ which was ratified by the UK Government in 1991 stipulates:

“All children have the right to express and have their views given due weight in all matters that affect them”

Article 23 gives disabled children and young people the right to social integration and to actively participate in their community.

In other words, all children and young people, including disabled children, have the right to be involved in decisions that are made about them and their lives. This right is embedded in various legislation such as the Children Act 1989, Section 22(4), in the Human Rights Act 1998 (the rights to communication and self-expression) and in the National services Framework which reinforces the right of disabled children and young people being asked for their views and participating in decision-making about their care.

The Children Act 1989⁵⁰ “places... duties on SSD’s [Social Services Departments] with regard to involving children in planning their future. These arrangements apply whether or not the child has a disability or special need... Children and young people should be given the chance to exercise choice and their views should be taken seriously if they are unhappy about the arrangements made for them. Plans should be explained, discussed and, if necessary, re-assessed in the light of the child’s views. The social worker should be aware and acknowledge that there may be good reasons why the child’s views are different from those of his parents or the SSD.”

Section 53 of the Children Act 2004⁵¹ strengthens the requirement to empower participation by amending the 1989 Act by placing a duty on local authorities to ascertain the child’s wishes and feelings and give them due consideration (having regard to the child’s age and understanding), as far as is reasonably practicable in:

- Section 17 (4A) – Children in Need.
- Section 47 (5A) – Child Protection Enquiries

Section 10 of the Children Act 1004 also requires the co-operation of children’s services and their partners to work together to improve the outcomes and well-being of children in their area:

⁴⁸ Kirby, P., Lanyon, C., Cronin, K. & Sinclair, R. (2003). Building a Culture of Participation. Involving children and young people in policy, service planning, delivery and evaluation. Handbook. DfES.

⁴⁹ United Nations Convention on the Rights of the Child (1989).

⁵⁰ DoH. (1991). The Children Act 1989: Guidance and Regulations, Volume 6.

⁵¹ The Children Act 2004. HMSO.



- a) Physical and mental health and emotional well-being.
- b) Protection from harm and neglect.
- c) Education, training and recreation.
- d) The contribution made to them by society.
- e) Social and economic well-being.

The five outcomes are inter-dependent and whilst children's participation is central to them all, 'making a positive contribution' has specific targets and indicators for local authorities.

Furthermore, Section 17 of the Children Act 2004 requires local authorities to consult with relevant children and young people in the preparation of local Children and Young People's Plans and to be provided with a copy. The Draft Regulations (2005) state:

"The genuine participation of children, young people, parents, carers and families is crucially important."

In November 2002, a group in India⁵² declared that "children's participation is the most important principle and element in the Convention on the Rights of the Child that cuts across all other rights, namely: the right to development, survival and protection."

In June 2002, the DoH set out its plans for developing children and young people's participation:

"Participation should go beyond consultation and ensure that children and young people initiate action and make decisions in partnership with adults, for example, making decisions about their care and treatment or day to day decisions about their lives"⁵³

An interim report from the Social Policy Research Unit indicated that 27 of 129 social services departments were not currently, or have not within the past 12 months, involved disabled children in their own care planning or service development⁵⁴. The research indicated that 57 authorities identified 70 different project initiatives where disabled children were actively involved in more general service development. Of these, 31 (44%) stated that there were changes made as a result of the involvement in decision-making of disabled young people.

The two greatest challenges identified through the research were:

- Time;
- Lack of skills of social work staff.

⁵² South Asian Task Force on Children's Participation (2002). '*Notes from second meeting and definition of children's participation*' cited in Crimmens, D. & West, A. (2004). Having Their Say. Young People and Participation: European Experiences. Russell House Publishing.

⁵³ Department of Health (2002). Listening, Hearing and Responding.

⁵⁴ Franklin, A. & Sloper, P. (2004). Participation of disabled children and young people in decision-making within social services departments. Quality Protects research initiative. A survey of current and recent activities in social services in England. The University of York.



There are a number of models of participation (see for example, Roger Hart's Ladder of Participation, 1992; reclassified by Barbara Franklin, 1997; and made into a wheel by Phil Treseder, 1997). White⁵⁵ offers distinctions between consultation and participation:

- “Consultation means listening to young people’s voices and views, and giving them appropriate feedback. Its use is largely restricted to mechanisms that bring young peoples’ views to adult-led initiatives. Young people are essentially reactive and the power remains in adults’ hands – no formal transfer or sharing of power and responsibility.”
- “Participation refers to young people taking an active part in a project or process, not just as consumers, but as key contributors to both direction and implementation. By participating, young people are essentially proactive and have the power to shape the project.”

Consultation and advocacy are separate, yet intertwined concepts that are tools of participation. Advocacy⁵⁶ is a process which helps someone to speak up for themselves, to get something started, stopped or changed.

Enabling effective participation for children and young people is a real challenge; for disabled children and young people, it can be even more so due to issues of access, attitudes, assumptions and communication needs. There are a range of resources available to assist with empowering children and young people’s participation – see some suggested resources at the back of this resource book.

The Audit Commission have produced a factsheet⁵⁷ that provides some guidance about empowering young people’s participation. They specifically identify:

- Support effective communication;
- Demonstrate the belief that young people’s views matter;
- Ensure opportunities to make general day-to-day choices so that it becomes part of everyday living;
- Remember that too much choice can be overwhelming;
- Provide opportunities to ‘talk through’ practical things;
- Make decisions as a family;
- Encourage the use of advocacy services;
- Take time to think about important matters;
- Encourage young people to take chances and try new things;
- Support young people to develop strategies to manage any worries;
- Ensure young people know about their rights and have access to information;
- Plan for meetings;
- Ask one question at a time;

⁵⁵ White, P. (2001). *Local and Vocal* cited in Crimmens, D. & West, A. (2004). [Having Their Say. Young People and Participation: European Experiences](#). Russell House Publishing.

⁵⁶ CROA (2000). [Total Respect Training Manual](#). CROA and Department of Health.

⁵⁷ Audit Commission (2003). [Factsheet 1: Involving young people in decisions about their lives](#).



- Don't lead a young person's answers or decisions;
- Be patient and take time – check things out and start again if needed;
- Allow young people to say what they want in a way they want to say it – be creative and use a range of methods for recording views, wishes and feelings (e.g. art, video, tape, reports, questionnaires etc.)
- Circulate copies of the young person's views with other people's – this again demonstrates the value you are placing on what they are saying;
- Ensure specific needs are met to enable accessibility (physical environment, communication; recording etc.)
- Code of conduct for the meeting explicitly identifying expectations, roles and responsibilities.

For further suggestions, see Sloper and Franklin ⁵⁴ and 'Basic Tips for Communicating' taken from 'Two Way Street' on page 33.

Standards for Participation

'Hear by Right'⁵⁸ is a standards framework for both statutory and voluntary sector organisations to enable them to assess the active involvement of children and young people. It is a toolkit that supports organisations to improve policy and practice. The self-assessment enables organisations to map their position in relation to children and young people's participation on the Seven S model of organisational change.

In addition to the standards framework, 'Act by Right'⁵⁹ is a skills development programme for 14-19 year olds (although it can be used with younger children with adequate support). It enables young people to develop the skills and knowledge to empower them to take action and achieve change in the services they use and in their communities. The programme is accredited. For further information, see 'Resources' on page 33.

⁵⁸ National Youth Agency (200DATE). [Hear By Right](#).

⁵⁹ National Youth Agency (200DATE). [Act By Right](#).



ADVOCACY

Many Local Authorities now commission advocacy services which are independent from other service provision and have a duty to provide advocacy services for looked after children and care leavers making, or intending to make, a complaint or representation to the local authority⁶⁰. [See also, Department for Education and Skills (2004). 'Get it sorted. Providing effective advocacy services for children and young people making a complaint under the Children Act 1989'.]

The National Standards for Advocacy⁶¹ define advocacy as:

“Speaking up for children and young people. Advocacy is about empowering children and young people to make sure their rights are respected and their views and wishes are heard at all times. Advocacy is about representing the views, wishes and needs of children and young people to decision-makers, and helping them to navigate the system. Advocacy services provide independent and confidential:

- Information
- Advice
- Advocacy
- Representation
- Support”

There are ten national standards which are summarised below:

- Advocacy is led by the views and wishes of children and young people
- Advocacy champions the rights and needs of children and young people
- All Advocacy services have clear policies to promote equalities issues and monitor services to ensure that no young person is discriminated against due to age, gender, race, culture, religion, language, disability or sexual orientation.
- Advocacy is well-publicised, accessible and easy to use.
- Advocacy gives help and advice quickly when they are requested.
- Advocacy works exclusively for children and young people.
- The Advocacy service operates to a high level of confidentiality and ensures that children, young people and other agencies are aware of its confidentiality policies.
- Advocacy listens to the views and ideas of young people in order to improve the service provided.
- The Advocacy service has an effective and easy to use complaints procedure.
- Advocacy is well managed and gives value for money.

⁶⁰ Adoption and Children Act 2002. Section 119 creates a new section of the Children ACT 1989, Section 26A. HMSO

⁶¹ Department of Health (2002). National Standards for the Provision of Children's Advocacy Services. Issued under section 7(1) of the Local Authority Social Services Act 1970.



Models of Advocacy

There are a range of models of advocacy:

- **Self-Advocacy:** “Speaking up for yourself”. A person expresses their own needs, issues, concerns and wishes and represents their own interests. Sometimes groups of individuals will come together to self-advocate on common issues and to develop their skills in doing so (collective or group advocacy).
- **Citizen Advocacy:** Also known as ‘long-term advocacy’. A trained and supported volunteer works with a person who is at risk of not being heard. Not usually time-limited.
- **Peer Advocacy:** Advocacy by someone who has similar experiences, difficulties or has similar life experiences as the person themselves.
- **Professional Advocacy:** Paid, trained workers that provide support re specific issue or reason. May also be called casework or issue-based advocacy. Can be long-term depending on issue/needs/client.

Non-Instructed Advocacy

This model recognises that people have fundamental rights and needs even though a person may not be able to express them in a way. It can be used with people who, through their age and/or cognitive ability and understanding, are excluded from the use of more conventional models of advocacy. This could mean that for very young children, people with the most profound level of disability and/or cognitive impairment could be excluded from having their rights secured to participate in decision-making and to ‘have their voice heard’.

This model assumes that an adapted alternative model of advocacy is better than not providing a service at all. The application of this model is only where an advocate cannot be ‘instructed’ (or directed by the service user) as with the peer or professional models of advocacy: the advocate can neither represent an opinion that has not been given or has not been understood by the advocate.

The use of non-instructed advocacy is not about the advocate offering their own views or opinions about what is in the ‘best interests’ of the service user. Moreover, it is about using established techniques such as observation, interviewing/consultation and knowledge to explore whether fundamental needs are being met. It is therefore safeguarding an individual’s rights as well as ensuring they are provided with care and support that meets their needs and maximises their quality of life. It also meets the National Standard relating to the promotion of equalities issues and ensuring that no young person is discriminated against.



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- MENCAP. Listen Up: Helping Children with a Learning Disability Complaint About the Service They Use. A pack including video, CD Rom, workbook, game and guide. Photocopiable material. Toolkit to support children and young people to develop their own 'Listen Up' material. Focussed on supporting children to think about their lives and the choices that have and make. FREE.
- National Youth Agency (). Act By Right. A skills development programme for 14-19 year olds (although it can be used with younger children with adequate support). It enables young people to develop the skills and knowledge to



empower them to take action and achieve change in the services they use and in their communities. The programme is accredited. (see: www.nya.org.uk).

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Websites

www.ace-centre.org.uk – lots of info re communication and communication aids.

www.audit-commission.gov.uk/disabledchildren - information re published reports and research.

www.childrenssociety.org.uk – variety of information re tools such as 'I'll Go First'.

www.dfes.gov.uk – various information.

www.direct.gov.uk/dsiabledpeople - information about the Disability Discrimination Act and Disability Rights Commission. Also has info re rights.

www.everychildmatters.gov.uk – up-to-date information re policy and legislative framework.

www.mencap.org.uk – various info including research and resources such as 'Listen Up', e-bulletins and good practice guidance.

www.ncb.org.uk/cdc - free downloadable magazine called 'Getting a Life' for anyone who works with, cares for or is a disabled young person in transition to adulthood. The Council for Disabled Children (CDC) is a national forum for discussion, dissemination of policy and practice issues for disabled young people and those with special educational needs.

www.triangle-services.co.uk – organisation that provides services for disabled children and young people with a strong children's rights and communication focus. Also provide training and consultancy.

