Working with children and young people with disabilities

Please note: This information is intended to offer assistance and provide information where appropriate and Community Southwark is not liable for action taken, or not taken, as a result of reading this briefing.

You may already work with, or are thinking of working with, children and/or young people with disabilities.

If this is the case it is important to understand the key legislation and issues surrounding this work.

This fact sheet provides a basic overview of some key legislation and guidelines and outlines some of the issues and safeguarding needs when working with children and/or young people:

Did you know…?
- 90% of disabled children live at home
- ¾ of families with disabled children live in unsuitable homes
- Disabled children are 13x more likely to be excluded from school
- 55% of families with a disabled child live in, or on margins of, poverty
- ¼ of families with disabled children say services are poor and lack coordination
- Only 1 in 3 families get services from their local social care services
- Only 16% of mothers with disabled children are in paid employment

What is disability?
The Disability Discrimination Act (DDA) defines a disabled person as:
‘Someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities.’

In 2005 the DDA was amended to ensure that people with HIV, Cancer and MS are deemed to be covered from the point of diagnosis, rather than from the point when the condition has an adverse effect on day-to-day life.

There are four main groups of disability:
1. Hearing impairments;
   - In the UK there is an estimated 9 million deaf or partially hearing people: 688,000 severely or profoundly deaf.
   - Each year 840 babies are born in the UK with significant deafness
   - 12,000 children 0-15 years were born deaf
   - 20,000 children 0-15 years old are moderately to profoundly deaf
   - 1 in 1,000 children in the UK are deaf at 3 years old.

2. Visual impairments;
   - There are 3 main groups of visual impairment: Partially Sighted; Low Vision and Legally Blind.
- Partially sighted children may require special education
- All individuals unable to view without aid may require adaptations i.e. large print, braille etc.
- Less than 20/20 vision in better eye or limited field of vision are considered legally blind

3. Learning Impairments;
- Experienced by around 1/5 of the UK’s population
- 1 in 220 children has some level; of learning disability
- Cabinet Office report ‘Improving Life Chances of Disabled People’ (2005) estimated that 11m million adults and 770,000 children in the UK are disabled (and tis figure is likely to have risen since)

4. Physical Impairments;
- Refers to a broad range of disability including orthopaedic, neuromuscular, cardiovascular and pulmonary disorders.
- Often rely on assertive devices i.e. wheelchairs, canes, crutches, artificial limbs etc.
- Not always visible.

Rights of Children, Families and Carers
There is a whole range of legislation on this subject; two key pieces which set out the rights of children, families and carers are below. A fuller list can be found later in this document:

‘Me Too Charter of Rights for Disabled Children and Young People.’
- To have the right to learn and celebrate our culture in and out of school/settings
- To be listened to and taken seriously
- To have more choice in what we learn and how we learn and develop
- To express ourselves and have equal opportunity to be involved in activities
- To be included in decisions that affect our lives
- To be treated equally and respected for being unique individuals
- To have the chance to grow and be successful
- To feel safe and be safe
- To not be bullied because of our impairments, culture or backgrounds
- To help change and improve services.

‘Aiming High for Disabled Children’
This National Core Offer is a statement of standards which families with disabled children can expect across the country from local services:

1. Information and Transparency: Information tailored to individual needs of children and their parents and in readily accessible formats. Providing greater information and transparency about decision-making will empower families to find their own ways to meet needs

2. Assessment: Disabled children and young people receive child-centred, multi-agency coordinated services from point of referral through identification and access to delivery.

3. Participation and Feedback: Disabled children and young people and their families routinely involved and supported in making informed decisions re: treatment, care, support and shaping services.
**Issues faced by children with disabilities, their families and carers**

Children with disabilities may face many barriers including:

- Access to suitable communications systems
- Access to independent facilitators
- Lack of trained staff in different communication methods
- Inappropriate equipment
- Information not being passed on regarding the child’s needs
- Treated as if they are unable to communicate and therefore child ‘switches off’
- Lack of up-to-date assessment
- Specific accessibility needs not met
- Attitudes and assumptions held by others can increase vulnerability of children with disabilities
- Negative attitudes create both vulnerability to abuse and make it less likely a disabled child will be listened to about their experience
- Lack of awareness of vulnerability of disabled children and indicators of abuse
- Failure to recognise impact of abuse on a disabled child
- Attitudes may mean disabled children are more vulnerable to bullying and intimidation
- Possible double barriers for disabled children and young people from BAME backgrounds

There will be many more barriers faced by each individual and it is important to understand what the barriers are in order to find solutions.

**Communication**

Communication is crucial to working with anyone, especially when working in the voluntary and community sector. For children with disabilities, good communication is important for:

- **Self – esteem**: effective communication empowers people to value others and build a positive self-image
- **Physical needs**: communication about physical needs i.e. pain, hunger, coldness etc. is central to working within the Children’s workforce
- **Self-Actualisation**: Personal growth and self-actualisation are often helped by effective communication with others in sharing ideas
- **Emotional Needs**: Effective communication can help people feel safe. Poor communication can make people feel threatened or unsafe
- **Affection/belonging**: Effective communication skills are important for individuals to show and receive affection. Effective communication between people results in a sense of belonging and being listened to. Poor communication may make the person feel like an outsider

There are lots of different ways of communicating depending on needs:

- British Sign Language (hearing impairments)
- Blissymbolics (physical impairments)
- Braille (visual impairments)
- Chailey Communication System (symbols – learning impairments)
- Cued speech – lip reading
- Deaf Blind Manual Alphabet
- Finger spelling (or standard manual alphabet) – supplements BSL
- Makaton Language Programme for communication, language and literacy problems – uses small nucleus vocabulary and symbols
- Mayor Johnson PCS Symbols – picture communication symbols
- Moon – reading by touch using raised shapes for those who find braille too difficult
- Objects of Reference
- Paget Gormoan Signed Speech – signing used at same time as verbal
- Picture Exchange Communication System (PECS) – exchange pictures for something they want
- Photographs
- Rebus symbols – collection of stylised pictures to help aid reading
- Sign-a-long – English Language
- Signed English (SE)/ Sign Supported English (SSE) – signs in spoken word order, only signed in English
- Symbols
- The Triangle Communication Handbook

It is unlikely that one organisation will have all of these in place but it is important to think about the work that you do and which methods may be the most suitable to train staff up in or bring in specialists for.

**Working with Children with Disabilities**
When working with children and young people with disabilities, each case will be different but there are some key ideas that will work across most beneficiaries.

As well as taking a holistic approach and having a good knowledge of the family support system, there may be a need to redress power imbalances and work against discrimination. It is crucial that the child is seen as first and foremost and that each family will have its own needs. Below are four useful areas to think about when working with children:

**Consistency**
A consistent approach when dealing with children often leads to more productive and positive behaviours

**Planning**
Highly recommended that you plan strategies that can be implemented regularly

**Positivity**
Whether the child is acting out, involved in conflicts, bullying or being verbally or physically aggressive; it is important to ensure you have a positive interaction and refrain from calling the child ‘bad’; it is behaviour being exhibited that you are unhappy about not the child.

**Time**
Acceptable and appropriate behaviour is developmental – it happens over time and is greatly influenced by parental support and guidance, peers, previous experiences and intervention techniques employed by teachers, caregivers and parents.

**Siblings**
It is important to remember that siblings are often carers and there may be problems to overcome such as bullying, jealousy, resentfulness, tiredness, and/or embarrassment.
Professionals can help support the siblings of disabled children feel as though they are part of what is going on, through speaking, listening, understanding, offering and supporting.

The Children’s Act, 1989 states that ‘…the needs of brothers and sisters should not be overlooked and should be provided for as part of a package of services for the child with a disability.’

Local authorities have a duty to provide services to children who have been assessed as ‘in need’ under the Children’s Act or as ‘affected by disability’. Sometimes siblings who provide substantial care are ‘young carers’ and are entitled to an assessment of needs in their caring capacity.

**Transitions**

As disabled children transition into adulthood, how can they be supported?

**Did you know…?**
- Disabled young people are 70% less likely to move out of the family home
- 50% less likely to gain paid employment
- 65% say they are less likely to be in a ‘good job’ and have a regular partner by the time they are 30
- 70% say they have problems in accessing a social life or getting a holiday
- 65% have been bullied or felt unsafe
- 40% say they are heavily dependent on their parents for multiple areas of their life

A good transition depends heavily on:
- Multi-agency transition protocol
- Multi-agency working
- Effective practice
- Information available for young people and parents
- Evaluation of provision
- Youth and carer services
- Post-16 opportunities
- Leisure and social life opportunities

If your organisation works with children, do you work alongside organisations that can work with the same children when they transition into adulthood?

**10 National Standards for Advocacy**

1. Advocacy led by views and wishes of children and young people
2. Champion rights and needs of children and young people
3. 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.
4. Well publicised, accessibly and easy to use
5. Gives help and advice quickly when requested
6. Works exclusively for children and young people
7. Service operates to a high level of confidentiality and ensures children, young people and other agencies are aware of its confidentiality policies
8. Listens to views and ideas of young people in order to improve services provided
9. Service has effective and easy complaints procedure
10. Well managed and gives value for money

Safeguarding Issues
The Common Assessment Framework (CAF) covers 3 key areas relating to development, parenting capacity and family and environmental factors.

Childs Developmental Needs
- Health: general health; physical development; speech, language and communication
- Emotional, social and behavioural development
- Identity: self-esteem, image; social presentation
- Family and social relationships
- Self-care skills and independence
- Learning: understanding, reasoning and problem solving; participation in learning, education and employment; progress and achievement aspirations

Parents and carers should explore areas such as:
  - Basic care, ensuring safety and protection
  - Emotional warmth and stability
  - Guidance, boundaries and stimulation

Family and Environmental Factors
- Family history, functioning and wellbeing
- Wider family
- Housing, employment and financial considerations
- Social and community elements and resources including education
- Myths about can happen to disabled children etc.

Several Key factors when assessing children with complex needs:
  - Think about own understanding of disability
  - Use and limitations of developmental milestones
  - Boundary between control, treatment and abuse: involvement of children in assessment process; be clear about position of service; take responsibility for communication; try to take child’s perspective

There are clear links between disability and abuse:
- Abuse creates and exacerbates impairments
- Abuse is itself disabling in many ways
- Disability increases the risk of abuse
- Disability reduces the chances of protection
- Disabled young people may be more vulnerable to coercion – a sexual relationship may not be consensual.
- Disabled children may be dependent on their abusing carer
- Some children learn to be compliant from past experience
- May receive intimate personal care from a number of different carers – therefore increasing the risk of abuse

Barriers to safeguarding
- Reluctance to challenge carers
• Assessments can be dominated by a child’s medical condition
• Assessments may focus on needs relating to impairment
• Lack of familiarity with impairment
• Insufficient time to carry out assessment
• Families of disabled children may resist yet another assessment
• Reluctance to believe disabled child is at risk of abuse
• Assumption that disabled child could not be a credible witness
• Behaviour and/or physical symptoms are seen as related to impairment
• Abusive practices are unrecognised

Key Guidance & Legislation

   Article 12 ‘Every child has the right to participate in decision-making on matters that affect their own lives’

   Places a duty on Local Authorities to ascertain wishes and feeling of a child before making any decisions concerning the child

   Places a new duty on Local Authorities to ascertain wishes and feelings and to give due consideration to them, in relation to assessments of children in need under section 17 and child protection investigations under section 47 of 1989 Act.

   States what disability is and provides 4 main types.
   Brought in a duty on all public authorities to promote disability equality.
   2005 act made some changes to the definition outlined in 1995

   International convention that embodies rights of disabled people to equal participation in public, political (article 29) and cultural life (article 30) and to participate with their community (article 19).

   Article 7 – right to express their views on all issues which affect them and right to be provided with appropriate support to enable them to do so.

   New childcare Act was a pioneering piece of legislature – the first Act to be exclusively concerned with early years and childcare

7. Education and Inspections Act (2006)
   Section 6 introduces two new sections into the Education Act 1996: Section 507A and Section 507B.

8. Working with Children and Young people with Disabilities - Children’s Workforce Development Council (CWDC)
9. **Hear by Right**
Standards for organisations to assess and improve practice and policy on children and young people’s participation based on the 7 S’s Model:
- Shared values
- Strategy
- Structure
- Systems
- Staff
- Skills & knowledge
- Style of leadership


11. **Inclusion Charter** – all children have the right to be included in every aspect of society: Disabled children should not have to ask or fight to be included.

12. **Transition Guide for all Services**
Transition to adulthood is an all-encompassing process covering every aspect of a young person’s life. Supporting disabled young people in their transition can be a challenge to service providers.

13. **When will we be heard?**
Use of advocacy considered to be one way to progress achievement of disabled child’s right to participate in decision making.

Seeks to improve outcomes for children and young people

15. **Government White Paper: Our Health, Our Care, Our Say: a new direction for community services**
Gives service users more choice and power to influence the type and standard of service they receive locally

**Resources**
- Southwark Council and NHS – [Safe Organisation Checklist](#)
- Private Fostering – [www.privatefostering.org.uk](#)
- A guide to inter-agency working to safeguard and promote the welfare of children
- Southwark Safeguarding Children Board (SSCB)
- The Children’s Society [Safeguarding disabled children Practice guidance](#)
- NSPCC [We have the right to be safe](#)

**Support**
If you would like any support with safeguarding policies, or signposting, please contact the Development Team at Community Southwark: development@communitysouthwark.org or 020 7358 7020.