

Information Pack
Special Needs

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Disability

Kate and Laura are sisters, Laura is 10 years old. They get on well together, and enjoy doing things together – listening to music, going shopping for clothes with Mum, trips to McDonalds and the cinema. But Kate sometimes feels left out – she cannot always go on trips. Kate has Cerebral Palsy and needs to use a wheelchair to get around – she cannot walk. If they need to take a bus trip, Kate has to stay at home with Dad. The buses don't have ramps to accommodate her wheelchair so she cannot go on a bus. Kate can only go to certain shops, cinemas and other buildings because not everywhere is wheelchair accessible. Everyone feels sad about this. It doesn't seem fair.

Laura sometimes feels bad for Kate. She hears other children make fun of people with special needs and never knows what to say. She has talked to mum about this. Mum has told Laura that children do this sometimes because they don't know any better. They probably feel awkward because they have not been around people with disabilities. They may feel nervous or afraid and don't know how to act. They might think that making someone else feel bad will help them to feel better. People who tease are only looking at how the person with a disability is on the outside. They don't know them and don't realise that they have the same feelings as everyone else.

Laura knows this because she knows Kate, she realizes that although Kate uses a wheelchair, she is still like everyone else and deserves the same respect. Others need to learn this. In our society, people with disabilities are still excluded and discriminated against. There are many reasons for this. We live in an unequal society and more dominant groups oppress the less powerful. Historically, people's attitude towards the disabled has been one of pity and charity: disabled people have been segregated and excluded. By marginalizing disabled people, they are denied the possibility of realizing their full potential. Indeed it is often not their disability that prevents them from participating in society to the full, but the injustice and attitudes of others.

Today, in more enlightened times, things are changing but we still have a responsibility to highlight discrimination and endeavour to change society's attitude. We can start by educating our children.

Patricia McDonnell

Project Worker
Barnardos

(Taken from Children's Books for Special Needs: Disability Barnardos NCRC and Fingal County Libraries)

Arthritis (Juvenile)

Arthritis Youth

1 Clanwilliam Square

Grand Canal Quay

Dublin 2

Tel: 01 661 8188

Arthritis means disease of, or damage to, a joint or joints. Rheumatic disease is a term used to cover all types of arthritis and rheumatism. There are 200 different types of rheumatic disease and several types of arthritis affect children.

Systemic illness - arthritis with fever and rash – begins with a fever and affects glands in the neck, groin, and axilla (under the arms). Very rarely pericarditis (inflammation of lining of the heart) and pleurisy may occur. At this stage there may be no swollen joints or some swollen joints.

Polyarticular arthritis – where many joints are inflamed – may start as a systemic illness or without general illness. It can occur at any age from a few months old. Girls are more often affected than boys. The extent of the disease can usually be assessed after a few months.

Pauci-articular arthritis – in which only a few joints are affected – is the commonest form of juvenile arthritis. Where only one joint is affected, it is known as **monarticular arthritis**. Children with the condition have a high risk of an associated eye condition (**chronic iridocyclitis**). It also occurs in a small number of children with **polyarticular arthritis**.

Juvenile spondylitis – occurs mostly in boys of 9 upwards. They usually carry a genetic factor (HLA-B27). Family members may have ankylosing spondylitis. The eye disease **acute iridocyclitis** is associated with the condition.

Adult type rheumatoid arthritis – occurs mostly in girls of 11 upwards. The hands, feet and in some cases the knees are affected.

Psoriatic arthritis – arthritis in association with the skin disease psoriasis.

(Taken from **Barnardos Child & Family Directory 2000** and **CaF Directory of Specific Conditions & Rare Syndromes 4th Edition May 1997**)

Asthma

Asthma Society of Ireland

Eden House

15-17 Eden Quay

Dublin 1

Tel: 01 8788511

E-mail: asthma@indigo.ie

Asthma is a condition in which there is a reversible narrowing of the airways in the lung due to inflammation, which causes swelling of the lining, and spasm of the muscle around the airways. Asthma may be caused by an allergic (atopic) response to inhaled, ingested or injected substances. Allergic mechanisms become more important as children get older. Viral infections commonly cause attacks in the very young and this may be a different form of asthma from the later allergic type. Exercise and smoke may also trigger symptoms. Eczema may be associated with asthma in some cases.

Many children grow out of asthma during their teens but symptoms may recur later, in adult life. However, asthma persists in many people throughout life. Asthma is not a psychological disorder although in certain cases stress may be a factor in precipitating an attack. Asthma varies greatly in its severity and occurs at all ages. In severe cases the condition may be life-threatening.

It is important to seek a diagnosis where a child is regularly wheezy, coughs or is short of breath, so that appropriate medication and treatment can be given if necessary. Wheeze is only one symptom of asthma. Inhaled steroid treatment at normal doses is safe.

One in seven children have asthma symptoms at sometime.

(Taken from **Barnardos Child & Family Directory 2000** and **CaF Directory of Specific Conditions & Rare Syndromes** Update December 1997)

Attention Deficit Hyperactivity Disorder

HADD (Hyperactive/ Attention Deficit Disorder Family Support Group)

Stephanie Mahony

25 Lawnswood Park

Stillorgan

Co. Dublin

Tel: 01 288 9766

Attention Deficit Hyperactivity Disorder: ADD: ADHD: Hyperkinetic Disorder

Hyperkinetic Disorder is the term recognized in official UK publications and by the World Health Organisation's International Classification of Disease. The terms Attention Deficit Hyperactivity Disorder: ADD: ADHD are more commonly used.

Attention Deficit Hyperactive Disorder is an impairment of activity and attention control. The problem presents as a child who is always on the go, does not settle to anything, has poor concentration, cannot stay still and cannot wait for others.

The diagnostic features are :

Inattentiveness – very short attention span, over- frequent changes of activity

Over activity – excessive movements, especially in situations requiring calm such as classrooms or mealtimes.

Impulsiveness – affected person will not wait their turn, acts without thinking, thoughtless rule-breaking.

The problems are handicapping and start at an early age, and they are present in more than one situation, e.g. home and school. Sometimes affected children show discipline problems, underachievement at school, poor sleep, temper tantrums and experience unpopularity and accident-proneness. However, all these can have other causes too.

There are several causes. Twin studies indicate a strong genetic contribution. Environmental causes include brain damage , intolerance to certain foods, hearing impairment, toxic and infective agents during pregnancy, and psychological stress. There are some specific treatments, including stimulant medication, behaviour therapy and dietary exclusion approaches in selected cases.

(Taken from **What do I do now?** Parents Future Planning Group 2000 and **CaF Directory of Specific Conditions & Rare Syndromes** 5th Edition December 1998)

Autism including Asperger Syndrome

Irish Society for Autism

16 Lower O'Connell Street

Dublin 1

Tel: 01 874 4684

E-mail: autism@isa.iol.ie

Autism is a pervasive development disorder, which affects social and communication skills. It may also occur with other learning difficulties. In the majority of cases the condition is present from birth or it is apparent in the first three years. The language impairment of autism extends to all modes of symbolic thought and communication and, therefore, the rules of language and social behaviour are incomprehensible to the autistic child. This results in what has been termed autistic behaviour. The cause of autism is believed to be organic brain damage.

ASPIRE (Asperger Syndrome Association of Ireland)

Des McKernan

85 Woodley Park

Dundrum

Dublin 16

Tel: 01 295 1389

Asperger Syndrome is the name now being used to describe some of the people at the very able end of the autistic continuum. There are many similarities between Autism and Asperger Syndrome, but also differences. In Asperger Syndrome, early language development is not delayed. Gestures are used, though their use may be inappropriate. The typical aloofness of autism is not present. Clumsiness is also a feature of the syndrome. The child is normally solitary and tends to become obsessed with particular systems or ideas for, perhaps, long periods. Severe difficulties in relationships may be exhibited in adolescence.

(Taken from **CaF Directory of Specific Conditions & Rare Syndromes** Update December 1997)

Cerebral Palsy

Cerebral Palsy Ireland

Sandymount Centre,
Sandymount Avenue,
Dublin 4
Tel: 01 269 5355

Cerebral Palsy is a disorder of movement and posture, which is apparent in the early years. It is due to damage or failure in development of the part of the brain concerned with movement. Adjacent parts of the brain may also be injured and this may lead to poor sight, deafness or other perceptual difficulties. Children with cerebral palsy may also have learning difficulties.

The effects of cerebral palsy vary with each individual. Disability resulting from cerebral palsy may be very slight or very severe.

Difficulties include awkwardness in walking, or of hand and arm movements, or speech. Severely affected children may require physical support and other forms of assistance.

There are three main forms of cerebral palsy: spasticity - disordered control of movement, often associated with tight muscles; athetosis – frequent involuntary movements; ataxia – unsteady gait with problems of balance.

(Taken from **Barnardos Child & Family Directory 2000** and **CaF Directory of Specific Conditions & Rare Syndromes** Update May 1998)

Cystic Fibrosis

Cystic Fibrosis Association of Ireland
24 Lower Rathmines Road
Dublin 6
Tel: 01 496 2433
E-mail: cfthouse@internet-ireland.ie

Cystic Fibrosis causes the mucous glands to produce abnormally thick, adherent mucus and the sweat glands to produce excess salt. The two main areas of the body involved are the lungs and the pancreas (part of the digestive system). The mucus is responsible for the principal complications.

In Cystic Fibrosis the lungs are normal at birth but become susceptible to bacterial infection and damage. The thick mucus collects in the lungs blocking some airways and resulting in damage caused by the infection. Much of this damage can be prevented through adequate treatment of infections.

In the pancreas the small channels (through which the enzymes produced in the pancreas flow to reach the intestines) become blocked with mucus. This results in cysts being formed and these lead to fibrosis in the pancreas. The enzymes produced by the pancreas are vital to normal digestion. Digestive enzyme preparations can replace most of the digestive enzymes produced by the pancreas. Insulin is also produced. However, in most cases of cystic fibrosis, the pancreas

usually manages to produce enough insulin in childhood but diabetes is increasingly common in adults.

Cystic fibrosis is a life-threatening condition. 75% of affected children now survive to young adulthood and the average survival is around 30 years.

(Taken from **CaF Directory of Specific Conditions & Rare Syndromes** Update December 1997)

Deafness

National Association for Deaf People (NAD)
35 North Frederick Street
Dublin 1
Tel: 01 872 3800
E-mail: nad@iol.ie

The ear is a sensory organ which performs two functions, hearing and balance. In order to hear properly the ear, the nerve of hearing and the relevant parts of the brain must be kept working effectively. Hearing defects may be related to dysfunction in any area. Balance is a complex function and disorders of balance can occur in association with hearing disorders or can occur alone.

Deafness, or hearing loss, can be divided into categories: **conductive** deafness where the causes are malfunction, malformation or occlusion in parts of the outer and middle ear, and **sensorineural** deafness where the cause is a malfunction of parts of the inner ear or nerves of hearing. **Mixed** hearing loss occurs when there are conductive and sensorineural components to the hearing loss.

Some kind of conductive deafness such as 'glue ear' (otitis media with effusion or fluid in the middle ear) are temporary. Other types of deafness are permanent. One the most common types of inherited deafness is bilateral severe to profound sensorineural deafness which is usually of autosomal recessive inheritance. Other causes include problems at or around the time of birth such as infection or marked prematurity (perinatal causes) infections during pregnancy e.g. Rubella, or infections during childhood e.g. meningitis. Early diagnosis and treatment is important. Testing babies for hearing can be carried out at any age.

(Taken from **Barnardos Child & Family Directory** 2000 and **CaF Directory of Specific Conditions & Rare Syndromes** 4th Edition May 1997)

Down's Syndrome

Down's Syndrome Association Of Ireland

41 Lower Dominick Street

Dublin 1

Tel: 01 873 0999

E-mail: dsi@tinet.ie

Down's Syndrome, Trisomy 21, a genetic disorder, occurs when there is a whole additional chromosome 21. Therefore, affected individuals have three chromosome 21 in place of the normal pair.

A chromosome is a rod-like structure present in the nucleus of all body cells, with the exception of the red blood cells, and which stores genetic information. Normally humans have 23 pairs of chromosomes, the unfertilized ova and each sperm carrying a set of 23 chromosomes. On fertilization the chromosomes combine to give a total of 46 (23 pairs). A normal female has an **XX** pair and a normal male an **XY** pair.

(Taken from **Barnardos Child & Family Directory 2000** and **CaF Directory of Specific Conditions & Rare Syndromes 4th Edition May 1997**)

Epilepsy

Brainwave – The Irish Epilepsy Association

249 Crumlin Road

Dublin 12

Tel: 01 455 7500

Epilepsy is a tendency to have recurrent seizures or fits. The epileptic seizure is the result of excessive or disordered discharge of brain cells.

Seizures are divided into two categories, namely generalized or partial seizures.

In the **generalized seizures** both hemispheres of the brain are involved. The seizures include major convulsive episodes with jerking of all limbs and unconsciousness (tonic clonic seizures); seizures when the body goes stiff (tonic) or floppy (atonic); jerks of the limbs (myoclonic jerks) and momentary lapses of consciousness (absences or petit).

In **partial (or focal) seizures** the disturbance of brain activity starts in, or involves, a specific part of the brain. The nature of such seizures depends upon the area of the brain involved. Partial seizures may be simple or complex. The affected person may experience an 'aura' at the start of the episode. Consciousness is not always lost.

Causes of epilepsy are variable and may be idiopathic or symptomatic.

Idiopathic epilepsy starts in childhood or adolescence and is intrinsic to the individual. It is not due to structural change or lesions in the brain.

Symptomatic epilepsy may be due to brain damage or anomaly from any cause (e.g. cerebral palsy), infection, tumors, or specific syndromes such as Sturge-Weber, Tuberous Sclerosis, or some metabolic disorders.

(Taken from **Barnardos Child & Family Directory** 2000 and **CaF Directory of Specific Conditions & Rare Syndromes** Update May 1998)

Visual Impairment

National Council for the Blind (NCBI)

PV Doyle House
45 Whitworth Road
Drumcondra
Dublin 9
Tel: 01 8307033
E-Mail: ncbi@iol.ie

The eye is the sensory organ of sight. In order to see properly the eye, the relevant nerves and part of the brain must be working effectively. Visual impairment may be related to dysfunction in any area. Blindness is a symptom of visual impairment which is either or total and may be congenital or acquired.

There are three categories of visual impairment:

1. Malfunctions and inherited disorders of the eyes which may range from cataracts, defects of the iris (coloboma) to anophthalmia (the bilateral absence of both eyes) and include retinitis pigmentosa and retinoblastoma;
2. Acquired eye disorders such as retinopathy or prematurity and including accidents;
3. Brain disorders or ‘cortical blindness’ either congenital or acquired, examples are congenital malformations of the brain, hydrocephalus, brain tumors and trauma.

Visual impairment in these categories is often associated with additional handicaps such as deafness (Usher Syndrome and congenital rubella), learning difficulties (in 10% of cases of retinoblastoma in children) epilepsy and cerebral palsy can occur in cases of cerebral dysfunction.

(Taken from **Barnardos Child & Family Directory** 2000 and **CaF Directory of Specific Conditions & Rare Syndromes** 5th Edition December 1998)

Rare Syndrome Associations

Angelman Syndrome

Risenary Teggin, Parent Contact in Ireland
51 Springhill Park, Killiney, Co. Dublin.
Tel- 01 285 5626
Email: rosemaryteggin@tinet.ie

Asperger Syndrome

Asperger Syndrome of Ireland (ASPIRE)
Des McKernan Hon. Secretary
85 Woodley Park, Dundrum, Dublin 16
Tel: 01-2951389.

CAINT (for families of children with speech
and language disabilities)

Geraldine Graydon,
10 Bayview, Killiney Hill Road, Killeney, Co.
Dublin
Tel: 01 282 3584

CRI DU CHAT SYNDROME

Peter and Nuala Cassidy
37 Upr Eden Road, Dun Laoghaire, Co.
Dublin
Tel: 01 280 1281

FRAGILE X SYNDROME

Irish Fragile X Society
Mary Smyth, Chairperson
24 Aren View, Tullamore, Co. Offaly.
Tel: 0506-52796

NEUROFIBROMATOSIS ASSOCIATION OF IRELAND

C/o Carmichael Centre for Voluntary Groups
Carmichael House, North Brunswick Street,
Dublin 7
Tel: 01 873 5702

PRADER-WILLI SYNDROME

Irish Prader – Willi Syndrome Support Group.
Lena Lawlor Kilmurray, Kilmacanogue, Co.
Wicklow.
Tel: 01-2868119

RETT SYNDROME

Mairide Woods
17 Del Val Avenue, Dublin 13
Tel: 01- 832 4780

SOTOS SYNDROME

Sandra Pedreschi, 59 Hillview Estate,
Ballinteer, Dublin 16.
Tel:01- 296 0206

SPINA BIFIDA and HYDROCEPHALUS

Irish Association for Spina Bifida and
Hydrocephalus.
Old Nangor Rd. Clondalkin Dublin 22.
Tel: 01- 457 2329

SUPPORT ORGANISATION FOR TRISOMY

(SOFT)
Angela Lambert 81 Glenageary Avenue,
Dunlaoire, Co.Dublin.
Tel: 01- 285 4907

TOURETTE SYNDROME

Tourette Syndrome Association of Ireland.
39 Elderwood Road, Dublin 20
Tel: 01- 623 0500

UNIQUE

(rare chromosome disorder support group)
Peter and Alice O'Brien.
19 St. Patrick's Rd, Walkinstown, Dublin 12
Tel: 01- 456 9643

WILLIAMS SYNDROME

Ann Breen, Hon. Secretary
13 Kilgarve Park, Ballinasloe, Co Galway
Tel: 0905 43247

Rights

People with a disability have social and economic rights. Uniquely among other citizens, they lack the voice and the means to lobby for the resources needed to give meaningful expression to those rights. They cannot overcome the barriers alone.

There the National Parents' and Siblings' Alliance (NPSA) has established this Charter of Rights and will be campaigning to enshrine these rights in Ireland's Constitution to secure a future for all children with special needs.

It is hoped that this Charter will inform all parents of the minimum standards required for the well being of their children.

1. The right to a full and detailed assessment of needs at the time of diagnosis of disability, to regular assessments thereafter and to all essential services arising from assessment;
2. The right to a free and full medical care and all aids as necessary;
3. The right to an education geared to the potential and abilities of the person;
4. The right to training and too meaningful work where appropriate;
5. The right to live as independent and social a life as possible with appropriate support, including proper income support and full access to public services;
6. The right to be free from discrimination and from economic, sexual, or other forms of exploitation;
7. The right to long-term care when the need arises;
8. The right of people with disabilities, their parents, guardians and siblings to participation and needs consultation in the formulation and implementation of all policies which affect the lives of people with a disabilities;
9. The right of people with disabilities, their parents, guardians and siblings to elect their own representatives onto the boards of all service providers, including all statutory agencies, to ensure effective representation;
10. The right of parents, guardians and siblings of people with a disability to counseling, support and respite care when needed, and to information and consultation about the of their child, irrespective of age.

(Taken from **“What do I do now?” The Parents Future Planning Group** Health Promotion Unit October 2000)

The Social Model of Disability

The social model of disability – the way of thinking about disability – has been developed by the disabled people’s civil movement. One of the clearest explanations of the social model, and how it differs from the medical model of disability, has been put forward by the Greater Manchester Young Disabled People’s Group. They say:

For many years doctors, social workers and other people have told disabled people that they are disabled because of ‘what is wrong with them’ – their legs don’t work, they can’t see or hear or they have difficulty learning things, just to give a few examples. This is known as the medical model of disability. It says that it is the person’s ‘individual problem’ that they are a disabled person.

What we say is that yes, we do have bits of us that don’t work very well, this we call our impairment: for example a person who cannot hear very well has a hearing impairment. What we say is that it is not this impairment, which makes us a disabled person, it is society, which makes us disabled. Society does not let us join in properly – information is not in accessible formats, there are steps into buildings, people’s attitudes towards us are negative. So society puts barriers before us, which stop us from taking part in society properly – it disables us. This is known as the social model of disability.

Greater Manchester Coalition of Disabled People, Young Disabled People’s Group (1996), Resource Sheet 1.

The social model of disability therefore separates out impairment - the functional limitations of someone’s body or mind – from disability – the disabling barriers of prejudicial attitudes and unequal access to education, housing, transport, leisure activities and so on. Impairment is not being able to see; disability (oppression) is when a school refuses to provide printed material on tape or in Braille. Impairment is not being able to talk ; disability is local health, education and social services authorities arguing about whose responsibility it is to provide you with a communication aid. Impairment is not being able to walk; disability is the bus company refusing to buy accessible buses. Impairment is finding it difficult to read and write; disability is being written off as ‘ineducable’.

Another way of explaining the social model of disability is that presented by David Barker in his guide for employers on employing disabled people (see next page). Figures 1 and 2 illustrate clearly how the medical model is a pessimistic way of seeing things, identifying the disabling barriers which can be tackled in order to create more opportunities and a better quality of live for disabled people.

Figure 1: The medical or individual model of disability

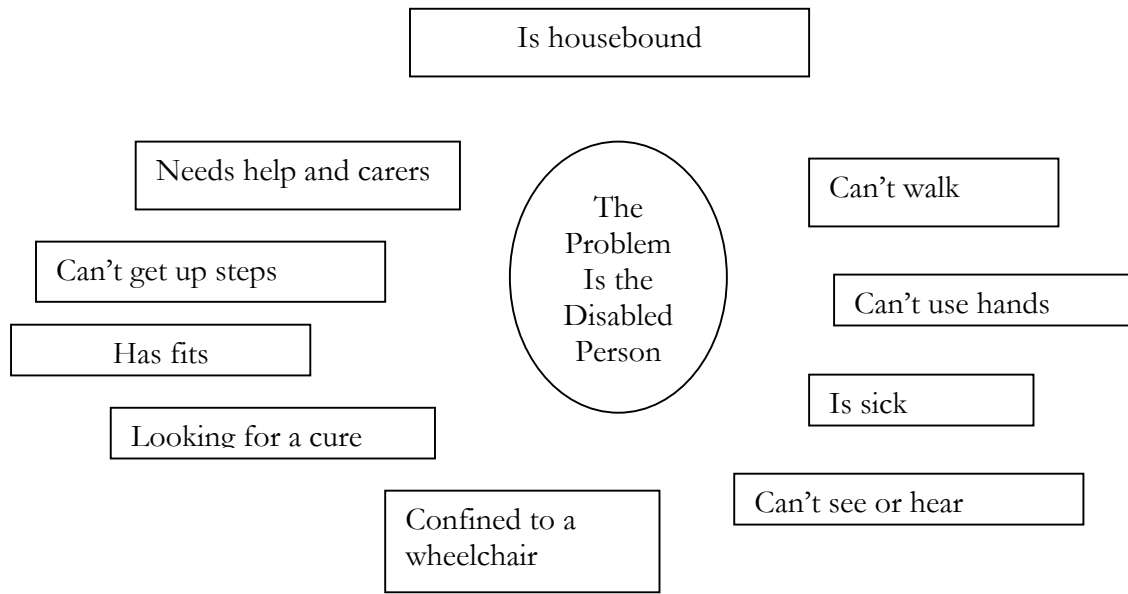
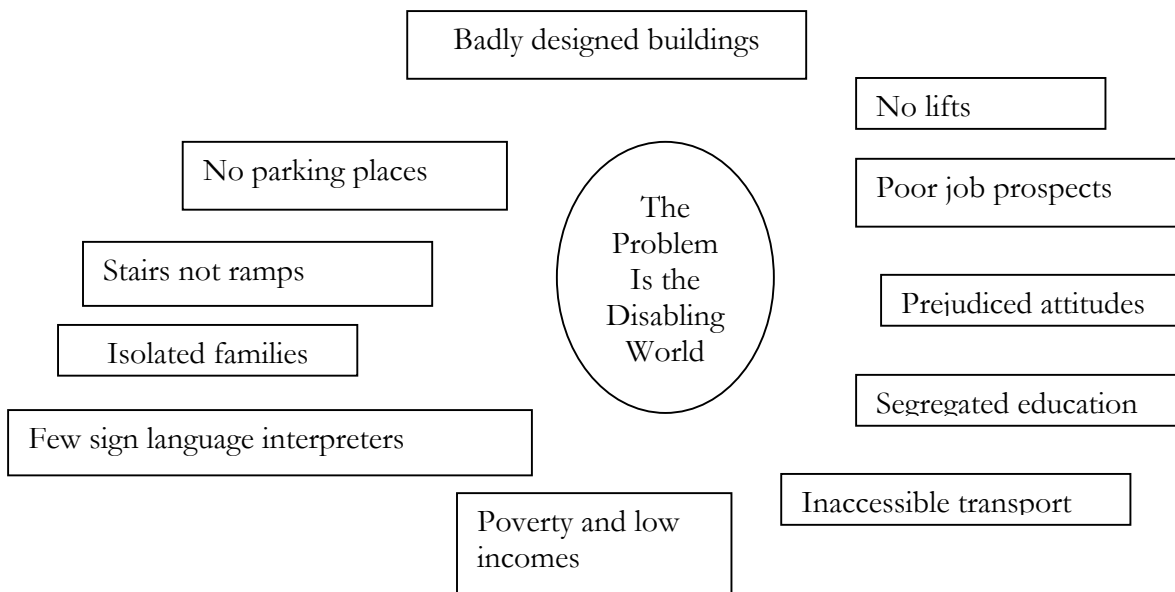


Figure 2: The social or structured model of disability



(Taken from Morris, Jenny "Move On Up" Barnardos UK 1999)

Living with disability - the experiences of siblings

This Highlight explores the experiences of young people who either have a birth sibling with disabilities, or whose families have adopted or fostered a young person with disabilities. Much information about these young people comes from parents, including personal accounts as well as research data, and from social workers and other practitioners, who work with families whose members include a young person with disabilities. The siblings themselves have gained a voice through initiatives such as Mencap's 'Sibs Group'. Also, while there are important ethical and practical considerations in ensuring that young people's views are accurately portrayed, some research studies have sought to ascertain the views of siblings.

The term 'disability' subsumes an enormous range of conditions and impairments, with likely differential impact on family life. A review of the American literature has concluded, however, that the methodological shortcomings of many studies mean that a clear relationship between the type and nature of a young person's disability, and the psychological adjustment of his or her siblings, cannot be identified with any confidence.

Numbers and definitions

Surveys which the Office of Population, Censuses and Surveys (OPCS) undertook in 1985 and 1989 concluded that there were around 360,000 young people under 16 years in Britain with physical and learning disabilities, just over three per cent of the age group. Approximately 97,000 were estimated to have disabilities associated with intellectual functioning. Proportionately more boys (37 per thousand population) than girls (26 per thousand population) were affected. The vast majority were living in private households.

The OPCS surveys employed a broad definition of disability: 'a restriction or lack of ability to perform normal activities, [resulting] from the impairment of a structure or function of the body or mind'. Young people were allocated to one of ten categories, according to the severity of their disabilities. For example, a boy aged six with leukaemia was defined as severity category 2, being '...often unable to settle at night (and sometimes miserable and fearful)'. Allocated to severity category 10 was a girl aged 10 with the following difficulties: 'cerebral palsy...finds it impossible to understand anything her family say to her...is aggressive, violent-tempered or destructive or screams and shouts every day...cannot feed self without help...!'

The parents' perspective

Much material on the effects of having a sibling with disabilities has been obtained by asking parents about the behaviour and responses of their able-bodied children. The consequences for their children of having a brother or sister with disabilities is demonstrably of concern to parents. The OPCS survey revealed that around 48 per cent of parents felt that the siblings suffered from lack of parental time and attention. When one child was severely disabled, Glendingning found that a significantly higher proportion of 268 families interviewed - nearly three-quarters (72 per cent) - expressed the view that the siblings were affected, though not always adversely.

Several studies have identified parental anxiety about the emotional and intellectual development of their other children and highlighted the parents' dilemmas about how best to help these children to understand the disabilities experienced by their siblings and to enable them to cope with sometimes unsympathetic peer group reactions. Parents have also reported difficulties in reconciling the different demands of everyone in the family and in deciding how much responsibility their other children should take, as they grow up, for the sibling with disabilities.

Based on her own experiences and those of 50 families whom she interviewed, McCormack showed that parents try to be positive, emphasising that having a sibling with disabilities has made their other children more mature and considerate. This finding has been reiterated by Glendenning. Yet McCormack's overall judgement was that these young people can have a 'rough ride'. Certainly, the adverse experiences which some siblings undergo has long been recognised. A Bristol University study, undertaken in 1978, asked 217 mothers about the attitudes of their other children towards the sibling with disabilities. According to the responses of this group of mothers, 20 per cent of siblings had problems with doing homework, because of interruptions, noise, emotional upset and destruction of papers; 44 per cent had difficulties looking after their possessions; and 34 per cent had problems entertaining or playing with friends. The authors concluded that the presence of a child with severe disabilities, especially severe learning disabilities, had 'quite extensive repercussions for the siblings'.

Family circumstances

Whatever the level of disability, it is widely accepted that the birth of a child with disabilities will significantly alter and, especially initially, disrupt family life. Gath, for example, suggested that there was a higher occurrence of marital breakdown or severe marital disharmony following the birth of a Down's Syndrome baby, in comparison with marital relationships following the birth of a child without disabilities. Some children see their parents, especially their mothers, being worn down by a physically exhausting routine; and, at worst, suffer watching a sibling endure serious illness and maybe die .

Several factors appear to influence the circumstances of siblings. One is the ability of the parents successfully to re-adjust and cope following the birth of a child with disabilities. The socio-economic status of families is also important. Gath found that the siblings of young people with Down's Syndrome were more likely to be rated as deviant, by their teachers and their parents, when they lived in large families and their fathers were in poorly-paid occupations. This suggests that siblings may be more likely to be adversely affected when the family is experiencing problems additional to those associated with bringing up a young person with disabilities.

Gender and birth order

An American review highlighted evidence about the influence of gender and birth order. When the sibling with disabilities lives at home, the psychological adjustment of older sisters seems more vulnerable than that of older brothers. This may be linked to the greater childcare responsibilities which older sisters carry. Younger siblings, especially brothers, have also been found vulnerable. It has not been established, however, whether this may be true also in families where no child has a disability.

A second American study focussed on the relatively poorer adjustment of siblings younger, or closer in age, to the young person with disabilities and suggested that male siblings seemed more affected than females; though the influence of gender may interact with that of age in, as yet, unknown ways. The authors conjectured that the experiences of siblings may depend partly upon the temperament of the able-bodied sibling. Those who can recognise and accept their own different rate and level of development, relative to the sibling with disabilities, perhaps cope better.

Relationships between birth and fostered or adopted children

From the 1970s onwards, many specialist family placement programmes were established to enable young people with 'special needs', including those with disabilities, to live with families in

the community. Little is known about the impact on birth siblings of losing a brother or sister with a disability to adoption or fostering. Social work research interest in sibling relationships is relatively recent.

As far as the birth children in foster care or adoptive families are concerned, Gath found that they reacted similarly to young people whose birth sibling had disabilities. The older 'children' took an interest in, and identified with, their parents' caring role. This similarity between the responses of birth and foster siblings extends to the rivalry and irritation some children reportedly felt when their parents fostered or proceeded to adopt a young person with disabilities. Anecdotal accounts have referred to birth children's resentment about their reduced personal space and privacy once a placement is made.

The siblings speak

Macaskill's study of twenty families who had adopted a child with severe learning disabilities concluded that there 'was little evidence of the handicapped child destroying family life or adversely affecting siblings'. Macaskill described how siblings were positive about the adopted child even when the social work practitioners making the placement had expressed serious reservations.

A study undertaken for the Fostering Service of Barnardo's North-West Division sought the views of young people whose parents fostered young people with severe learning disabilities. Several workshops were held to which the birth children of foster care families were invited. The assumption was made that young people would talk more openly about their experiences and feelings in the company of their peers and away from their own homes.

The findings showed clearly that fostering is an activity in which the whole family is involved. The feelings and experiences of the 23 young people whose views were sought varied. While most pointed to positive outcomes of fostering, a few young people expressed mixed feelings or highly negative reactions. These were all girls or young women, generally near in age to the young person placed and who either played an important caring role for the young person placed or whose lives had been altered significantly as a result of the placement.

The following factors were found important in making fostering a satisfactory experience for the birth children:

- That their parents could devote sufficient time and energy to them;
- That they did not perceive their caring responsibilities to be too onerous;
- That they had adequate privacy and personal space;
- That they were consulted and informed about the placement and, if difficulties arose, they had the opportunity to talk over their feelings.

In conclusion, these findings suggest that the birth children in families who foster a young person with disabilities experience a similarly complex range of emotions as young people whose birth siblings are experienced.

Janet Ames Reed - - March 1993

(Taken from **Highlights**, produced by the Library and Information Service of the National Children's Bureau together with Barnardo's as a joint project to share current research, development, policies and practices.)

Websites, Contact Details and Resources for further information:

Barnardos National Children's Resource Centres:

Christchurch Square, Dublin 8.

Tel: 01 4549699

Fax: 01 4530300

Email: ncrc@barnardos.ie

Bowling Green, White St., Cork

Tel: 021 4310591

Fax: 021 4310691

Email: ncrc@cork.barnardos.ie

10 Sarsfield St, Limerick

Tel: 061 208680

Fax: 061 440214

Email: ncrc@midwest.barnardos.ie

River Court, Golden Island, Athlone

Tel: 090 6479584

Fax: 090 6479585

Email: ncrc@athlone.barnardos.ie

41-43 Prospect Hill, Galway

Tel: 091 565058

Fax: 091 565060

Email: ncrc@galway.barnardos.ie

<http://www.barnardos.ie/>

The National Children's Resource Centres have many resources on this area – please contact your local centre for more details. All resources referenced in this information pack can be read in the centres.

Contact A Family (UK)

170 Tottenham Court Road, London W1P 0HA

Tel: 00 44 207 383 3555

CaF provides a service of putting parents and professionals in contact with support groups or with individual families.

Disability Federation of Ireland

2 Sandyford Office Park, Blackthorn Avenue, Dublin 18

Tel: 01 295 9344

Email: info@disability-federation.ie

Website: <http://www.iol.ie/~dfi/>

Irish Council of People with Disabilities

4th Floor, Park House, North Circular Road, Dublin 7

Tel: 01 868 3502

Email: cipd@indigo.ie

National Disability Authority

25 Clyde Road, Dublin 4

Tel: 01 668 4181

Email: nrb@iol.ie (*Library and Information Service*)