



























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We appreciate Lesley Johnston's (Carers Northern Ireland) review of sections of this book. Her comments were very helpful. The Family Information Group takes full responsibility for the accuracy of the information in this book.

In the production of this book, a vital part has been the views and opinions of parents over a period of time. These views and opinions helped identify the

issues and concerns. This publication has been the result of partnership working – WHSSB, Family Information Group, Foyle Trust, Sperrin Lakeland Trust, professionals and parents.

We hope you think it was worth the effort.

■ The information in this book is available in other formats. For further details contact:
Family Information Group • Tel: 028 7128 5675

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INTRODUCTION



This publication is for all parents of disabled children – no matter whether the disability is physical, sensory or learning (or any combination of these); has no confirmed diagnosis; or conditions which do not fall into any of these categories. This book will also be useful to those who work with families of disabled children, both in the voluntary and statutory sectors.

The Western Health and Social Services Board (WHSSB) has funded this publication to help parents of disabled children in the Foyle Trust and Sperrin Lakeland Trust areas.

It is intended that this book will point parents in the right direction, as finding relevant information can often be very difficult. Further information about WHSSB is available from their website:

www.whssb.n-i.nhs.uk or telephone: 028 7186 0086.

Information on children and young peoples' issues in relation to the WHSSB is available from:

www.wacy-pc.org

By the time an information book is printed, it is sometimes already out of date. To try and minimise this, mainly contact numbers, rather than addresses, are given.

Use this book as a signpost and a guide to act on. It does not contain all the answers but it might just help you on your way.

The first thing to do – to avoid searching for odd bits of paper or spending frustrating hours looking for a telephone number – is to keep a record of important contacts in the Key Contacts Section at the back of the book. Then just dip in and out of the book whenever you feel the need.

Brendan McKeever
Family Information Group

ISSUES FOR PARENTS

The issues below have been compiled from concerns that parents have identified from their own experiences of caring for a disabled child and his/her siblings.

These issues have also been identified in research findings and by those who work in the voluntary and statutory sectors as being priority issues that need to be addressed.

Of course there are other issues. However, as these are the ones that parents themselves have identified as the most important, they will be addressed in this book.

- ✓ ACCESS TO SERVICES
- ✓ BENEFITS
- ✓ THE CARER
- ✓ DIAGNOSIS/DISCLOSURE
- ✓ DIRECT PAYMENTS
- ✓ EDUCATION
- ✓ RESOURCES/EQUIPMENT
- ✓ KEY WORKING
- ✓ RIGHTS OF CHILDREN
- ✓ SHORT BREAKS
- ✓ TRAINING FOR PARENTS
- ✓ TRANSITION

ACCESS TO SERVICES

Services are available from statutory organisations (organisations which legally have to provide specific services), voluntary and community groups (set up to meet gaps in service provision), and private enterprises (businesses).

For some parents/carers it is the doctor (GP) who puts them in touch with different services. For others, it is the health visitor, social worker or some other professional or therapist. This is called “referral”. Sometimes, depending on the service, parents and carers can refer themselves as often happens in the voluntary and community sectors.

To get certain services, often an “assessment” is carried out. This is simply obtaining details of what is needed by the disabled child, the parent or carer. Often there is a fear that an assessment is about how people are coping and there is a reluctance to share information. However, experience has shown that the more details that are given, the easier it is to plan support. It must be emphasised that all information given is treated with the utmost confidentiality.

In this book, some information will apply to all parents, no matter where they live. However,

because of the way services are delivered, there will be different ways to get these services, depending on whether you live in the Foyle or Sperrin Lakeland regions and, indeed, what services are available in each region. Some services are also available outside the local areas.

At times, all this may seem like a maze. And sometimes it is. However, often those who work with your family (possibly the health visitor, GP, social worker, therapist or someone from a voluntary group) can help point you in the right direction. Do not give up until you contact the person you need to contact, even if this is very frustrating at first.

THE CARER

A carer is someone who regularly provides a substantial amount of care to a family member, friend or neighbour who is ill, disabled or is an older person. This includes parents of disabled children, who often do not see themselves as carers. It also includes young people who are often young carers of their siblings. The needs of parents and young carers are very important, as much for their own sake as well as in relation to their caring role.

Carer's Support Needs Assessment

Carers have a legal right to an assessment of their support needs. The purpose of a carer's support needs assessment is for you, as a carer, to discuss with the social worker what help you need with caring as well as any additional help that may be needed to maintain your own health. It is important to balance caring with other aspects of your life such as work and family commitments. Social services use this assessment to decide what help to provide.

Since 2003, local Health and Social Services Trusts are able to provide services directly to carers, usually termed "carers' services". These can be anything which will help the carer to look after the person they are caring for or help maintain their own health and wellbeing. Examples are: information,

training, referral to support groups, counselling or alternative therapies to deal with emotional issues and stress.

Sometimes it is the combination of community care services and carers' services which can make a real difference. For example, a carer may have a community care service, such as a sitting service, which enables them to get a break. The carer realises that after five years of caring they have lost touch with friends and family and feel isolated. They speak to their social worker about this and the social worker looks at how the carer can get back some of their social life. As a result, an adult education course is arranged as a carer's service in addition to the existing sitting service.

The combination of the two services means that not only does the carer get a break, but she/he also feels the benefit of doing something that has nothing to do with caring which leaves them more able to cope with their caring situation.

Although services can be identified to support the carer, it may not always be possible for the relevant trust to meet these needs. However, this is not a reason not to have a carer's support needs assessment. Needs may be able to be met through community or voluntary organisations. Needs that are unable to be met are recorded as 'unmet' needs.

Trusts report figures of unmet need to the Department of Health and Social Services on a quarterly basis.

Further information from:

- **Carers Northern Ireland**
Tel: 028 9043 9843

- **Centre for Independent Living**
Tel: 028 9087 5001

- **Carers' Support Worker**
Tel: 028 6634 4000
(Sperrin Lakeland Trust)

In Sperrin Lakeland Trust – as part of the regional carers' support strategy *Valuing Carers* – the trust is keeping a confidential database register of carers. It is hoped that this register will not only help give the trust more information on carers but will also help carers be better informed of what is happening in the trust area and elsewhere. The Carers' Support Worker in this area has been appointed to involve carers in the carers' support strategy and to ensure this strategy is implemented.

DIAGNOSIS AND DISCLOSURE

The details of your child's condition (diagnosis) and how this was all explained to you (disclosure) often can leave you shocked and numbed. There is a deep sense of loss when your child is diagnosed with having a disabling condition. Sometimes this loss and hurt can be deepened if the diagnosis and disclosure are not handled sensitively.

Some parents feel that they are failures and that the condition is their fault, others are hurt that the expectations and dreams they had for their child are shattered. If their child's condition is terminal (leading to an early death) then the family will often become totally preoccupied with this.

At this time, shock, numbness, and disbelief can often prevent any real information getting through to family members. Indeed, the person making the diagnosis and giving the information may be the target of the families' frustration, anger and bitterness so she/he may not be listened to at all initially. On the other hand, an overload of information at this point could possibly lead to even more confusion.

Certainly parents should feel free to ask questions and expect realistic answers from their doctor, nurse,

health visitor, support group, or anyone else involved with the family

There is the danger that all the emphasis will be on the condition and not the child, and at times, inaccurate or inappropriate information is gathered (eg from the Internet). For relevant and accurate information on specific conditions and, if required, support groups, get in touch with:

Contact a Family

Tel: 028 9262 7552

Or online at: www.cafamily.org.uk

Parents can learn from other parents in similar situations, but only if their experiences have not dragged them down. Time is needed; this is really a different way of living, which no-one is prepared for.

It may seem the end of the world, but many families have proved that it is not, hard though it may be.

There are people who can be with you, work with you, support you, when this is needed, even though that cannot take your pain away.

From those around you, you will probably gain information on your child's condition, the future

prospects, what help is available, what type of things you will need, whether benefits are available, etc.

You should not be afraid to ask and to find out who is the best person to answer your queries. You are not alone, and life may not be as bleak as you might think; though you have every right to think this with the news that you may just have been given.

Sometimes this period is compared to the sense of loss people feel when someone close to them has died. In a real sense there is a loss, the loss of an old way of living, the loss perhaps of dreams and expectations, and for many, a loss of hope.

There are no easy answers, no quick-fit solutions.

Many parents later on will often talk of the positive things that have happened to them, that it is not all doom and gloom.

KEY WORKER

In the confusion that can often arise when there is a number of different “professionals” from various agencies working with families – especially around the time of diagnosis and disclosure – the appointment of a key worker to co-ordinate services to families would be very beneficial. Although not widely available at present, this service is being looked at locally.

Within some Learning Disability Services there are key workers who are social workers. Some voluntary agencies also have their own key workers in their particular fields eg Horizon House (NI Children’s Hospice). Currently, Barnardos are piloting a key working project in Foyle Trust with a limited number of families, which it is hoped – if evaluated positively – may lead to such a service being more widely available.

Many parents have said how difficult it is to deal with so many different people, particularly in the early days or at other critical moments. Also at times there can be so many appointments to attend, at different places and at different times, that rather than help the family, these actually increase the stress on them.

Another major issue is that many parents do not know what different professionals actually do and what they have to offer them.

The key worker would be able to inform the family of who does what and how to access particular services. Also he/she could inform “the professionals”, thus alleviating the family from having to relive the diagnosis and disclosure every time someone new was coming into the family to offer a service. The key worker could also help to build a bridge between the family and the statutory and voluntary services.

DIRECT PAYMENTS

Direct Payments are about you receiving the resources (in lieu of services) from your local trust to pay for the personal social services that your disabled young person (over sixteen) needs and has been assessed for. If you are **over** sixteen and disabled and meet the requirements and criteria, then you can apply for Direct Payments yourself. If the disabled child or young person is **under** sixteen years old, it is the parents who apply for Direct Payments, again when the criteria and requirements are met.

It is not a benefit. A social worker or social work assistant, key worker or other appropriate person usually carries out the assessment. The payment is to assist with daily living tasks.

It means that you have more choice over who provides certain services. But there are then certain responsibilities that you will have which you would need to find out about, including your own willingness and ability to manage Direct Payments.

As arrangements and services differ from trust to trust, further information should be sought from your

local health trust or board, appropriate voluntary groups or from:

- **The Centre for Independent Living**
Tel: 028 9087 5001

- **Carers Northern Ireland**
Tel: 028 9043 9843,

- **Carers' Support Worker**
Tel: 028 6634 4163
(Sperrin Lakeland Trust)

BENEFITS

As a parent, you are providing most of the extra care and attention that your disabled child requires, you are meeting most of the additional costs linked to disability, and often you are also trying to bring up other children and run a home.

No benefits will compensate you for all of this; all they will do is help towards a better quality of life than there would be if you did not receive them.

Information on benefits, which many people have a right to, is available from a variety of sources (see *below*).

It is often difficult to actually apply for benefits, because of the rules and conditions which must be met especially in relation to Disability Living Allowance and Carer's Allowance. It is therefore suggested that applicants get support from any of the agencies mentioned.

■ **Association of Independent Advice Centres**

Tel: 028 9064 5919

(For details of your local advice centre)

■ **Benefit Enquiry Line**

Tel: 0800 2206 74

■ **Carers Northern Ireland**

Tel: 028 9043 9843

■ **Disability Living Allowance**

Tel: 028 9090 6182

(Enquiry line)

Disability Living Allowance (DLA) is the main benefit available to parents of disabled children to help them meet their child's additional care and/or mobility needs. When applying for this benefit, it helps to keep records of the type of the disability and for how long and when care is needed, as well as details of mobility problems.

The benefit is broken down into:

(a) the **care component**

(b) the **mobility component**.

The **care component** is then broken down into three different parts:

- ▶ Lower
- ▶ Middle
- ▶ Higher

The rate awarded depends on how much care is needed and whether it is needed during the day, or night, or both.

There is no lower age limit for the DLA care component. For DLA mobility component, children can get the higher rate of mobility from age three and the lower rate from age five.

Three different amounts of benefit are paid out, with the highest being paid for the most amount of care.

The **mobility component** is broken down into:

- ▶ Lower Rate
- ▶ Higher Rate

with the Higher Rate paying out more money where the disability impacts the person's mobility in a more severe way.

Blue Badge (formally Orange Badge) is a scheme that allows you to park your vehicle in areas where usually you may not – near shops, the hospital etc – if you have your disabled child/young person with you and you meet certain conditions.

Your child must be: disabled, over two years old, along with you in the car, and in receipt of the mobility component of DLA.

The Department for Regional Development is responsible for issuing the badges, which contain the photograph of the disabled child/young person. Application for the badge must include verification of the disability, usually from a doctor.

Road tax exemption for your car can also be applied for at a Local Vehicle Licensing Office.

Application forms for the Blue Badge are available from:

Disabled Persons Badge Scheme
Department for Regional Development
Castle Barracks
Wellington Place
Enniskillen
BT74 7HN
Tel 028 6634 3700

Carer's Allowance is available to carers to help towards caring costs, but there are rules about the amount of hours a parent is allowed to work and how much income they are allowed to earn.

You must care for your disabled child for more than 35 hours per week and your child must be receiving the DLA care component at the middle or higher rate. You cannot earn more than £84.00 per week (net).

Further information on this benefit can be obtained from **Carers Northern Ireland, Carers' Support Worker** (Sperrin Lakeland Trust), or through your local **Citizen's Advice Bureau**.

Social Fund is a government fund to help people in need. To be eligible you must be on certain benefits and there are certain conditions. Further information is available from the Benefits Office or Citizen's Advice Bureau. There are some regulated grants such as Sure Start maternity grants, which are available if you are eligible, but most of the grants are discretionary. Discretionary payments are usually for items you cannot afford out of weekly benefits and these can be in the form of grants or interest free loans. There are three main types: community care grants, budgeting loans and crisis loans. As this area can be quite complex, it is advisable to get information from local advice centres or benefit offices.

Tax Credit – Working Tax Credit is means tested. This means that whether you get it (and if so, how much you actually receive) depends on your income. It is for working people on low incomes. As a parent, you or your partner must be working at least sixteen hours per week and your child/young person must be under sixteen (or under nineteen if in full-time education).

Child Tax Credit is available to anyone with a dependant child. If you have disabled children/young people, you may be entitled to more. It is paid in addition to Child Benefit. Whether you work or not, you can apply for this benefit. Check what the earning limits are, currently they are quite high. Couples must make a joint tax credit application.

Information on Child Tax Credits is available from:

- **Inland Revenue Office**
- **Tax Credits Helpline**
- **Online** at www.taxcredits.inlandrevenue.gov.uk

Child Benefit is not means tested and is paid for all dependant children up to the age of sixteen (or nineteen if in full-time education).

Information on Child Benefit is available from:

- **Inland Revenue Office**
- **Benefits Office**
- **Citizen's Advice Bureau**
- **Resource Centres / Advice Centres**

Hospital Fares can help with cost of travel to/from hospital, and some appointments to help you bring your child for treatment. This help is available if you receive Income Support, Income Based Jobseekers

Allowance or Pension Credit. Information is available from Benefits Office, advice centres or hospitals/clinics.

NHS Benefits such as prescriptions, glasses and dental treatment are available to those who qualify. Check with Benefits Office, advice centres, chemists, opticians or dentists for further details.

Family Fund Grants are currently available from the Family Fund to families with disabled children under sixteen years of age. Grants are only accessible to families whose earnings are under a certain amount so check with the Family Fund. However, this organisation is fully aware of the cost of disability and these costs are considered in each grant application. Grants can be for a variety of items; each application is assessed on its merits, but can include holidays. Contact the Family Fund for further information.

Sure Start Maternity Grants, valued at £500, are available for those who:

- ▶ are on income support
- ▶ are on income based Jobseekers Allowance
- ▶ receive Child Tax Credit awarded at a rate higher than the family element (or higher family element if you are responsible for a child under one)

- ▶ receive Working Tax Credit where a disabled worker is included in the assessment at the time of the claim
- ▶ are an Asylum Seeker, receiving support from the National Asylum Support Service.

Information and application forms can be obtained from your local Benefits Office, ask for Form SF 100. A claim can be made from the eleventh week before the baby is due and up to three months after the birth.

EDUCATION

This is a key issue for many families, particularly when there are young children involved. It is really up to individual parents and their children as to what is best for them, in consultation with the various schools and the education board. There are advantages and disadvantages in different education systems, and these all have to be weighed up before any decision is made.

It could be that Special Education is the choice. Or it could be integrating their children into Mainstream Education (what is usually referred to as primary and secondary education). Or Inclusive Education, where children with disabilities/special needs are fully included in the education system. Here, their needs are met but also all the children learn from each other and value each other whether they have a disability or not. Concerns around education and getting what is best for their child are constantly to the fore for many parents.

If a parent is concerned about their child's educational development, she/he can ask the local education and library board for an assessment of their child's educational needs. This could involve the child's teacher at school, the educational psychologist, possibly other staff involved with the family, and

perhaps the doctor and any health and social services staff. Sometimes this assessment can begin before the child actually enters primary school. The educational statement is a legal document detailing how these needs are to be met, including services which are not primarily educational. Information on this is available from schools and the Western Education and Library Board.

Several voluntary organisations can help with this process and advice can also be sought from the Special Educational Needs Department of the local Education and Library Board. It is important for parents and carers to realise the importance of the legality of this document and when finalising what actually goes into the statement, that they are content that all their child's need are accurately recorded. The statement is reviewed annually but can also be reviewed if there are changes in circumstances. Local educational and library boards should have information booklets/leaflets on this process.

Currently, there are five education boards to cover all of Northern Ireland; each of them have a specific department specialising in special educational needs (this includes the statementing process) for all types of schools, not just special educational schools. However, the boards have responsibility for a lot more than this.

- **Western Education and Library Board**

Tel: 028 8241 1411

- **SENAC (Special Education Needs Advice Centre)**

Tel: 028 9079 5779

(General advice and information; limited opening hours from 10am on Mon, Wed and Fri but answering machine available.)

If parents/carers disagree with the decision of the Education and Library Board in regard to whether an educational statement is made or not, they can go to an Appeal Tribunal and seek support from SENAC. Again, other voluntary organisations can also help with this.

After the child's fourteenth birthday, the annual review then involves what is called the Transition Plan, as preparations begin with the young disabled person to plan ahead for the future. These reviews continue annually until the young person leaves school, usually between sixteen and nineteen (see *Transition Section*).

The educational development of a child and young person is important for all parents and the inclusion of disabled children in education is becoming more of a reality.

CHANGES IN EDUCATION

In 2005, changes were made to bring education in line with the Disability Discrimination Act to try and prevent discrimination on the grounds of disability in education. The Special Educational Needs and Disability (Northern Ireland) Order 2005, referred to as SENDO, came into place on 1 September 2005 and under it, special educational need is defined as:

“A physical or mental impairment which has a substantial long-term adverse effect on [a child’s/young person’s] ability to carry out normal day-to-day activities.”

(This mirrors the definition under the Disability Discrimination Act.)

For children with special educational needs:

- ✓ it strengthens their right to be educated in mainstream schools.

For schools (including colleges etc), it means that:

- ✓ they will have to make reasonable adjustments to all policies, procedures and practices to ensure that disabled pupils/students are not disadvantaged
- ✓ they do not treat disabled pupils/students less favourably than others (in relation to disability)

- ✓ they have a duty to work towards making education more accessible for disabled pupils/students in relation to premises, curriculum and information.

These changes apply to pupils/students already in education but also to prospective pupils/students who may wish to attend them.

To help parents and children/young people there is information and advice available and complaints procedures in place. However, if a complaint is being initiated, ensure that the guidelines on timescales are understood, as these are clearly set out for these procedures.

Very few parents want to go down the long legal route to resolve issues – unless they really have to. As in any area where there is an issue or a complaint, it is best to try and get this resolved at local level first through the internal complaints procedure with the person or establishment which seems to be causing the difficulty, if this is at all possible.

Failing this, under this new education and disability legislation, there are groups and organisations that can be contacted for information and help, depending on the nature of your complaint and who it is against.

Advice And Information Service

Tel: 028 8241 1286 (WELB)

DARS (Dispute Avoidance and Resolution Service)

Tel: 028 3751 2383

(Offers advice and information and tries to help resolve any issues before they have to get to court.)

Equality Commission

Tel: 028 9050 0600

(Conciliation Service)

SENAC (Special Education Needs Advice Centre)

Tel: 028 9079 5779

(Voluntary organisation offering support and general advice and information. Limited opening hours – answer machine available.)

SENDIST (Special Education Needs and Disability Tribunal – schools complaint tribunal)

Tel: 028 9032 2894

Western Education and Library Board

Tel: 028 8241 1411

SHORT BREAKS/TIME OUT

Everyone needs a break; families with children who have disabilities equally so, if not more. The pressures and strains of looking after and caring for a child with a disability can be phenomenal and many parents' health have been adversely affected by the stresses involved.

Although some parents do prefer a complete break from their child, many parents would prefer just a couple of hours off to go shopping, go out for the evening, or perhaps just to spend time with the rest of the family.

Some parents want a break away with their disabled child while others want the other brothers and sisters to have a break. Some want time to spend with the siblings; again flexibility is the key. There are those who want separate specialist facilities while some parents want totally inclusive provision, where disabled children are included in mainstream events eg playgroups, after-school clubs, youth clubs etc.

Below are some examples of services that are available, but not in all areas:

- ▶ Overnight stays in residential homes/settings eg "The Cottages", "Horizon House", etc

- ▶ Domiciliary care in the family home
- ▶ Specialist childminding service
- ▶ Host families – breaks provided by other families (learning disability in Foyle, all disabilities in Sperrin Lakeland)
- ▶ Inclusive projects with young people (eg Cedar Foundation)
- ▶ Playgroups, after schools, summer schemes, clubs (specialist and inclusive).

More information is available from social workers.

RESOURCES AND EQUIPMENT

Sometimes specific equipment will be available from the local health trust, from private suppliers or from voluntary groups and/or charities. However, it should be noted that sometimes there are certain rules and regulations to be followed before obtaining certain equipment, and sometimes an assessment of need has to be carried out. But this should not put parents off.

Requests for specific equipment for a disabled child often have to go through an occupational therapist from the local health and social services trust or child development clinic.

Many disability organisations, eg Disability Action, Mencap, Down's Syndrome Association etc, will have directories and contact details of organisations, trusts and charities such as Whizz Kidz or the Variety Club which provide equipment to disabled children who meet their particular criteria.

Other more general financial support comes from charities such as the Family Fund, who again have their criteria but who have built up a very positive relationship with parents in Northern Ireland and include assistance towards holidays in their package of assistance to families.

Many of those who have worked with families of disabled children, both in the voluntary and statutory sectors, have built up a knowledge of which organisations are best to contact for specific items and what their criteria are. Often those who work with families need to support applications for specific equipment. In the first instance it is probably better for parents/carers to check out from someone who works closely with them what is available, before rushing off to a directory or to the Internet.

However, all avenues are worth exploring when the aim is to enhance the quality of life of the disabled child and his/her family.

RIGHTS OF CHILDREN

Children have rights. Disabled children have rights.

Often rights are enshrined in law, and the law to most of us is very complicated. However, there are enough organisations out there who can inform us of our rights such as the Children's Law Centre, the Law Centre, Children's Commissioner, Ombudsman, Citizen's Advice Centre, and Resource Centres as well as a number of voluntary organisations.

There are a number of laws that help to protect children and the rest of us such as:

- Disability Discrimination Act 1995
- Section 75 of the Northern Ireland Act 1998
- Children (Northern Ireland) Order 1995
- The Carers and Direct Payments Act 2002 (Northern Ireland)
- United Nations Declaration of Human Rights.

There are other laws too, but these are the main ones.

What is beneficial to parents and carers, and those who work with them, is that the law can be used if the rights of children are infringed and/or if the absence of some service affects their rights.

As well as the range of legislation available, many organisations have in-house Complaints Procedures (see *Complaints Section*) which can be used not only where there is a complaint but where an issue has to be raised, or where there is a concern. Also, in cases where it is believed a complaint has not been dealt with properly, and if all the proper channels have been followed with no satisfaction, then the Children's Commissioner or Ombudsman could be asked to take up the case if it is appropriate for that organisation.

Legislation does not have to be confusing when parents and carers work with those who have an expertise in these fields and issues.

SUPPORT

Often, most support comes from family members and friends. Sometimes, therefore, by actually giving support to those closest to the family, indirect support is being given to the family itself. Grandparents are a prime example of this.

Organisations in the voluntary and statutory sectors have a role to play in this support structure as well as the families themselves. Support given at the right time can often act as a preventative measure, helping the family through a difficult time, which could mean they will need fewer support services in the future.

Some organisations can offer a range of support, both directly and indirectly, with information on conditions, newsletters, fact-sheets, contacts etc on the issues affecting families. Also, they can put you in contact with the wide range of support groups which specialise on specific conditions, some of which are listed in this booklet.

Other organisations concentrate on support for carers. This includes parents of disabled children. Information is available on issues affecting carers such as carers' assessments, Carer's Allowance, carers' groups, Direct Payments, lobbying issues,

rights etc. Several such support organisations produce regular newsletters.

For many families, there are concerns about the health and wellbeing of the disabled child/young person, sibling/s, parents, carers and family members. There may be mental health issues that are often swept aside as the daily pressures take their toll.

The impact of disability is very devastating for many families and stress and anxiety levels can naturally be high. Often parents ignore their own health needs while concentrating so much on their children.

Sometimes the mental health needs of disabled children and young people are overlooked because of the disability impact. Very often siblings and other family members do not even get a look in.

Within trusts, and in the voluntary sector, there are people who can offer support and help. Indeed, there are now groups in the community led and run by people who have knowledge and experience of these issues.

Also, there are preventative measures that can be taught and used to fight many of the negative impacts of mental illness. Information can be

obtained from the Mental Health Team in your area and/or from the voluntary groups who work in this area.

Parents have a right to look after themselves, not just for the sake of their children but also for their own sake. Children and young people also have this right.

Further information on support/carers organisations from:

- **Carers Northern Ireland**

Tel: 028 9043 9843

- **Contact a Family**

Tel: 028 9262 7552.

TRAINING / EDUCATION OF PARENTS / CARERS

The needs of parents and carers concerning education, training and development are often ignored or overlooked. Many carers and parents miss out on such activities because of the pressures that result from caring for someone. Courses on offer often do not take their specific needs into consideration when being planned.

Skills are needed when caring for someone. Few courses address practical concerns and issues around advocacy, for example. Some of the criteria relating to certain benefits prevent people from accessing courses eg Carer's Allowance. Parents and carers are people too and they also have their own needs. This must be recognised and ways found of addressing these needs.

There are more opportunities for learning for parents, particularly when their young child starts attending school. Sometimes there are courses in the community, in the local schools and colleges, back-to-work courses as well as learning using the computer. Sometimes childcare support is available for specific courses which enables parents to access courses. Information is

available from local community groups, colleges of further education and relevant schools.

Online education is available, such as “Learning for Living” (targeted at unpaid carers) and more specific learning – www.carebra.org.uk – for parents and carers of brain injured children. Further details of these and similar courses can be accessed through the Internet.

Of course some parents/carers want to learn the skills to be able to speak out for themselves and their children, to be able to write letters, to take part in meetings without being overwhelmed, to learn more about their rights and to have a better understanding of what services are available. Some support groups run short courses on these.

TRANSITION

This simply means moving on from one set of circumstances to another during a period of change. Usually the period when your child moves from childhood into young adulthood (between fourteen and nineteen years old) is referred to as the “Transition Years”. It is this period that this information is about.

As your child turns fourteen, a Transition Plan must be drawn up by his/her school. This will include your child, yourself and others in order to start planning for the future beyond school. Each year after Year 9 (when your child turns fourteen), this plan must be updated by all those involved to include any new details – this is called a Review. It is vital that your child’s views are listened to and acted upon at all stages.

Besides your child and yourself, other people involved in this process could include the school principal, teachers, Social Services representative, someone from careers, therapists, Special Educational Needs Co-ordinator and indeed anyone who could significantly contribute towards your child’s future.

The years pass quickly and with some young disabled people now leaving school at sixteen and

not nineteen, it does not give much time for future planning. It has to be stressed that the future planning is not about school life, but every aspect of your child's life – social skills, money management, transport requirements, job/training/education plans, housing and transport requirements just to mention a few. It is about making informed choices and obtaining the relevant information to do this.

This may all seem very frightening but there are organisations that can help you or give you information and remember the interests of your child are protected by the law through the Transition Process. Contact a Family can give excellent support and information locally, as well as your local Education and Library Board.

RAISING ISSUES / COMPLAINTS

Most parents and carers do not complain. This can be for a number of reasons. Some people feel they have enough to contend with, never mind complaining. Others feel that there is no point in complaining as nothing ever changes anyway. Still others fear that they will be victimised if they do make a complaint. Then there are those who just do not want to.

All are very valid reasons. But if things are to ever change then parents and carers will have to raise issues and concerns. So if there is something wrong, make a complaint. Below are some points for anyone who wants to follow up on this. If there is a Complaints Procedure already in place, follow this and contact the Complaints Officer, if there is one. If not, read over these points:

- ✓ Keep brief notes on all contacts, who you talked to and when, and where they worked.
- ✓ As far as possible, contact should be made by letter to the appropriate department.
- ✓ First take the issue, concern or complaint up with the person responsible, if you can.
- ✓ If unsatisfied, contact that person's supervisor.

- ✓ If unsatisfied, contact the head of department.
- ✓ If unsatisfied, contact the Chief Executive.
- ✓ If you exhaust all of these and are still not satisfied, then find out from the Children's Commissioner or Ombudsman does your complaint fall within their remit.

Please remember that often the person delivering a particular service to you may not be responsible for the planning or funding of that service and that your complaint may not be personally against them.

Information on complaints procedure available from:

- **WHSSB Council**
Tel: 028 8225 2555

or if you have exhausted other channels contact:

- **Children's Commission**
Tel: 029 9031 1616
- **The Ombudsman**
Tel: 028 9023 3821

Or WHSSB, Foyle Trust or Sperrin Lakeland Trust.



Information

ORGANISATIONS / SERVICES

Health and Social Services

Currently, there are four health and social services boards to cover all of Northern Ireland. Within each of these boards there are a number of Health Trusts which offer a variety of services. In this area:

- **Western Health and Social Services Board**

Tel: 028 7186 0086

- **Altnagelvin Hospital Trust**

Tel: 028 7134 5171

- **Foyle Health and Social Services Trust**

Tel: 028 7126 6111

- **Sperrin Lakeland Trust**

Tel: 028 8283 5285

This will change when the present Review of Public Administration is complete.

Housing

Information is available on all aspects of housing from the Northern Ireland Housing Executive (NIHE) – whether socially rented housing or owner occupied houses – such as contacts for Housing Association properties or grants for disabled people, including children. Both Fold and Shelter have an additional function of offering advice/support to applicants for the

Disabled Facilities Grant, covering different geographic areas, while Housing Rights offer advice on rights issues. There are a number of Housing Associations, details of these are available from NIHE.

Housing adaptations for disabled children in the private sector under the Disabled Facilities Grants Process, when recommended by an occupational therapist, are no longer subject to a means test on parents.

- **Northern Ireland Housing Executive**

Tel: 028 9024 0588

- **Fold Housing Association**

Tel: 028 9042 8314

- **Housing Rights Service**

Tel: 028 9024 5640

- **Shelter**

Tel: 028 7188 2147

Support

Many organisations offer different kinds of support, and there are groups which specialise in certain disabling conditions. Some parents feel they need immediate support from people who are, or have been, in their situation. Others want nothing to do with support or support groups.

There are organisations which offer general support, information and advice. General information on community groups is available from the Northern Ireland Council for Voluntary Action (NICVA). At the time of diagnosis and disclosure, many parents are in shock, unable to take in any information, and are in total confusion. They need time. When they do seek information on their child's condition, such as whom would be good to talk to, or about support groups, then Contact a Family could be their first point of contact.

Parents also have the role of carer, and information is available from Carers Northern Ireland and Carers' Support Worker (Sperrin Lakeland) on carers' rights and benefits and the assessment of carers.

There then is a host of other organisations, each offering their own unique support and/or information service.

Listed are some of the main organisations which provide information, services and/or support. This section is divided into three parts:

- 1. Regional Organisations.** These are primarily located outside the Foyle and Sperrin Lakeland areas and for the most part are regional contacts.

They are very useful in identifying branches of their organisation in your area, if there is one, or giving information if there is no local contact.

2. Foyle Health and Social Services Trust Area. Contacts in the Foyle area.

3. Sperrin Lakeland Health and Social Care Trust Area. Contacts in the Sperrin Lakeland area including Omagh and Fermanagh

REGIONAL ORGANISATIONS

Action Multiple Sclerosis

Tel: 028 9079 0707

ASBAH (Spina Bifida and Hydrocephalus)

Tel: 028 9079 8878

Barnardos

Tel: 028 9067 2366

Carers Northern Ireland

Tel: 028 9043 9843

Cedar Foundation

Tel: 028 9066 6188

Children's Law Centre

Tel: 028 9024 5704

Circles Network

Tel: 028 6638 5067

Contact a Family

Tel: 028 9262 7552

Cystic Fibrosis Trust

Tel: 028 3833 4491

Deaf Youth Association (NI)

Tel: 028 9043 8566

Disability Action

Tel: 028 9029 7880

Families in Contact

Tel: 028 9065 6692

Family Fund

Tel: 0845 130 4542

Law Centre

Tel: 028 9024 4401

Lifestart

Tel: 028 4273 9130

Mencap (Learning Disabilities)

Tel: 028 9069 1351

Muscular Dystrophy Campaign

Tel: 028 9079 0708

National Deaf Children's Society

Tel: 028 9031 3170

PAPA (Autism and Asperger Syndrome)

Tel: 028 9040 1729

Parents Advice Centre

Tel: 028 9023 8800

Parenting Forum

Tel: 028 9031 0891

PHAB

Tel: 028 9079 6565

RNIB (Blindness and related conditions)

Tel: 028 9032 9373

RNID (Deafness and related conditions)

Tel: 028 9023 9619

Sense

Tel: 028 9083 3430

Skill

Tel: 028 9028 7000

These are only a selection of organisations, groups or agencies, which provide information and/or support. Further information is available from those who work with families, from other families, from directories and other information resources.

FOYLE HEALTH AND SOCIAL SERVICES TRUST

Western Health and Social Services Board is divided into Foyle Trust and Sperrin Lakeland Trust. Foyle Trust covers Derry City and the surrounding area including Limavady and parts of Strabane District Council area, while Sperrin Lakeland covers the council areas of Omagh, Fermanagh and the remainder of the Strabane council area.

Health and Disability Programmes cover learning, physical and sensory disabilities as well as providing services to children who have significant ill health in the community. In Foyle Trust there are separate services for learning disability while physical and sensory disabilities are grouped together. There is also an additional support service for those with sensory disabilities from Sensory Support Services. For children and young people who need more help and support because of more complex and/or specific needs, the Child Development Clinic in Gransha Park offers a range of services.

There are a number of ways of trying to access services. Sometimes you may contact the Trust directly for information, at other times someone else may direct or refer you or your child. For many parents, it is the family doctor or health visitor who

makes the first contact. Below is a list of contact numbers, starting with social workers, of people who might be able to help, give information or point you in the right direction.

Social Work Teams

Physical Disability

The Team	Tel: 028 7135 4031
Duty Social Worker	Tel: 028 7135 4031
Out of Hours	Tel: 028 7134 5171

Learning Disability

The Team	Tel: 028 7127 2950
Out of Hours	Tel: 028 7134 5171

Sensory Disability

The Team	Tel: 028 7137 4619
Out of Hours	Tel: 028 7134 5171

Clooney Family Centre

Tel: 028 7132 9444

Community Nursing (Learning Disability – Strabane)

Tel: 028 7138 4114

Community Psychology Services

Tel: 028 7186 0261

Continence Adviser

Tel: 028 7134 9355

The Cottages (Shepherd's Way)

Tel: 028 7134 4484

Creggan Day Centre

Tel: 028 7126 9082

Dentist (Community)

Tel: 028 7186 4334

Dietics

Tel: 028 7134 5171 Ext 3417

District Nursing

Tel: 028 7135 1350

Tel: 028 7138 4114 (Strabane)

Early Years Team

Tel: 028 7132 0950

Health Visiting/School Nursing

Tel: 028 7136 5177 (City Side)

Tel: 028 7132 0100 (Waterside)

Home Based Services (Domiciliary Care)

Tel: 028 7135 5000

Home from Home (Learning Disability Short Breaks)

Tel: 028 7182 0261

Nursing (Learning Disability/Strabane Health Centre)
Tel: 028 7138 4114

Occupational Therapy (Community)
Tel: 028 7186 5228

Orthoptics
Tel: 028 7134 5171 Ext 3228

Physiotherapy
Tel: 028 7134 5171

Podiatrist (Children)
Tel: 028 7186 5100

School Nursing
Tel: 028 7186 5104

Sensory Support Services
Tel: 028 7137 4619

Shantallow Family Centre
Tel: 028 7135 2522

Speech & Language Therapy
Tel: 028 7186 4345

Strabane Family Centre (Barnardos)
Tel: 028 7138 2658

Stradreagh Hospital
Tel: 028 7186 5210

Transition (Learning Disability)
Tel: 028 7186 0261

Transition (Physical Disability)
Tel: 028 7181 3631

Twilight Nursing
Tel: 028 7135 1350

First talk to your doctor, nurse, social worker or health visitor, as some of these services can only be accessed by referral.

Child Development Clinic

In the Foyle Trust area, at Gransha Park on the outskirts of Derry in the Waterside, is located the Child Development Clinic. Many different therapists and other professionals such as consultant paediatrician, physiotherapist, occupational therapist, speech and language therapist, dentist, orthoptist, and dietician work out of there with families whose children have more additional needs.

Depending on your child's needs, sometimes you may only see one or two of the therapists on your visit or, if the need arises, most or all of this team.

Often many of the early assessments of children take place here and children can be referred to the clinic by the doctor, community paediatrician, therapist or other social/health professional.

Further details of the services offered at the Child Development Clinic, and how to obtain these, can be obtained from:

Little Acorns
Child Development Clinic
Bridgeview House
Clooney Road
Derry
BT47 6TG
Tel: 028 7186 0056

Sexual Health Services – Information on sexual health education, family planning, contraception services, and any issues relating to sexual health matters for disabled young people, adults and their families can be obtained from:

Family Planning
Shantallow Health Centre
Racecourse Road
Derry
Tel: 028 7135 1350

OTHER CONTACTS (FOYLE TRUST AREA)

Accord

Tel: 028 7136 2475

Aware

Tel: 028 7126 0602

Bridge Accessible Transport

Tel: 028 7126 7555

Cedar Foundation

Tel: 028 7181 3631

Citizen's Advice Bureau

Tel: 028 7136 2444

Creggan Day Centre

Tel: 028 7126 9082

Crown Buildings

Tel: 028 7131 9500

Derry City Council

Tel: 028 7136 5151

Derry Community Services

Tel: 028 7136 8320

Disability Action
Tel: 028 7136 0811

Foyle Advocates
Tel: 028 7126 3461

Foyle Disability Resource
Tel: 028 7126 6593

Foyle Down's Syndrome Trust
Tel: 038 7134 5991

Foyle Newpin
Tel: 028 7134 4477

Inclusive Youth
Tel: 028 7130 9191

Law Centre
Tel: 028 7126 2453

Lifestart
Tel: 028 7126 9833

Little Orchids
Tel: 028 7186 4338

Mencap
Tel: 028 7126 2227

Mind Yourself
Tel: 028 7126 3461

NIAMH
Tel: 028 7126 9517

NI Deaf Youth
Tel: 026 7126 2699

NIHE (Grants)
Tel: 028 7137 2000

NIPPA
Tel: 028 7131 3004

North West Forum of People with Disabilities
Tel: 028 7130 9191

NSPPCC
Tel: 028 7126 6789

Old Library Trust
Tel: 028 7137 3870

Parents Advice Centre
Tel: 028 7137 2006

Relate
Tel: 028 7137 1502

Resource Centre
Tel: 028 7135 2832

RNIB
Tel: 028 7137 4619

RNID
Tel: 028 7296 8000

Samaritans
Tel: 028 7126 5511

SENSE
Tel: 028 7137 4619

Sensory Support Services
Tel: 028 7137 4619

Social Security Agency (Shantallow)
Tel: 028 7135 2066

STEER
Tel: 028 7127 9995

Surestart
Various venues, contact Foyle Trust

Waterside Churches Advice
Tel: 028 7136 2536

SPERRIN LAKELAND HEALTH AND SOCIAL CARE TRUST

The Sperrin Lakeland Trust covers a wide area, which includes large towns such as Omagh and Enniskillen as well as smaller rural towns and villages and individual homes. Some of the services are based in one of the two main towns; others have separate departments in each of the towns while some have outreach facilities into the wider community. Part of Strabane District Council and all of Omagh and Fermanagh councils are included in this area.

A detailed information pack on services is available from:

■ **Health and Disability Programme**

(Children's Team / Fermanagh)

Tel: 028 6634 4000

Health and Disability Programmes cover learning, physical and sensory disabilities as well as providing services to children who have significant ill health in the community. There is also an additional support service for those with sensory disabilities. Information on services is available from:

■ **Health and Disability Programme (Omagh)**

Tel: 028 8283 5069

As in Foyle Trust, there are a number of ways of trying to access services. Sometimes you may contact the Trust directly for information, at other times someone else may direct or refer you or your child.

For many parents it is often the family doctor or health visitor who makes the first contact. Below is a list of contact numbers, starting with social workers, of people who might be able to help, give information or point you in the right direction.

Social Work Teams

Omagh

The Team	Tel: 028 8283 5050
Duty Social Worker	Tel: 028 8224 3521
Out of Hours	Tel: 028 8283 3100

Fermanagh

The Team	Tel: 028 6034 4000
Duty Social Worker	Tel: 028 6634 4000
Out of Hours	Tel: 028 6638 2000

Omagh

Consultant Community Paediatrician

Tel: 028 8224 3521

Fermanagh

Tel: 028 6632 4711

Community Nursing (Learning Disability)

Tel: 028 8224 3521

Tel: 028 6634 2922

Omagh

Continence Adviser

Tel: 028 8225 5067

Dental Services

Contact Fermanagh

District Nursing

Tel: 028 8225 5117

Family Aide

Tel: 028 8224 3521

Health Visiting / School Nursing

Tel: 028 8224 4117

Home Based Services (Domiciliary Care, Home Help etc)

Tel: 028 8224 3521

Neuropsychology (Brain Injury)

Contact Fermanagh

Nutrition/Dietics

Tel: 028 8283 5535

Occupational Therapy

Tel: 028 8283 5010

Orthoptics

Tel: 028 8283 3195

Fermanagh

Contact Omagh

Tel: 028 6632 4711

Tel: 028 6632 4711

Tel: 028 6634 4000

Tel: 028 6632 4711

Tel: 028 6634 4000

Tel: 028 6632 4400

Tel: 028 6638 2174

Tel: 028 6634 4000

Tel: 028 6638 2174

Omagh

Physiotherapy

Tel: 028 8283 3404

Podiatry

Tel: 028 8283 5005

Time Out / Short Breaks

Tel: 028 8283 5050

Sensory Unit

Contact Fermanagh

Speech & Language

Tel: 028 8283 5100

Specialist Community

Tel: 028 8224 3521

Transition

Tel: 028 8283 5050

Fermanagh

Tel: 028 6638 2421

Tel: 028 6638 2111

Tel: 028 6034 4000

Tel: 028 6632 4400

Tel: 028 6634 4096

Tel: 028 6634 2922

Contact Omagh

OTHER CONTACTS (SPERRIN LAKELAND TRUST AREA)

Omagh

Aisling Centre

Contact Fermanagh

Arthritis Care

Tel: 028 8224 3755

CAUSE (Mental Health)

Tel: 028 8225 8307

Cedar Foundation

Contact Fermanagh

Cherish Sure Start

Contact Fermanagh

Chest, Heart & Stroke Association

Tel: 028 8225 1640

Citizen's Advice Bureau (Information available on Rural Outreach Project in Belleek, Roslea, Lisnaskea and Irvinestown)

Contact Fermanagh

Citizen's Advice Bureau (Cookstown)

Tel: 028 8676 6126

Fermanagh

Tel: 028 6632 5811

Tel: 028 6632 6148

Tel: 028 6772 1798

Contact Omagh

Tel: 028 6634 4200

Tel: 028 6862 1970

Contact Omagh

Tel: 028 6632 4334

Contact Omagh

Omagh

Erne Carers

Contact Fermanagh

Forget Me Not (Women's Group)

Contact Fermanagh

Friendly Carers' Group

Tel: 028 8775 8570

Jobs & Benefits Office

Contact Fermanagh

Leonard Chesire

Tel: 028 8224 5285

Mencap

Tel: 028 8225 9249

Mental Health Carers Group

Tel: 028 8283 5070

Palliative & Supportive Care Team

Tel: 028 8283 3117

Positive Future

Tel: 028 8225 4430

Omagh Independent Advice Service

Tel: 028 8224 3252

Fermanagh

Tel: 028 6632 2654

Tel: 028 6632 4889

Contact Omagh

Tel: 028 6634 3333

Contact Omagh

Contact Omagh

Contact Omagh

Tel: 028 6638 2197

Contact Omagh

Contact Omagh

Omagh

Omagh Jobs & Benefits Office

Tel: 028 8225 4222

Red Cross

Tel: 028 8225 1116

Social Security Agency

Contact Fermanagh

Sperrin Carers Group

Tel: 028 8164 8862

Toy Library

Contact Fermanagh

Welfare Rights

Contact Fermanagh

Fermanagh

Contact Omagh

Tel: 028 6632 6916
(Limited opening)

Tel: 028 6634 3333

Contact Omagh

Tel: 028 6634 4000

Tel: 028 6632 7267

KEY CONTACTS



	Name	Tel No.
Key Worker	_____	_____
Doctor	_____	_____
Doctor (Out of Hours)	_____	_____
Consultant Paediatrician	_____	_____
Health Visitor	_____	_____
Social Worker	_____	_____
Nurse	_____	_____
Physiotherapist	_____	_____
Occupational Therapist	_____	_____
Speech Therapist	_____	_____
Hospital	_____	_____

KEY CONTACTS



Name

Tel No.

Health Centre

School/Teacher

Support Group

Friend

Chemist

Other
