

Helping You and Your Family

Self-Help Strategies for Parents
of Children with a Disability



Published by
the Association for Children with a Disability
July 2001
ISBN 09577 31809
ABN 39 835 407 788



Acknowledgements

We would like to thank the Jack Brockhoff Foundation and the Besen Family Foundation (the Sussan Group) who provided a significant contribution towards the cost of printing this booklet. Thanks also to the parents and professionals involved in producing the 1992 booklet 'Helping Parents Help Themselves'. We are grateful for their permission to reproduce much of the text from that booklet in this publication. The cover picture is by Luke McCarthy (aged 9).

Strength through parent stories

Our bi-monthly magazine, 'NoticeBoard' includes parent stories, real life accounts about what life is like for families of children with a disability. They are a great source of strength and inspiration and a reminder that you are not alone and share similar experiences with many other families.



To receive NoticeBoard, you need to become a member of our Association. Membership costs only \$10 for families (\$5 for those on a low income) and \$25 for organisations. See the application form on the back cover of this booklet or contact our office on (03) 9500 1232 or 1800 654 013.

Most of our members are parents of children with a disability, but family and friends, students, professionals and service providers are also welcome to join and enjoy the benefits of receiving 'NoticeBoard'.



Association for Children with a Disability

We are a parent support organisation providing information, support and advocacy to all parents who have a child with any type of disability. We are a non-profit organisation run by parents of children with a disability. Our Parent Support Workers and our Committee of Management are parents of children with a disability.

We work in close co-operation with a network of Regional Parent Support Co-ordinators in Victoria and various statewide and national parent support groups. For parents/carers we provide free telephone information and advice about any issues relating to children with a disability including education, respite, aids and equipment, home care and recreation.

Our contact details are:

Association for Children with a Disability

590 Orrong Road, Armadale, Vic 3143

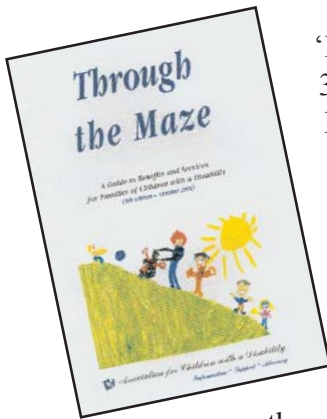
Phone: (03) 9500 1232 • Fax: (03) 9500 1240 • Freecall: 1800 654 013

Email: mail@acd.org.au • Internet: www.acd.org.au

Contents

Chapter	Page
1. Introduction	1
2. Diagnosis	2
3. Working with Doctors and other Medical Specialists	4
4. Support for Parents	6
5. Family Relationships	8
6. Dealing with Friends and the General Public	11
7. Finding out about Services	13
8. Using the Service System	15
9. The Role of Parent Support Groups	17
10. Conclusion	18
Glossary of Terms	19

Through the Maze



'Helping You and Your Family' is designed as a companion volume to the 30 page booklet 'Through the Maze: A Guide to Benefits and Services for Families of Children with a Disability', also published by our Association and available free of charge. 'Through the Maze' provides an overview of the services available to support families caring for a child with a disability, including: early childhood intervention services, child care and pre-school, schools and education, respite, therapy, aids and equipment, home/personal care, transport, recreation etc. If you don't already have a copy, contact our office on 03 9500 1232, 1800 654 013 or mail@acd.org.au. You can also print/download 'Through the Maze' and other information from our Internet site www.acd.org.au. A summary version of 'Through the Maze' is available in various community languages.

Further Information and Support

For further information and support on any issue, please do not hesitate to ring and speak with a Parent Support Worker at our Association on 03 9500 1232 or 1800 6540 13. Our Parent Support Workers are themselves parents of children with a disability, so in addition to providing you with professional information and advice, they will understand you and your situation in that special way that only another parent can. We work in close co-operation with a network of Regional Parent Support Co-ordinators and various statewide and national parent support groups. Through these networks, we can put you in touch with other parents and groups in your local area and/or those who have a child with the same disability as your child.

Developmental Delay/Disability/Illness

For children under 6, the word 'disability' is often not referred to as part of a diagnosis. Commonly used alternative terms include 'developmental delay', 'global developmental delay' and 'language delay'. This booklet is relevant to parents of all children with a diagnosis that includes the word 'delay'. It is also relevant for families of children diagnosed with a severe illness. For space and other reasons, throughout this booklet we use the term 'disability' to refer to all children with a disability, 'delay' or severe medical condition or illness.

Introduction

1.

It is often because of the efforts and persistence of parents that their children live positive and fulfilled lives. When a child has a disability, parents strive even harder for the best outcomes for their child's future. A disability may be due to a medical condition but the potential outcomes for the child and family are in the hands of you, the parent, as much as, or more than, the therapist and specialist. Knowing this will give you the strength and energy to pursue the best for your child.

This booklet has been written by parents, for parents. It is a parent's perspective. It is the result of our own experiences and listening to other parents. It looks at problems and issues faced when searching for a diagnosis, becoming familiar with the service system and learning to take charge of the situation.

The stories and comments reflect different parents' views and responses to their situations. What is right for one parent may or may not be right for you. What worked for some parents may or may not work for you. In producing the booklet, it became clear that while there are different opinions and responses, there is also a large common area of agreement amongst parents.

This booklet aims to help by:

- sharing other parents' experiences
- giving you some practical ideas and strategies.

The one message we, as fellow parents, want to give to you is that it is very much up to you. Professionals can and do help, but if you want the best possible outcomes for your child you need to take control of the situation. You are responsible for ensuring the rights of your child are respected. Find out what is available: learn how the service system works and how to get what you want for your child. There are many people who can support you, you are not alone!

And of course, it's not just about the child or children with a disability. Everybody close to the situation - grandparents, siblings, friends - will be affected in some way. In thinking about what's best for the child, we need to take into account the whole family situation.

When there is a child or children with a disability in your family you are likely to:

- learn a whole lot about yourself, your strengths and weaknesses;
- learn a range of practical skills to assist your children;
- begin to learn about a complex service system and negotiate your way through it;
- develop strong social networks to support you;
- encounter problems with services and begin to take action to overcome the difficulties;
- become the case manager/coordinator of your child's services and development (even if you have a professional case manager); and
- learn that being different (in society's view) can cause difficulties but that doesn't mean there aren't joys.

'I kept waiting for somebody to take control of the situation and fix everything. Then I realised I had to do it. I had to take charge and co-ordinate everything.'

'Know your instincts, the inner voice telling you what is right for you and your child. And keep searching. It might take some time, but search. It's no good waiting for two and a half years as happened to me for the right diagnosis.'

2.

'We probably all knew by looking at our children and comparing them with other children. You know there is something wrong. Sometimes the problem is convincing the doctors that something is wrong'.

'I remember feeling like I was in a hazy state, and lots of info washed over me as I thought, Why? What went wrong? What could I have done differently? Then I snapped and thought, Okay, how can I minimise the impact on my child and family and moved on.'



Diagnosis

Early diagnosis and timely intervention can help your child achieve his or her full potential. More often than not it will be you, your family or friends who first recognise that something is wrong.

It is important to trust your own feelings and observations. If you have concerns, check them out. If you are not satisfied with the advice you are getting, seek a second, or third opinion if necessary.

The purpose of diagnosis is to find a medical explanation for your child's condition. Unfortunately, it is not unusual for people to only get a diagnosis after years of uncertainty – and some families may never get an actual diagnosis. Developmental delay may be the only diagnosis given, while the actual cause is undetermined. Keep in mind, however, that you do not need a firm diagnosis to use various services, including early childhood intervention and specialist children's services.

Sometimes a condition is evident at birth, and the doctors at the hospital can identify the disability and provide a diagnosis. Some conditions are almost unnoticeable at the start. They emerge slowly, or at a later stage of the child's development. It may be your general practitioner (GP), maternal and child health nurse, or a worker at a community health centre who identifies a problem during one of your regular visits. Some children acquire a disability later in life as a result of accident or illness. Acquired disability may be the result, for example, of a head injury.

The diagnosis is important in helping your child obtain appropriate support and assistance, and in promoting your own peace of mind.

The usual place to start looking for a diagnosis is your GP. If initial tests do not reveal much, ask for a referral to a paediatrician. The paediatrician may put you in touch with a specialist or you may request a referral to a specialist. At times, several specialists are required to make a full diagnosis. This is usually coordinated by your paediatrician and referred to as a multidisciplinary diagnosis.

The purpose of seeking a second opinion is to get satisfaction about legitimate concerns and outstanding problems. Sometimes people go from one doctor to another, bargaining with them in an attempt to make the disability 'go away'. This is part of the grieving process associated with acknowledging and coming to terms with the disability.

Difficulties You May Encounter

- Diagnosis can be extremely difficult, particularly when professionals don't see the child in everyday situations. Often you see the problem before they do.
- Some people focus more on the medical condition and can tend to ignore your feelings.
- Sometimes GPs are not experienced in children's disabilities; their primary expertise is in general practice. Even experienced doctors often lack knowledge about rare conditions.
- Sometimes doctors may not inform you of the diagnosis, even if they know or suspect it. They may not want to inform you until they are absolutely sure.
- Some doctors may find it hard to deliver bad news - it is difficult.

Strategies that May Work For You

- Provide the doctor with as much information as possible about symptoms. Keep a record of the date, time and description of symptoms, especially things that are not obvious at the time of consultation. This can help the doctor in diagnosis.
- You may like to consider recording your child's symptoms on video to assist with diagnosis.
- Trust your own instincts and feelings, as often you are right.
- Wherever possible, find a doctor who is willing to work with you, one whom you can develop a rapport with and who can help you obtain relevant professional help.
- Ask as many questions of your doctor or specialist as you need until you are clear about the diagnosis and what it means, you may have to persist for answers.
- If you have difficulty remembering all the things you need to ask the doctor, write out your concerns, observations or questions and take them with you to the doctor or specialist and also write down their responses.
- Take any press or magazine articles you may have read about the condition. These strategies can be invaluable in promoting communication.
- When visiting your GP or specialist you may find it helpful to take your partner or a friend with you to provide moral support, to be an advocate, and to assist understanding. It can be helpful to have someone else with you who is also listening to what the doctor or specialist is saying because they may hear something that you don't. This is especially important in the early stages when you may still be in a state of shock.
- Don't be put off at any stage. Never be told that you don't need to see a specialist if you really feel that is what you want.
- Listen attentively; always feel in control.
- It may help you to talk with another parent who has a child with a similar disability. It's important to share and talk to others. You're not alone!

Ideas to Think About

- You have a right to know the full diagnosis, as far as possible, and what this means for the future. Research it yourself until you understand as completely as possible all that's involved.
- Consider using the Internet as part of your research.
- University libraries or the Department of Human Services library (Ground floor, 555 Collins Street, Melbourne) can be useful when researching your child's condition. You may not be able to borrow books, but you will be able to read the book in the library. If you find a particularly helpful book you could possibly arrange an inter-library loan through your local library.
- Sometimes the actual cause of a condition is never found, but this should not stop your child from being helped.

'The time when there was no diagnosis was a nightmare. I know the medical people were trying their best, but I don't think they really understood how desperate we felt.'

'We had two extremes. Most doctors were technically competent but we had ones that just couldn't communicate. We had to get rid of them. One specialist had the ability to tell us bad news and we went away feeling better'.

'As soon as the diagnosis was clear, I wanted to know everything, to read everything I could get my hands on. I researched books, articles and a friend helped me search the Internet'

3.

Working with Doctors and Medical Specialists

'When seeing our first paediatrician, he told us quite clearly that he 'didn't have all day to talk to us because he had other patients.' My daughter then wee'd down his leg. We trusted her judgement and changed paediatricians.'

Constructive working relationships with your general practitioner and medical specialists are important for your child's wellbeing and your own. When you look for a partner in life or business you usually give it a bit of thought. It is reasonable to think in a similar way when choosing your doctor.

Having a good local doctor who listens and gives good advice is very important. A good doctor can:

- be a ready source of advice and support;
- refer you, where necessary, to appropriate specialists, therapists and other services;
- be available in emergencies;
- ensure that you are looking after yourself as well as your child; and
- write support letters for equipment or services.

Doctors are human. You will get along with some and not others. Some doctors listen, are sympathetic and communicate clearly. Others don't and you may not have good experiences with them. Find a doctor who you feel comfortable with and who respects you. This is a normal and natural thing to do. Remember that often it is a matter of persisting with your doctor and educating him or her rather than changing doctors, although sometimes changing doctors is the right thing to do.

Don't let doctors 'talk down' to you - you too have a brain. Make sure your doctor is aware of any research and information you have gathered. Don't be afraid to put forward your opinions and suggestions – they are valid.

If there are any problems identified or issues unresolved, your GP can make a referral to a specialist for further testing or diagnosis. The role of the specialist is crucial in reaching the correct diagnosis and planning future treatment and support for your child.

Most doctors refer to a range of specialists they use regularly and have close contact with. You can, however, ask for a referral to the specialist of your choice. It is important that you find a specialist who is able to communicate clearly and simply to you.

Problems of compatibility sometimes arise. As with GPs, specialists' 'bedside manner' vary significantly. Parents report having good and bad experiences with specialists.



Difficulties You May Encounter

- Sometimes doctors don't accept that you know there is something wrong.
- GPs tend to refer to particular specialists. Not all people will necessarily get on with the specialist they are referred to.
- There may be communication difficulties. The GP or specialist may not listen attentively or explain things clearly. They may assume you understand when you don't. You may not know what questions to ask.
- Some specialists tend not to give you all the information. They may consider that you are not ready for all the information about your child.
- Depending on their skills and time constraints, doctors may focus on the medical problem and may miss out on what is happening in the family as a whole.

Strategies that May Work for You

- Be selective and find doctors and specialists you feel good with. Other parents may be able to recommend a good doctor.
- Once you have found the doctor and/or specialist you can work with, it is important to build up a relationship of trust and partnership.
- When trust and sound communication have been established, talk freely about your child's condition and needs, about your needs and feelings, and the situation of the family as a whole.
- Ask the doctor or specialist to explain things in detail and in words you can understand. If necessary, sum up their statements in your own words, and ask if that's a correct understanding.
- If you have questions, ask them. Don't worry if the doctor/specialist seems to be in a hurry. It's their job to take the time to answer your questions. It sometimes helps to write a list of questions before the appointment. You may like to take another person with you to the appointment. They may hear something you miss.
- Write down their responses - sometimes you will be presented with a lot of information that is difficult to absorb. Ask for information sheets/support groups if you have a particular diagnosis and need more information.
- Sometimes when making an appointment it can be helpful to request a longer appointment time. This is especially so if you know you will be receiving test results and need to discuss the implications of the findings.
- Keep a book in which to record details of medical practitioners, service providers, of appointments and outcomes etc. (You can also use the Notes page at the back of this booklet to record this information.)

Ideas to Think About

- You can play a key role in educating doctors and other professionals, by creating awareness in them of your needs and of the difficulties you face. Working with your doctor to help him or her understand your needs will help the parent that follows you.

'It's like a soap opera. You find out a bit of information. Then – to be continued next time at your next visit.'

'I was really happy about my first specialist. He said I really don't know what to do but whatever we do we do together; and if you stand by me I'll stand by you. I don't know that she will survive but whatever we do we do together!'

'I always used to feel rushed at the doctor's. He would say things and later I realised that I hadn't really understood what he'd said. It only got better when I got the courage to tell him I needed him to slow down and explain things better.'

4.

Support for Parents

If you are going to pursue the best outcome for your child, you will need to understand the diagnosis and the implications for the future. If your child's condition has not been diagnosed then there is the additional challenge of living with uncertainty.

It may be devastating to you. You may have a delayed reaction and go on regardless because you feel that someone has to cope. It always catches up with you eventually. The problems and difficulties won't go away. Try to be aware of the stresses you are facing; the chances are that unless you take steps to look after yourself you will risk being burnt out.

It helps to let go of your feelings. You need to be able to share your feelings and experiences with someone you trust.

The health of your child and family is dependent on you looking after yourself and dealing constructively with the range of emotions that can envelop you. It is alright to be angry, sad, frustrated, to feel self-doubt, and to cry. It is not helpful to bottle it up and deny the situation you are facing.

Many people find parent support groups extremely valuable to assist them to cope with the situation. You may be surprised to hear others tell of feelings of anger, guilt, regret, sadness etc. that reflect exactly how you feel. These feelings are natural. Giving voice to them in a safe environment will help. Other people find support from families and friends. The bottom line is that we all need support at some time – you don't have to do it alone!

You also have to come to terms with the grief and loss you feel about having a child with a disability. To grieve for the child you thought you were going to have – your 'normal/perfect' child – and accept the child you do have.

Difficulties You May Encounter

- In the early days you might be easily upset. You will often feel emotionally fragile. You may feel that you are living on a roller coaster, and this may continue.
- You can put unrealistic expectations on yourself.
- It is common to deny your own feelings and to suppress them. This is not good for your long-term health.
- Some parents assume a selfless approach, forgetting about their own needs.
- Sometimes parents, in their anguish and confusion, seek to do more than is realistically possible for their child and family to cope with.
- Some doctors and professionals may be inexperienced in recognising the emotional needs of parents and suggesting options for support.
- You can get trapped by your own misplaced sense of guilt.

'I remember thinking at one stage that my child should have died at birth and wished for his sake that he had. I felt tremendous guilt just for thinking it. It wasn't until I began talking about these feelings (and many more!) that I realised that they were very normal thoughts and I began to accept myself, the situation and my child a lot more easily.'

'You feel this heavy rock like presence within you. It comes upon you at different times, then lifts for a while – weeks, months, years – then it is back again. Someone told me it was grief!'

'After years of thinking about it, I finally decided to go to a workshop on loss and grief. It was the best thing I ever did. I started to understand how my grief had affected me and I learnt strategies to deal with it positively.'

Strategies that May Work for You

- It is important to allow yourself to 'let go' without feeling ashamed.
- Try to remember that the feelings you are experiencing are 'normal'.
- Talk to others who have gone through it; share your experiences.
- Contact your Regional Parent Support Co-ordinator (see page 20) and find out about local parent support groups and ways of meeting other parents.
- Take time out for yourself; it is critical to find a way to do this.
- Look after yourself - exercise, relax, eat well, sleep well.
- Develop a support network of close friends or relatives. Learn to accept offers of assistance and support.
- Try to recognise your grief and the best ways of dealing with it. Talk with a counsellor if you feel your grief is getting you down.
- Try to be a good negotiator for your family and avoid confrontation. Try to become a good 'deal maker'.
- Make sure you have as much information as you can about services and payments you are entitled to. (See 'Through the Maze; A Guide to Benefits and Services for Families of Children with a Disability', also published by the Association.)

'Our little boy, then nine months, was obviously delayed in his development - but cerebral palsy! It conjured the most dreadful pictures in my mind. The future looked as bleak, hopeless and sad as any nightmare can possibly create. The "if onlys" haunted my mind relentlessly and feelings of guilt, resentment and absolute sorrow kept me from sleep all too often. I felt an incredible "aleness".'

Ideas to Think About

- We are all different and we will have different way of dealing with our situation.
- Each of us is human and has limits of coping. We all have our breaking points. Don't be afraid to admit when you are not coping.
- We all need someone to care for us.
- We all deserve to be treated with dignity.
- It helps to remember that your child with special needs is a child first, his or her special needs come second.
- Don't put unrealistic expectations on yourself and your family. Know your own strengths and weakness - don't overcommit yourself.
- It is normal to feel sadness for the child you thought you were going to have.
- This sadness may continue in various ways and it may be ongoing. It is very important to recognise and deal with grief.

'I remember the first parent support group meeting I went to. I was describing my son's disability and to my surprise the parents there listened and asked me more questions. I was used to other people quickly changing the subject.'

5.

Family Relationships

Taking care of yourself and your family relationships is just as important as taking care of your child. You are a family first. Try to reach out to each other and communicate from the start – it will be worth it in the long run.

'When the going got really tough (with our son) we were both so exhausted it was hard to find the energy to care for each other. We made a rule that we had to talk to each other at least once a week about something not to do with disability. It seemed to help.'

Couples/Partners

Having a child with a disability places a high level of stress on couples/partners. Some relationships will deepen and strengthen in love and commitment. Being aware of these extra stresses requires a degree of maturity, self-assurance and support. It is important to talk to each other about your feelings. Give each other support.

Sadly, many relationships don't survive the pressure and they break down. Sometimes parents get to the stage where they need to blame something or someone and because there is no-one else to blame, they blame each other.

Each partner will grieve and come to terms with the child's disability in different ways and in their own time. They also have different strategies for coping with stress. Men and women share and demonstrate emotions differently. Generally women find it easier to share their feelings and this makes it easier for them to ask for help or join a parent support group.

There can be enormous financial pressures. One partner may have to stop work or forgo their career to care for the child.

For any successful relationship, there is a need for commitment, good communication and mutual support. For good communication, recognition of each other's needs as well as your child's, is critical.

Sole Parents

When it comes to making decisions for your child, being a sole parent can be a lonely experience. You might need to be particularly focussed to ensure you use all the other supports available to you e.g. extended family, other parents, friends, services, etc.

Extended Family

Grandparents, uncles, aunts, cousins. Sometimes we underestimate the extent to which extended family members are willing to help and support. Don't be 'too proud' to ask for help. Usually extended family members will themselves feel better if they can help you in some way.

Mothers

All families have choices about how to divide and share responsibilities. In many families it is the mother who has the greatest responsibility for the care of children. Many women go into 'super mum' mode and forget their own needs. It is important to be sensible about how much you can do on your own. Don't feel ashamed to ask for help. You will probably be able to be more of a 'super mum' if you are getting some help and support.

'One part of being a sole parent that I enjoy is being in charge of all the decisions. I get all the support I need from my friends and family.'

Fathers

It can be very difficult for fathers. Some find it hard to be involved with their children because of work commitments. Many fathers experience a sense of guilt about the amount of time they spend at work while their partners are coping with difficulties at home. Others become workaholics – hiding from their feelings by being constantly busy at work.

Quite often fathers miss out on mutual support. They tend to have less access to parent support groups because the meetings are during the day, or they feel the women in groups don't welcome them or they don't feel comfortable discussing their own feelings.

Many fathers are not as experienced or as confident about sharing their personal feelings and they don't feel as if they can let it all out.

Much of male culture is about a concept of strength that undermines a genuine sharing of feelings between men. Often they don't see it as a problem themselves. They feel stressed but don't know why. It can gnaw at them without them understanding why.

With changes in community attitudes, men tend to be more involved in parenting these days. A supportive and understanding man can be a great source of assistance in sharing the tasks of looking after children (or taking the primary caring role at home).

Brothers and Sisters

Care must be taken not to sacrifice the needs of the other children in your family. The extra attention required by your child with a disability may be interpreted by brothers and sisters as favouritism. It may create tensions between siblings and feelings of rejection in non-disabled children.

Explain to siblings, at their level of understanding, what the situation is. They can be a great help. Be alert to your other children's needs. Inform them. Include them in your decision-making.

Give each child their own area of responsibility and their own special time alone with you. It can be difficult, but it is very important. You are a family first, second and last, and the thoughts, feelings and needs of siblings cannot be overlooked.

Difficulties You May Encounter

- Many factors can place pressure on relationships between parents. These include denial of grieving, different coping styles, the tendency to 'blame', and breakdown in communication about feelings and needs.
- One or both parents may work to breaking point without recognising their own needs.
- There are also difficulties faced by siblings of the child with a disability: jealousy and feelings of rejection are common reactions.

'I often feel guilty about being at work, knowing what my partner is coping with at home. I know in my case that being at work is much easier than being at home.'



'It's hard for Mum. She has to spend so much time looking after my brother she doesn't have much time left over for me.'

Strategies that May Work for You

'I started to breathe easier on meeting other mums of kids with disabilities and the kids themselves. With those meetings came hope, new suggestions, enlightening stories, real empathy. These people really knew where you were at! Now I could start to really do something for my son. The chains that bound me in my hellish pessimism began to fall away.'

- Look after yourself.
- Talk to your partner and family about feelings and needs. It does help to be open and share your feelings and thoughts.
- Make sure you have someone to confide in, and share your experiences. Parent support groups have sympathetic listeners.
- Fathers need to know who to trust and how to share their feelings.
- Fathers should be encouraged to develop suitable support systems, including meeting other parents/fathers with similar family situations.
- Taking care of yourself and your family relationships is as important as taking care of your child.
- Seek professional advice from your doctor or a counsellor if you have difficulties coping.
- Make sure you have breaks from your child. Time out is crucial; ask friends and relatives or use a respite care service.
- For couples, take time out together.
- Set goals not only for your child, but for yourself and the family.
- Share tasks, providing a role for all members of your family.
- Encourage non-disabled siblings to talk about their feelings, and work out ways to support them.
- Give each child their own area of responsibility and their own special time alone with you.

Ideas to Think About

- No family is perfect.
- Looking after yourself is not an 'optional extra'. It must be part of the overall plan for your family if you want to last the distance.

'I used to feel guilty about this thing they called respite. I don't any more. It gives us time to just relax and talk - to recharge the batteries. Respite - I need it, we need it and I don't feel guilty about it one bit.'

Dealing with friends and the general public

6.

It's challenging enough dealing with your own feelings and uncertainties and those of your family. The additional problem of coping and dealing with other peoples' fears, guilt and anxieties can be very trying.

In the past, people with disabilities were 'put away' or not encouraged to be a part of the whole community. This means that some older people have had little or no contact with people with disabilities. They have not had the opportunity to think through their attitude to disability, and to learn how to comfortably interact with children and adults who have disabilities. Their behaviour may be paternalistic, patronising and otherwise inappropriate. This is underlined by ignorance, fear and, in some cases, prejudice.

It is important to think about how you will deal with and cope with this type of behaviour. You can ignore some people. Others can be more difficult, for example your parents or in-laws, other extended family members, other children or friends.

Most of the people in your personal network are prospective allies to help you help your child reach his or her full potential. For a while you may have to do a balancing act – work first with those who are least prejudiced or most helpful, and develop an understanding relationship. Others may be kept at arms length for the time being, and then encouraged with explanation, patience and good humour at a later time when things are more settled.

Most parents of children with a disability make many new friends, particularly among families who also have children with disabilities. But old friends are important too, as supporters, encouragers and respite carers. It is important to try and bring them along with you and your family. The stronger your personal support network, the less the risk of isolation.

Difficulties You May Encounter

- Some people interfere and try to offer advice, thinking they are helping.
- Having to deal with people's inappropriate behaviour can trigger strong emotional reactions. It is common to initially feel embarrassed or overwhelmed by anger at what people say and do.
- Few people are experienced in dealing with people with disabilities. They often don't know how to communicate with them or with you. Often people do and say things that are at best unsympathetic and at worst cruel and unkind.
- Some people overcompensate and protect children with a disability. They don't let them get on with living and always treat them as babies.
- Some family members and close family friends may deny your child's disability. They may refuse to come to grips with it.
- You may find that some friends can't cope with your grief or your child's disability. These friends may gradually disappear. This can be another source of loss and source of grief.
- Strangers may stare, ask awkward questions or say hurtful things.
- If your child looks 'normal', you may find people saying he or she just needs more discipline to make him or her behave acceptably.
- Some people never accept a child with a disability.

'I sometimes think that it affects our close friends quite hard. They have found it difficult to deal with their emotions, whereas more distant friends have coped well. Maybe they feel a need to be an immediate support to you and they don't know how. They feel the stress too.'

'My child doesn't look disabled so people don't understand why he behaves like he does. I get dirty looks from people all the time, like it's my fault. It used to worry me, but I figure it's their problem, not mine.'

Strategies that May Work for You

'I used to feel like I had to apologise all the time for his behaviour, to explain it to people and educate them to be more understanding of him and other kids. Then, suddenly I got tired of having to do it all the time, so I just stopped apologising. Other people should be able to work it out themselves.'

- Find someone you can confide in and cry with them without feeling embarrassed or awkward.
- Get support from other people who have children with disabilities. They understand what you are going through.
- Children are inquisitive and willing to learn. Explain your child's disability to them and the adults around can learn in a non-threatening way.
- It's better to discuss behaviours you find difficult. It helps you and the person understand what is appropriate.
- Don't get trapped in the house.
- Find a support network of friends you can confide in and seek support from in difficult times.
- Participate in self-help groups that undertake public education.
- Be open and honest about your feelings and ask family members and friends to do the same.

Ideas to Think About

- It is OK to be assertive.
- People experiencing difficulty with their feelings towards your child is not your problem.
- Develop your own personal strategies to deal with insensitive comments from friends, family members and other people.
- Be open and honest about your feelings.
- It's OK to say you don't have time to do everything.
- It is OK to feel hurt, but do not let that hurt stop you trying.

'Sometimes people try and help us in public when we don't really need any help. It can be annoying, but I suppose it's better than people not wanting to help at all.'

Finding Out About Services

7.

If you are not already an information expert, you will need to become one! You will need to develop ways, not only of finding out what is available, but also how to seek out alternatives and evaluate the competence of professionals and organisations.

As always, a good place to start is talking to other parents. Make sure you contact your nearest Regional Parent Support Co-ordinator (see page 20) and ask what information they have about services. Make sure you are on the Regional Parent Support mailing list to receive newsletters and updated information.

The Internet is also a great source of information. It includes information on specific disabilities, support groups around the world, and services and programs available for your child and family.

Three sites you may find particularly useful are:

- Disability Information Victoria: www.disabilityinfo.org.au
- InfoXchange: www.infoxchange.com.au
- Association for Children with a Disability: www.acd.org.au

Difficulties You May Encounter

- You may end up learning about services by accident.
- It can be difficult finding out what services are available, and who can help.
- It can take some time to find out what is needed to best promote your child's development and then to find the right services.
- Sometimes when you find the right service there might be a waiting list or some other reason why you can't use it. This is very frustrating!
- As your child's needs change over time, new information must constantly be sought.
- Some professionals may not have a network to draw on for comprehensive information. Don't assume that your doctor or case manager will know about all the available services.
- Some agencies, as a matter of policy, will not tell you about non-traditional therapies.
- The service system varies from area to area, and region to region. If you move regions, you may have to start gathering information all over again.
- Things change constantly - names, locations, policies, procedures and so on.
- You can't believe everything you hear and read. Various sources of information, including the Internet, might include inaccurate information.

'I stumbled on help. I didn't know what services were out there.'

'I've always found that other parents are the best source of information. I've learnt more from talking to other parents at my parent support group than from anywhere else.'

'Most of the professionals I've met only know about the part of the system they work in. They don't seem to know the full range of services for families. I learnt very early on that the only person who could gather all the information I needed was me.'

Strategies that May Work for You

'There seem to be so many different program names, it's hard to know what's what.'

'There are some really good newsletters and information guides that are worth reading cover to cover and keeping for future reference'

'I was amazed to discover how much disability related stuff there is on the Internet.'

- Learn about the services yourself. Keep asking questions. Be persistent. Ask for written information, booklets, brochures etc.
- Try to attend any information meetings or expos about services in your area. If you can't make it, ask for key information to be sent to you.
- Educate yourself about jargon and acronyms. Whenever a worker says something you don't understand, ask them to explain the details.
- Make contact with other parents, through Regional Parent Support Co-ordinators and/or other relevant groups. Other parents are often the best source of information.
- Make sure you have up to date copies of key documents and guides including: 'Through the Maze: A Guide to Benefits and Services for Families of Children with a Disability' (available free from the Association for Children with a Disability); 'A Guide to Your Local Health Services' from your Regional office of the Department of Human Services (see page 21); Your Local Council Community Directory; any local/regional information kits available through Regional Parent Support Co-ordinators (see page 20). Try and find the time to read them.
- Use the Internet to find the latest information. If you do not have a computer at home you may be able to access the Internet through your local library, neighbourhood house, TAFE College or an Internet Cafe. Or contact the Association for Children with a Disability for Internet training.
- Ask professional workers if they can help you get the information you need.
- Some services are based in local areas and available to residents who live in a particular Local Government Area (LGA). A range of other services are based on regions defined by government departments. There are also a range of Statewide services. When searching for services, make sure you are clear which LGA you live in and which region of the Department of Human Services (DHS) you are in. See list page 22.
- Don't limit your search to services which have a disability focus. There are a range of general non-disability services which may be of help to your family, e.g. community health, neighbourhood houses, financial counselling etc.

Ideas to Think About

- It costs nothing to ask questions.
- Learning is by trial and error.

Using the Service System

8.

Getting the best services for your child and family is often a case of constantly battling and wondering 'why does it have to be this difficult?' or 'why do I have to battle for every little thing?' However, we also see many 'success stories' - parents who, once armed with information and some tips on how to negotiate, are able to go ahead and organise the services they need for their child.

The mix of services and organisations varies from region to region, so the types of services available to you and your family will depend on where you live. In some regions, especially parts of rural Victoria, some services may be in short supply, or not available at all. It may not be fair but the fact is that often, to get the best services for your child and family, you have to fight very hard.

The strategies identified here are designed to give you the confidence to be your own best case-manager.

'It's no good being passive. I only started getting the services we needed when I started jumping up and down and demanding that things be done properly.'

Difficulties You May Encounter

- Finding out about the services you need can be difficult.
- Different services have different eligibility criteria and each new service may require a new assessment process.
- There is often bureaucracy in the system. Things are not always logical or fair.
- There may be a waiting list for a service you want to access.
- In some regions, some services may be in short supply, or not available at all.

'The case manager went on with this long story about why she couldn't help us because there were families more needy than us. I'm not stupid, I know there are families in a worse position, but the way she said it was really demeaning to me and my child. Just because some families are worse off shouldn't mean we can't have what we need.'

Strategies that May Work for You

- Draw on the knowledge and experience of parent support groups.
- Plan ahead. You need, for example, to start planning for transition to school at least twelve months ahead.
- Don't be put off if you are told there is a waiting list for a service you want to access. Make sure you're put on the waiting list and ring regularly to find out what is happening with your request. Otherwise you are invisible and may be forgotten. Keep a written record of who you have spoken to, what they told you and the dates of each phone call. You may have to refer back to this in the future.
- Most services have a range of official quality standards they are supposed to meet. You may like to ask your service provider how they measure and monitor their quality of service. Most agencies should have a committee or some other way of seeking direct input from parents and other consumers/service users about their services.
- It may be helpful to have a brief written summary of your family situation, including your child's history of involvement with services. Ideally, you can keep the summary on computer and update it for on-going use. The summary will save time and allow you and others to concentrate on dealing with the specific issues at hand.

When negotiating keep the following general principles in mind:

'I think early on I got labelled a trouble-maker because I was always complaining. I changed my style a little bit by making sure I was organised with a clear plan of what we needed. They seemed to listen more after that.'

'I've always been a bit shy, but I've learnt that to get what we need I can't afford to be shy.'

When negotiating keep the following general principles in mind:

- Be calm and positive! Be clear about what you want. Plan/list what issues are the most important to you.
- Gather any relevant facts, figures or documents to argue your case. Have your documentation sorted so it's easy to find.
- Be organised to make notes of key points. Know the rules of 'the game' (eg policy, guidelines). Think about the sort of arguments others may use and how you might best respond.
- If you are negotiating on the phone, always make sure you know the name and position of the person you are speaking to so you can follow up with them next time if needed.
- Don't always expect to strike conflict. Others might agree with you, but be prepared for conflict. Be assertive, not passive or aggressive.
- Don't try to talk in the 'jargon' - be yourself. If you don't understand something ask people to explain it again.
- Listen carefully. If necessary, counter arguments with facts. Don't get into personal attacks on individuals. If you need to draw on strong emotion, that's OK!
- Ask for important issues, decisions etc. to be formally noted in writing. Note the issues you've agreed on, and try and find a strategy for dealing with any disagreements. Don't accept 'cop-out' excuses for indecision or lack of action (politely).
- If applicable, make sure there is an agreed process for follow-up. Be prepared that you may need to do some specific follow-up to ensure the things which are agreed on are done.
- If you have concerns about the quality of service, speak to the person delivering the service directly, eg the class teacher, therapist etc. On most occasions problems can be resolved at this level.
- If you still have concerns speak to their supervisor, team leader, manager or Principal. Keep diary notes.
- The next step is to speak to and put in writing your concerns to the Head Office of the Service, or the Regional Office with a copy to your Local Member of Parliament and the relevant Minister. (See contact numbers on page 21.)
- If you still feel your concerns have not been addressed, make an appointment to see your Local Member of Parliament. Give them a copy of your diary notes, letters, etc. Ask for assistance to resolve the matter. Sometimes your Local Member can arrange for a delegation to the Minister responsible.

Ideas to Think About

- Other parents have experience of services you can learn from.
- What is right for someone else may not be right for you.
- You will continue to be your child's main advocate long after individual professionals and services have left the scene.

The Role of Parent Support Groups

9.

Parents helping and supporting each other! These simple words are the underlying principle behind parent support groups. Not all parents are looking for the same type of support. Some simply want to chat on the phone with someone who understands the issues; some want to go to local meetings, have a cup of coffee and exchange information; some just want to be on the mailing list to receive information; and some need support to access services for their child and family.

Regular contact with other people experiencing similar problems is very important as it offers the opportunity to exchange information and give and receive emotional support. Without this contact you can feel isolated.

A variety of groups exist including: local, regional, statewide, and disability specific groups (for example Down syndrome, cerebral palsy etc). Support groups can also be organised via telephone hook-ups or using 'chat rooms' on the Internet.

Most groups undertake a range of common activities:

- **Support** - being there to listen to you and your story and provide emotional support when needed.
- **Information** - providing a range of information on issues that affect families with a child with a disability. This is done in a number of ways, for example: responding to requests for specific information; newsletters; information forums; workshops; and access to the Internet.
- **Individual Advocacy** - providing information and advice to empower parents to become their own, and their child's best advocate. Some parent support groups can also provide you with another person to act as your advocate.

Some groups are also actively involved in community education and lobbying:

- **Community Education** - raising community awareness is important for gaining wide recognition of the needs of children with disabilities and their families. Often parent support groups undertake a range of public speaking and community education activities designed to educate professionals, service providers and the general public about what life is really like for families of children with a disability.
- **Lobbying and Systemic Advocacy** - many groups meet with decision makers, politicians and service providers. This is an important focus of groups which ensures that the views and experiences of parents of children with a disability are fed back to professionals, bureaucrats and politicians.

To find out about a support group to meet your needs contact the Association for Children with a Disability on 03 9500 1232 or Freecall 1800 654 013 (Rural Victorian callers only) or contact your Regional Parent Support Coordinator (see pages 1, 2 and 30 of 'Through the Maze'.)

'My parent support group was a life-line. It's just nice to be with other people who really understand what it's like.'

'Our group is very low key. We just have coffee and talk.'

'Early on I was just too busy and exhausted to go to a group. But I kept getting the newsletters and then, one day, I got the energy to go and I loved it!'

10.

'I went to a parent workshop once and there seemed to be two contradictory messages: (1) that I had to take control and organise everything and (2) I was supposed to look after myself.'

It's hard to do both. It's a constant juggling act. Sometimes I get the balance right. I just try to enjoy life as much as I can and keep going!'

Conclusion

With this booklet we have tried to draw on our own experience and that of other parents to provide information and advice to help you and your family.

Having a child with a disability presents many challenges. The nature of these challenges varies from child to child and family to family. Each situation is unique. By concentrating on the common issues and themes for families we hope we haven't overlooked the most important issues for you in your situation.

One of the main messages from this booklet is that getting the best for your child and family is very much up to you.

It may not seem fair but the reality is that you need to take control to ensure everything is done properly. Good, supportive professionals can and do help, but they can't replace your role as the parent. Even if a professional case-manager is involved with your family, you still need to be your own case-manager.

This means getting all the information relevant to your situation and then negotiating with professionals and service providers for an appropriate package of support for your child and family. It is not an easy job!

You are not alone. There are thousands of other parents who are in a similar situation to you. With these shared experiences there is power and energy.

At various stages in this booklet we have talked about the benefit of contact between parents. The value of emotional and other support parents provide for other parents cannot be underestimated.

For a variety of reasons, we understand you may not be in a position to attend a parent support group. Even so, you should ensure that you are on the mailing list to receive newsletters from your Regional Parent Support Co-ordinator and/or other relevant parent support organisations, including our Association (see page 20).

There are also other creative ways you may be able to initiate and maintain contact with other parents. For example, using the Internet or telephone hook-ups.

Another main theme of this booklet has been to reinforce the importance of you looking after yourself. Your child and family depend on you. You need to be realistic and sensible about how much you can do on your own. It is not a sign of weakness to ask for help. Whether it is from family, friends, respite or other services, make sure you get an appropriate level of help and support.

Finally, please remember that for information and support on any specific issues for your family, you can contact a Parent Support Worker at the Association office.

Best wishes for you and your family.

Glossary of Terms

Acronym: A word formed from the initial letters of other words. For example DHS (Department of Human Services) GP (General Practitioner).

Advocate: Any person who works with you and/or supports you in dealing with organisations or professionals.

Assessment: Assessment is the process of gathering and sharing information to promote understanding about your child, family and services. Its purpose is to assist in making informed decisions for the planning and use of services.

Case Manager: A professional worker who is employed to help a family plan and manage a range of services for the child/family.

Criteria: Standards or rules for assessing whether you are eligible for a service or benefit. They are generally formally written statements.

Counsellor: A person who gives advice or counseling.

Diagnosis: Examination of a child to establish his or her clinical state by a combination of questioning, testing and observing.

Early Childhood Intervention: A name used for a group of services involved in the planning and provision of educational, health and community services to enhance the development of young children with developmental delays and disabilities.

Eligibility: Entitlement to use a service or facility. Most organisations have a formal criteria to determine whether you are able to receive the service or facility.

Paediatrician: A doctor who specialises in children's health and development. The paediatrician works closely with other professionals and can refer you to other specialists when necessary.

Policy: The formally agreed course of action by government or an organisation. Normally describes who is able to use particular services, how services are provided and what outcomes are expected from them.

Professional: A person who has generally received tertiary training in a particular discipline or skill area and is practicing that particular skill or discipline.

Quality Standards: A written statement of the minimum standard of service that users of a service have the right to expect.

Region: A geographic area defined by government departments to help organise the delivery of services.

Referral: The process of identifying a service that can be of assistance and then linking the child and family with the service.

Service System: The whole system of organisations providing services and programs, and their respective policies, procedures and eligibility criteria.

Specialist: one who specializes in a particular occupation, practice, or branch of learning.

'Have you ever been to one of those meetings when all the professionals do is talk in acronyms and jargon? Very frustrating!'

'I really hate the term Case-Manager. I don't like being thought of as a 'case'. Surely there's something better.'

Association for Children with a Disability Membership Form

I would like to become a member and enclose payment:

- \$5 Low income earners (including families of children with a disability who are low income earners)**
- \$10 Other families of children with a disability**
- \$25 Everyone else (including organisations, service providers)**

Note: Relatives, including grandparents can join at the \$5 or \$10 rate. (Credit Card Payment is available). All new members will receive a free copy of our Magazine, 'NoticeBoard' and 'Through the Maze'.

I am a:

- | | |
|---|---|
| <input type="checkbox"/> Parent/Carer | <input type="checkbox"/> Family Friend/Concerned Person |
| <input type="checkbox"/> Grandparent | <input type="checkbox"/> Service Provider |
| <input type="checkbox"/> Other Relative | <input type="checkbox"/> Other |

Name:

Postal Address:

.....

Postcode: Tel:

If parent, child's name, Date of Birth and disability (optional):

.....

Name of organisation (if applicable):

.....

and Service Type

Payment Details

Enclosed is a cheque/money order for \$ _____

Please debit my credit card \$ _____



Card No: _____/_____/_____/_____

Cardholders Name: _____

Expiry Date: _____

Cardholders Signature: _____



Association for Children with a Disability