

# HELPING YOU AND YOUR FAMILY

Information and support for  
parents of children with a  
disability in New South Wales



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Information and support  
for  
parents of children with a disability  
in  
New South Wales

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www.ACD.NSW.org.au

### Language Interpreters:

If you need a language interpreter contact ACD NSW, please contact the Translating and Interpreting Service (TIS) on 13 14 50.

Tell the operator your preferred language and that you want to speak to the Association for Children with a Disability NSW on 1 300 851 603. TIS is a free service.

### Hearing Impaired People:

Telephone calls between a person with a TTY and ACD NSW need to be made through the National Relay Service (NRS). To make calls via the NRS phone 133 677.

Australian Association for Families of Children with a Disability (AAFCD)

Telephone 1800 222 660  
Fax: 03 9818 2300  
Email: mail@aafcd.org.au  
Web www.aafcd.org.au

## Association for Children with a Disability NSW (ACD NSW)

We provide information and support to parents and families who have a child or young adult with any type of disability or developmental delay across NSW.

Parents run our Association, so we know what it's like to have a child with a disability. We understand issues from a parent and family perspective.

ACD NSW seeks to give strength to the voice of families caring for a child with a disability.

Our activities include:

- A bi-monthly newsletter issued free to members that provides information on what's happening and what you need to know, as well as stories from families that are a great source of strength and inspiration for other families and for professionals who work with families.
- Free information seminars on issues ranging from advocacy and supported accommodation, through to establishing trusts and will writing.
- Advocating for improved services, and raising awareness of the issues and difficulties facing parents, carers and families.
- Telephone support and networking with other parents and families.
- Working with other groups, service providers, the government and other decision-makers on issues affecting families.
- Publication of *Helping You and Your Family*, and *Through the Maze*, a handbook that has been produced by ACD NSW for parents, carers and families.

### Australian Association for Families of Children with a Disability

Australian Association for Families of Children with a Disability (AAFCD) is a national organisation that advocates to government and other decision-makers for improvement to services and support for families of children with a disability.

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## Your feedback

Your feedback on this booklet is welcomed. Please feel free to contact us with feedback at any time.

Telephone:  
1300 851 603

We are particularly interested in finding out

- what you like most about this booklet
- suggestions for improvements for future editions

## ‘Disability’

The word disability means different things to different people.

Some people and organisations try to avoid using the word “disability”, preferring instead phrases such as “special needs”, “additional needs” or “children of different ability”.

In this booklet we use the word disability.

We understand and respect that for some people, disability is a word they would prefer is not used to describe their child.

Disability does not have to be a negative word.

When you have a child with a disability, it is important to understand and acknowledge the difficulties and limitations that it means for your child and family.

It is also important to focus on your child’s strengths and abilities.

We might use different words to describe our situation, but what brings us together is a shared belief in our strengths as parents, as we strive for what is best for our children and families.

## ‘Carer’

It can be difficult to identify a carer because some parents don’t use this word to describe themselves. Parents who have just had their child diagnosed with a developmental delay or disability for example are unlikely at this stage to think of themselves as “carers”.

Nevertheless, we are carers, as well as parents.

Carers are usually family members who provide support to children or adults who have a disability, or any other illness or condition. Carers can be parents, partners, brothers, sisters, friends or children of any age.

In *Helping You and Your Family* we refer to both parents and carers, as carers deserve recognition for the significant role they play in supporting children and adults with a disability. Carers may provide all the care every day, or provide support for a few hours each week.

## Introduction

This booklet has been written by parents of children with a disability for parents of children with a disability, across all areas of NSW.

We are a unique and diverse group of people with a wide variety of experiences and knowledge.

As parents of children with a disability, we share a common bond. We also face many challenges.

We have written this booklet to help you and your family by:

- sharing information about experiences, ideas and suggestions of other parents;
- providing links for further information about services and support.

When we draw on our strengths as parents, share information and support each other, we not only help our own family but others as well.



**“ I have been amazed to discover how many families of children with a disability there are in my own local community, and throughout NSW. ”**

## Diagnosis

Parent and family experiences around the identification of a child's disability greatly vary.

Some conditions are evident at birth or soon after. Others can occur as a result of an accident or sudden onset of illness. For many families, the identification of a child's disability is a gradual process that occurs over many months or years.

For some children, a clear diagnosis of a specific condition or disability (or multiple disabilities) is possible. For others, the diagnosis of a specific condition may not be possible, or may be reliant on further tests and observations in future years.

The process of identification or diagnosis of disability often places significant stress on families.

It can be very emotionally challenging for parents and other family members. Experiences at this time can include: fear, confusion, isolation, loss, grief, hope, shame, anger, blame, despair, exhaustion, relief, love, protectiveness and more!

### “You're not alone”

The range and depth of emotions we experience are often difficult for us, and those close to us, to understand.

Please remember that you are not alone. Other parents and support services are available to help you and your family during the difficult times of raising and caring for a child with a disability.

*“ That consultation when my son was officially given his diagnosis is one that I will never forget. It seemed to be happening in slow motion, like in a movie. I walked out of the room in a daze. When I got to the car, I burst into tears and cried all the way home. ”*



## Roller coaster of emotions

The emotional ups and downs we experience are often difficult for others to understand.

For many of us, our emotions are never far from the surface, especially when we find ourselves in a situation where our child's differences are obvious.

We all cope and respond differently to the challenges we face. There is no right or wrong way. Every child and very family situation is different.

Being able to discuss problems, experiences and feelings with other people who understand can be beneficial.

Some parents find it helpful to write down their thoughts, feelings and emotions. Others like to get involved in practical activities.

## Seek support if you need

The different ways in which people respond can sometimes cause tension between partners, other family members and friends.

Seeking advice and support at this time can benefit all family members. Sometimes it can be as simple as understanding the different ways that women and men tend to approach the difficult issues.

## Celebrate achievements

It is also important to celebrate and appreciate our children's achievements and successes, no matter how big or small.

With all the strong emotions that come with having a child with a disability, it can sometimes be difficult to maintain a positive outlook.

Despite all the challenges we face, our families can still experience plenty of joy and happiness.



*“ From day one it's been a real rollercoaster of emotions – a big rollercoaster. We try and enjoy the ups when they come and ride through the downs as best we can. ”*

*“ I know family and friends wanted to help us, they just didn't understand the sort of help we needed from them. Looking back now, I wish I could have found a simple way of letting them know.”*

## Family and friends

Disability can challenge us, our family, and our friends.

For some of us, family and friends may have been a great source of support from day one, asking what they can do and offering practical help and understanding.

For others, friends may have drifted away and family members have become more distant.

Within our extended network of family and friends, we soon discover who is able to support us during emotional and stressful times.

Keep in mind that it may not be easy for family and friends to understand our situation. They could be so overwhelmed that they just don't know what to say or do. Some family members and friends may even be initially in a state of denial.

Families come from many diverse cultural backgrounds, with a variety of needs. This may influence how they react to having a child with a disability.

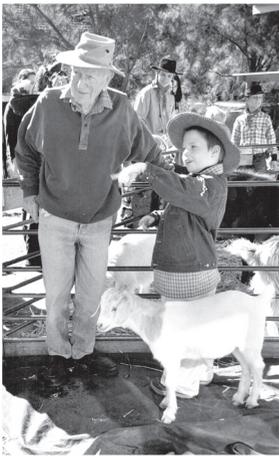
## Little things can make a big difference

Sometimes people don't realise that there are little things they can do to help, or they may not have enough knowledge of our situation to understand the support we need. Don't be afraid to let those close to you know how you are feeling. Wherever possible, be specific about the things they could do to help.

This may not always be easy to do. Admitting to yourself and others that you need help is sometimes very difficult.

Amongst all the challenges of disability, open communication with family and friends can sometimes lead to closer relationships.

Having a child with a disability can open the door to new friendships and support networks.



## Siblings

Brothers and sisters of a child with a disability face some unusual challenges.

It is important to recognise sibling experiences and viewpoints, which are different to ours as parents.

A sibling's level of understanding of their brother or sister's disability will change as they grow and develop through childhood.

For example, it is not uncommon for a young child to think that they may have done something to cause their sibling's disability. As adults, it is sometimes difficult for us to imagine how a child would make such a connection.

### Finding the right words

Finding the right words to explain a child's disability to another child can be very difficult. Depending on the sibling's age and stage of development, take into consideration their capacity to understand the issues and their ability to express themselves.

As children grow older, they tend to ask more questions and seek more detailed explanations. Some of the questions don't have easy answers!

Having open communication contributes significantly to a sibling's well being. Our children need to know that we are available to answer questions about any aspect of their brother's or sister's disability.

It's important to be aware of the additional caring responsibilities that may fall upon siblings. There are services that offer specific support to brothers and sisters who are in this role.

Sometimes siblings may also need an opportunity to talk to someone outside the family environment.



*“ Life is different when you have a brother or sister with a disability because the experiences you go through in life, good or bad, are very different to other kids. ”*

## Looking after yourself

We are all different, and for each of us, looking after ourselves can mean many different things.

With all the other demands and responsibilities in our lives, we often tend to put our needs and ourselves at the bottom of the list.

Amongst all the hospital visits, specialist appointments, therapy sessions and everything else we are involved with for our children, we also need to make sure that we don't forget to consider ourselves and our own needs.

It could mean finding time to be with our friends or our partner, spending some quality time with our other children, enjoying a hobby, or doing some voluntary or paid work.

It is important to continue with parts of the life we had before having a child with a disability and to maintain some 'non-disability' connections with others.

*“ I realise that finding time for me can be work in itself, but the benefits are enormous.”*



## Your support network

As parents and carers, we all need support.

In addition to professionals and services, it is also important to think about other types of support that might benefit you and your family – your personal and family support network.

Three ingredients for a strong support network are:

- Information
  - knowing how to access, current and relevant information
- Support
  - meeting other parents and sharing knowledge and experience
- Advocacy
  - belonging to groups that advocate for improvements for better services.

When you combine all three you have a powerful information and support network.

There is a range of general disability associations and syndrome specific associations and support groups, along with various local, regional and state/territory information and advocacy groups that offer support to families.

These groups assist families and carers in building support networks.

*“ My main support network is the parents at my child’s school. Some of these car-park conversations with other parents have been more helpful than anything else. ”*



## The role of services

It is often difficult to take the first step and ask for help.

By creating and funding services to assist our families, society has acknowledged that we do have special needs and we deserve access to appropriate support.

We should never feel guilty about requesting assistance from support services. They are there to help you and your family.

In addition to services designed specifically for children with a disability and their families (sometimes referred to as “specialist disability services”), there is also a range of other services available to all families. These are sometimes called “mainstream” or “universal” services”.

## Find out what works for you

Every family is different, with different needs and priorities. The services available to families should be flexible and capable of being adapted to suit the family’s circumstances.

Some services are provided in the home and some services are offered out of the home.

It is reasonable to expect that service providers will work in partnership with each family to identify and deliver the support that is most important.

“*It took us a long time to get used to the idea that it’s okay to ask for help from services.*”

## Be creative

Sometimes you have to be creative when working with service providers to put together a package of different services to achieve the range of support your family needs.

There are even services that are designed to help parents and carers request support services from service providers.

Some services have long waiting lists and this can be very frustrating. It is always better to know about the service (and be able to explore options for getting access to it in the future), than not know it is available.



## Working together with professionals

Good professionals listen to parents, respect our point of view and see themselves as working in partnership with us.

There are many wonderful, committed professionals and service providers to assist us and our children. But we can never assume that professionals will always know best about everything.

It's important to trust our instincts as parents, and that we have our say about what we believe is the right thing for our child and family.

As parents, it is important to encourage good working partnerships with professionals. We need to respect their role and listen to their point of view. We also need to be prepared to ask questions to understand, or agree or disagree.

## Trust your instincts

Sometimes situations can arise which require us to challenge a professional. This is not always easy to do, and some professionals do not react kindly to being challenged. But if you don't feel comfortable with the advice given by a professional, you should trust your instincts and seek further information or a second opinion.

In many areas of our lives as parents, we soon discover that we need to become very good at standing up for ourselves (and our child). We make sure our voice is heard and understood by the people who are making decisions that affect our family.



***“ I used to be shy, but I've learnt that for my children and myself to get what we need, I can't afford to be shy. If I don't speak up and question things, we never seem to get anywhere. ”***

## The information maze

The service system is complex and confusing.

Some services are totally funded and administered by the NSW Government. Others are totally funded by the Australian Government. Some involve a combination of New South Wales and Australian Government funding.

Most local governments (councils or shires) also provide an important contribution to the service system for families of children with a disability. In many areas, services are delivered by community organisations with or without the support of government funding.

It can sometimes take a considerable amount of time to find our way “through the maze” to the information we need. Thankfully, this task is made easier with the help of various services which specialise in providing information.

## Putting it all together

As parents, we need to develop skills (and find the time and energy) to piece together the information most relevant to our particular family circumstances.

Seeking information from a range of sources, rather than relying on one professional or service provider generally achieves the best results. It does take some time to explore all the options, but it's worth the effort.

*“At first I was overwhelmed with all the information. Gradually, I learnt how to sift through it all and work out what was relevant and what wasn't.”*



## First steps through the maze

There are some key places to start when working your way through the maze of services and support available for your family.

### Early childhood health care services and centres

The nurse in your local early childhood centre can provide links to a range of additional services and support, including playgroups and parent groups, therapy and hospital services.

### Centrelink

The majority of families of children with a disability are eligible for a fortnightly payment from Centrelink called Carer Allowance (Child). Eligibility includes families on all income levels. Applications can be made before a diagnosis is confirmed.

### Child care

Early Childhood Intervention Services (ECIS) are provided to children from birth to school entry, and include a range of government and non-government services. Early childhood intervention services are offered by a range of personnel including special education teachers, physiotherapists, occupational therapists, speech pathologists, psychologists, social workers, doctors, nurses, orthoptists, audiologists and others.

Through the Inclusion Support Program there is support available for children with a disability to access all forms of childcare, including vacation care. ECIS work with childcare centres, preschools, family day care and occasional care centres to support the inclusion of children with disabilities or developmental delays. ECIS and mainstream children's services work together to meet the child and family needs.

### Kindergarten

There is funding available to support children requiring additional assistance to be included in childhood settings, and settings which prepare them for regular schools or preschools.

*“We were amazed to discover that our family was eligible for the Centrelink Carer Allowance (Child) payment. It's not much, but that little bit extra it gives us a fortnight really helps.”*



## Local government

All local governments (councils/shires) can provide access to a range of support services for families of children with a disability.

## Commonwealth Carelink Centres

These centres provide contact details to services in your local region.

## Equipment Aids and Contenance Aids

See under “Key telephone contacts”, page 15.

## “Through the Maze” – A guide book

Every child is unique and every family is different.

To empower families and carers ACD NSW has produced a publication called *Through the Maze*, which provides a comprehensive and current guide for parents, families and carers to disability services in metropolitan and regional NSW.

*Through the Maze* covers the stages from diagnosis of a disability or developmental delay in childhood through to adulthood.

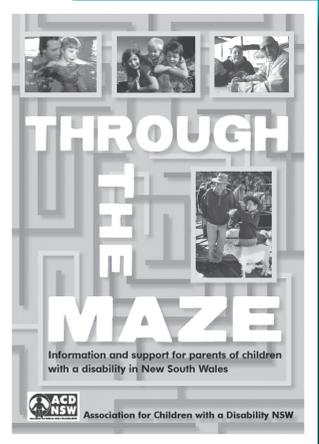
It is a guide to services available and a key to understanding the way the disability support system works.

Parents of children with a disability who are experienced using the services outlined in the publication wrote *Through the Maze*.

A series of *Through the Maze* information sheets have been published on the ACD NSW website: [www.ACDNSW.org.au](http://www.ACDNSW.org.au).

Printed copies of the publication can be requested from ACD NSW:

Telephone 1300 851 603, or write to ACD NSW at:  
PO Box 141  
Northmead NSW 2152  
Email: [acdnew@optusnet.au](mailto:acdnew@optusnet.au)



**“ I needed help with some of the more practical things, and I found what I needed and more in *Through the Maze*. ”**

## Parent advocacy

Being an effective advocate is one way to work towards getting the best for your child and family.

It isn't easy being an advocate for your child. Sometimes emotions take over.

Advocacy can also be exhausting!

But with persistence and the right support, parent advocacy is crucial to getting what you and your family needs.

To be an effective advocate you need to:

- be clear about what you want
- find out who is responsible or accountable for the decision and action you seek
- listen to other people's points of view
- think about the sort of arguments others may use and how you might respond
- be prepared with a positive strategy if you do strike conflict
- be open-minded; others might suggest solutions that you may not have thought of, or different ways of doing things that may be just as effective
- make a written record of conversations and meetings, including names and date
- ask a friend or professional to help you with advocacy if you need some support.



*“ I made sure I was organised with a clear plan of what we needed. They seemed to listen more after that. ”*

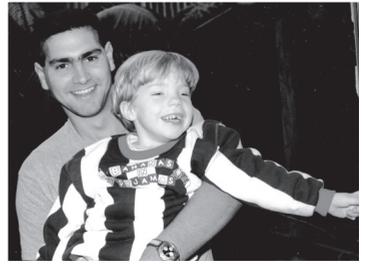
## Key telephone contacts

### Aids and equipment

Independent Living Centre NSW – 1300 885 886

Technical Aid for the Disabled NSW  
(02) 9808 2022, 1300 663 243

PADP (Program of Appliances for Disabled People)  
Contact your local public hospital for details of your nearest PADP Lodgement Offices.



### Child care

Child Care Access Hotline (accredited centres & vacancies)  
1800 670 305

Inclusion Support Program – 1800 157 818

### Child health care centres, (Department of Health)

For centre locations throughout NSW, consult your local White Pages under the heading 'Early Childhood Health Centre' or 'Community Health Centre'.

### Department of Ageing, Disability & Home Care (DADHC)

Phone: (02) 8270 2000, TTY: (02) 9270 2167

### Department of Education and Training (DET)

131 536 – Callers are connected to the nearest regional office.

### Early Childhood Intervention Services (ECIS)

Early Childhood Intervention Infoline – 1300 656 865

### National Carer Counselling Program (NCCP)

Carers NSW – 1800 242 636

### Playgroups

Playgroup Association of NSW – (02) 9604 5513, 1800 171 882

### Respite

Commonwealth Carer Respite Centre – 1800 059 059

### Commonwealth Carelink Centres

1800 052 222

## Useful websites

Association for Children with a Disability NSW –  
[www.ACDNSW.org.au](http://www.ACDNSW.org.au)

Association of Independent Schools of NSW –  
[www.aisnsw.edu.au](http://www.aisnsw.edu.au)

Carers NSW – [www.carersnsw.asn.au](http://www.carersnsw.asn.au)

Catholic Education Commission (NSW) –  
[www.cecnsw.catholic.edu.au](http://www.cecnsw.catholic.edu.au)

Centrelink – [www.centrelink.gov.au](http://www.centrelink.gov.au)

Community Child Care NSW – [www.ccccnsw.org.au](http://www.ccccnsw.org.au)

Council for Intellectual Disability NSW – [www.nswcid.org.au](http://www.nswcid.org.au)

Department of Education and Training  
[www.det.nsw.edu.au](http://www.det.nsw.edu.au)

Department of Aging, Disability and Homecare –  
[www.dadhc.nsw.gov.au](http://www.dadhc.nsw.gov.au)

Department of Health – [www.health.nsw.gov.au](http://www.health.nsw.gov.au)

Department of Families, Community Services and Indigenous  
Affairs (FaCSIA) (Commonwealth) – [www.facsia.gov.au](http://www.facsia.gov.au)

Early Childhood Intervention Australia (NSW) –  
[www.ecia-nsw.org.au](http://www.ecia-nsw.org.au) [www.ecinfoonline.org.au](http://www.ecinfoonline.org.au)

Family Assistance Office – [www.familyassist.gov.au](http://www.familyassist.gov.au)

Association of Genetic Support of Australasia (AGSA) –  
[www.agsa-geneticsupport.org.au](http://www.agsa-geneticsupport.org.au)

E.bility (Information and Resources) – [www.e-bility.com](http://www.e-bility.com)

Infoxchange Australia – [www.infoxchange.net.au](http://www.infoxchange.net.au)

Playgroup Association of NSW – [www.playgroupnsw.com.au](http://www.playgroupnsw.com.au)

Raising Children Network – [www.raisingchildren.net.au](http://www.raisingchildren.net.au)

New Children's Hospital Westmead – [www.chw.edu.au](http://www.chw.edu.au)

Sydney Children's Hospital Randwick – [www.sch.edu.au](http://www.sch.edu.au)

SIBS (for siblings) – [www.sibs.org.au](http://www.sibs.org.au)

## Information Networking

Benefits of membership of ACD NSW include a bi-monthly newsletter, which includes provides information about support services and government policy changes, and includes family stories. Our website is regularly updated.

If you are not already a member of our Association, you might like to join.

Membership to ACD NSW is free for families, carers. And service providers, other organisations and concerned persons are also encouraged to join ACD NSW. An annual fee of \$30.00 applies. Only families have voting rights in the Association.

We encourage families to become members of our Association in addition to membership of local/regional groups and disability specific support groups. Our aim is to work together on issues that reach across all disabilities.

### Donations

We welcome donations from families, community organisations private sector businesses and corporations, concerned persons, and bequests.

ACD NSW is a benevolent institution with charity and deductible gift recipient endorsements. All donations are tax deductible.

ABN: 25091565485

### (AAFCF) Australian Association for Children with a Disability

Australian Association for Children with a Disability (AAFCF) is a national organization that advocates on behalf of families of children with a disability. Membership is free to families of children with a disability and self-help groups.

If you would like to join, contact AAFCF:

Telephone  
1800 2220 660

Email  
[mail@aafcd.org.au](mailto:mail@aafcd.org.au)

Web  
[www.aafcd.org.au](http://www.aafcd.org.au)