THROUGH THE MAZE

2008 2ND EDITION

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

Association for Children with a Disability NSW

Phone 1300 851 603
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www.acdnsw.org.au
An information and support handbook for parents and carers of children and young people with a disability
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:

• maintaining a website with a range of information, including an electronic copy of Through the Maze available for download from www.acdnsw.org.au
• publishing a quarterly newsletter, 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
• organising information seminars on issues ranging from advocacy and supported accommodation to establishing trusts and will writing
• advocating for improved services, and raising awareness of the issues and difficulties facing parents, carers and families
• providing 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.

Helping You and Your Family is a booklet that has been produced by ACD NSW for parents, carers and families. The publication is a short guide designed for families with a child who is newly diagnosed with a disability or developmental delay. It focuses on the emotional and relationship concerns that will impact on the family. An overview of the service system is also provided.

If you would like to join the Association for Children with a Disability NSW, contact 1300 851 603. Membership is free to families of children with a disability. Service providers and other organisations are welcomed; a membership of $30 applies to those organisations.

Association for Children with a Disability NSW
Web: www.acdnsw.org.au
Email: acdnsw@optusnet.com.au

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.
Foreword

The Association for Children with a Disability NSW (ACD NSW) is a non-profit organisation and a registered charity. ACD NSW exists so that families can help other families in situations similar to their own.

We identified some time ago that a real need existed to help parents through the unknown territory that confronted them when it became apparent that their child may have a disability. As our own children grew, we also realised that the territory changes with every new stage in a child’s life – transition from pre-school to school, transition from primary school to high school, the different system that operates when a child turns 16, and so on.

We have sought to condense information in this guidebook that relates to these life stages, whilst also addressing issues that cut across all stages of life. These include advocating for your child and understanding the financial and legal options available to support your child. It has been an ambitious task but I am extremely proud of the finished product.

I wish to thank the former President of ACD NSW, Sue Griffin, who prepared the initial draft and sought feedback from a range of parent groups, thus creating the impetus for this guidebook.

I also wish particularly to thank Fiona Andrews-Dorrian, a long-serving Committee member of ACD NSW, for the enormous effort that she has contributed to making this guidebook a reality. Fiona has worked tirelessly to research, compile and source the information for this guidebook, to check and double-check the phone contacts and website addresses and to ensure it has been presented in an easily digestible fashion!

An electronic copy of the guidebook is available on our website where we endeavour to keep the information as up-to-date as possible. To help us with this process, we would be happy to receive any feedback you may have on changes that we could make to the content to assist other families in navigating the disability service system.

Everyone involved in this process has learned something new. We hope that this information will help you to understand the maze of services available to you and your child.

Katrina Clark
President
ACD NSW
Acknowledgements

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In 2007 the content of *Through the Maze* was updated and reviewed by a Reference Group comprised of parents of children with a disability and representatives from government and non-government disability sector organisations and associations. *Through the Maze* is available free of charge to our members thanks to a funding grant ACD NSW received from the NSW Department of Ageing, Disability and Home Care in 2007, with further assistance provided in 2008 for a reprint.

The development of this information was undertaken by the Association for Children with a Disability NSW (ACD NSW) with assistance from the NSW Department of Ageing, Disability and Home Care. However, the information presented and the views expressed do not necessarily reflect the views or information held by the Department, the NSW Government or the Minister for Ageing and Disability Services.

Every care has been taken in the preparation of this publication and the information it contains. While it is believed to be accurate, no reliance should be placed by any person on the information presented and it is suggested that professional advice be sought where necessary.

This version of *Through the Maze* is based on a corresponding publication produced in 2006 by the Victorian Association for Children with a Disability.

*Through the Maze* is provided as an information guide. ACD NSW has made every effort to ensure the content is correct at the time of publication. This resource will be updated from time to time on the Association’s website.

This handbook may be reproduced and distributed in full or in part as long as appropriate acknowledgement is given.

Your feedback on this handbook is welcomed. Phone 1300 851 603 with your comments. We are particularly interested in finding out:

- what you like most about this handbook
- suggestions for improvements on future editions.

Note: *Through the Maze* is not linked to the *Travelling through the Education Maze* event run by The Institute of Family Advocacy and Leadership Development Inc (Family Advocacy).

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*Through the Maze*: Information and support for parents of children and young people with a disability in NSW.
Contents

Making it happen 1
  Making it happen .............................................................. 1
  How to find out about the things you don’t know! ..................... 37

Medical and health issues 2
  Medical issues ........................................................................ 2
  Dental and sleep issues .......................................................... 3
  Therapy ................................................................................. 17
  Mental health ................................................................. 101

Counselling and support 5
  Services specific to people with a disability and their carers .......... 5
  Support services for Aboriginal families ................................... 58
  Support services for families from non-English speaking backgrounds... 60
  General counselling services .................................................... 7

Early childhood services 9
  Early childhood intervention services ....................................... 9
  Child care and preschool support ............................................. 12
  Child care options – types of child care ................................... 13

School options 19
  Choosing a school .................................................................... 19
  Transition to secondary school ................................................. 24

Helping your child through adolescence 26
  Teenages, puberty and sexuality ............................................. 26
  Turning 16 Years .................................................................. 27

Moving from school to adulthood 29
  Further education and training ................................................ 29
  Employment .......................................................................... 30
  Rights at work – wages and employment conditions .................. 34

Accommodation and daily living 39
  Supported accommodation .................................................... 39
  Supported living .................................................................... 40
  Aids and equipment ............................................................ 42
  Communication aids ............................................................ 44
  Aids for personal care ............................................................ 47
  Home modifications ............................................................. 53
  Home help .......................................................................... 89
Transport
- Mobility ................................................................. 49
- Assistance animals and mobility ................................ 52
- Private transport ......................................................... 54
- Public transport and community transport .................. 56

Legal and financial
- Support payments and entitlements ....................... 62
- Taxation ...................................................................... 68
- Legal and financial planning ..................................... 72
- Guardianship and financial managers ...................... 75

Respite and relaxation
- Respite services ........................................................ 84
- Sport and leisure ........................................................ 77
- Holidays and travel .................................................... 81

Advocacy
- Advocacy organisations ............................................. 92
- Complaints .................................................................... 95
- Support information for specific groups .................... 98
- Large support organisations ..................................... 99

Glossary of acronyms .................................................. 102

Index ........................................................................ 104
Making it happen

As parents of children and young people with a disability we share many emotions and experiences, yet each of our children is an individual with specific needs. We all need the information and support that is relevant to the age and development of our child. However, one of the frustrations we face is finding that information and support.

The disability service system in NSW can be complicated and difficult to negotiate, with no single guide to what is available. It is when we don’t know where to start or what there is available that we are often unable to get the help we need.

We have written this handbook to help you ‘through the maze’, to identify and access the services most helpful for your child and family, irrespective of the nature of your child’s disability. As a parent you will need to work with a variety of service providers to coordinate support for your child. While the handbook won’t answer every question you may have, it will at least point you in the right direction.

When you first start looking for help, it can be a bit daunting. Many service providers use ‘disability jargon’ that can sound like a whole new language. (Acronyms, on pages 102 –103 of this handbook, explain some of the jargon). Don’t be afraid to ask as many questions as you need. The services outlined in this handbook have been created to support families who have a child or young person with a disability.

One thing to know is that each service has its own eligibility criteria and it is possible that the demand for the service might mean that there is a waiting list. In negotiating access to a service, never underestimate your situation. Service providers make decisions based on the information you give them. Tell it like it is!

This handbook is a general information guide designed to support parents and carers of children with a disability. If you are interested in finding out about an association related to a specific genetic syndrome in NSW, contact the Association of Genetic Support Australasia (AGSA). AGSA facilitates support for those affected directly or indirectly by genetic conditions. The Association has a contact register representing over 750 genetic and details of associated support groups. Phone (02) 9211 1462 or email info@agsa-geneticsupport.org.au.

If you have any further questions or are having trouble finding something, don’t hesitate to call us at the:

Association for Children with a Disability NSW
Phone: 1300 851 603
Email: acdnsw@optusnet.com.au
Web: www.acdnsw.org.au
Medical and health issues

When consulting doctors, it is important to establish good communication. You should be able to talk freely about your child's condition and needs, about your needs and feelings, and about the situation for the family as a whole. The doctor or specialist should be able to explain things in detail and in words that you can understand.

Make a list of the things that are concerning you about your child, and write down questions. Take the list with you when you see the doctor. Take your partner, a friend or relative with you to the appointment to provide support and help in understanding the discussion. They can also share the responsibility of weighing the advice and making any decisions. A helpful website which contains links to many other consumer health websites is at: library.scgh.health.wa.gov.au/consumer.aspx.

Local general practitioners

As part of the ongoing medical care of your child, it is important to have a good local doctor or general practitioner (GP) with whom you feel comfortable, and who listens to you and your family. General practitioners make referrals when necessary to specialists. If you have a concern about your child's development, you have the right to be referred to a specialist.

Paediatricians

Many families who have a child with a disability or developmental delay find it helpful to regularly see a paediatrician. Paediatricians are doctors who specialise in caring for children. They understand about the nature, severity, long-term outlook and causes of disabilities in children, and they manage any complications that may arise. Access to paediatricians is via a referral from your local GP.

Hospitals

Hospitals throughout NSW such as the Children's Hospital at Westmead and the Sydney Children's Hospital at Randwick offer many different services and clinics. To access the services or clinics at a hospital, you usually need to be a patient at the hospital or be referred by a general practitioner or paediatrician who has an association with that hospital. Many children are outpatients at these hospitals, receiving services without being admitted to the hospital.

Searching for a diagnosis

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.

It is often wise to go for further genetic assessments as your child grows, as technology and expertise are constantly advancing. Keep a diary or log of your child's development and behavioural characteristics as over time it becomes difficult to remember and report things accurately to future general practitioners.

Hospital Ward Grandparents Scheme (AWCH)

The Australian Association for the Wellbeing of Children in Healthcare (AWCH) is a voluntary organisation with the aim of ensuring the needs of hospitalised children and their parents are met. A “grandparent” is a volunteer who spends time with a child in hospital when the parents cannot be there for whatever reason. Hospitals that are now part of the scheme include: the Children's...
Hospital (Westmead), Sydney Children's Hospital (Randwick) and Allowah Children's Hospital (Dundas); Royal North Shore Hospital (St Leonards), Royal Prince Alfred (Camperdown); Liverpool, St. George, and Gosford Hospitals, John Hunter Hospital (Newcastle) and Port Macquarie Base Hospital. To contact the AWCH National Office phone (02) 9817 2439 or 1800 244 396 (parent line) or visit www.awch.org.au.

Continence Aids Assistance Scheme (CAAS), and Program of Appliances for Disabled People (PADP)

You may be eligible for financial assistance purchasing continence aids and other essential equipment for your child: For information on CAAS, PADP and subsidised continence aids and equipment programs, see page 47 of this handbook.

Dentistry

The oral problems for a child with a disability can vary greatly. For example, it can be difficult just cleaning your child's teeth, and teaching your child to care for his or her own teeth can take many years of perseverance. However, the results of poor dental care make such perseverance worthwhile.

There are a limited number of specialist paediatric dentists practising in NSW who have further qualifications in treating children with a disability. Contact your local hospital to see if they can help you locate a paediatric dentist in your area (for locations of NSW Health regional offices, see page 10 of this handbook). It can also be helpful to speak to other parents of children with a disability to find out which dentist they visit with their son or daughter.

It can be a challenging experience getting your child examined by a dentist, but the sooner regular visits begin, the easier it will become for both you and your child. It might take you several visits before your child will even sit in the dentist's examination chair!

Remember that, just as your child will get used to getting a hair cut, with perseverance they will also start to take visits to the dentist in their stride. Remember, too, that if your child has difficulty in communicating it will be hard for you to know if there is pain caused by a toothache.

Diet can play a role in dental disease. Limiting the frequency and overall amount of sugar and simple carbohydrates consumed by your child can help to reduce the risk of dental decay.

Sleep disorders

Some children with a disability suffer from erratic sleep patterns. Sometimes this is a behavioural problem that may be improved with good pre-bedtime practices. However, the problem can also be due to the medications the child is on or to the body's failure to release the sleep-inducing hormone, melatonin, at the appropriate time. If your child suffers (and therefore the family suffers) from this problem, help is available.

First focus on the pre-bedtime routine. The pre-bedtime routine should aim to accentuate the three physical cues for sleep: darkness, a drop in body temperature and elevation of melatonin level. During that period, you should:

- use non-physical cues for sleep such as hot plain milk (not chocolate) and relaxation techniques such as breathing, meditation and quiet music
- avoid caffeine (e.g. cola drinks) and high doses of sugars (e.g. sweets and chocolate)
- avoid activities that stimulate the brain (e.g. TV, computer games, loud music)
- enhance a drop in body temperature by giving your child a warm bath or shower within half an hour of bedtime
• keep the bedroom cool and not overdress your child or apply too many bed covers
• avoid non-sleep-related activities in bed (e.g., eating, watching TV, checking the time).

Your child should go to bed and rise at much the same time each day to help the body to establish a good sleeping pattern. Also, exposure to sunlight for 10 to 15 minutes early in the day will help boost the natural melatonin production later in the evening.

If you see no improvement after about 6 weeks, you may need to consult your GP, paediatrician or a specialist in sleep disorders. Sleep clinics are also available in some public and private hospitals (e.g. The Children's Hospital (Westmead) and Sydney Adventist Hospital). A study is undertaken to determine the reasons why your child's sleep is disturbed. Urge your GP or paediatrician to conduct a sleep study if your child is still unsettled.

Discuss with your child's doctor appropriate medications to help with your child's sleeping problems. Depending on the nature of your child's sleep disorder, the doctor may prescribe melatonin. This can be purchased under prescription from a compounding chemist. (See Yellow Pages Directory under Pharmacies.)

Tresillian Family Care Centres will provide advice to parents with a child 0–5 years and offers residential units to parents of children up to 2 to 3 years. Phone 1800 637 357 or (02) 9787 0855 or visit www.tresillian.net.

Karitane helps parents with children up to 4 years. Phone (02) 9794 2300 or visit www.karitane.com.au.
Counselling and support

The Network of Carer Associations

In each State and Territory there is a Carers Association working to bring the needs, views and concerns of carers to the attention of the community as a whole including government, policy makers, health professionals and service providers. Each Carers Association operates independently and offers a range of services and support such as:

- information and referral services
- carer support services such as counselling, carer support groups and friendship groups
- policy advice and advocacy about issues affecting carers
- carers newsletters
- community development
- education and development – workshops and information sessions for carers and service providers
- research and policy.

Each State and Territory has a Carers Association which operates a National Carer Counselling Program for carers (funded by the Commonwealth Government) to provide several options regarding counselling for people caring for a person with a disability.

In particular the program aims to:

- provide short term counselling through professionally qualified counsellors
- target the provision of counselling services to the specific needs of carers
- facilitate the establishment of group counselling services for carers
- ensure that the counselling service is well integrated with all other forms of education and support services offered to carers.

Counselling is available for issues such as:

- stress management or crisis counselling
- coping skills and strategies (for example, in coping with a major deterioration in the well-being of the person in care)
- bereavement and loss for former carers on the death of the person they supported
- transition issues relating to the person being supported moving to a residential care facility, assisted accommodation or to another primary carer in the community
- practical problem-solving techniques.

The focus of services is on the particular needs of the individual carer in relation to the caring role. Assistance may be provided on a one-off basis or over several counselling sessions. Services can be provided in a location to suit the carer, such as in the home or at the counselling service. For carers in rural and remote areas, counselling may be telephone services or face-to-face counselling through a local service provider.

Free information packages on a range of topics are mailed on request. Phone 1800 242 636 or visit www.carersaustralia.com.au for links to a Carers Association in your State or Territory.
Carer Line – Carers NSW

Carers NSW is part of the Network of Carer Associations, and provides information, support and referrals to carers regarding services, financial assistance, carer support groups and other avenues of support. They produce a range of fact sheets with information about support for carers, many of which have been translated into other languages. Phone 1800 242 636 or visit www.carersnsw.asn.au.

Young Carers (Carers NSW)

This website is specifically for young carers aged 25 years or under, caring for someone in their family. This website is for young people who help care for someone in their family with a long-term illness, disability, mental illness, drug or alcohol problem. Visit www.youngcarersnsw.asn.au.

Family Relationship Service for Carers

In each state, the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) has funded this service to assist parents, carers, and other family members reach agreement on important issues.

Issues commonly addressed include:

• anxieties around planning for the future
• arrangements for future financial management
• concerns about the capacity of parents to maintain a caring role; and
• conflict or disagreement associated with relationship breakdown, cultural or generational differences.

In NSW, contact Interrelate, phone (02) 9840 8777 or 1300 736 966 (also see below).

Gowrie Child Care and Family Infoline

This is a telephone information and referral service for parents and carers of children 0–13 years in NSW. It provides information on child care services, parent support groups, and services for families with a child with a disability and children with health and behaviour problems. Phone (02) 8594 4244 or 1800 803 820.

SIBS (Sisters, Individuals, Brothers)

This group provides support for siblings of children with a disability, based in Victoria, phone 1800 654 013 or visit www.sibs.org.au.

My Time – Peer Support Group

This is a Commonwealth Government initiative and is coordinated nationally by the Parenting Research Centre. Peer support is a type of informal social support. Meeting with others who are in a similar situation to share information ideas and experiences can be helpful. In My Time groups, other parents, as well as the group facilitator, provide support. Phone 1800 889 997 or visit www.mytime.net.au.

Intensive Family Support Options (IFSO)

Intensive Family Support Options (IFSO) is an intensive support service funded by DADHC, for families who have a child or adolescent (0–18 years) with a diagnosed disability. The disability can be physical, intellectual or sensory. The service is for families who are experiencing a high level of stress or a crisis. It is particularly useful for families who are at risk of requiring a placement for their child, or where there are child protection or safety issues. There are also IFSO services
specifically supporting Aboriginal families and families from non-English speaking backgrounds. For information contact your local DADHC Information Referral and Intake team.

**Working Carers Support Gateway**

This is a website designed to help people trying to juggle the responsibilities of paid employment with their caring role. Visit www.workingcarers.org.au.

**SPELD (Specific Learning Difficulties Association)**

This is a non-profit association of parents and professionals who are interested and involved in advancing the education and general well-being of children and adults with learning difficulties. Services include advocacy, information and referral, counselling, organising and sponsoring seminars, regular meetings, professional courses, community education and access to a large library. Phone (02) 9144 7977 or visit www.speldnsw.org.au.

**Families Supporting Families Inc.**

This organisation has produced a free handbook for parents and carers of children and young people with a disability called “Operation Adaption”. To download the handbook visit www.ebility.com.au/fsf/ or phone 0417 431 562.

**AGSA (The Association of Genetic Support Australasia)**

AGSA facilitates support for those affected directly or indirectly by genetic conditions throughout Australasia. The Association has a Contact Register representing over 750 genetic conditions and over 200 chromosomal abnormalities and details of support groups. AGSA provides a forum for the exchange of information between support groups regarding available community services, a rural carers program that includes telegroup counselling, face-to-face counselling and sibling workshops. Phone (02) 9211 1462 or email info@agsa-geneticsupport.org.au.

**Genetic counselling**

If you wish to see a genetic counsellor, your GP should be able to refer you to a specialist in one of the children’s hospitals (Randwick or Westmead).

**Family and relationship counselling**

The following services are not specific to people with disability; they are general counselling services:

**Dalmar Child and Family Care (Wesley Mission)**

Dalmar provides counselling services for families experiencing difficulties in areas such as parent and child communication; family crisis; change caused by separation or death; or behaviour difficulties. Phone (02) 9804 7255.

**NSW Family Services Inc.**

This association has information on over 170 independent organisations that operate family support services throughout NSW. It provides personal support, counselling and education for families at risk. The aim is to prevent family breakdown. Phone (02) 9692 9999.

**Interrelate**

Interrelate provides relationship counselling and courses for groups to cover personal growth, parenting skills, self-esteem, and more. Phone (02) 9840 8777 or 1300 736 966.
Raising Children Network
The Raising Children Network is a parenting website, focusing on children 0–8 years. The website includes a disability section which covers common issues and concerns of parents, with topics that include choosing child care and schools, routines, play, health, siblings, as well as working with professionals and service providers. Visit www.raisingchildren.net.au.

Karitane Care Line
Tresillian and Karitane Family Care Centres both provide assistance to families with young children who have problems with sleeping and feeding. Both provide 24 hour telephone advice. Child and family health nurses are available for consultation on a wide range of issues concerning infants and children up to 5 years. Phone (02) 9794 1852 or 1800 677 961 (regional NSW).

Tresillian
To contact Tresillian, phone (02) 9787 0855 or 1800 637 357 (regional).

Parent Line
Parent Line provides telephone advice and information for parents of children living in New South Wales on relevant issues and services regarding a wide range of parenting situations. These include behaviour and emotional problems, discipline, adolescent issues, family relationships, sole parent issues, school problems, child care and juvenile justice. Monday to Wednesday, 9.30 am to 8.30 pm, Thursday to Saturday, 9.00 am to 4.30 pm. Phone 132 055.

Child Abuse Prevention Service
This is an Australian telephone service providing 24 hour counselling and support. The service also provides regional home or personal visits, group sessions and drop-in centres. Phone (02) 9716 8000 or 1800 688 009.

Kids Helpline
From anywhere in Australia, this help line provides a professional counselling service based on the principles of empowerment and child-centred practice. It is available 24 hours a day for children and young people 5–18 years. Phone 1800 55 1800 or visit www.kidshelp.com.au.

Salvo Care Line
The Salvation Army’s counselling service offers accredited professionals to provide support, guidance and counsel to individuals, couples and families. The service is open to people of all ages. Phone (02) 9331 6000.

Lifeline
Counselling services are available to people in crisis 24 hours a day. Phone 131 114.

Centrelink
Centrelink Social Work Services in Centrelink Customer Service Centres and Call Centres provide social workers who are available to help clients. Phone 136 150.

School counsellors
All government schools have access to school counsellors who provide counselling support to children and their families when needed. Most Catholic and Independent schools also have school counsellors. Ask your school principal for assistance in contacting a school counsellor.
Early childhood intervention services

Birth to school entry

Early Childhood Intervention Services
Throughout NSW there are many services provided to support families of young children with a disability 0–6 years. These are called early childhood intervention services. They provide support for infants and young children who have a developmental delay or a disability. The focus is on promoting the child’s development and their inclusion from birth to school entry, and supporting their families and communities.

Developmental delay describes a young child who is not achieving new skills within the expected age range. Disability is a physical, sensory, intellectual or behavioural impairment that affects the child’s development.

The type and style of early childhood intervention service available varies. Some services are centre-based, where the child and parent attend a program based outside the home. Some services involve home visits, where a professional visits the family at home to provide support, advice or therapy services. Services can also be provided in early childhood centres, preschools, long day care centres or hospitals.

Some associations or organisations provide early childhood intervention services for children with specific disabilities such as autism (Autism Spectrum Australia–Autism Behavioural Intervention – ABI), cerebral palsy (The Spastic Centre of NSW), vision impairment and hearing impairment (Royal Institute for Deaf and Blind Children).

Early intervention services involve a mixture of specialist teaching, therapy and other support programs for your child as well as providing information and support for the parents.

Early Childhood Health Centres
Attending an Early Childhood Health Centre is a good way to check if your child is meeting expected developmental milestones. A clinic nurse will regularly check your child’s progress free of charge.

If you feel your child is not meeting milestones, start asking questions. Find an early childhood health nurse who listens to your concerns. Ask the nurse about the implications, and whether you should be referred to a GP, paediatrician or therapist.

Early Childhood Health Centres are a rich source of information. Collect any relevant brochures and find out as much information as you can about local services from the clinic nurse. The nurse in your local early childhood health centre can provide links to a range of additional services and support, including playgroups and parent groups, therapy and hospital services.

Early Childhood Intervention Services
Information on services available in your area to families of children with a disability 0–6 years is available from the Early Childhood Intervention Infoline on 1300 656 865.

There are different avenues for accessing early intervention services for your child. These include:

- Department of Ageing, Disability and Home Care (DADHC)
- area health services – usually hospital based therapy
- non-government organisations e.g. The Spastic Centre of NSW, Royal Institute for Deaf and Blind Children, Life Start
- playgroups
- early childhood intervention programs offered in some schools. Call the Department of Education and Training in your area and ask to speak with the Disability Programs Consultant.
NSW Department of Ageing, Disability and Home Care (DADHC)

DADHC is a NSW Government department that provides therapy services, needs assessment, behaviour intervention, respite services and information and support services for children with a disability. You can “self refer” to DADHC if you have concerns about your child or you may be referred by a general practitioner or health professional. There may be a waiting list for these services. Contact the DADHC Intake, Referral and Information service (IRI) in your region (see list below).

DADHC Head Office – Phone (02) 9270 2167 or (02) 8270 2000 (TTY)

**Sydney Metropolitan South**
Level 3, 56 Railway Parade, Burwood NSW 2134
Phone (02) 9334 3700
PO Box 1332, Burwood NSW 1805

**Sydney Metropolitan North and Metropolitan West**
Level 6, 93 George St, Parramatta NSW 2150
Phone (02) 8855 4200
PO Box 3004, Parramatta NSW 2124

**Hunter Region**
796 Hunter St, Newcastle NSW 2302
Phone (02) 4908 5200
PO Box 2161, Dangar NSW 2309

**Southern Region**
Level 3, 7–9 Morisset St, Queanbeyan NSW 2620
Phone (02) 6200 7300
PO Box 2245, Queanbeyan NSW 2620

**Northern Region**
Level 5, 29 Molesworth St, Lismore NSW 2480
Phone (02) 6621 1400
PO Box 421, Lismore NSW 2480

**Western Region**
Level 1, 130 Brisbane St, Dubbo NSW 2830
Phone (02) 6841 1500
PO Box 865, Dubbo NSW 2830

NSW Area Health Services

Each Area Health Service administers the hospitals and community health centres within NSW Health. Within each Area Health Service there is a team of therapists. Services vary from area to area.

**METROPOLITAN AREA HEALTH SERVICES**

**Northern Sydney, Central Coast Area Health Service**
Hornsby, Ku-ring-gai, Ryde, Royal North Shore (St Leonards), Macquarie, Mona Vale, Manly Hospitals; Central Coast region covers Gosford, Wyong and Woy Woy.
Phone: (02) 4320 2333 Web: www.nscchealth.nsw.gov.au

**South Eastern Sydney, Illawarra Area Health Service**
Hurstville, St George (Kogarah), Sutherland, Botany, Royal Hospital for Women (Randwick), Prince of Wales (Randwick), Sydney Children’s Hospital (Randwick), StVincent’s (Darlinghurst), Sydney Hospitals (Macquarie St), Waverley, Woollahra; Illawarra region covers Wollongong to Shoalhaven areas.
Phone: (02) 4253 4888 Web: sesiahas.health.nsw.gov.au

**Sydney South West Area Health Service**
Balmain, Bankstown, Canterbury, Concord, Sydney Dental Hospital, Redfern, Marrickville, Burwood, Fairfield, Liverpool, Camden, Royal Prince Alfred, Campbelltown, Camden, Bowral Hospitals. Karitane, Tresillian.
Phone: (02) 9828 5700 Web: www.sswahs.nsw.gov.au

**Sydney West Area Health Service**
From Parramatta, Blacktown, Mt Druitt, Auburn, Westmead, Blue Mountains, Lithgow, Springwood, Nepean, Hawkesbury, Cumberland to Penrith.
Phone: (02) 9845 7000, (02) 4734 2120
Web: www.wsahs.nsw.gov.au

**RURAL AREA HEALTH SERVICES**

**North Coast Area Health Service**
From Maclean, Coffs Harbour, Grafton, Woolgoolga and Dorrigo, Port Macquarie, Casino, Lismore, Byron Bay, to Tweed Heads.
Phone: 1800 108 078 (24 hours), (02) 6620 2100
Web: www.ncahs.nsw.gov.au

**Hunter New England Area Health Service**
From Morrisset, Newcastle, Singleton, Taree, Quirindi, Tamworth, Armidale, Glenn Innes, Tenterfield, Inverell, Moree, to Boggabilla.
Phone: 1800 063 635 HealthLink (24 hours), (02) 4921 4960
Web: www.hnehealth.nsw.gov.au

**Greater Southern Area Health Service**
From Hilston, Young, Goulburn, Queanbeyan, Cooma, Bega, Albury, Deniliquin, Riverina, to Hay.
Phone: (02) 6128 9777 Web: www.gsahs.nsw.gov.au

**Greater Western Area Health Service**
Bathurst, Broken Hill, Dubbo, Mudgee areas.
Phone: (02) 6841 2222 Web: www.gwahs.nsw.gov.au
Information and support for parents of children with a disability in NSW

Tresillian Family Care Centres and Karitane

Tresillian and Karitane Family Care Centres both provide assistance to families with young children who have problems with sleeping and feeding. (See page 8 of this handbook for contact details; also see “Sleep disorders” on page 3).

Children’s Services Central

This is a service that supports professional and inclusive children’s services. It also provides a Helpline that will assist you to find out the information you will need in order to make an informed decision when looking for a placement for your child. Phone 1800 157 818.

Local councils

Most local councils have a disability support worker or a children’s services officer who has information about local services. Also ask if there is a disability services directory or a community health directory that has a disability section. Many of these local directories are linked to the councils’ websites. (See under “Government” in the front section of the White Pages Telephone Directory).

Playgroups

There are different types of playgroups:

- open playgroups run by a facilitator (e.g. therapist) where children with a disability and other children can attend together
- playgroups for children with a disability only, involving parents, staff that can include educators, therapists (occupational therapist, speech pathologist and physiotherapist, as required) and volunteers; and
- regular playgroups where children with a disability may attend with other children but where therapists would probably not be available.

For more information on playgroups, contact:

- The Early Childhood Intervention Co-ordination Program. Phone 1300 656 865.
- The Playgroup Association Special Needs Officer. Phone (02) 9604 5513 or 1800 171 882 (Note: Not all playgroups come under the umbrella of the Playgroup Association).

Gowrie Child Care and Family Infoline

See page 6 of this handbook for information.

Learning Links

Learning Links is located in six regions in NSW. Services include assessments and early intervention for children 0–18 years. Phone (02) 8525 8222 or visit www.learninglinks.org.au.

Toy Libraries

Some local libraries have a toy lending section. There is usually a charge for this but there are special rates for families with a child with a disability. Phone your local council for details.

There are toy libraries specifically for children with special needs. A comprehensive listing of toy libraries can be found in the White Pages Directory under “Toy Libraries”.

Noah’s Ark Mobile Toy Library is a service for children with special needs. Borrowing locations are: Artarmon, Baulkham Hills, Ryde, Thornleigh and Wahroonga. Phone (02) 9411 4429.
Child care and preschool support

Child Care Access Hotline
The Child Care Access Hotline provides up-to-date information and contact details for Commonwealth funded child care services in all regions throughout Australia. For information on programs that support the inclusion of children with a disability or developmental delay, accredited centres and vacancies, phone 1800 670 305.

NSW Department of Education and Training (DET) Intervention Support Program (ISP)
The DET Intervention Support Program (Young Children with Disabilities) provides supplementary support towards the cost of delivery of educational services for children with a disability aged from 0–6 years. The program supports learning and educational development opportunities for children with a disability attending non-government, not-for-profit early childhood settings, to prepare them for entry into regular preschools and schools. ISP is funded through the Commonwealth Government “Programs for Schools”. Phone DET ISP on 1800 064 767 or visit www.det.nsw.edu.au/eas/isp.

NSW Child Care Inclusion Support Agencies (ISA)
Through the Inclusion Support Subsidy (ISS) (see next entry on page 13) there is funding available for children with a disability to access all forms of child care, including child care centres, out of school hours services, preschools, family day care centres, occasional care centres and vacation care centres. This funding is for the service provider, not provided directly to the family. Contact your closest Inclusion Support Agency for information.

Inclusion Support Agencies in NSW:

**METROPOLITAN**
- Inner Sydney – SDN Children’s Services (02) 9557 0183
- Sydney North – SDN Children’s Services (02) 9955 3665
- Sydney Central West – SDN Children’s Services (02) 9897 3635
- Sydney Inner West – KU Children’s Services (02) 9707 1050, (02) 9707 4499
- St George-Sutherland – KU Children’s Services (02) 9522 6322, (02) 9522 6769
- Sydney Central North – KU Children’s Services (02) 9484 2077, (02) 9484 6768
- Gosford-Wyong – KU Children’s Services (02) 4340 5300
- Sydney North West – Penrith City Council (02) 4732 7843
- Sydney South West – KU Children’s Services (02) 4647 9140, (02) 4647 9149

**REGIONAL NSW**
- Illawarra – Illawarra Children’s Services (02) 4283 9935
- NSW South East – Illawarra Children’s Services (02) 4283 9935
- NSW South West – KU Children’s Services 0417 269 744
- NSW Central West – Lady Gowrie Child Centre (02) 6331 4333
- NSW West – Lady Gowrie Child Centre (02) 6881 8210
- NSW North – Armidale and District FDC Ltd (02) 6772 5300
- Richmond-Tweed – Ballina District Community Services Association Inc. (02) 6686 7776
- NSW Mid-North Coast – St Joseph’s Family Services (02) 6584 3865
- Hunter – KU Children’s Services (02) 4967 2411, (02) 4967 2400
Information and support for parents of children with a disability in NSW

Inclusion Support Subsidy (FaHCSIA)

This program has been established to promote access for children with ongoing high support needs in Commonwealth funded children services.

The support involves firstly assessing the competency of the child care service to provide an inclusive environment. Through the writing of a Service Support Plan, goals and strategies to include your child are highlighted. If the child’s needs are of a high demand, funding may be allocated for staff training or employing an additional worker. This worker does not work one-to-one with your child; the worker increases the adult/child staff ratio to support an inclusive service.

Assistance may also include audio, visual and print resources, and specialised resources such as toys and equipment. An application can be lodged for equipment. The program also provides parents and carers with information to help them make a more informed decision about child care. You can either talk to your child care service provider, contact your closest Inclusion Support Agency (see list on page 12 of this handbook) or Children’s Services Central. Phone 1800 157 818.

Child Care Benefit (CCB) and Child Care Tax Rebate

See page 70 of this handbook for options available in obtaining assistance with the cost of care.

Child care options – types of child care

Family day care (Family Day Care Service)

Family day carers care for up to five children in the carer’s own home. This type of child care is supported by the Commonwealth Government and coordinated by sponsoring organisations such as the local council, churches and community groups. Family day care can be full or part-time. Although designed for children under school age, it is also available to primary school aged children before and after school and during school holidays. Almost all schemes have the Child Care Benefit and you can check with the family day care coordinator or by calling Centrelink’s Family Assistance Office. Family day care is also able to access the Inclusion Support Subsidy for children with a disability. Phone 136 150.

In-home care (Family Day Care Service)

In-home care provides quality child care in your own home. It provides a flexible service for families needing full-time, part-time, roster, on-call, evening, weekend and school holiday care.
Association for Children with a Disability in NSW

It is available to families who are unable to access mainstream children’s services or whose child care needs cannot be met by existing services. This includes:

- parents who work shift work or non-standard hours
- families with three or more children under school age
- families where parents or the child have a disability or illness.

Contact your local Family Day Care Service provider for information.

Occasional care centres

Centre based care is provided for children 0–6 years and centres are usually run by local councils or non-profit groups, including shopping centres. Children can be offered a short number of hours on a weekly, fortnightly or monthly basis depending on demand. Some Occasional Care Centres cater for children with a disability. Some Occasional Care Centres now offer Child Care Benefit as well.

Vacation care

Centre based care is combined with outing days for school age children. Generally the service is for children up to the age of 12 years or when they start secondary school. Remember to keep open the communication lines with your service provider so that you can negotiate any concerns you may have regarding your child being too old for vacation care.

Vacation care centres are often run by local councils or local children’s services. Centres generally welcome and accommodate children with a disability and support the children’s participation with the Inclusion Support Subsidy (FaHCSIA). Vacation care centres can be approved for the Child Care Benefit if registered with DoCS. (See page 88 of this handbook for more information on vacation care. See pages 12–13 of this handbook for information on Inclusion Support Agencies and the Inclusion Support Subsidy).

Preschools and long day care centres

Most child care services have a waiting list of often up to 12 months, especially those that are non-profit services. It’s a good idea to put your child’s name down as early as possible. This is particularly so in relation to a child with special needs. Services have limited ability to enrol children with high support needs and may need to plan ahead by applying for additional government funding as referred to above. It is a good idea to regularly phone the service while on the waiting list.

To discuss your child care options, contact your local council and ask for the Children's Services Officer or Disability Support Worker.

Preschools

A preschool program is designed to stimulate a child’s thinking, communicating, investigating, exploring and problem solving skills. Children are encouraged to join in physical activities and to develop health and safety habits. Play based activities teach children how to positively interact with other children and accept their own feelings and those of others.

Preschools generally operate from 9am to 3pm during school terms, though some have extended hours. They provide services to children from 3 to 6 years, with some preschools giving priority to children the year before they begin school. Preschools are usually either:

- community based (non profit)
- operated by the local council
- private (for profit)
- government (NSW Department of Education and Training).
The NSW Department of Community Services (DoCS) licenses non-government preschools in NSW. For information on these preschools and services in your area contact the Child and Family Information Referral Service in Sydney. Phone (02) 8594 4244 or 1800 803 820 (regional NSW).

Private preschools

Varying fees are charged by preschools. Most preschools receive funding from the NSW Government and can apply for additional funding to assist them to enrol children with a disability or other additional needs.

You need to find the service that will welcome your child. Non-profit, community based services generally welcome children with special needs. It is often good to ask “Do you currently have any children with special needs enrolled or have you had some recently?” You also need to ask what support the centre can provide for your child.

Government Preschools

The Department of Education and Training (DET) operates preschools in approximately 100 public schools across NSW. These preschools provide educational programs for children for one year prior to enrolment in Kindergarten. A child may be eligible for enrolment in preschool from the beginning of the school year if they turn 4 years on or before 31 July that year.

Operation is generally during school hours. Attendance patterns vary depending on the needs of families. Some preschools offer a half-day session, with children attending either five morning or five afternoons each week. Others provide full day attendance for two, three or five days each week.

Children with a disability are able to attend DET preschools. Programs for children with a disability are also available in 50 early childhood intervention support classes in government schools across NSW. Decisions about the most appropriate placement for a child with a disability and their specific support needs are made in consultation with parents or carers, the principal, and the relevant early intervention support or preschool teacher.

Long Day Care Centres

Long Day Care Centres are licensed in NSW by DoCS and provide centre-based child care for children aged from 0–6 years. They operate for eight or more hours per day, 48–52 weeks per year. These centres can be:

- operated by local councils
- community based (non-profit)
- based at work places (e.g. hospitals, large companies, universities) with preference given to children of employees or students
- private (for profit).
Provided that the long day care centre is Commonwealth accredited, you will have access to the Inclusion Support Subsidy and Child Care Benefit.

**Network of Community Activities (NCA)**

Network acts as a link up for community activities and for Out of School Hours Care Services run by autonomous community groups and local councils. Network is committed to helping promote quality community based services for school aged children, including children with a disability. Network provides information advocacy, and support for:

- out of school and vacation care centres
- advice on funding/management
- community arts and activities
- child friendly environments
- activities for children with a disability
- community education and skills exchange
- information and resources.

To contact NCA phone (02) 9212 3244 or email network@netoosg.org.au or visit www.netoosh.org.au.

**Inclusion Tip Sheets**

The Association for Children with a Disability in Victoria has developed a range of useful Tip Sheets in easy to read format for parents with a child about to attend “Kindergarten” (known as “Preschool”). For a free copy call 1800 654 013 or download from the ACD Vic website, www.acd.org.au. Remember though that references to funding options are not applicable for NSW.
Therapy

Therapy includes physiotherapy, occupational therapy, speech pathology, orthotics and podiatry, rehabilitation after surgery and other various therapies. Access to therapy services depends on the age of the child, the disability and the availability of services at the time in your area. Often when it comes to therapy you need to investigate the benefit to the child, the options, and research the costs involved.

Private health insurance will cover some of the cost of some therapies but as each insurer is different in the type and amount of cover offered, you need to investigate closely before committing to a service.

It is important to invest time helping your child to develop skills in the early years. In many instances, the longer the instruction and practising of the skill is left, the harder it will be for a child to master. This principle is true right through to developing age-appropriate social skills.

However, it is easy to wear yourself out visiting different specialists and carrying out all the activities required by the therapists at home. Before your child starts school and most of your therapy services happen under “the one roof”, specialist appointments alone can become almost a full time job. So remember the time you spend on your child with a disability needs to be balanced with the time required for the rest of your family, and the time you need to set aside for yourself.

Types of therapists

Therapy services are provided by the following health care workers.

Physiotherapist
- provides advice and practical support for mobility issues, gross motor skill development, equipment needs, positioning and respiratory/fitness.

Occupational therapist
- provides advice and practical support for fine motor skills, and everyday activities such as dressing, eating, playing, and seating.

Speech Pathologist
- provides advice and support for difficulties in relation to eating and drinking, communication, and communication-based behaviour problems.

Additional health care services are provided by:

Psychologist
- provides assessment of general developmental and intellectual abilities and behavioural programming support.

Case workers, community nurses and social workers
- provide case management and referral to other support services, including respite and advocacy services.
Access to therapy services

Therapy for school aged children
For children of school age, therapy services may be provided by therapists from the Department of Ageing, Disability and Home Care (DADHC) or other funded therapy services such as The Spastic Centre of NSW. Parents can access such services by contacting the DADHC Information, Referral and Intake service (IRI) at your local DADHC regional office (see page 10 for locations). Schools can also refer, with parental consent.

Independent and Catholic schools may have access to their own therapists or can use funding that they receive to organise therapy services for children with a disability in their care.

There is likely to be a waiting list for therapy services, so it is important to make a referral as soon as the need is identified.

Hospitals
For families with regular contact with a hospital, therapy might be available as part of the hospital’s assessment and treatment, through mainstream NSW Health therapy services (including dieticians). Often if you are seeing a paediatrician or other specialist who is associated with one of the Children’s Hospitals you will be able to access limited therapy services at that hospital.

Large disability support organisations
Organisations such as The Spastic Centre of NSW and the Royal Institute for Deaf and Blind Children provide ongoing therapy support services for children with a disability. See page 99 of this handbook for a list of these organisations.

Incorporating therapy activities into your child’s daily life
Your child can maintain and improve the skills gained during therapy if the skills are practised regularly during daily life. Your therapist will give you ideas on how to incorporate these skill-building activities into your routine. Families work together with the therapist to achieve these goals.

Private therapy services
A wide-range of options exists for families in a position to pay for therapy. Speak to your paediatrician or GP.

You may have a need to see a specialist practitioner such as an ophthalmologist or orthotist. These types of specialists are generally found in a private practice or at one of the children’s hospitals (Randwick or Westmead).

Assistance is also available for a limited number of therapy sessions through the Commonwealth Medicare (ECP) Health Care Program for allied health services such as dental and audiology. Detailed information about the program is available through the Medicare website or your GP.
School options

There are a number of different options when it comes to choosing a school for your child. It is a good idea to spend some time well in advance planning for your child to start school. Have a look at the options in your area and visit the schools so that you know what it is they are offering and get a feel whether the school is the right one for your child.

One of the things you are looking for is how the school supports children with a disability. You also need to assess the school’s capacity to work with you and your child, and the way the school will use disability funding received to support your child.

Children between the ages of six and fifteen are required by law to be enrolled at a government school or registered non-government school, to attend on a regular basis or to be registered for home schooling.

Every child with a disability has the right to attend the local school. Your child might also be eligible to attend a special school or a support unit within a mainstream school. It may be possible to have an enrolment at a special school that participates in an integration program at a mainstream school or independent school.

There are three sectors providing educational facilities in NSW: Catholic schools (Catholic Education Commission NSW), Government schools (NSW Department of Education and Training), and independent schools (Association of Independent Schools of NSW).

The NSW Board of Studies serves government and non-government schools in the development of school education for Years K–12. The Board sets the core curriculum by developing syllabuses for Kindergarten to Year 12 catering for all students and provides support material for teachers and parents. Useful information can be accessed from the Board’s website: www.boardofstudies.nsw.edu.au.

Disability Standards for Education

The Disability Standards for Education have been formulated under the Disability Discrimination Act 1992. The Standards clarify and make more explicit the obligations of education and training service providers under the Act and the rights of people with a disability in relation to education while, at the same time, balancing the needs of students with the interests of all parties affected. The Standards apply to government and non-government providers in all education sectors, preschool, school, vocational education and training, higher education and adult and community education, as well as to organisations whose purpose it is to accredit curricula and courses.

The Standards seek to ensure that students with a disability can access and participate in education on the same basis as other students. The Standards and accompanying guidance notes can be found at: www.dest.gov.au/research/publications/disability_standards.

Support for students with a disability

The process for providing disability support services or funding to schools is different for government (DET) and non-government (Catholic and independent) schools.

NSW Department of Education and Training (DET)

Students with a disability in government schools may be enrolled in a range of locations that include:

- regular ("mainstream") classes
- support classes in regular schools
- special schools.
The decision on where to enrol a student with a disability and with what level of support will depend on a number of factors. One of these factors is parental choice of educational setting. DET is responsible for ensuring that students in government schools have access to the services and resources necessary to support educational programs. The regional Disability Programs Consultants and the Student Services Coordinator are just some of the specialist staff who can assist you with enquiries about enrolment, transport, specialist support, health care procedures and many other issues. Questions about enrolment issues can be directed to your local regional office. Phone 131 536.

Regular or “mainstream” class

Government policy clearly states that all children with a disability (including those with a severe disability) have the option of receiving a quality education through their local neighbourhood school. This means that your child can attend their local school in a regular class, if you so choose. 

Funding for additional support (e.g. teacher time, teacher’s aide (special), equipment, building modifications) is available though it varies depending on the level of support needed.

In collaboration with your school’s learning support team, you need to consider whether the funding is adequate to support the full inclusion of your child, and how support services and funding are best allocated to support your child’s needs. The school learning support team plays a key role in ensuring that the specific learning needs of students experiencing difficulties in learning, including students with learning difficulties, disabilities and language disorders, are met. The team assists teachers to plan class programs to meet the specific learning needs of all students, including those experiencing difficulties in learning. It incorporates the development, implementation, monitoring and evaluation of learning support plans.

Factors to consider

- **Physical access issues and how your child will move around the school if he or she has a physical disability.** Does the school have ramps? Are there any other modifications that need to be made to the classroom or other rooms your child may be using? DET has funds available specifically for building modifications to help with access issues.

- **Time needed to implement plans for enrolment.** Sometimes those within the school find it difficult to facilitate the changes that are needed. You can speak to the Disability Programs Consultant in your local regional office of DET and organise a meeting of all involved. Sometimes it can all seem too difficult, but it is just a matter of working with professionals to find solutions. (Note: You will need to allow time to put any building modifications into place. It can take up to two years from starting to look at a school to having building modifications completed).

- **Health care support for the child at school.** Extra funding can provide a teacher’s aide (special), the amount of funding you will receive for extra help in the classroom will depend on the specific needs of the student. Some of the issues that need to be considered before deciding how the funding should be used to support your child include: whether your child has high medical support need; whether he or she is continent; and whether your child can independently find his or her school bag and lunch.

- **Equipment in the school.** The school can access funding to purchase special equipment and aids your child may need to fully participate in the class. Once again, you need to discuss with the school what you see as being your child’s needs and how they will use the funding to meet those needs.
Support class within a regular school

Many schools have a support unit as part of the school. Some of these classes cater for children with specific disabilities such as autism, physical disability and mild intellectual disability. They have a smaller number of children in each class and parents can work with the school to bring in therapy support services as needed. Support classes offer the opportunity for children to integrate with the whole school at different times during the school day.

Special school (School for Specific Purpose)

The Department of Education and Training provides a range of special schools including some that focus on particular disabilities e.g. physical disability, emotional disturbances, behavioural difficulties, intellectual disability. To be eligible to attend one of these schools, you need to submit an “access request” form supported by a recent assessment of the child (within the last two years) to your local regional DET office. Special schools have small class sizes, support staff, and access to a range of external support services, such as therapists, as needed. There may be opportunities for some integration into regular local schools if the school participates in an integration program.

Learning Assistance Program

The Learning Assistance Program (DET) supports students experiencing difficulties in learning in regular classes, regardless of the cause. It includes support for students with significant learning difficulties, mild intellectual disabilities and language disorders.

Each DET region has a team of specialist teachers (Learning Assistance Teachers) to provide further support for students with significant learning difficulties and their teachers.

The Regional Learning Assistance Program includes the Palm Avenue/Dalwood Assessment Centre.

The Palm Avenue School/Dalwood Assessment Centre is a joint Department of Education and Training and NSW Health facility. It provides specialist services for primary age students in rural areas of NSW who have significant learning difficulties. Palm Avenue School/Dalwood Assessment Centre provides assessment, a residential program for students with significant literacy difficulties, language problems/behaviour problems, consultation and in-service support for rural schools.

Regional Student Service Teams

Regional student services teams consist of specialist personnel in the areas of special education and student welfare and counselling that support and guide schools to accommodate students with disabilities and learning difficulties. The Disability Program Consultant is a member of this team based in local DET regional offices. Their role is to provide support to parents and schools. They can assist with enquiries about enrolment, transport, specialist support, healthcare procedures and other issues concerning students with additional support needs. Phone 131 536 or visit www.det.nsw.edu.au.

Independent schools

Independent or private schools have a range of options for children with special needs. Each school individually determines the resources that can be provided. Most children with special needs in independent schools are enrolled with their peers in the mainstream. Only a small number of schools have special classes but there are a number of independent special schools across NSW.

Independent schools are a diverse group of schools serving a range of different communities. Many independent schools provide a religious or values based education. Others promote a particular educational philosophy or support specific communities. Independent schools include schools affiliated with larger and smaller Christian denominations; for example, Anglican, Lutheran, Presbyterian schools, non-denominational Christian schools, Islamic schools, Jewish schools,
Montessori schools, Rudolf Steiner schools, some Aboriginal community schools and schools that specialise in meeting the needs of students with a disability. There are also a number of independent special schools run by non-government organisations e.g. Autism Spectrum Australia (Aspect), Royal Institute for Deaf and Blind Children, Warrah, Giant Steps and Kingsdene schools. Independent schools include small and large day schools, boarding schools, co-educational and single-sex schools.

The Association of Independent Schools (AIS) can provide geographical lists of independent schools and advice on Commonwealth Government funding available to support students with special needs in independent schools. Phone (02) 9299 2845 or email admin@aisnsw.edu.au or visit www.aisnsw.edu.au.

Catholic schools
Within the Catholic Education system, resources for children with special needs are directed primarily to support children integrated into regular classes. Support for the implementation of your child’s individual planning is provided by special education teachers and by itinerant specialist teachers, or teacher’s aides (special). All dioceses have Education Officers, guidance officers and/or itinerant support services. There are also a small number of special schools, such as St Lucy’s for children with a wide range of disabilities; St Dominic’s Centre for children with hearing impairment; and St Edmund’s School for children with vision impairment. Contact the Special Education Officer within the Catholic Education Commission.

For further information contact the State Coordinator; Special Learning Needs at the Catholic Education Commission New South Wales, who will be able to provide contacts for each Diocese, Congregational or special schools within New South Wales. Phone (02) 9287 1555 or visit www.cecnsw.catholic.edu.au.

Home schooling
Some parents may choose to educate their child at home, but you need to be accredited. This involves an interview and assessment by Board of Studies personnel. Phone (02) 9367 8111 or visit www.boardofstudies.nsw.edu.au

School Student Special Transport Scheme (DET)
The School Student Special Transport Scheme, provided through DET, assists eligible students with a disability to access educational services in government and non-government schools in NSW, when parents or caregivers are unable to do so. This is not an automatic service. The child’s school will need to complete a request form and you will need to write a letter stating why the transport should be provided. Your school principal will advise you, and you can contact the DET Special Transport Unit. Phone 131 071.

Therapy services for school aged children
See the Therapy section of this handbook on page 17 of this handbook.

School sport/excursions
If your child is in a wheelchair or has mobility problems, talk to the school about ensuring suitable transport arrangements are made for school events. It is possible to book wheelchair accessible buses through local councils or community transport organisations.
Information and support for parents of children with a disability in NSW

Tips for getting the most from your school

• Speak to the School Learning Support Team about someone addressing the staff at the school about your child’s particular disability. It is helpful for all the staff to be aware of your child's specific needs (playground staff and relief teachers, for example).

• Have regular meetings with all the staff involved in your child’s education (teacher and therapists), so that any new issues can be discussed.

• Meet with the school each year to work through the issues for your child. Don’t assume the school will automatically remember to take your child’s specific needs into account.

• If you are having difficulties with physical access at the school, Access Auditors can assess the issues and help come up with solutions. Telephone Spinal Cord Injuries Australia (Access Consultancy) or (02) 9661 8855 (Rehabilitation and Peer Support Team), 1800 819 775 (regional) or email: office@scia.org.au. You will be referred to the appropriate person to assist. A fee may be charged.

• Occupational therapists can also help with access issues.

• Without your input, the school may not be able to think through all the implications of your child’s disability. Work closely with staff and request regular meetings with everyone involved with the care and development of your child.

Advocacy and Schools

Sometimes you may need someone to speak on your behalf or to help you access the support that your child will need to attend a particular school. There are a number of advocacy bodies that you can approach (see the section of this handbook on Advocacy, page 90). In certain circumstances health professionals or support workers may be able to help.

Publications

Useful references include:


• Transition to School for Young Children with Special Learning Needs, Department of Education and Training. This book contains guidelines for families, early childhood services and schools. Available from local regional offices or DET Disability Programs Directorate.

• One of the Kids: Educating children with and without disabilities together, in the same classes at school, Stroeve, W (1998). This booklet covers all three school systems (government, independent and Catholic) and is available through Family Advocacy, phone (02) 9869 0866.
Transition to secondary school

The change from primary school to secondary school for a child with a disability can be a stressful move from a safe, familiar environment with considerable individual attention, to a seemingly impersonal and intimidating environment in secondary school.

For most children the transition creates new issues for parents and carers that need to be considered. There are many challenges: different teachers; moving from class to class; new peer groups; study demands and puberty. The move from primary school to secondary school needs to be well planned, and you will need to be well organised.

Choosing a school

In choosing a school, and when the team is writing your child’s transition plan, some of the questions you need to ask include:

- What can the secondary school offer? How can the primary school support this?
- What will transition plan look like?
- When will it take place?
- Who will be involved?
- How many students are enrolled at the school? How many students have a disability?
- Will my child be placed in every mainstream class or will some time be spent in an alternate setting/learning centre? Can my child be eased into mainstream classes with ongoing support?
- What are the alternatives?
- How will extra funding be used to support my child?
- Who will transport my child?

Take your child on many orientation visits to the new school. Identify key people in the school for them, introduce them on these visits, and make a photo album for your child.

If there are access issues, these should be raised at the transition planning meeting, where you could suggest that the school consider timetable variations so that the needs of your child can be accommodated. It is important to consider details such as the height of tables in science labs and design and technology rooms, the width of doorframes, and using classrooms within close proximity to each other. Does the school have ramps? Remember to allow adequate time for funding for building modifications to be approved, and the actual construction work to be completed.

Communication

The transition plan for your child needs to give consideration to developing systems for communicating with all class teachers. There needs to be a team where all members interact as equals and where participation is encouraged and supported. This fosters a team that functions as a tight unit. Initially, the team is likely to include a staff member from the primary school your child is attending. At a government secondary school, the team supporting your child usually consists of the Disability Programs Consultant, the Itinerant Support Teacher (integration), identified key people responsible for your child at school, parents and any advocate you may take along with you to meetings for support.
It is important for parents to develop a good relationship with at least one hands-on staff member (a teacher or year coordinator) who is prepared to coordinate communication with other teachers and is an advocate for your child. A daily communication diary with this teacher is also beneficial.

Meetings
Don’t feel too shy to call everyone in the team together for a meeting if you feel there are problems or issues affecting your child that need to be immediately addressed.

When team meetings on your child’s progress are convened at the school, take notes and set deadlines for evaluation and review of the programs and supports that have been established. Determine what has worked and what needs to be changed. This is a collaborative process.
Helping your child through adolescence

Teenagers, puberty and sexuality

As children grow they have different needs particularly when going through puberty. It is important to be prepared for changes that occur and to talk to someone about how best to communicate with your child about issues such as sexuality and family planning.

Sexual expression is a natural part of life and as children become teenagers they need to receive appropriate sex education and information about sexual health.

For all children, preparation for adolescence involves teaching them about appropriate responses to the changes that are happening to them, and changes that are going to happen to them in the future. Many children with a disability become anxious and resist change, so it is wise to prepare your child well for puberty, with an emphasis on teaching practical coping skills.

It can be challenging to realise that your child is going to have an adult body, but that he or she may not have an understanding of the implications of these changes. Even if you feel shy or have concerns about the changes happening to your child, talk with your GP or paediatrician, Family Planning NSW, disability specific organisations, and of course, where possible, with your child.

Information and advice

- For advice concerning your child’s sexuality and sexual health contact Family Planning NSW. This organisation provides training programs for people to increase their awareness and knowledge of sexuality issues relating to people with a disability. Phone 1300 658 886 (Health Line) or visit www.fpnsw.org.au.

- Some of the information available will be general, and other information will relate to a specific syndrome or disability. For example, for a family with a child who has Autism Spectrum Disorder, there are two helpful books published. These include: Aspergers Syndrome and Sexuality from Adolescence to Adulthood, (2006) by Isabelle Henault, Jessica Kingsley Publications; and Autism-Asperger’s and sexuality: Puberty and beyond, (2002) by Jerry and Mary Newport, published by Future Horizons. Both books are available from Book in Hand, Autism and Aspergers resources and supplies. Visit www.bookinhand.com.au.

- If your son or daughter has a diagnosed syndrome, it would be beneficial to contact the syndrome association to see if they produce any information for families on adolescence specific to the child’s disability. For example, Talk to Me is a publication produced by Down Syndrome NSW. It is a personal development manual for women and girls with Down Syndrome, and their parents. It covers topics ranging from self-esteem, menstruation, relationships, and protective behaviours to deal with unwanted advances. Visit www.dsansw.org.au.


- The Intake, Information and Referral service (IRI) provided by your local DADHC regional office would also be able to provide you with information about local services that can support you in this matter. (For contact details see page 10 of this handbook).
Turning 16 years

Centrelink

When your child turns 16 years of age the payment system administered by Centrelink changes. Soon after your child’s 15th birthday, you need to talk to Centrelink about the following:

- assessment for the Adult Carer Allowance
- your child’s eligibility for the Disability Support Pension
- eligibility for the Youth Allowance if your child does not qualify for the Disability Support Pension
- eligibility for a Mobility Allowance to help with travel to training or work
- other allowances such as Education Entry Payments, Pensioner Education Supplements or Rent Assistance.

The contact number for Centrelink is 132 717.

Centrelink will require original documents (copies are not acceptable) of one or more of the following:

- Birth certificate
- Current Australian passport
- Medicare card
- Recent bank statements in the name of your child
- Recent bank statements in your name
- Health Care Card in your child’s name
- School reports signed by the principal
- if your child is unable to complete the forms due to his or her disability, you will also need an original letter from your GP explaining this to be the case.

When your child turns 18, you will need to complete a nominee form so that you can continue to represent your child and receive information concerning your child.

In relation to any Centrelink payments made to you or your child, it is important that you notify Centrelink when circumstances change.

Other financial issues

Prior to your child turning 16, also consider:

- opening a bank account for your child – the identification requirements are less stringent for a child less than 16 years
- obtaining a Tax File Number for your child – this will assist Centrelink to make payments directly to your child’s account

NSW Photo Card

The Roads and Traffic Authority (RTA) introduced the Photo Card for people who are unable to obtain a driver’s licence and need proof of identity in order to use everyday services. It has the same security features as a NSW driver’s licence. For information contact your closest NSW Motor Registry.
PADP

PADP provides continence aids only to children from 3–15 years who have a permanent or indefinite disability. The CAAS scheme provides continence aids for a wider age group. Contact your Area Health Service PADP Office for information on changes that may affect your eligibility to PADP when your child turns 16 years and see page 47 for information about the CAAS scheme.

Transition Care Website – NSW Health

As children become adults, they outgrow the expertise of children’s services such as paediatrics and need to find an adult health service. The NSW Health Transition Care Program is aimed at improving the continuity of care for young people with a disability as they move from children’s services to adult health services. Visit www.health.nsw.gov.au/gmct/transition.
Moving from school to adulthood

All young people and their parents are faced with important decisions about the directions their lives will take after they complete their secondary education. In addition to the range of opportunities for further learning that are open to school leavers, such as study at TAFE or a university, there are some options that have been designed particularly for students with a disability. To assist your child and to assist you in giving them informed guidance, there are also a number of government and non-government support services ranging from school careers advisers and counsellors to advisory services related particularly to post school learning and employment.

Post school options – NSW Government

The NSW Department of Ageing, Disability and Home Care (DADHC) funds two post-school programs, the Transition to Work and the Community Participation Programs for school leavers with a disability. A student in Year 12 who wants to be considered for one of these two post-school programs needs to be assessed by education staff who are familiar with the young person's needs.

Assessments are conducted each year for DADHC by teachers from the NSW Department of Education and Training, the NSW Catholic Education Commission and the Association of Independent Schools NSW. The assessment is then forwarded by DADHC to the University of Wollongong for analysis.

Before an assessment for the programs is conducted, written consent from the young person, their parent or their guardian is required. Interpreter services are available.

Transition to Work Program

The Transition to Work Program aims to develop skills over a period of two years that may assist a school leaver gain paid employment, vocational education or training. It is a two-year program with the aim of achieving employment for young people with a disability. The program provides services to young people with a range of support needs, but is primarily targeted to young people with moderate to high needs who are unable to immediately access employment or attend TAFE or university due to their support needs.

This program typically provides three days of support each week to school leavers.

Community Participation Program

The Community Participation Program teaches life skills and community involvement as an alternative to paid employment.

This program has been developed for young people with a disability with moderate to very high support needs who require an alternative to paid employment or further education in the longer term. The service is usually provided in a group environment.

Funding for both of the programs is portable (the young person can move between service providers), and each young person has an individual plan. Funding is allocated according to the individual's assessed needs.

The Community Participation Program provides a minimum of 24 hours of support each week to those with moderate to high support needs and up to 30 hours if the person is assessed with having very high or exceptional support needs. Service providers deliver both of these programs across NSW. Booklets with details of service providers are published annually by DADHC in print and on the DADHC website.

Eligible school leavers will receive information on service providers in their area when they are advised of the outcome of their assessment.
General information and information for school leavers for both of DADHC's Post School Programs is also available on the Post School Options Infoline. Phone 1800 761 030 or visit www.dadhc.nsw.gov.au.

**Post school options – Commonwealth Government**

**Tertiary Education and Training**

**National Disability Coordination Officer Program (DEEWR)**

From 1 January 2008, the Commonwealth Government will fund a National Disability Coordination Officer (NDCO) Program through the Department of Education, Science and Training (DEST). A national network of 31 coordination officers offer information coordination and referral services for people with a disability who are interested in or enrolled in post-school education and training from 15 years.

The program provides information to assist people with a disability to move from school into training and higher education, and then into their chosen career. This includes information and advice on:

- post-school options
- supports and services
- scholarships, apprenticeships and traineeships;
- assistance in understanding the transition to post-school education and training to employment
- links with appropriate people to plan and make a successful entry into further study and employment
- advocacy to improve your region's services.

The program has also made available online a thorough list of current tertiary scholarships available to people with a disability. The service is free, and a free e-newsletter about education and employment is available by subscribing at the website. Phone 133 873 or visit www.adcet.edu.au/rdco; for your regional contact details visit ndco@dest.gov.au.

**TAFE NSW**

It is TAFE NSW policy that vocational education and training is available to everyone.

The best way to see if a course at TAFE may be appropriate is to contact a Teacher/Consultant at the TAFE college in the local area. That way you can find out what options, assistance and support may be made available to you for a chosen course. The TAFE NSW website, although comprehensive, does not list all possible courses and options available to those with or without a disability.

Visit the TAFE NSW website: www.tafensw.edu.au or call the TAFE NSW Information Centre, phone 131 601.

**TAFE NSW Disabilities Services**

This service assists people with disability who meet entry requirements for a TAFE NSW course. Contact the TAFE Disability Programs Unit on (02) 9244 5092 or visit:

University

University Disability Advisers

All universities have a Disability Adviser who can support and advise people with a disability attending the university. Assistance may include enrolment assistance, arrangement of access to buildings, provision of note-taking support, volunteer readers, loans of equipment, letter of support to lecturers, issue of access cards to service areas, issue of parking permits, special exam conditions, mentoring, information directories, consulting advice to teaching and administrative staff. Contact the Disability Adviser at your university.

Employment Programs

People with a disability work successfully in a wide range of jobs and industries. Suitability for a particular job depends on the individual possessing the necessary skills, abilities and personal attributes.

With appropriate supports, people with a disability, even many of those who have high support needs, are able to find meaningful employment. In fact, the majority of Australians with a disability who are employed work at productivity levels equivalent to their co-workers and receive a full award wage.

For those people whose disability makes it difficult to work at full productivity or within the mainstream workforce, there are additional arrangements (such as the Supported Wage System) available to assist with vocational options.

A range of employment services and employment incentive programs has been set up to support people with a disability to gain and maintain employment. Specialist employment agencies will match the right person to the right job. At first it can be very confusing and overwhelming when making decisions as to suitable employment options, vocational services and incentive programs. The type of employment assistance required and which services are most appropriate will largely depend on the level of support needed by the individual.

Centrelink can be a good starting point when deciding on which services and types of assistance may be most appropriate.

Vocational assistance available through Centrelink

Centrelink employs Disability Officers who are specially trained to provide assistance to people with a disability. You can make an appointment with a Disability Officer, phone 131 021.

The types of vocational assistance provided include:

- assessment and advice on appropriate employment assistance
- help with access to training and vocational rehabilitation
- advice on eligibility for Disability Support Pension and other disability and carer related payments e.g. Mobility Allowance
- information about employment services in the local area and referral to appropriate services.

Centrelink also has a range of other vocational services to assist people with a disability, including:

- self-help facilities in most of its offices such as computers, photocopiers, Australian Jobsearch Touch screens
- assistance through Career Counselling Services and Career Information Centres located at most Centrelink offices
- JET (Job, Education and Training) Advisors who assist parents and carers to enter or re-enter the workforce
- language, literacy and numeracy programs to assist people to improve language, literacy and numeracy skills in order to enhance chances of employment.
NSW Department of Education and Training, (DET) Industry Programs

Apprenticeship and Traineeship program

This program provides on-the-job trade training opportunities in State Government departments and statutory authorities to people with assessed disabilities. It provides opportunities for career development and offers a work environment that encourages people with a disability to function at their full potential, and help them achieve job satisfaction. The program encourages departments and authorities to recruit people with a disability. To be connected to the DET Apprenticeship and Traineeship program in your local region phone 132 811. For general information visit www.det.nsw.edu.au/industryprograms.

Open Employment – Commonwealth Department of Education, Employment, Workplace Relations (DEEWR)

The Commonwealth Government funds and provides open employment services, which assist people with a disability to receive employment support and obtain employment in the open labour market. These services include the Disability Employment Network and Vocational Rehabilitation Services. The Commonwealth Government also provides financial incentives for employment in the open labour market, including the wage subsidy scheme, the supported wage system and the workplace modifications scheme. In addition to measures directed at employment in the open labour market, the Commonwealth Government funds a network of Business Services outlets that provide supported employment services. Disability Employment Services are also known as Open Employment Placement Agencies.

These services provide training and employment placement, with ongoing support where needed, in mainstream or “open” employment. Some of these agencies specialise in assisting jobseekers with a particular disability e.g. a physical disability or a psychiatric disability. If this is the case, this will be listed in the service’s eligibility criteria.

These agencies will generally provide some or all of the following support to jobseekers:

- information and education about the employment of people with a disability, such as integration of people with a disability into the workforce; making ‘reasonable adjustments’ and disability discrimination
- advice and assistance with accessing employment incentives schemes and subsidies e.g. workplace modifications and wage subsidies
- assessment of the jobseeker’s skills and aptitudes
- assistance with development of a resume and completing job applications
- advice on likely employment opportunities and suitable job vacancies
- training or retraining to increase job readiness e.g. training in office skills and travel training
- assistance to help the jobseeker market themselves to potential employers and assistance with interview skills
- job placement
- ongoing support and training at the worksite once the person is employed.
Disability Employment Services

Below are some of the organisations that assist people with a disability to gain and maintain employment:


**Disability Employment Services NSW** provides a list of the community-based organisations that assist with the employment of people with a disability in NSW. Visit [www.eeo.nsw.gov.au/disabil/resources/employment_services.htm](http://www.eeo.nsw.gov.au/disabil/resources/employment_services.htm)

**Diversity@work** provides consultancy services, resources and training for organisations engaged in assisting employers in the public and private sector in the areas of human rights, diversity, inclusion and accessibility. Visit [www.diversityatwork.com.au](http://www.diversityatwork.com.au).


**Deaf Society of NSW** is a free service that offers specialised employment assistance to hearing impaired people. Phone 1800 893 855 or visit [www.deafsocietynsw.org.au](http://www.deafsocietynsw.org.au).


Job Network

This is a national network of around 200 private, community and government employment services funded by the Commonwealth Government offering a range of services such as job matching, job search training and individually tailored intensive assistance for disadvantaged people.

If a person is registered as requiring "intensive assistance", this generally means they are eligible to receive a higher level of assistance from the Job Network agency than other jobseekers, in recognition of the impact that a person’s disability may have on them finding and keeping a job. If a person with a disability requires a higher level of support and training than that provided through “Intensive Assistance” providers, higher levels of employment assistance are available through specialist “disability employment services”. Contact the Employment Services Information line on 136 268.

The Disability Employment Assistance Program

This program funds employment assistance to people with a disability through open employment services that assist them to gain and retain paid employment in the open labour market. It also assists supported employment services that support the paid employment of people with a disability for whom competitive employment at or above the relevant award wage is unlikely, and who, because of their disabilities, need substantial ongoing support to retain paid employment. Contact FaHCSIA for all current advice and up-to-date information on Disability Employment Services (see list above), Disability Employment Assistance, and Disability Employment Funding, phone 1300 653 227.

Employment Incentive Programs

FaHCSIA also provide a range of employment incentive schemes and payment of subsidies to employers who are considering employing a person with a disability. Such incentive schemes include:

- the Supported Wage System
• the Workplace Modifications Scheme
• the Wage Subsidy Scheme.

These incentive schemes are designed to encourage the employment of people with a disability and provide greater access to mainstream open employment for workers with a disability.

Information about this assistance is also available by contacting FaHCSIA. Phone 1300 653 227.

Commonwealth Rehabilitation Service (CRS)
The Commonwealth Rehabilitation Service (CRS) is national provider of rehabilitation, injury and disability management services, and provides vocational rehabilitation and ‘return to work’. CRS is a national organisation with relatively standard processes across all offices.

• CRS employs a cross section of professional staff including job placement specialists, marketers, occupational therapists, physiotherapists, speech therapists and social workers.

• CRS does not provide the same level of on-the-job training and support, as do Open Employment Services. If a CRS jobseeker requires extensive work site support, CRS will work in conjunction with an Open Employment Service to ensure this occurs.

CRS also offers a range of free and fee for service consultancies, including workplace assessments, staff training on OHS, as well as rehabilitation and placement services for insurers. Phone 1800 624 824 or visit www.crsaustralia.gov.au.

Supported Employment Business Services
Supported Employment Business Services are services that provide paid employment within a supported environment for people with a disability who are unable to work within mainstream employment due to their disability. These employment services generally provide the highest levels of support and work-site training to workers with a disability, and so may be considered the most appropriate vocational option for those workers who have high support needs and who are not ready to work within the mainstream open workforce. Sometimes workers with a disability employed within Supported Employment Business Services may move into open employment at a later stage, often with assistance from an Open Employment Placement Agency.

The type of work undertaken by these businesses and the wages and conditions of employment can vary greatly from service to service. It is also worth noting that wages and conditions of employment within some of these services differ from industry standards (i.e. they may not be in line with the relevant industry award or agreement) so it is advisable to find out all the details of employment first and to ask questions of any potential employer. Centrelink should also have detailed information on the services in your local area.

Wages and employment conditions for people with a disability

Disability Services Act (DSA) and Disability Services Standards
The Commonwealth Disability Services Act (DSA) and the Disability Services Standards apply to all disability employment services and CRS services. It is important to be aware that service quality is measured against these Standards and any potential service user can ask the service about its compliance with the Standards.
Rights at work, wages and conditions of employment

All workers, regardless of whether they have a disability or not, have industrial rights relating to wages and conditions of employment.

Relevant legislation and regulations that can protect the rights of workers with a disability includes:

- Workplace Relations Act (Commonwealth)
- NSW Industrial Relations Act (including Section 125 relating to Special Wage Permits)
- Disability Discrimination Act (Commonwealth)
- Disability Services Act (Commonwealth)
- Human Rights and Equal Opportunity Act (Commonwealth)
- Occupational Health and Safety Act (NSW)
- Anti Discrimination Act (NSW).

For all workplace matters, visit www.awna.com.au. Advocates and mediators of disputes can contact 1800 333 666 for free advice.

Human Rights and Equal Opportunity Commission (HREOC)

The HREOC website contains practical advice and resources from State and Territory equal opportunity bodies, and information on discrimination issues relating to employment. (For contact details see page 92 of this handbook).

Supported Wage System (SWS)

The SWS was set up to assist people with a disability who cannot obtain a job at full award wage rates because of the effects of a disability on their productive capacity.

The SWS arranges for an independent assessment of the worker's productivity (known as a 'wage assessment'), which is measured against the basic performance levels for other people in equivalent positions in the workplace. The level of wage paid to the employee is dependent on the assessed productivity level of the worker and the particular industry award pertaining to the job.

Employees assessed under the SWS are paid a productivity-based wage; for example, if an employee is assessed as being 70% productive, they will be paid at 70% of the full award rate. A review of the worker's productivity and wage rates is undertaken every 12 months.

Most employees on the SWS who were receiving the Disability Support Pension may continue to receive part-pension payments, depending on the amount of wage payable. The worker will also retain all of the entitlements linked to Disability Support Pension, such as the Health Care Card.

Phone FaHCSIA on 1300 653 227 or Centrelink on 132 717.

Wage Subsidy Scheme

The Wage Subsidy Scheme aims to increase the competitiveness of workers with a disability in gaining employment within the open labour market. Through subsidised employment placements, workers are able to obtain employment and acquire valuable skills and experience. Under the Wage Subsidy Scheme, the government pays a proportion of the wage for the employee (called a 'subsidy') for a maximum period of 12 weeks. This 'wage subsidy period' provides an opportunity for both employer and employee to trial the job placement.

The Wage Subsidy Scheme is only available to jobseekers with a disability who are receiving assistance through a FaHCSIA funded disability employment service or CRS. Phone FaHCSIA 1300 653 227 or Centrelink 132 717.
Workplace Modifications Scheme

If a person with a disability needs modifications to the workplace to be able to perform a job, funding is available from FaHCSIA through the Workplace Modifications Scheme. This funding is subject to meeting eligibility criteria (workplace modifications are generally available to clients of FaHCSIA funded disability employment services and Job Network Intensive Assistance clients). Funding through the Workplace Modifications Scheme can be used for structural alterations, as well as for the purchase or hire of specific equipment or aids. A specialist workplace assessment may also be available to determine what might be necessary in the way of physical modifications or equipment. Phone FaHCSIA on 1300 653 227.

Job Applications and interviews

In terms of disclosure of information about a person’s disability to an employer, the following general points should be noted:

- during a job interview, questions should be framed as for any other job applicant to ascertain the individual’s ability to perform the essential requirements of the job
- questions relating to disability should only be asked in order to identify whether any adjustments will be required to assist the person to do the job
- inappropriate and unnecessary questioning about a person’s disability (i.e. that are not about the person’s ability to perform the essential elements of the job) may be in breach of the Commonwealth Disability Discrimination Act or NSW Anti Discrimination Act.

Useful contacts

NSW Department of Commerce, Office of Industrial Relations (OIR)
GPO Box 847 Darlinghurst NSW 1300
Phone: 131 628
Web: www.industrialrelations.nsw.gov.au

Commonwealth Department of Education, Employment, Workplace Relations (DEEWR)
GPO Box 9879 Sydney NSW 2001
Phone: (02) 9246 0600
Web: www.dewr.gov.au

Centrelink
Phone: 13 27 17 or 13 36 77 (TTY)
Web: www.centrelink.gov.au

Supported Wage Unit
Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA)
Phone: 1300 653 227
Web: www.FaHCSIA.gov.au

Workplace Modification Unit, FaHCSIA
Phone: 1300 653 227

Wage Subsidy Scheme, FaHCSIA
Phone: 1300 653 227

WorkCover Authority
Phone: (02) 4321 5000
Web: www.workcover.nsw.gov.au
Complaints Resolution and Referral Service
Hotline (CRRS)
Locked Bag 2705 Strawberry Hills NSW 2012
1800 880 052 or 1800 301 130 (TTY)

Publication

The Carers’ Guide for Graduates with a Disability is a publication produced by Graduate Careers Australia that was sponsored by the Employees Network. It recognises the high number of people with a disability graduating from university and it provides information on the supply of, and demand for, new graduates in the Australian work force. Visit www.graduatecareers.com.au/content/view/full/3062.
How to find out about the things you don’t know

Don’t assume that because certain information is important to your child that someone will tell you about it. You will often need to research it for yourself!

As parents the more we know the better equipped we are to help our children. Often we don’t access services, or obtain financial help and other support simply because we don’t know what exists. We need to ask lots of questions. Below are some ways to go about doing that.

Medical Appointments

• Ask lots of questions. It may be useful to prepare your questions in writing to remind you of what you need to know.

• Maximise every contact you have with professionals. Find out as much as you can.

Networking

• Go to meetings for the groups with which you are involved. You will often find out what is happening and how it will affect you and your child.

• Find a key person. In most services there are some really knowledgeable people with whom you can consult.
Browse: (remember you are looking for something you don’t already know)

- Browse through parent libraries. Lots of early intervention services have parent libraries. Hospitals also have libraries. Make use of your local council’s library and enlist the help of the librarian to find information that may be available from other libraries or online.

- When searching the Internet, use keywords together such as “disability” and “child”. One of the better search engines is www.google.com.au. Start with a page you know and search all the links. Local community and disability service directories are often available on the internet. Check the website of your local library or view all the links at www.datadiction.com.au/lincs. Be cautious however about the wide variety of advice and opinions that you will receive from websites.

- Electronic newsletters: many of the new e-newsletters are free, e.g. *The Scene* published fortnightly by The Spastic Centre of NSW. Register at: www.thespasticcentre.org.au.

- The Association for Children with a Disability NSW (ACD NSW) produces a quarterly newsletter. Visit www.acdnsw.org.au.

Conferences, expos and seminars

- These events usually have information stands that provide useful materials.

- Talk to other people at the conference or seminar. Ask questions to find out what services they are tapping into to see if they are appropriate sources of information for you.

- You can find out about conferences, expos and seminars from newsletters. Some organisations put out regular newsletters and often have other information services. Ask other parents about useful information they have received from newsletters.

Information packs, brochures

- Actively read brochures and information packs and highlight useful information.

- Read any information you are given. If you are on information overload at the time make sure you come back to it when you are ready.

- Revisit your information. Look over it regularly. It is amazing what you will pick up that you didn’t notice before or that you had forgotten.

Libraries Australia

Anyone with an internet connection can select from more than 40 million items held in over 800 libraries across Australia. Many online items are digitised images and full text government publications can also be accessed online. This database is constantly growing and items for loan are constantly being added. Check the fee charged by your library for inter-library loans.
Supported accommodation

In NSW there is a range of options that support people with a disability to live in their local community. The level and type of support varies from drop-in support every few days in the family home, to group home accommodation which offers 24 hour support, seven days a week. New models are progressively being introduced including alternative family placements, villas and apartments, cluster models and villages.

Supported accommodation in group homes aims to provide people with a disability with support to increase their independence, achieve personal goals and live full and productive lives. Staff are trained, dedicated and committed to improving the lives of the people they support.

There are support packages available such as Attendant Care packages where a person with a physical disability can contract the type of personal care and domestic support they require to live independently in their own home.

Currently there are approximately 600 group homes in NSW, which provide 24 hour a day support for four to six people mainly with an intellectual disability who need a high level of support. Some group homes are for particular groups of individuals with particular needs such as for people with complex health care requirements. Some houses are designed with modifications to make the houses accessible for people who may have a physical disability and most resemble a family home.

New group home locations are selected in areas where there is appropriate housing that can be modified to become a group home, and in areas where there is a need for more housing for people with a disability. Group homes are usually located in residential neighbourhoods that are close to community services like public transport, shopping, work, medical care and other activities.

The first port of call if you are seeking supported accommodation for your relative or friend is to contact your local DADHC Regional office. An assessment will be made of your needs and you will be referred to services that can best meet your needs. This may include placement on a Regional Accommodation Register.

With more demand for supported accommodation than there are places available, Regional Accommodation Placement Committees have been formed to ensure individuals are best matched to available vacancies. Individuals on the Accommodation Register whose profiles match an available vacancy are prioritised according to their circumstances. For instance, priority of access is provided to people who are homeless.

To find out about supported accommodation in your area, see page 10 of this handbook for contact details of your local Regional office of the NSW Department of Ageing, Disability and Home Care (DADHC) or contact the Disability Support Worker in your local council.
Supported living

The principles of supported living

Information in this section is taken from the ‘Supported Living Website’ (www.supportedliving.org.au) and has been reproduced with permission. The principles of supported living are outlined below, along with some practical suggestions for supporting a person with a disability living in their local community.

Supported living is about people with disability:

- living in their own home
- making choices about their lives
- getting support to live the way they want to live.

Housing and support are separate things

Housing and supports are provided by different organisations. A person may live in a home they rent, own or share with others. As the person’s life changes, their housing may change but their support networks may stay the same. The person’s home looks like the homes of other people in the same street and neighbourhood.

How supported living works has been described like this:

“…A person with a disability who requires long-term, publicly funded organised assistance allies with an agency whose role is to arrange or provide whatever assistance is necessary for the person to live in a decent and secure home of the person’s own.”


- The funding a person gets is just for them. It is individual.
- The funding goes with the person and it changes if their needs change.
- An agency helps the person to get the supports they need to live in the home they choose and be part of their neighbourhood and community.
- The agency does "whatever it takes" to get good results for the person.
- Supported living is based on the belief that people with disability have the same rights as everyone else to live in and belong to their community;
- An agency supporting a person coordinates the supports needed for a person to live in a home of their choice and to become contributing members of their neighbourhoods and communities.
- It implies a "whatever it takes" approach to achieving positive outcomes for people.
- Supported living is based on a particular view about the worth, rights, membership and potential contribution of all people.

Ideas for supported living

This is a collection of all kinds of ideas for supported living that were listed at the Supported Living website: www.supportedliving.org.au. These ideas might suit some people and not others. This is not a checklist of things to do.
Information and support for parents of children with a disability in NSW

• Help people understand supported living. Family and friends may never have heard about people being supported in this manner. Some ideas for getting your support network on the same track might include sharing the Supported Living website with them, talking to them about why you think this is the best option for your family member or getting them to come to seminars in which these ideas are discussed. The Supported Living website is regularly updated with details of coming events, and you can also contact advocacy organisations that run seminars. Some are listed at the website.

• Support Circles. A group of family, friends and allies could help you think about the life your family member wants. Some families have found they get great ideas, commitment and moral support from a circle of friends.

• Think about what kind of home the person would want; what kind of roles and connections the person would ideally enjoy in the community. Build a vision of the life the person would want so you are clear about what you’re working towards.

• Think creatively about your community. Think in a detailed way about your family member’s interests and skills. Who do you and others in your support network know in the community? What groups and activities, work or volunteering possibilities are offered in the community? (Think about anything and everything from the local conservation volunteers to the musical society, from the local the church to the soccer club.) What are some potential starting points to forge community connections for the person you’re thinking about? You may find yourself starting very modestly with a few activities and connections may grow with time and effort.

• Where possible involve the family member with a disability in decision making about supported living.

What help can you get?

• Consider, for example, domestic support or personal care through services like Home Care Service of NSW, Attendant Care Program, and the HACC High Need Pool.

• Look at the Department of Housing website. You might apply for public housing. Discuss your interest in community housing with the Department. Visit www.housing.nsw.gov.au.

• Community Housing Association. Contact your local community housing or housing cooperative or look for ideas on the Community Housing NSW website. Visit www.communityhousing.org.au.

• The Benevolent Society of NSW has a Homeshare Program where older people or people with a disability can be ‘matched’ with someone who can provide some support in exchange for free housing. Could this kind of co-residency work for you? If you have your own house to work with, could you organise something like this yourself? Visit www.bensoc.org.au.

• Can you rent a home or flat on the open market? Can you access rental assistance or subsidies to achieve this?

• Do you know of other families in your city who want the same kind of thing? Could you set up some get-togethers to talk about what you want? Maybe sharing your dreams about what you want with other people thinking about similar things will help you. Homes West in Queensland (visit: www.homeswest.org.au) and the Community Living Project in SA (visit: www.clp-sa.org.au) are examples that actually began from groups of parents getting together with a shared vision. You can read about Homes West’s history on its website.
Aids and equipment

Many children and young adults with a disability enhance their daily living and independence by using different types of aids and equipment; for example, wheelchairs, walking frames, communication devices, special eating utensils, artificial foot orthosis (AFOs), oxygen, continence aids, hoists, swings, protective clothing like helmets, and wheelchair accessible vehicles. Also highly recommended for ideas in this area is a booklet produced by Families Supporting Families called *Operation Adaption Guide* available at www.ebility.com.au/fsf.

Program of Appliances for Disabled People (PADP)

Some equipment can be obtained from NSW Health’s Program of Appliances for People with a disability (PADP) scheme. This is a State Government funded program that provides items to assist eligible people with a lifelong or long-term disability participate in community life, by providing appropriate equipment, aids and appliances. PADP will generally pay for an appropriate communication device for your child if prescribed by a speech pathologist, audiologist or occupational therapist.

Once you have been allocated an item, it remains the property of PADP Area Health Service, which is also responsible for maintaining, repairing or replacing it, as a result of “normal wear and tear”. PADP is not responsible for repairing items that are damaged through misuse or neglect. The item needs to be returned to PADP when it needs replacing for any reason or when the person no longer needs the item.

If a person already owns an aid or item, it is possible that PADP will upgrade, repair or maintain the existing item.

If the item you require is not standard PADP stock you will need to source a manufacturer and obtain a quote for PADP. An application for this type of item can take up to 6 months to be processed by PADP.

A full copy of the PADP policy is available online. Visit www.health.nsw.gov.au or phone 1300 366 455.

How to apply

A PADP application form is available from the Area Health Service PADP Team, and must be submitted to Area Health Service Lodgement Centre (See page 10 for regional contact details). The application must be accompanied by a prescription from a medical practitioner and an assessment by a qualified therapist (speech therapist, physiotherapist or occupational therapist). A copy of your latest Tax Office Notice of Assessment or details of Centrelink Pension or Health Care Card should also be submitted.

Application assessment

Generally, a Local PADP Advisory Committee, which includes the PADP Coordinator and therapists, assess the application. Equipment is available based on priority according to need and financial situation. If for some reason there is a dispute, the application is forwarded to the Area Advisory Committee for consideration.

Range of equipment

Items, aids and equipment range from nappies and continence aids, beds, mattress protectors, communication devices, walking frames, wheelchairs, hoists, cushions and wedges, kangaroo pumps and feed bags (not tubes or connectors), commodes, rooms, catheters, shower chairs, shower stools and bath aids, and more. PADP no longer supplies oxygen. Generally, you will need to install the equipment if it requires installation.
Information and support for parents of children with a disability in NSW

Independent Living Centre (ILC)
The ILC will provide information and advice on all types of equipment, aids and home design to help with a wide range of daily activities and appliances. ILC has a showroom with many different products on display from different manufacturers at 1 Fennell St, North Parramatta. You can try before you buy. Drawings and plans can be checked for accessibility and functionality, but this may incur a fee. The ILC has a searchable database of equipment from Australia and overseas, with over 6000 items on its website, including a list of second-hand equipment and publications (like a guide to kitchen and bathroom planning). Phone (02) 9890 0940 or 1300 885 886 (info line) or email help@ilcnsw.asn.au and make an appointment to visit the showroom. Visit www.ilcnsw.asn.au.

Clothing
Listed below are some ideas and several companies that may be able to assist you in your search for suitable clothing for your child.

Bibs and neck scarves
Some children with a disability continue to need clothing protection for feeding and dribbling. It is difficult to find bibs that are appropriate as children grow. Some options to consider are:

• “Love Libby” will make up bibs for your child in any one of a number of fabrics available for viewing on the website www.lovelibby.com. Cost in 2007: $12 plus postage. Phone (02) 9337 3158 or 0413 616 515.
• “Drybib” sell large and small bandannas (neck-scarves) with a thin layer of fleece covered with 100% cotton. The fleece absorbs moisture through the day. Available in a range of colours. Cost at time of publication: $10 for small and $15 for large (includes postage). Phone (02) 9560 9840 or 0425 336 926 or visit www.drybib.com.eu.

Socks
“Socks for Orthotics” is a company that makes socks especially designed for AFOs. The socks won’t slip down on the plastic, and they are available in sizes toddler, child or youth. Cost at time of publication: $16.50 plus postage. Phone (02) 9748 3838 or email advance@grogangroup.com.

Clothing for wheelchair users
• Financed by the Swedish Heritage Fund, and the brainchild of Meagan (Australia) and Susanne (Sweden), the Fashion Freaks has patterns for downloading, simple sewing instructions, tips and other useful information for people confined to wheelchairs who have problems with the fit of clothing (e.g. pants too tight at crotch, skirts too short at the back). Email: fashionfreaks@independentliving.org or visit: www.independentliving.org/fashionfreaks/introeng.html
• Adaptive Clothing Company
This website has information on clothing and health care apparel, covering children through to adults. Visit www.makoa.org/clothing.htm.
Arm restraints

If your Occupational Therapist (OT) advises that your child could benefit from arm restraints, to minimise hand mouthing, for example, consider the Alimed Comfy Goniometer-Elbow Orthosis available from Lenjoy Medical Engineering in the US. It is comfortable and adjustable. A second cover is recommended. Email: lenjoy99@aol.com.

Seating Difficulties

The Malu Positioning Triangle is a soft cloth triangle that prevents a child's hips from slipping forward whilst seated. It is inexpensive, easy to use and suitable for a variety of seats including a baby car seat, a booster seat, a school chair, a wheelchair and a dining chair. Phone (02) 4782 3391 or visit www.malu.com.au.

Further assistance

Sometimes funding the equipment that children need is a daunting task. Some funding possibilities are outlined in the Financial Section of this handbook, page 62. You could also consider:

- asking family and friends to contribute towards a particular item for your child's birthday or Christmas present. Show them a picture of what you would like to buy for your child and explain how the item would assist your child.
- organise an afternoon tea, dessert night, picnic in the park or whatever, where you invite family and friends. Make it clear you are inviting them to come and see some of the things that would be useful for your child, and invite them to contribute towards the cost of a particular item.
- hiring equipment if you only need it for a short time period.

Electronic and computer communication devices

In this era of technology, there are lots of ways to help children communicate and improve their quality of life. PADP will pay for an appropriate communication device for your child if prescribed by a speech pathologist, audiologist or occupational therapist.

In the Sydney metropolitan area, the Northcott Society's Computer Assistive Technology Services section provides advice on computers, communication options, switches and other related equipment. They also have a hire service available so that you can try out equipment to see if it works for your child. Phone (02) 9890 0181.

The Spastic Centre of NSW provides a service called Technability which offers advice and assistance and trialling of communication aids, technology supplies, switches, etc. Phone (02) 9975 8240.
There are numerous companies that supply communication aids, audio and vision technology, computer technology, and mobility aids. Several are listed below to get you started:

Ability Technology  
Ph: (02) 9907 9736  Web: www.abilitytech.com.au  

Honeycom Solutions  
(Assessment, advice, training, products for communication and interaction, audio and vision.)  
Ph: (02) 9499 6512  
Web: www.honeycom.com.au  

Spectronics  
(Touchscreen computer monitors and computer technology)  
Ph: (07) 3808 6833  
Web: www.spectronicsinoz.com  

Novita Children's Services (South Australia)  
Ph: (08) 8243 8243  
Web: www.novita.org.au  

(His website has good links to other websites. Communication devices, computer technology, books)  

Technical Solutions Australia (Victoria)  
Ph: (03) 9737 9000  
Web: www.tecsol.com.au  

(This company designs, manufactures, and sources equipment for people with a disability)

Technical Aid for the Disabled (TAD)

TAD develops specific aids to suit individual needs, particularly where you are finding it difficult to locate the item commercially. Technical Aid to the Disabled is a charitable organisation. It uses the services of volunteers. TAD NSW provides the services listed below.

- **Custom Designed Aids Service**  
  Designs and constructs devices for all age groups that are not commercially available for people with a disability. TAD makes aids and equipment for the home including ramps, rails, and modification to beds and other furniture. They have an information service providing information on aids and technology, as well as a bank of plans of previously manufactured items of equipment. A physiotherapist and an engineer will assess your problem (at no charge) and then refer it to a suitable volunteer who will devise a solution. You pay for the cost of materials. They also make standing frames and corner chairs for young children.

- **Freedom Wheels**  
  A popular service that creates the highly customised bikes that allow people with a disability, mostly children, to ride a bike.

- **The Computer Loan Service**  
  Refurbishes donated computers and loans these out at affordable rates to people with a disability. They also provide assistance with discounted dial-up internet access. Corporate groups and individuals donate all the computers. They are IBM compatible computers only. They can also supply a printer. There is a minimal cost to hire the computer each year. Phone (02) 9808 2022 or 1300 663 243 or visit www.technicalaidnsw.org.au.

- **The Information Service**  
  Provides information on aids and technology to people with a disability, rehabilitation and engineering professionals.

The services are available to people of all ages with a disability and are available to anyone within NSW. No formal referrals are necessary, but it will take some time to be assessed as the service is well utilised. Phone (02) 9808 2022.
Technology Solutions for Computer Access, Seating and Communication (TASC)

This service run by The Spastic Centre of NSW is designed to meet the technology, seating and mobility needs of people with a disability. There is a fully equipped workshop to modify or repair wheelchairs and manufacture customised equipment. It is based at Allambie Heights with regular services offered at The Spastic Centre of NSW sites across Sydney and Newcastle metropolitan areas. Phone (02) 9972 8183.

IDEAS

The IDEAS website provides a high quality accessible portal for people with a disability and their families and carers and other supporters to access and search for information that promotes their independence. Online versions of resources (databases on services, equipment suppliers and travel options, Infobyte fact sheets and newsletters) maintained by IDEAS can be found at the website as well as their blog, events diary and links to other disability services. Visit www.ideas.org.au.

Hearing impairment

For assessment and details about the range of services for children with a hearing impairment, contact Australian Hearing Services on 131 797.

VisionCare NSW

VisionCare NSW is administered by the NSW Government for recipients of full rate Centrelink Pensions, Benefits and Allowance and very low-income earners. Applicants receive a free pair of frames and lenses from a list of approved frames and lens types. Low vision aids may be supplied if appropriately justified. Phone 1800 806 851.

Vision Australia

Vision Australia provides blindness and low vision services. Phone 1300 847 466 or visit www.visionaustralia.org.au.

HumanWare Guide

The free HumanWare Guide of Low Vision, Blindness and Learning Disability Products allows you to interact in virtual demonstrations, and provides product information in their brochures, as well as review of product applications. It’s an ideal resource for anyone looking for assistive products for the home, school or office. Visit www.humanware.com.

Telstra services

Telstra’s Disability Equipment Program provides a range of specialised telephone products for people with a disability. For more information phone Telstra’s Disability Enquiry Hotline 1800 068 424 (voice) or 1800 808 981 (TTY).

National Relay Service

The National Relay Service assists with phone calls for people who are deaf or have a speech or hearing impairment. Phone 133 677 or 1800 555 660 (regional NSW) or 1800 555 630 (TTY).
Aids for personal care

Program of Appliances for Disabled People (PADP)

Refer to page 42 of this handbook for information on PADP aids and equipment.

Continence Aids Assistance Scheme (CAAS)

CAAS is available to people aged five years and over with permanent and severe incontinence due to:

- neurological conditions such as paraplegia, cerebral palsy, multiple sclerosis or spina bifida
- permanent and severe intellectual impairment
- non-neurological conditions such as autism, cancer, prostrate disease or dementia. In such cases, the person needs to hold a Pensioner Concession Card; if the person is under 16 years, their parent/guardian needs to hold a Pensioner Concession Card.

Applicants will need to provide a health report from an appropriate health professional such as a GP or continence nurse advisor about their condition. Eligible CAAS clients receive a subsidy of $479.40 per year for continence products. For an application form call 1300 366 455 or click on the “Healthcare” section of the website www.intouchdirect.com.au to locate a copy of the CAAS form.

Continence Advisory Service (ParaQuad NSW)

The Continence Advisor is a registered nurse with specific qualifications in the management of bowel and bladder conditions. The advisor can provide a service that includes specific management plans and assessment and advice on the aids and appliances available. Paraquad provide continence aids, disability aids, equipment, information, peer support, counselling, occupational therapy, and attendant care, and is registered as a charity. Visit www.paraquad.org.au, email paraquad@paraquad.org.au or phone 1300 886 601.

Continence Foundation of Australia

The Continence Foundation of Australia provides continence information and can give you the contact number of your nearest continence nurse. Phone the National Continence Helpline on 1800 330 066 or visit www.continence.org.au.

Discount nappy companies

The companies below sell most major brands of nappies and nappy wipes in bulk and will deliver in the metropolitan area. For cheaper nappies and nappy wipes you could try the following:

Toilet Paper Man
Mobile: 0412 976 917
Email: sales@toiletpaper.com.au
Web: www.toiletpaper.com.au

Baby Wishes
Phone: (02) 9837 1101
Email: inquiries@baby-wishes.com.au
Web: www.baby-wishes.com.au
Suppliers of continence products include:

- Cello Paper P/L (previously Incohelp – sample continence products available)
  Phone: 1300 654 525

- Sanicare (sample continence products available) Phone: 1800 655 152

- Independence Solutions (continence aids) Phone: 1300 788 855

- Night ‘n’ Day Comfort (rewashable nappies, swim pants, pads, and bed protectors)
  Phone: (02) 9531 2011

- Admed (shower aids, toilet chairs, continence products) Phone: (02) 9618 5000

- Tena Phone: 1800 623 347

- Tyco Lille/Tyco Health Care (continence aids) Phone: (02) 9418 9611

- Kimberly Clark (Depend continence products for adult/young adult continence)
  Phone: 1800 028 334

Showering and toileting

There are numerous chairs, commodes, toilet seat aids and bath aids available. Speak to your child’s occupational therapist (OT) before you buy anything to ensure that the product is suitable for your child.

The OT will help with problems you have with bathing, showering or toileting your child.

Financial assistance is available to modify bathrooms, such as modifying shower recesses for use with shower chairs and installing railings. (For information on home modifications see page 53 of this handbook).

There are a variety of companies in the Yellow Pages Directory supplying aids for bathing. Also try a “Google” search of the web for the item you need.

Managing incontinence

Website for bladder/bowel health – public toilets

NSW Health has a website with information for people affected by incontinence. The National Public Toilet Map – www.toiletmap.gov.au – provides details on the location, opening hours and wheelchair accessibility to more than 14,000 public toilets nationally.

Wheelchair accessible toilets

Contact Spinal Cord Injuries Australia (SCIA) on phone (02) 9661 8855 or 1800 819 775 for a list of accessible public toilets in NSW. These are locked with a Master Locksmith Access Key (MLAK). A MLAK key is used to operate some public toilets, some elevators at railway stations, and wheelchair-friendly playground equipment. The keys are available to people with disability who have mobility difficulties and have a referral from their general practitioner, a disability organisation, a local council or a community health centre. You can purchase the key from your local Master Locksmith for around $10. For your nearest master locksmith, call the Master Locksmith Association on 1800 810 698.

SCIA’s website gives a list of places in NSW that use the key: www.spinalcordinjuries.com.au. Each local council will also have a list of wheelchair accessible toilets in the area.
Mobility

Equipment

Sometimes it is helpful to know the sort of equipment that is available before you need it and where you can get professional advice to help you make the right decisions. This will help you to know in advance both what it is you’re asking for and if there is a better way of doing it. One of the frustrations we can have as parents is that we are always on the back foot, only finding a solution for a problem when we become desperate. Being pro-active and having aids and equipment in place for when they’re needed can make life a lot easier.

Northcott Equipment Solutions (NES)

NES provides services and products for people with a disability and mobility and rehabilitation needs. Services such as those listed below are available to both clients of the Northcott Society and the general public.

- Wheelchair maintenance and repairs for mobility equipment including manual and power drive wheelchairs, hoists and scooters. A mobile repair unit is also available throughout the Sydney and Newcastle metropolitan areas and the Central Coast;
- Seating Solutions provide assessment and advice as well as manufacture and fitting of specialised seating requirements.
- Orthotics and custom-made footwear can be supplied including assessment and manufacture of specialised footwear and shoe inserts, as well as splints, callipers and braces. Shoes can also be modified for orthotics and callipers. For information phone (02) 9890 0195.

Technology Solutions for Computer Access, Seating and Communication (TASC)

For information on TASC, see page 46 of this handbook.

Technical Aid for the Disabled (TAD)

For information on TAD, see page 45 of this handbook.

Independent Living Centre (ILC)

For information, see page 43 of this handbook.

NRMA road service for wheelchairs

The NRMA will do simple emergency wheelchair repairs free of charge. When you ring you must tell them it is for a wheelchair, phone 131 111.

ParaQuad Engineering NSW

ParaQuad Engineering makes wheelchairs to individual specifications, repairs wheelchairs, and carries ramps, hoists and slider transfer boards, phone (02) 8741 5600.

Megalong Positioning Service

This company assesses and manufactures wheelchair inserts, night time positioning and alternative seating and positioning options, phone (02) 4784 3971.

Equipment suppliers include:

- Able Rehabilitation Equipment (goanna potty chairs, over toilet aids) Phone: (02) 97141100
• Dejay Medical and Scientific (wheelchairs, car seats, walking frames, standing frames, specialised footwear). Phone: (02) 9838 8869
• Paediatric Mobility Equipment (wheelchairs, walking frames, toileting equipment, showering aids, car seats). Phone: 1300 131 884
• Relpar (mealt ime aids, modified equipment, bikes, toilet aids). Phone: 1300 555 534

For further suppliers of equipment look under “Disabled Persons Equipment and/or Services” or “Invalid Aids/Equipment” in the Yellow Pages Directory.

Hiring equipment

Sometimes it is possible to hire equipment if it’s needed for a short time. See “Invalid Aids/Equipment” in the Yellow Pages Directory for hire service companies. Some companies only hire equipment for adults but some carry equipment for children as well. Local hospitals may have a hire service. Companies that hire out equipment for children as well as adults include:
• The Hills Community Medical Equipment Pool. Phone (02) 9686 1878
• Meta-lite (wheelchairs and walking frames). Phone (02) 9905 3947
• Disability Hire and Sales. Phone (02) 4573 6788
• Gillespies Hire Sales service. Phone (02) 9411 2180

Some companies that sell wheelchairs and walking frames for children will let you try the chair or frame for a short period of time before you buy, to check that it is suitable for your child. You should consult with your child’s occupational therapist before finalising a purchase.

Equipment loan pools

Many hospitals and disability services have equipment loan pools for children who use their services. For example, PATH at Penrith. Phone (02) 4721 0866.

Second hand equipment

Many equipment items can also be purchased second hand. Whether you are buying or selling, there are numerous places you can try for second hand equipment such as:
• Classified section of the Paraquad website. Visit www.paraquad.org.au.
• The Spastic Centre NSW fortnightly e-newsletter called The Scene. Visit www.thespasticcentre.org.au
• IDEAS e-news. Visit www.ideas.org.au
• ACD NSW newsletter called Noticeboard. To subscribe email acdnsw@optusnet.com.au
• Wheelchair Sports NSW website “buy and sell” section. Visit www.wsnsw.org.au
• The Independent Living Centre website under “ILCNSW Services” then “ILC 2nd hand equipment”. Visit www.ilcnsw.asn.au
• www.gizbytes.com is a wheelchair and disability equipment “garage sale”
• E-Bility has a similar site. Visit www.e-bility.com/buyandsell.php
• Trading Post and eBay both have sections on “Disability equipment”.

50 Through the Maze
Issues to keep in mind about second hand equipment.

- Your child's needs are very individual and their equipment might not suit anyone else.
- If you want to get funding with assistance from PADP or Variety Club, the waiting time can be an issue. The buyer would have to find the right piece of equipment second hand and submit an application for funding for this piece equipment (with supporting documents from a therapist). The equipment is approved and the funding body approves paying the seller (which it may not as funding bodies usually have to pay a company or organisation, not an individual), the buyer may then need to go on a waiting list for the funding.
- It is important to obtain the advice of your child’s therapist before you buy any second hand equipment, to check the suitability of the item.
- Australia is a large country and it may not be possible to inspect the item prior to purchase. Organising transportation and delivery can also be problematic.
- Remember too, that if an item of equipment has been provided through PADP or by the Variety Club, it needs to be returned to that organisation when it's been outgrown by your child. Before you buy or sell an item, check to see if it has a sticker displaying the provider of the item, and whether it needs to be returned as a loan item.
Assistance animals and mobility

Guide Dogs NSW/ACT

Mobility Services
This organisation offers advice and assistance to people with a disability on how to learn safe and manageable ways of getting about. As each person’s needs will be different and programs are tailored to individual needs, Guide Dogs NSW/ACT services are quite broad. Most people who are blind do not need a guide dog but they do gain benefit from other types of training, such as training in crossing roads safely.

Services are free to residents of New South Wales and the ACT and are provided flexibly where instructors visit the home, school or work or wherever required. Contact your closest regional office. Locations are available at www.guidedogs.com.au or phone (02) 9412 9300.

Pets as Therapy
Pets as Therapy is a service provided by Guide Dogs NSW/ACT; they supply trained companion dogs for people with a disability. The service is open to any person with a disability, whether child or an adult. An assessment process takes place to ensure that the recipient has the means, space, and ability (whether it’s the person themselves or their carer) to look after a dog. There is no charge for the dog, but once the person has it, all costs are their responsibility. The dogs provided are either Golden Retrievers or Labradors and are over 18 months of age.

A guide dog can be a wonderful companion for a person with a disability and provide a great deal of stimulation and support.

Guide Dogs NSW/ACT also provides dogs trained to assist people who are blind with mobility in the community. Phone (02) 9412 9300.

Australian Support Dogs
This organisation trains and provides support dogs for people with a disability. Phone 1300 788 721.

Assistance Dogs for Independence Australia
This organisation trains dogs to support people with severe physical disabilities. Dogs are trained to assist the person with daily living activities, such as picking up objects, pulling open doors, etc. Phone (02) 9548 3355 or 1800 688 364.
Home modifications

NSW Home Modification and Maintenance Services (HMMS)

This is a Home and Community Care (HACC) program. The HMMS website contains practical advice for parents and carers, including how to apply for home modification and maintenance services and the location of your nearest office. The service is available to people who are frail aged or their carers, a younger person with a disability and carers of an adult or a child with a disability.

HMMS provides minor alterations to bathrooms, including the supply and installation of grab rails, handrails and ramps, widening doorways, through to major modifications to bathrooms and kitchens. Maintenance work includes simple jobs such as testing smoke detectors, changing the temperature on hot water systems, adjusting the height of tables, chairs and beds or repairing unsafe stairs, as well as gardening and lawn mowing where unsafe and dangerous access to a client’s home can be alleviated with a one-off yard clearance and rubbish removal.

The major emphasis of the work of HMMS is on access, safety and independence.

Costs

For minor alterations, the client is asked to pay for the cost of all materials plus a subsidised hourly rate. Where possible, materials are provided at discounted prices. If you have difficulty paying your account, assistance is available and can be negotiated with the staff. For information phone (02) 6622 8386 or visit www.nswhmms.org.

Independent Living Centre (ILC)

For information see page 43 of this handbook.

Spinal Cord Injuries Australia (SCIA)

SCIA can help with checking house plans and provide advice on design (e.g. bathroom design) to suit wheelchair access. Phone (02) 9661 8855 or 1800 819 775 or visit www.spinalcordinjuries.com.au.

Technical Aid for the Disabled (TAD)

For information on TAD see page 45 of this handbook.

Portable ramps

There are several companies that sell portable ramps. For suppliers, see under ‘Disabled Persons Equipment and/or Services’ or ‘Invalid Aids and/or Equipment’ in the Yellow Pages Directory.

NSW Department of Housing, Home Purchase Advisory Service

The Department of Housing provides free information and advice on purchasing a home, buying land, building a house and obtaining a home loan. Phone 1800 806 653 or visit www.housing.nsw.gov.au.
Private transport

Vehicles and vehicle modifications

The ability to get from point A to B at any given time is something most people take for granted. However, transport is a significant difficulty for many families of children with a disability, particularly if their child uses a wheelchair.

It is wise to undertake considerable research before you purchase a vehicle for conversion, as not all vehicles can be converted for wheelchair accessibility. You will also need to assess the entry method to the vehicle that is best for you and your child.

Conversions to commercial and private vehicles are now available so that the wheelchair travels in either the front, second or third seating rows, depending on the type of vehicle to be converted. Rear or side hoists or ramps can be installed, which include wheelchair restraint systems and track and other fittings. Conversion for wheelchair accessibility generally involves the loss of more than one passenger seat.

There are no concessions or government financial assistance currently available for families who need to modify a vehicle for a child in a wheelchair.

It is also possible to hire wheelchair accessible vehicles. Check the supplier in your local area.

Also highly recommended for ideas in this area is Section 6 of a booklet produced by Families Supporting Families called Operation Adaption Guide available at www.ebility.com.au/fsf.

Lifts and hoists: types of conversions for wheelchair access to a motor vehicle

Side entry lowered floor conversions

The side entry lowered floor wheelchair accessible conversion involves the lowering of the front and middle section of flooring. This is to enable wheelchairs to access the vehicle from the left side door via a ramp and then the wheelchair can be positioned in either the front or middle of the vehicle.

This type of conversion allows the wheelchair occupant to be seated with their family or friends rather than be positioned at the rear of the vehicle. In the case of clients who have high support needs, they are close by and easily observed. This conversion is only suitable to a limited number of vehicles.

Rear entry lowered floor conversions

The rear entry conversion is where the rear section of floor access through the rear door is lowered and an entry ramp allows the wheelchair to access the vehicle from behind. This type of conversion is suitable to a larger variety of vehicles depending on the client’s needs and size requirements.

Side and rear entry hoists

Standard wheelchair hoists can be fitted to either the side or rear door positions of the vehicle. This is a conversion suited to larger vehicles with more head room. The vehicle does not need any structural modifications and the hoist can be fitted out quickly or even refitted to another vehicle. Larger seating capacities or multiple wheelchair occupants are available depending on the vehicle chosen. This type of conversion is best suited to community service organisations with multiple clients.

Under floor hoist (side door position)

The under floor hoist allows access for a wheelchair to the vehicle without taking up valuable interior room. This conversion only suits front wheel drive vehicles such as the Volkwagon transporter.
Information and support for parents of children with a disability in NSW

Suppliers

Private companies who specialise in new and used vehicles and equipment to transport people with disability include:

- Fleetworks Mobility. Phone: 1800 222 377, Web: www.fleetworks.com.au
- Freedom Motors Australia P/L. Phone: (02) 9673 4033, Web: www.freedommotorsaustralia.com.au
- Paraquad Engineering. Phone: 1800 424 096 or (02) 8741 5600, Web: www.infolink.com.au/companies/ParaQuad-Engineering
- Automobility. Phone: 1300 660 773, Web: www.automobility.com.au
- Tysons Pty Ltd. Phone: (02) 9771 3855, Web: www.tysons.com.au

Modified car seats and hoists

“TURNY HD” swivel seat

The TURNY HD car seat swivels through the door opening and lowers to the correct position for comfortable transfer to or from a wheelchair, by pressing a button to operate it. The TURNY HD is suitable for some cars and most 4WDs and mini-vans. In 2007, the estimated cost of this type of conversion was $12,000. Visit: www.bruno.com/bruno-turning-automotive-seating.html. To import and install this seat contact Western Truck Equipment on phone (02) 9672 1973 or visit www.bruno.com/bruno-turning-automotive-seating.html.

Roof Hoist

This type of hoist sits on the roof racks of the vehicle and is used with a sling to transfer a person with a disability from their wheelchair to a vehicle. A manual model (approximately $2,000 in 2007) and more expensive electronic models are available for installation.

GST concessions

For information see page 71 of this handbook.

Mobility Parking Scheme

This scheme provides a parking permit for adults and (the parents of) children over three years who are unable to walk or whose health becomes affected by walking. It is also available to those who are permanently blind. You will need the RTA form certified by a GP.

The permit allows the holder to park for longer in time-restricted parking spots, to park for free in metered parking spots and to use specified wheelchair parking spaces. There are permanent and temporary permits. If you qualify for a permanent pass, it is valid for three years. A fee of $50 (2007) is charged for the permit. The application form is available from an RTA office or the RTA website, www.rta.nsw.gov.au.
Public transport and community transport

Buses for school

See page 22 of this handbook for information.

Community transport (Ministry of Transport)

The purpose of community transport is to meet the needs of specific transport for disadvantaged groups in the community including isolated families, the frail aged, younger people with a disability and their carers. Community transport has given many people with a disability access to recreation, shopping, medical care, social services and social contact, where conventional public transport systems are not generally considered viable or appropriate.

The Ministry of Transport has direct day-to-day administrative responsibility for three community transport programs:

- Home and Community Care Community Transport Sub-program
- NSW Community Transport Program
- Area Assistance Scheme – Community Transport Pick-up Projects.

For more information contact your local council or phone the Ministry of Transport on (02) 8836 3100 or 1800 227 774.

Community transport is not only provided for elderly people. The buses are for anyone with a disability, including children.

Taxi Transport Subsidy Scheme

This scheme is for people with a permanent disability such as:

- permanent inability to walk or total permanent dependence on a wheelchair
- severe permanent ambulatory problems or permanent use of large walking aids
- constant need for the assistance of another person for mobility
- total loss of vision or severe permanent vision impairment
- severe and uncontrollable epilepsy
- intellectual disability causing behavioural problems and/or requiring constant assistance of another person for travel or public transport.

The scheme provides half rate concessions on the prescribed taxi fare for adults and school aged children. There is a maximum subsidy each trip of $30 (2007). Phone 1800 623 724.

Wheelchair Accessible Taxi Service

In the Sydney Metropolitan area, wheelchair accessible taxis may be booked 24 hours a day through a central booking service. Wherever possible, it is advisable to book wheelchair accessible taxis in advance.

To book a wheelchair accessible taxi in Sydney, phone (02) 8332 0200 or 1800 043 187. In country areas, contact your local taxi service. For more information, contact the NSW Taxi Industry Association on (02) 9332 1266.
NSW public transport

CityRail
Selected CityRail stations have facilities such as lifts, ramps, continuous handrails, plasma screens, hearing loops, wheelchair accessible toilets and portable platform-to-train ramps. You often need to phone ahead as some stations only have access on one platform, and not all stations have these facilities. A brochure Accessing CityRail is available for people with a disability.

Phone 131 500 (TTY) 1800 637 500 or www.cityrail.info.

Countrylink
Countrylink provide a range of services and facilities for people with a disability. They are outlined in a brochure Countrylink’s Guide for People with Special Requirements.

Phone 132 232, (TTY) 1800 637 500 or visit www.countrylink.info.

Buses
For information on timetables and bus route information for accessible routes, use the contact details for Cityrail: 131 500.

Driver Rehabilitation and Fleet Safety Services
This service provides training for people with a disability who have difficulty with driving.

Phone (02) 9351 9331 or (02) 9351 9308.

Local government access committees
Most local councils have an Access Committee responsible for assessing issues of public access within the council area. As a ratepayer, you can write a letter to the committee raising awareness of access issues, e.g. parking spaces, public footpaths, height of kerbs and gutters, community transport and signage. Local councils have money allocated to improve these services. If there is no local committee, you can contact the council’s Community Services Team and encourage them to establish one. Most local councils have a Social Plan, and can ask for community input on such issues.
Support services for Aboriginal families

Aboriginal Disability Network (ADN) NSW

The Aboriginal Disability Network brings together Aboriginal and Torres Strait Islander people with a disability to provide opportunities for supporting each other and a place to get information and advocacy help within Aboriginal communities in NSW. ADN NSW is a non-profit, non-government organisation and is currently based with the advocacy organisation, People with Disability (PWD). For information, phone PWD on 1800 611 889 or (02) 9370 3100 or 1800 422 016 (TTY) or email adnnsw@pwd.org.au or visit: www.pwd.org.au/adnnsw.

Aboriginal Services Directory 2007

This is a directory of Aboriginal services in the Northern Sydney area. The directory includes services such as the KU Children’s Services Aboriginal and Torres Strait Islander Playgroup (Northern Sydney Region). For information, phone (02) 9481 4011, or email: ku.nssplaygroups@bigpond.net. For further information on the directory, contact Hornsby Council’s Community Services on (02) 9847 6611. Download at: www.hornsby.nsw.gov.au/uploads/documents/ATSIservicedirectory.pdf.

Carers NSW

For information on the Aboriginal and Torres Strait Islander Care Program, contact the Aboriginal Development Worker, phone (02) 9280 4744 or 1800 242 636 or visit www.carersnsw.asn.au.

Carers NSW Aboriginal Carer Support Groups

Aboriginal Carer Support Groups are set up across NSW. For more information phone 1800 242 636.

At the time of publication, support groups were located at:

- Ballina
- Campbelltown
- Grafton
- Hebersham
- Inverell
- Lismore
- Mt Druitt
- Moree
- Penrith
- Wickham

NSW Department of Ageing, Disability and Home Care (DADHC)

The Aboriginal Policy Unit can be contacted on (02) 8270 2144 and can provide information on the services that DADHC has for Aboriginal communities in NSW.

Home and Community Care Program (HACC)

This community services program, outlined in more detail on page 86, includes services for older Aboriginal people, Aboriginal people with a disability and their carers. These services include home help, Meals on Wheels programs, transport services, respite services and case management and brokerage through the Community Options Program. Both the State and Commonwealth Governments fund the HACC Program, with DADHC administering it in NSW. For information, phone (02) 8270 2243 or 1800 804 135.
Information and support for parents of children with a disability in NSW

**Information kit for Aboriginal families of a child or young person with a disability**

The Department of Ageing, Disability and Home Care (DADHC) is developing an information kit to provide advice to Aboriginal families of a child or young person with a disability. The kit will be available towards mid 2008 from Regional DADHC Offices. It will comprise a DVD and an information booklet entitled *Shoulder to Shoulder*.

**Inclusion Support Agencies (ISA)**

This program provides access and inclusion for children with ongoing high support needs (primarily disabilities) or children of refugee or Aboriginal and Torres Strait Islander background in child care services. For information on your closest ISA, see page 12 of this handbook.
Support services for families from non-English speaking backgrounds

There are support groups available for carers who do not speak English as their first language. It’s best to contact either your state/territory Network of Carer Associations (Carer Line) on 1800 242 636 or the Commonwealth Carelink and Respite Centre on 1800 052 222. Your local council may also be able to provide you with this information.

- Multicultural Resource Centres, Migrant Resource Centres and community organisations for specific groups/languages also provide general support services. For example, the St George MRC has a Multicultural Carers Support Project Worker, on phone (02) 9597 5455. A list of organisations is available from the website of the Community Relations Commission for a Multicultural NSW. Visit www.crc.nsw.gov.au/communities/NSW_Community_Organisations.

- Ethnic Child Care Family and Community Services Co-operative Limited, phone (02) 9569 1288, offers a range of services for families and carers of culturally diverse backgrounds.

- National Ethnic Disability Alliance is based with the Multicultural Disability Advocacy Association, phone 1800 982 182.

- Carers NSW, in partnership with the NSW Department of Ageing, Disability and Home Care (DADHC), recently produced information for carers of culturally and linguistically diverse backgrounds in sixteen languages. Available from Carers NSW and DADHC websites. Visit www.carernsw.asn.au or www.dadhc.nsw.gov.au.

Multicultural Disability Advocacy Association of NSW (MDAA)

MDAA is the peak group for people from a non-English speaking background (NESB) with disability and their families and carers in NSW.

MDAA is the only advocacy service in NSW available specifically for people from a NESB with disability, their families and carers. MDAA aims to promote, protect and secure the rights and interests of these people. MDAA’s objectives are:

- promoting and safeguarding the rights of people from a non-English speaking background with disability and their family/carers
- improving the quality of life for people from a non-English speaking background with disability and their family/carers
- increasing participation by people from a non-English speaking background with disability and their family/carers in community activities.

Phone (02) 9891 6400 or 1800 629 072 or email mdaa@mdaa.org.au or visit www.mdaa.org.au.

For contact details for Regional Individual Advocacy Offices visit www.mdaa.org.au/contact.html.

Language assistance

Interpreting and Translation Services

Interpreters and translators are available to help carers and families who require assistance to communicate in English. However, carers/families will need to ask for an interpreter (or translated material) when they are dealing with an organisation.

Interpreters and translators are provided by several government agencies and private organisations.
For assistance from the Translating and Interpreting Service (TIS), phone 131 450 from anywhere in Australia for the price of a local call. Specific services can be arranged as outlined below.

- The Translating and Interpreting Service (TIS) provided by the Department of Immigration and Citizenship offers language services in over 100 languages. In New South Wales, TIS provides telephone interpreting, 24 hours a day, 7 days a week.
- For on-site interpreting phone 1300 655 082.
- Free interpreting services are provided to medical practitioners for matters that are not legal or insurance related.
- TIS offers a limited free translation service (e.g. of settlement-related documents) to permanent residents or Australian citizen within their first two years in Australia. Holders of 309, 310, 820 or 826 Visas are also entitled to free translation services.

**Community Relations Commission (CRC)** for a Multicultural NSW provides translation and on-site interpreting services in NSW. Phone 1300 651 500 or (02) 8255 6767. The CRC also provides a counter service from 8.00am – 5.00pm Monday to Friday at Level 8, 175 – 183 Castlereagh Street, Sydney.

**Health Care Interpreter Services (HCIS)** are provided throughout NSW. HCIS interpreters and translators are highly trained, understand medical terminology and are NAATI (National Accreditation Authority for Translators and Interpreters) accredited.

Your GP or health care provider will know which Area Health Care Service to contact to obtain a trained health care interpreter.
Financial matters

Centrelink payments

Centrelink is an Australian government agency that provides payments and services to support those in need.

Eligibility for government benefits, payments and allowances can change or may need specialist interpretation. It is advisable to seek advice from the relevant service or agency.

Contact Centrelink 132 717 for information on:

- payments when you are caring for a child (under 16 years)
- payments when you are caring for an adult (over 16 years)
- services and programs for carers
- publications if you are caring for people who are frail aged, ill or have a disability
- accommodation and rental issues
- information and advice for carers
- returning to work when you stop being a carer
- owing money to Centrelink or the Family Assistance Office.

Carer Payment

Payments when you care for a child (under 16 years) include:

- Carer Allowance (child) – a supplementary payment for people who care for a child with a disability or severe medical condition at home
- Carer Payment (child) – an income support payment for people who cannot support themselves through participation in the workforce while caring for a child with a profound disability who has extremely high care needs.

Payments when you care for an adult (16 years or over):

- Carer Allowance (adult) – a supplementary payment for people who care for an adult with a disability, severe medical condition or who is frail aged at home
- Carer Payment (adult) – an income support payment for people who cannot support themselves through participation in the workforce while caring for someone with a disability, severe medical condition or who is frail aged.

The Carer Allowance is free of income or assets tests and is not taxable. This allowance can be paid in addition to the Carer Payment or other Centrelink payments. Check with Centrelink for details regarding payment of the Carer Allowance.

The person you are caring for can be in hospital or respite care for up to 63 days per calendar year without you losing your payment.

Rent Assistance (Centrelink)

Rent Assistance is available to people with a disability under the age of 21 (and over the age of 16) years if they live away from home in accommodation that is provided by a recognised service provider of accommodation for people with disability, and who pay board or rent to that service provider. Rent Assistance is not available to people living at home until they are at least 21 years of age.
Some carers may be able to receive rent assistance as an add-on to their Centrelink payment(s). The person being cared for may also be able to receive rent assistance in addition to receiving a Social Security payment.

**Mobility Allowance**

You may get the Mobility Allowance if you:

- are 16 or over, and
- have a disability that prevents you from using public transport without substantial assistance for the next 12 months or longer (there does not need to be public transport in your area for you to qualify), and
- are undertaking vocational training, voluntary work, paid work, independent living/life skills training or a combination of these for at least 32 hours every four weeks on a continuing basis;
  
or:
- have an agreement to look for work through the Job Network or the Disability Employment Network;
  
or:
- are getting Newstart Allowance, Youth Allowance or Austudy and are required to satisfy the Activity Test, and
- need to travel to and from your home as part of your work, training or job seeking, and
- are an Australian resident, in Australia and not subject to the two year newly arrived residents waiting period.

To qualify for the higher rate of the Mobility Allowance you must also satisfy the following:

- be receiving Disability Support Pension, Newstart Allowance or Youth Allowance as a job seeker, and
- be working more than 15 hours per week at award wages, or
- be looking for such work under an agreement with an employment services provider.

In some instances the higher rate may remain payable if a customer leaves Newstart Allowance, Youth Allowance or Disability Support Pension.

After a person finishes employment or training, provided they continue to satisfy other conditions, the allowance is payable for 12 weeks before it is cancelled.

**Disability Support Pension (DSP)**

You may receive a Disability Support Pension if you have an illness, injury or disability and you are:

- aged 16 or over and under Age Pension age, and
- assessed as not being able to work or to be retrained for work of at least 15 hours per week within two years because of your illness, injury or disability or
- permanently blind, or are
- participating in the Supported Wage System (SWS).

The Disability Support Pension payment is income and assets tested (unless you are permanently blind).
If young people are still at school and aged 16 years or older they can claim the Disability Support Pension. The payment for 16 to 20 year olds is not subject to parental income and assets testing, but is income and assets tested on the applicant themselves with the exception of people who are permanently blind.

People aged 16 to 20 years on the Disability Support Pension receive a higher rate of payment than the Youth Allowance.

**Pensioner Education Supplement**

This supplement is payable to people who receive the DSP and are at school or in full-time training (e.g. TAFE or university or a traineeship).

This payment must be applied for separately to the application for the Disability Support Pension.

**Family Tax Benefit**

The family tax benefit is designed to help with the cost of raising children and has two parts:

**Part A: Family Tax Benefit**

This is payable to a person legally responsible for the day-to-day care, welfare and development of a child. Guardians, including foster parents and grandparents, responsible for the day-to-day care of children or grandchildren may be eligible for Family Assistance and should contact the Family Assistance Office at Centrelink for more information. You may be eligible for the Family Tax Benefit Part A if you:

- have a dependent child under 21 (including a foster child) or
- have a dependent full time student aged 21 to 24, and
- have income under a certain amount, and are living in Australia (that is, Australia is your permanent home), and
- you are an Australian citizen, a New Zealand citizen, the holder of a permanent visa or the holder of certain temporary visas.

Payment of the Family Tax Benefit Part A and Part B is income tested, but not asset tested. The maximum rate of payment changes. Throughout the year the maximum rate of payment a customer can receive for a certain payment is adjusted, normally in line with the Consumer Price Index (CPI). A family supplement is payable for your fourth and each subsequent child.

**Part B: Family Tax Benefit**

If your family is a single income family or you are a sole parent, the Family Tax Benefit Part B gives you an extra payment to help with the cost of raising children. It also gives extra help if your family has a child under the age of five.

The Family Tax Benefit Part B provides extra assistance to families with one main income where the youngest dependent child is under 16 (or up to 18 if they are a full time student and do not receive a Youth Allowance or a similar payment). It also provides extra assistance to families who have a child under the age of five.

You can make an online claim or download and fill in claim forms for the Family Tax Benefit Parts A and B by visiting: www.centrelink.gov.au. Contact Centrelink’s Family Assistance Office on phone 136 150 or 131 202 for the interpreter service.
Child Disability Assistance Payment

The Commonwealth Government is reviewing this payment. As at 2008, this is a $1,000 payment through Centrelink in July each year, for people who are receiving the Carer Allowance for children under the age of 16 years. The payment is intended to assist carers to purchase assistance that best suits the needs of the family.

Medicare dental provisions

It is possible for GPs to refer patients suffering from diseases or syndromes, which may be contributing to their oral condition, to private dentists for Medicare-funded dental treatment. The limit was increased in November 2007 to $2,100 per person per year.

The Commonwealth Government has also introduced a much wider interpretation of non-chronic dental disease. Previously people eligible for treatment only included those with diabetes, immune suppression, mental health problems or valvular heart disease. If you care for someone with a chronic condition that may be contributing to their oral condition, it is worth speaking to your GP or paediatrician to find out more about eligibility for the scheme. Also see below the Enhanced Primary Care Program (EPCP) or visit www.health.gov.au.

Medicare Health Assessments – Enhanced Primary Care Program (EPCP)

Intellectual Disability Health Assessment

People with an intellectual disability are entitled to an annual comprehensive health assessment covered by Medicare, items 718 and 719. Medicare rebates for certain allied health services are available for patients with chronic conditions and complex care needs on referral from their GP.

The new health assessments provide a framework for GPs to assess the physical and psychological health of patients with an intellectual disability, and to identify any medical treatment and preventative health care that the person needs.

The person with a disability, their parent, their advocate or support worker can approach the GP for an assessment. Ask the receptionist when booking for an extended appointment.

A brochure with information on Medicare items written for people with an intellectual disability, their family, friends, and disability service providers is available from the Commonwealth Health and Ageing website: www.health.gov.au.

Carer Adjustment Payment (CAP) (FaHCSIA)

At the time of producing this publication, the Carer Adjustment Payment is a one-off interim discretionary payment scheme that the Commonwealth Government is offering while a wide ranging review of the Carer Payment (Child) is under review. It is a one-off, non-taxable payment available to families in exceptional circumstances. The maximum amount payable to families is $10,000.

The CAP is intended to assist families to adjust following the diagnosis of a child with a severe injury or serious illness, aged between 0 to 6 years. To qualify, the child must require significant levels of care. Applications are considered on a case-by-case basis by an independent panel of experts.

For more information and to register your interest in applying for the CAP, contact Centrelink on 132 717 or visit the FaHCSIA website: www.FaHCSIA.gov.au.
DADHC Family Assistance Fund

The Family Assistance Fund aims to increase family well-being and strengthen the capacity of families to provide ongoing care for a child or young person with a disability in their home. Through the fund, small amounts of discretionary funding are provided directly to families to help them address needs that cannot be met through the standard range of services or other funding. Funding can be used to make practical changes at home, or to provide support or therapy services for individual family members that is otherwise unavailable, and to purchase non-recurrent assistive equipment. The primary purpose of this fund is to support the work that case managers are doing to assist families.

In 2007, the maximum grant was $2,000. For more information families should contact their case manager or DADHC regional/area office (see page 10 for contact details of DADHC regional offices) or visit www.dadhc.nsw.gov.au.

Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS)

- Transport for Health – IPTAAS is a subsidy program assisting eligible patients and their carers when travelling more than 100km each way to attend an appointment with their nearest medical specialist. Private motor vehicle use is reimbursed at a standard subsidy rate.
- If you need to stay overnight in connection with your specialist appointment, financial assistance towards commercial accommodation costs (hotel, motel, hostel) can be considered for eligible patients and their carers.
- A financial contribution fee of $40 or $20 for pension/concession cardholders for each return journey applies (2007).
- Air travel costs are only reimbursed when the medical practitioner or treating specialist has obtained prior approval from the Health Transport Unit.

More information about eligibility criteria, how to claim and application forms can be obtained from www.health.nsw.gov.au/living/transport or by calling your nearest Health Transport Unit located in each Area Health Service. Locations are listed below.

<table>
<thead>
<tr>
<th>Hunter New England Area Health Service</th>
<th>HNEAHS Health Transport Unit</th>
<th>1800 660 361</th>
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<tbody>
<tr>
<td></td>
<td>Locked Bag 9783</td>
<td></td>
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<td></td>
<td>Tamworth NEMSC NSW 2348</td>
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<tr>
<th>Greater Southern Area Health Service</th>
<th>GSAHS Health Transport Unit</th>
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<tr>
<td></td>
<td>Bourke Street Health Service Campus</td>
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<tr>
<td></td>
<td>PO Box 274</td>
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<td></td>
<td>Goulburn NSW 2580</td>
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<th>Greater Western Area Health Service</th>
<th>GWAHS Health Transport Unit</th>
<th>1800 601 324</th>
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<tr>
<td></td>
<td>Dubbo Campus</td>
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<td>Myall St</td>
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<td></td>
<td>Dubbo NSW 2830</td>
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Variety the Children’s Charity

This is a charity dedicated to helping children who are sick, have a disability or are disadvantaged and under the age of 18 years. Variety is often willing to provide financial assistance for the purchase of aids and equipment. Phone (02) 9555 1688.

Service Clubs

Financial help can sometimes be obtained from service clubs, such as Lions and Rotary.

Clubs NSW

By law, clubs are required to reinvest a percentage of the profits made from poker machines to assist the local community. Your local club provides two types of funding grants: Category 1 and Category 2. The categories assist both individuals who are disadvantaged and organisations that exist to assist disadvantaged people in the local community. Contact your local club for information application forms and closing dates for applications.

Smith Family – Learning for Life

The Smith Family provides financial assistance for low-income families to support their child’s education. Phone 1800 633 622.
Taxation

The information in this publication is provided for general information purposes only and accordingly does not constitute tax advice and should not be relied on as tax advice. The information in this publication does not take into account your objectives, financial situation or needs. You must determine whether the information is appropriate in your particular circumstances.

For tax advice that takes account of your objectives, financial situation or needs, you should consider seeking tax advice from a registered tax agent. You could also visit the Tax Office’s website at www.ato.gov.au and read the Tax Office’s annual publication, TaxPack (available from most post offices).

Dependent Rebate

You may be entitled to a tax rebate where you maintain an invalid relative (such as your child, brother or sister, parent or spouse’s parent) who is over 16 years and is receiving a disability support pension or special needs disability pension under the Social Security Act 1991.

The calculation of this rebate involves a number of steps, which are detailed in the Tax Office’s annual publication, TaxPack.

Medical Expenses Rebate

You may be eligible for a Medical Expenses Tax Rebate under section 159(p) of the Income Tax Act in respect of net medical expenses paid during the year. Further to the information below, ask your accountant or contact the Australian Taxation Office on 132 861 or visit www.ato.gov.au.

The rebate is equal to 20% of the amount by which those expenses exceed $1,500 and is claimed in your income tax return.

To calculate “net medical expenses”, you need to:
• determine which medical expenses are eligible for the rebate
• reduce those expenses by amounts received (or receivable) by you that are reimbursements of those expenses.

Eligibility

To be eligible for the Medical Expenses Rebate, the medical expenses must relate to particular categories of people. These include your children under 21 years and invalid relatives.

You should note that a relative might still be considered an invalid relative even when their dependent rebate is reduced to zero after applying the calculation methodology referred to in the TaxPack.

Eligible medical expenses include payments:
• to a general practitioner (including a laser eye surgeon), nurse or chemist/health food store (to fill general practitioners’ prescriptions) or a public or private hospital (including nursing homes and hostels for the aged and disabled), in respect of an illness or operation
• to a dentist for dental services or treatment or the supply, alteration or repair of artificial teeth (except dental services or treatment solely for cosmetic purposes)
• to a dental mechanic in respect of charges for the supply, alteration or repair of artificial teeth
• for therapeutic treatment administered under a general practitioner’s direction (such
as physiotherapy, occupational therapy, speech therapy, diathermic treatment, massage, dermacolor surgical cosmetics, dyslexia treatment, behavioural therapy and analysis for autism, chiropody and naturopathy)

- in respect of a medical or surgical appliance prescribed by a general practitioner (such as artificial limbs, artificial eyes, wheelchairs, wheelchair lifts/hoists/car access ramps, crutches, car controls for the disabled, kidney dialysis machines, Maximyst machines, teletypewriters, word prediction programs, voice synthesizers, speech and hearing aids, medical wigs and surgical braces, freestanding over bed frames, mobile shower commodes, dual valve high profile cushions and continence aids

- for the testing of eyes or the prescribing of spectacles (including contact lenses) by an optometrist or optician or the supply of spectacles in accordance with that prescription

- as remuneration of an attendant (excluding a person who is primarily engaged for domestic services) of a person who is blind or permanently confined to a bed or an invalid chair

- for the maintenance of a dog used for the guidance or assistance of, but not social therapy dogs.

Reimbursements

When you have calculated the amount of your eligible medical expenses, you must reduce that amount by reimbursements received or receivable, whether claimed or not, from Medicare or your private health fund.

You should note that generally a receipt that includes an amount for reimbursement of medical expenses as the result of a damages action should not reduce your eligible medical expenses.

The expenses need to be incurred under a medical practitioner, so it is important to keep all documents and records regarding the referral as well as the expense.

Special taxation provisions that apply to children with a disability

Note that this is not formal tax advice and you should check with your own accountant, financial adviser or the Australian Taxation Office before embarking on a new investment strategy. There are special rules about Tax File Numbers and whose name to use. Alternatively visit www.ato.gov.au.

Income taxation of minors

To discourage family income splitting income arrangements where income is diverted to people under the age of 18 years (“minor”), tax is levied at a punitive rate on “unearned income” (such as interest, dividends, rent and trust distributions). That is, generally income earned by a child (under 16 years) is taxed at a higher rate than income earned for adults. In 2007, for example, the tax-free threshold for a child is only $643 before income is taxed at the top marginal rate. For adults, the threshold is $6,000, which means someone classified as an adult can earn $6,000 before paying any tax (figures current 2007).

This punitive treatment does not apply to “excepted people”. Such exceptions apply when:

(a) the minor is a person:

(i) in respect of whom a carer allowance under the Social Security Act 1991 was payable;

(ii) to whom a disability support pension under that Act was payable; or

(iii) to whom a rehabilitation allowance under that Act was payable and who, immediately before becoming eligible to receive that allowance, was eligible to receive an invalid pension under that Act.
(b) the Commissioner has received a certificate issued by a general practitioner certifying or is otherwise satisfied, that the minor is:

(i) a child or adult with a disability, within the meaning of Part 2.19 of the Social Security Act 1991; or

(ii) a person who has a continuing inability to work within the meaning of Part 2.3 of the Social Security Act 1991 or is permanently blind;

(c) the Commissioner has received a certificate issued by a general practitioner certifying or is otherwise satisfied, that the minor is a person who, by reason of a permanent disability, is unlikely to be able to engage in a full-time occupation.

An “excepted person” is taxed in the same manner as any other taxpayer over 18 years and therefore has the benefit of adult marginal tax rates.

**Child Care Benefit (CCB)**

The CCB is a subsidy provided by the Commonwealth Government. It can be paid to Commonwealth accredited child care services on your behalf to reduce the fees you pay or can be claimed as a lump sum payment by parents at the end of the financial year. You can get the CCB whether you are in the work force, studying, looking for work or caring full-time for your child with a disability (generally, you need to be receiving the Carer Allowance for your child).

Note: You can register a grandparent or other family member with Centrelink’s Family Assistance Office so that you can claim the CCB for the child care work that they do.

To complement this provision there is the waiver for Grandparent Carers (GCCB) who have the primary responsibility for raising or caring for grand children. Work, study and training test are waived for eligible grandparents with primary care responsibilities. In some circumstances, this means they can access for each child in approved care 50 hours per week. To be eligible they must be in receipt of an income support payment. Centrelink offers the advice that those ineligible for the GCCB may wish to register as a carer with Centrelink. Visit the Family Assistance Office website: www.familyassist.gov.au.

**Child Care Tax Rebate**

If you are receiving the Child Care Benefit (CCB) for approved child care and meet the CCB work/study/training test of 15 hours per week, you can claim the tax rebate on approved child care expenses. This is a non-means tested rebate on child care costs of up to 30 per cent for out-of-pocket child care to a maximum of $4,210 for the year 2007.

Out-of-pocket expenses are the total fees you pay for child care expenses for approved care, less the amount of Child Care Benefit (CCB) you receive. The offset is not a ‘cash in hand’ refund. The offset reduces the tax payable on your income when you lodge your income tax return. Where the offset exceeds your tax liability, you are able to transfer the excess of the offset to your spouse.

The benefit of the tax offset is received when you lodge your tax return for the year following the year during which the expenses were paid.

For more information on the Child Care Tax Rebate, visit: www.ato.gov.au/individuals.
GST exemption – cars for use by people with a disability

Cars (up to a certain value) for people with a disability are GST free, if acquired for personal transport and the person buying or leasing the car intends to use the car for 2 years or until the car has travelled 40,000 kms.

Certain restrictions apply:

- The definition of “person with a disability” for the purposes of this exemption has a restricted meaning. The exemption is not available to all people who would generally be considered disabled. Accordingly, care must be taken before claiming the exemption (see www.ato.gov.au for applicable restrictions).

- The person buying the car only needs to have the intention to use the car for 2 years at the time it is bought. That intention may change after the car is bought without the loss of the exemption. The Commissioner has indicated that a person will be treated as intending to use a car for 2 years where that person has the intention to drive 40,000km while the car is owned or leased by the person.

- The person buying the car must use it for transport to and from gainful employment.

- Parts for these cars are also GST-free. However, the cost of their installation is not GST-free.

- The GST exemption only applies to that proportion of the GST-inclusive cost of the car that does not exceed the depreciation limit. This limit changes each year and is $57,123 for the 2008 year.

Legal and financial planning

Note: This information is offered as a general guide only. Obtain independent professional advice from your lawyer or accountant as to the accuracy of the information and its application to your particular circumstances before you take any other action.

One of the primary purposes of financial planning for families with a child with a disability is to maximise the ability of the person with a disability to retain the benefit of the Disability Support Pension and other Centrelink benefits that may be available. This is important while that person's parents are still alive, but even more important once his or her parents are deceased.

The purpose of this section is to set out the use of trusts generally (and, in particular, Special Disability Trusts) in financial planning for a child with a disability and to note some things to watch out for when structuring your estate.

Trusts

A trust can be a useful legal device for managing the flow of income within a family. Under a trust, a trustee is appointed to manage the assets held in the trust and the income generated from the assets is distributed each year to the people named as "beneficiaries". Tax on the income that is distributed is paid by each beneficiary at whatever tax rate applies to that beneficiary. The trustee must pay tax on any undistributed income at the highest tax rate, thus encouraging annual distribution.

Children under 18 years generally pay tax on any income “unearned” (such as interest dividends or trust distributions) at the highest tax rate. The exception to this is that marginal tax rates apply to any income received by a child with a disability if the child meets the medical criteria necessary for a parent to qualify for the Carer Allowance (the non means-tested allowance). In addition to these tax benefits, a trust has the following benefits:

- assets of a trust are not available to creditors of the beneficiaries
- assets of a trust are not available to a spouse in the case of marriage breakdown
- assets are controlled by the trustee
- assets are not counted as the assets of the beneficiary (unless the beneficiary has control or is the sole beneficiary).

Wills and Testamentary Trusts

Every parent of a child with a disability should have a will. It is advisable that a person’s will be reviewed every 3 to 5 years. You should consider carefully whether the executors should or should not be the siblings of a child with a disability as this may give rise to a conflict of interest.

If the value of your estate is likely to be more than $100,000, it is worth considering in your will to include the establishment of a trust, which comes into being on your death. Trusts of this kind are called “testamentary trusts”. Testamentary trusts have all of the advantages of discretionary family trusts identified above but in addition, distributions made to any person under a testamentary trust are taxed at the adult rate of tax, i.e. all child beneficiaries have available to them the marginal tax rates.

Below are several matters to consider when establishing a Testamentary Trust.

- The testamentary trust is similar in operation to a discretionary family trust. The discretion as to when and how the income and capital in the fund is to be distributed to the beneficiaries is held by the trustee.
- You can nominate any beneficiaries you like or, indeed, a class of beneficiaries.
- A pair of co-trustees is preferable to a single trustee. Ideally, at least one should have some
knowledge of how to deal with money and the other trustee should have a relationship and contact with the beneficiaries, especially the person with a disability.

- Legally a trustee can also be a beneficiary. However, the appointment of your child with a disability as one of the trustees of the trust will be taken by Centrelink to be the same as if you had simply transferred a portion of the assets of the Trust to that child outright, thereby potentially affecting his or her entitlement to the Disability Support Pension.

- It is suggested that you prepare and sign a set of guidelines and/or a memorandum of wishes explaining how you want the trust assets to be dealt with. These are instructions to the trustees of the testamentary trusts.

One major caution though! Unless set up as a Special Disability Trust (explained below), the nomination of a person with a disability as the sole beneficiary under a Trust will be taken by Centrelink to be the same as if you had simply transferred all of the assets of the Trust to that person outright, thereby affecting his or her entitlement to the Disability Support Pension and related Centrelink benefits.

**Special Disability Trusts**

Special Disability Trusts (SDTs) were introduced by the Commonwealth Government on 20 September 2006 to assist parents of a child with a severe disability (broadly defined in the legislation) in planning for the future care and accommodation needs of their child. The benefits of these trusts are that, to the extent that the trust holds $532,000 (as at 1 July 2008 and indexed annually) or less in assets:

- assets held in the trust for the person with disability will not reduce their pension entitlements
- gifts to the trust by certain immediate family members will not be used to diminish the contributor’s entitlement to a pension, i.e. they are exempt from the social security “gifting rules”. (Usually gifts proffered within 5 years of a person being entitled to a pension would be counted as the assets of the person, even though the money had been given away, thus reducing the contributor’s entitlement to a pension).

The principal home of the beneficiary is also exempt from the means test. Funds above these limits will be subject to the usual social security means tests.

**How can the money be used?**

Each SDT can be set up for only one beneficiary and the money can only be used for the care and accommodation needs of the person with the disability.

The Guidelines developed in relation to SDTs have taken a very restrictive interpretation of “care needs” and limited it to only those care needs that are necessary because of the disability. As a result of those restrictions, an SDT can generally not be used to buy food and clothing for the beneficiary, or to provide a holiday for the beneficiary, or to provide education. It can, however, be used to provide equipment needed, specific to the disability. It can also be used to buy a car for the beneficiary, even if other people will gain some benefit from the purchase of the car (but only as long as the benefit to the others is only “incidental”).

**How does tax apply to the SDT?**

Contributions to an SDT are not tax-deductible. Income generated from the assets in an SDT cannot be distributed to the beneficiary as cash. Therefore, there is no tax payable by the beneficiary on that income.

Like any trust, unexpended income is taxed at the highest marginal rate applicable in that financial year.
Who can contribute to an SDT?

Anyone can contribute to an SDT except the beneficiary or the beneficiary's spouse. Further information about SDTs is available on the website for the Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs at: http://www.facsia.gov.au/internet/facsinternet.nsf/disabilities/carers-programs_services.htm.

For a complete picture, make sure to read the Guidelines accessible by clicking on “Social Security (Special Disability Trust) (FaHCSIA) Guidelines” under “Further Information”, particularly the set of Guidelines named “Social Security (Special DisabiltyTrust) (FaHCSIA) Guidelines 2008”.

FaHCSIA Information Kit

FaHCSIA has published two booklets that might be helpful when undertaking future planning for a family member with disability: Planning for the Future: People with disability, and Special Disability Trusts: Getting things sorted.

The booklets can be downloaded from the FaHCSIA website at: http://www.facsia.gov.au/internet/facsinternet.nsf/disabilities/carers-publication.htm or printed copies of the booklets can be obtained by phoning either 1800 050 009 or 1800 734 750. Both booklets are available in 13 community languages.

For more information about Special Disability Trusts, please contact Centrelink’s Special Disability Trusts team on 1800 734 750. Veterans’ Affairs customers should call 133 254.
Guardianship and financial managers

Substitute decision making

In most cases people with a disability will either make their own decisions or have family members, friends or service providers to assist in decision making, or make decisions on their behalf. When everyone involved, including the person with a disability, is in agreement with the decisions being made, and there is no legal barrier to decision making, these informal arrangements are appropriate and desirable.

A person with a disability who is 16 years or over may wish to appoint an enduring guardian or a general or enduring attorney under a power of attorney.

An enduring guardian is someone you legally appoint to make personal or lifestyle decisions. The appointment only takes effect at times when the person lacks the capacity to make decisions themselves.

An attorney under a power of attorney is someone you appoint to make decisions about your financial affairs. A general power of attorney can be used even when you have the capacity to make decisions yourself but it ceases to have effect when you lose that capacity. An enduring power of attorney continues to have effect when you lose that capacity. A guide to assessing a person’s capacity can be found at www.lawlink.nsw.gov.au/lawlink/diversityservices/LL_DiversitySrvces.nsf/pages/diversity_services_capacity_toolkit..

To appoint an enduring guardian or an attorney under a power of attorney a person must understand the nature and effect of the appointment. Therefore, this option will not be available to all people with a disability. In that case, the informal arrangements described above are acceptable unless a dispute arises or there is a legal barrier to the decision making. See Guardianship and Financial Management (below) for the steps that can be taken in that instance.

Medical and dental consent

Consent requirements in relation to medical and dental treatment are set out in Part 5 of the Guardianship Act 1987.

It is the responsibility of medical and dental practitioners to ensure that the person they are treating understands the proposed treatment and has given a valid consent.

If a practitioner does not think the person can provide their own consent they must seek consent from the appropriate substitute decision maker.

In most cases this will be the ‘person responsible’ as defined in the Guardianship Act 1987.

The ‘person responsible’ is either:

- A guardian (including an enduring guardian) who has the function of consenting to medical and dental treatment
- Or if there is no such guardian:
  - The most recent spouse or de facto spouse with whom the person has a close and continuing relationship. ‘De facto spouse’ includes same sex partners.
- Or, if there is no spouse or de facto spouse:
  - An unpaid carer who provides support to the person or provided support before the person entered residential care.
- Or, if there is no carer:
  - A relative or friend who has a close personal relationship with the person.
If you are a parent caring for your child, you would fall into the category of "unpaid carer" without any need to make an application to the Tribunal.

The 'person responsible' can consent to all treatments except those categorised as 'special treatment' under the Guardianship Act 1987. Only the Guardianship Tribunal can consent to 'special treatment'. Also, a person responsible cannot consent if the person concerned is objecting to the treatment. Only the Tribunal can consent when the person objects to treatment.

**Guardianship and Financial Management**

Sometimes informal arrangements break down or there is a legal barrier to decision making. When this happens the Guardianship Tribunal can serve as an avenue of last resort by appointing guardians and/or financial managers.

The Tribunal only appoints guardians and/or financial managers if it is satisfied that the person is incapable of making decisions themself, they have a current need for decisions to be made and there is no appropriate informal means of assisting them with decision making.

If the Tribunal is satisfied that the person requires a guardian or financial manager it can appoint a private person such as a family member of friend as guardian and/or financial manager. If there is no suitable private person to appoint as guardian and/or financial manager, the Tribunal can appoint the Public Guardian and/or the Protective Commissioner.

For more information about enduring guardianship and enduring power of attorney, medical and dental consent, 'person responsible', special treatment, objections to treatment, guardianship and financial management, contact the Guardianship Tribunal on (02) 9555 8500.
Sport and leisure

Companion Card

The NSW Government is introducing a “Companion Card”. The Companion Card will allow people with a life-long severe or profound disability, who require attendant care at events and venues, to participate without having to pay for a second ticket for their attendant. The program will be rolled out in December 2008. Although you won’t be able to apply until then, you can register your interest by sending an email that includes your name, address and the name of the person who is eligible for the card to companioncard@dadhc.nsw.gov.au.

NICAN

NICAN is funded as an information service by the Commonwealth Department of Family and Community Services and Indigenous Affairs. NICAN provides an Australia wide information service relating to sport, recreation tourism and the arts to people with a disability. NICAN refers people to organisations that offer programs and activities for people with a disability. Phone 1800 806 769 or visit www.nican.com.au.

Physical Disability Council of NSW (PDCN)

This association has an online guide to recreation and travel. The organisation’s aims are to promote and develop sport for people with a disability in NSW, and to provide as many sporting opportunities and choices as possible. The members of the organisation include NSW Amputee Sporting Association; Blind Sporting Association; Deaf Sports and Recreation Association; NSW Push and Power Sports Inc; Mental Heath Sports Association; Sailability NSW Inc; Disabled Winter Sports Australia; Riding for the Disabled; Water Ski Association – Disabled Division; Disabled Golf Association; Goal Ball Association; and NSW Wheelchair Sports Association. Visit www.pdcnsw.org.au/guide/index.html.

Wheelchair Sports NSW

The Association conducts a wide range of wheelchair sporting events and programs for athletes of all ages and skill levels, in Sydney and across most of the state. It covers a range of sports including: basketball, table tennis and skiing and includes junior sports. Phone (02) 9809 5260 or visit www.wsnsw.org.au.

Riding for the Disabled (RDA)

The primary objective of RDA is to provide for people with a disability the opportunity to ride and enjoy all the activities connected with horse riding. It is a volunteer based, not-for-profit organisation. Riding for people with a disability can be both therapeutic and recreational and offers a multi-diagnostic service, catering for people with a wide range of disabilities, from riders through to harness driving. RDA operates 38 centres across NSW. Phone (02) 8116 9726 or visit www.rdansw.org.au.

Active Air Sports

Tandem hang gliding and paragliding are available for people with physical disabilities. Contact NICAN for information, phone 1800 806 769.

Disabled Surfers’ Association of Australia Inc (DSA)

DSA is a volunteer based organisation that helps people with all types of disability to access beaches and the surf. Visit www.surfershelpingsurfers.com or email dsa@disabledsurfers.org.
Beach/snow chairs

The “Freewheeler” is a comfortable wheelchair for use on sandy beaches. It has soft pneumatic balloon tyres that roll over sand and low waves easily when pushed by a carer. The Freewheeler is for anyone with mobility difficulties, aged 6 years and over.

Numerous surf clubs and local councils in metropolitan and regional NSW now have Freewheelers available for hire free of charge. Contact the respective council or club for terms, conditions and bookings.

- Manly Council, contact the Community Projects Coordinator. Phone (02) 9976 1562 or the Lifeguard at South Steyne. Phone (02) 9977 3434
- Pittwater Council. (Both Newport Surf Life Saving Club and Bilgola Surf Life Saving Club). Phone (02) 9970 1170
- Mosman Council: contact the Activities Coordinator, Aged and Disability Services. Phone (02) 9978 4056.
- Warringah Council, for use at Collaroy beach rock pool. Phone (02) 9942 2111.
- Terrigal, Wamberal, North Avoca, Avoca Beach, Copacabana, McMasters Beach, Ocean Beach and Umina Beaches. Contact Gosford City Council Lifeguard Services. Phone (02) 4385 8106.
- Saturday and Sunday you can phone the individual Surf Life Saving Club. Generally, the lifeguard on duty at the beach will be able to advise you on borrowing a freewheeler.

Local Councils are located under “Government” in the front of the White Pages Telephone Directory. In regional NSW the following councils provide this service:

- Tweed Shire Council: Contact Manager, Kingscliff Beach Holiday Park, phone (02) 6674 1311.
- Wollongong Council, phone (02) 4227 7111.

Contact the Northcott Society for information on borrowing a Freewheeler beach chair short-term. Phone (02) 9890 0100 or 1800 506 071 or visit www.northcott.com.au.

Hamilton Island, Queensland

The Whitsunday Island’s transport service has a public bus with rear entry and hydraulic lift to transport guests. The bus covers the route that circles the island daily every 40 minutes between 7am and 11pm.

Special Olympics

Special Olympics Australia provides year-round sports training and competition for children and adults with an intellectual disability. Through sport, athletes have the opportunity to get fit, develop skills, make friends and be part of a community.

Special Olympics provides sport for all people with an intellectual disability, regardless of their skill level. It caters for people who just want to participate, through to elite athletes who want to compete on an international level. Local, state, national and international competitions provide many opportunities.

The sports available are aquatics, athletics, basketball, bocce, golf, gymnastics, soccer, softball, tennis, and tenpin bowling.

Special Olympics is mainly organised by volunteers, so to determine the current contact person in your area visit www.specialolympics.com.au.
Sailing

Sailability Australia is a Yachting Australia Committee. Sailability Australia’s key objective is to encourage and facilitate sailing and boating throughout Australia for people with a disability in social, recreational and competitive activities. Phone (02) 8424 7400 or visit www.sailability.org.au/au/australia. There are clubs at: Albury Wodonga, Batemans Bay, Belmont, Callala, Central West, Chipping Norton, Coffs Harbour, Cronulla, Dubbo, Gosford, Griffith, Illawarra, Kogarah Bay, Manly, Manning and Great Lakes, Middle Harbour, Narooma, New England, Northern Rivers, Penrith Lakes, Pittwater, Point Piper, Port Stephens and Rushcutters Bay.

See also Sailors with Disabilities, a non-profit organisation which seeks to encourage people of all abilities to enjoy sailing. Phone (02) 8230 0880 or visit www.sailorswithdisabilities.com.

NSW National Parks and Wildlife Service


NSW Department of Sport and Recreation (DSR)

Sydney Academy of Sport Unit for Athletes with a Disability

Run through the NSW Department of Sport, Recreation and Tourism, the Sydney Academy of Sport offers programs that provide quality sport services for people with a disability including scholarships, participation schemes, and talented athlete programs. DSR coordinates a range of recreation services and facilities throughout NSW. Phone 131 302 or visit www.dsr.nsw.gov.au.

Swimsafe Program – NSW Department of Sport and Recreation

Swimsafe classes cater for children from 18 months to adulthood. Children with moderate to high support needs must be accompanied in the water by a parent or carer. Phone 131 302 or visit www.dsr.nsw.gov.au/swimsafe.

Scouts Australia

For information on Scout and Parascout groups throughout NSW, phone (02) 9413 1133 or visit www.nsw.scouts.com.au.

Girl Guides NSW and ACT

For information about Guiding in your area contact Guide House. Phone (02) 9698 3322 or visit www.guidesnsw.org.au.

PATH Inc

PATH Inc stands for Penrith Association for People with Disabilities and their Carers, Families and Friends. It is a community-based advocacy, support and information group. The PATH Integrated Recreation Officer helps children and young people to obtain opportunities for sport and other kinds of recreation. These opportunities can be after school or in the holidays. Phone (02) 4721 0866 or email path@eftel.net.au.
Examples of modified sporting and recreational equipment

Achievable Concepts (Victoria)

This organisation distributes adapted recreation and sporting equipment for people with a disability. It sells trikes and other cycling equipment and manufactures a beach wheelchair. It also sells gardening equipment, specialised games and crafts. Phone (03) 9370 0217 or visit www.achievableconcepts.com.au.

Bikes

• Tempo Tricycles (Qld) has a range of different bikes and accessories e.g. foot supports, hand supports, special saddle seats, and back supports. Visit www.tempolafak.com.au.

• Technical Aid for the Disabled: TAD provides a service modifying bikes and trikes. See page 45 of this handbook for information and contact details).

• Wheelchair distributors: Note that many wheelchair distributors also sell bikes for people with a disability.

Wheelchair Swings

Wheelchair swings are suitable for all wheelchair users, adults and children alike and also for people with limited mobility. The swings are easy to operate, with all instructions on the swing, and have been fitted with a lock to stop vandalism. The locks on the swing use a MLAK key (see General Information section, under “Wheelchair Accessible Toilets”, page 48). Contact your local council for the locations of swings. For more about the swing, visit www.libertyswing.com.au.
Holidays and travel

There are many disability friendly facilities available for holidays. However, it is always wise to ask questions about a venue before you book, as you know best your child’s particular needs. It is good to know if the venue has a microwave oven, bath, high chair, steps or stairs, the position of the bedrooms, and whether there is a babysitting service available.

It is also a good idea to ask other parents in a similar situation about places that they have stayed. The advertisement doesn’t always match the reality!

Initially, don’t try to be too adventurous or ambitious in your travels. Travelling with a child with a disability can be challenging; remember that the aim of the holiday is that the whole family benefits from a stay away from home.

It is recommended that you use established routines for your child’s sleeping and meal times as closely as possible. Avoid introducing new food types while travelling as they more cause unexpected dietary problems in your child, which can be difficult to manage while away from home.

Accessible accommodation and dining

- **The Spinal Cord Injuries Australia (SCIA)**
  SCIA has a database of detailed information on holiday destinations and wheelchair accessible accommodation. This information is not on the website, instead phone (02) 9661 8855

- **National Disability Services (NDS)**
  NDS has a comprehensive guide to accommodation and travel. At the NDS Home Page, select “website links page” and then select either “travel” or “accommodation”.
  www.nds.org.au

- **E-Bility**
  The e-Bilty website is regularly updated with travel and accommodation information.
  www.e-bility.com

- To find wheelchair accessible restaurants, click on that section in the “Features List” on the side of the home page of www.eatability.com.au.

- **Regional guide books**
  Most local governments (shires and councils) produce guides to accessible services in the area. Some examples are listed below:

  - **Access the Best**
    A guide to the Blue Mountains. To order a copy of the Blue Mountains guide, phone 1300 653 408 or visit www.bluemts.com.au/Accesssthebest/home.htm

  - **Accessible Facilities in Pittwater**
    To obtain a copy phone (02) 9970 1170 or visit www.pittwater.nsw.gov.au

  - **Easy Access Australia**, by Bruce Cameron
    Available from most bookstores; quote ISBN 0-9577510-1-X.
    Also distributed by Hema Maps. Phone (07) 3340 0030 or contact Bruce in Sydney on mobile 0407 317 397 or email: bruceea@vicnet.net.au
    PO Box 218 Kew Vic 3101
    www.easyaccessaustralia.com.au

  - **The disAbility, Leisure, Arts Sports and Lifestyle website**
    This website also provides advice and information about subjects ranging from travelling overseas through to wheelchair football and mouth painting. Visit www.d-ability.org.
Camps

The following camps offer holidays to children and young adults with a disability. Each camp has a different eligibility criteria and specific age groups for which it caters.

- Anglican Youthworks Holiday Camps. Phone (02) 8268 3346 or email holidaycamps@youthworks.asn.au
- Camp Breakaway. Phone (02) 4390 7624 or visit www.campbreakaway.com
- Camp David (for adults), Camp Jonathon (youth 8 to 18 years). Phone (02) 4396 4336. Contact the Yarramundi Recreation and Conference Centre, located in the lower Blue Mountains. Phone (02) 4770 1397
- Ignatian Children's Holiday Camp, St Ignatius' College Riverview. Phone (02) 9882 8222
- Camp Toukely is located near Tuggerah Lake. Primary age and teen camp. This camp and Eltham and Yarramundi camps (below) are operated by the Toukely Recreation and Conference Centre. Phone (02) 4396 4336 or visit www.camptoukely.com.au.
- Mount Victoria Recreation and Conference Centre is located in the Blue Mountains. Two camps are available: Years 3 to 12 (siblings discount), and “Wet n’ Wild” for secondary school students. Phone (02) 4787 1297
- Camp Kedron is a non-denominational Christian camp and a registered charity. The camp is available for hire by Church groups, schools and other approved organizations throughout the year. It is located at Ingleside on the Northern Beaches in Sydney, it is for young people aged between 15 and 22 years. Phone (02) 9450 1296 or (02) 9627 2320.
- Marist Children’s Holiday Camp. Phone (02) 9816 0808
- NSW Department of Sport and Recreation Camps. Phone 131 302
- The Sony Foundation sponsors a number of camps across Australia throughout the year. Visit www.sonyfoundation.org.au
- Support groups for specific genetic conditions often arrange camps for members.

Check in your local area as to whether there are any newly established camps. Sometimes genetic specific support associations also run camps.

The booklet produced by Families Supporting Families called Operation Adaption Guide available at www.ability.com.au/fsf has a useful list of things to remember when your child is going on camp.
**Travelling by plane**

Airlines and hotels are usually keen to assist people with a disability and their special travel needs. Always advise the airline of any special requirements your child has when you book, especially if travelling with a wheelchair, and if an upper body harness for seating is required. If booking online, you will need to phone the airline with these requirements. Airlines provide ground staff to meet and assist if requested. If travelling with a wheelchair you need to get to the gate one hour before the flight. A person in a wheelchair is usually first on and last off the plane.

An airline will normally allow passengers with a disability to use their own wheelchair until they reach the boarding gate. At the boarding gate the passenger should transfer into an aisle chair (a narrow push chair that fits in the aisle of the plane — it has two straps and a high back). Porters assist with pushing and transfers. The personal wheelchair is stored in the hold to be retrieved at the carousel on arrival.

The aisle chair is left at the airport. When checking in, remind the airline that another aisle chair will be required at the gate when the plane reaches its destination. If the flight takes off from or lands where there are no boarding platforms, then a forklift is used to lift the passenger onto the plane. No matter what the situation, there is always a way to move on and off the plane.

Clearance is normally required when use of any medical equipment is required in-flight. Not all battery or electrically powered equipment can be used onboard so first check with the airline. Other specialised equipment that you may need to take with you can be checked in and will be tagged with a special baggage tag.

Electric wheelchairs may need to be disassembled for flight, and wet cell batteries are subject to packaging. Wheelchairs with pump up tyres may lose some of their tyre pressure when in the cargo hold of the plane.

**Booking airline tickets or accommodation on the internet**

For holidays generally, some companies offer internet specials, but there may be no space on the booking form to register the needs of the person with a disability. You should phone the airline and ask for the special price for the person with a disability.

**Qantas Carer Concession Card**

NICAN administers the Qantas Carer Concession Card on behalf of Qantas.

The Qantas Carer Concession Card is issued to people with a disability and high level support needs who require the full-time assistance of a carer whilst they are on the plane. A person is eligible if they need to have one-on-one support when seated on the plane for assistance with meals/drinks, transferring to the bathroom orientation, communicating with the flight staff etc. A person would not be eligible if they only need assistance boarding the plane or when they arrive at their destination.

Qantas Carer Concession cardholders and their nominated carer will receive a discount on the full fare for Qantas domestic travel within Australia and New Zealand.

Phone NICAN 1800 806 769 or visit www.nican.com.au.
Respite

As a parent, one of the most important things to remember when caring for a child is to make sure that you look after yourself. This is even more important when you are caring for a child with a disability. Access to regular respite can mean the difference between coping and not coping.

Respite services provide you with a break from caring for your child with a disability. They provide a time to relax or enjoy the other members of your family or your friends. The time can be used to focus on other things that are important to you or simply to attend to the needs of your other children (e.g. for appointments or just to get a meal prepared).

Respite can be provided in lots of different ways to suit the individual needs and circumstances of families. It can be provided in your home or out of the home where your child attends a service or accesses the community with a support worker. Some respite services organise school holiday camps, social and recreational activities and regular peer support programs; some services provide overnight respite, and some can link you with a volunteer host family on a regular basis.

Whilst in respite, people who have experience in supporting children with a disability care for your child, and every service provider completes both the “Working with Children” and the “Criminal Record” check on the support workers they employ.

Before approaching a respite service, it is always helpful if you have some idea of what you are asking for, so think about what sort of respite would most benefit you and your family. Many respite packages are quite flexible in the way that they can be used so it is always worth asking if you have something particular in mind.

Planning ahead gives you the best chance of getting the respite service at a time that suits you and before you are possibly past the point of coping. You might want to access respite on a planned and regular basis, or just as a one-off support.

You are encouraged to talk to more than one respite provider to choose a service that will best meet your needs. Most services have a certain criteria you need to meet to be eligible. Some providers specialise in providing services to children only, or adults only, or only to people who are medically frail or who are from an Aboriginal background. Some services cater only for people with a mild-moderate disability whilst others cater only for people with a severe disability.

Most respite is organised within local government areas, so what is available to you and your child will depend on where you live.

Respite services are generally subsidised by the NSW Government, but sometimes service providers will ask for a contribution. Be aware that you will never be denied respite if in financial difficulty.

Another possibility when it comes to respite, for some families, is to get friends or family involved. (This is sometimes easier to do whilst children are still young.) Family and friends can often be willing to help, but aren’t sure of the best way to go about it. If you are able to organise it, somebody coming for an hour once a week to feed and bath your child or to take them out for a little while can be an enormous help when it is done on a regular basis.

If your child requires medication when they are in respite (particularly out-of-home or overnight respite) you will probably be required to supply the medication in a Webster Pack. This is a sealed package that can be made up by your chemist for a nominal charge.
Finding respite in your area

Commonwealth Carelink and Respite Centres (previously Commonwealth Carelink Centres)

Commonwealth Carelink and Respite Centres are information centres for older people, people with a disability and for those who care for a person with a disability. The Centres provide free and confidential information on community aged care, disability and other support services available locally, interstate or anywhere within Australia. This is a telephone service that provides information in your local area on:

- how to contact services
- eligibility criteria for services
- the cost associated with receiving services.

Phone 1800 052 222 or visit www.commcarelink.health.gov.au.

Commonwealth Carers Respite Centre

Commonwealth Carelink Centres are currently joining with Commonwealth Carers Respite Centres. The Carelink and Respite Centres will be responsible for coordinating access to respite services in your local area. They work with parents and carers to plan sensible approaches to respite and other support needs and also arrange 24 hour emergency respite care. CRC also provides funding assistance for respite through local service providers. The Centre is a single focal point for:

- respite options
- local respite services
- organising planned respite
- organising emergency respite.

Phone 1800 059 059.

Carer Line – Carers NSW

Carer Line provides information, support and referrals to carers regarding services, financial assistance, carer support groups and any other kind of support. Carers NSW produces a range of fact sheets with information about support for carers. There are fact sheets available in sixteen languages. Phone 1800 242 636 or visit www.carersnsw.asn.au

Home Care Service of NSW

Home Care provides respite in your home, as well as other services. For further information see details on page 86 of this handbook or phone the Home Care Service of NSW. Phone 1800 350 792.

NSW Department of Ageing, Disability and Home Care (DADHC)

Recreation Team

DADHC provides skill building recreational activities and outings for school age children during the school holidays, and after school. Contact your DADHC regional office Intake, Referral and Information service (IRI) for information on programs and intake. (See page 10 of this handbook for contact details).
Overnight Respite

Contact your DADHC regional office for information on overnight respite services in your local area (see page 10 of this handbook for contact details).

Camps

For camps run during the holidays for children with a disability, see page 82 of this handbook.

Holiday programs

In most areas the local council or the YMCA is involved in the organisation of holiday programs for school-age children. These programs often include children with a disability. Contact your local council or YMCA.

Home and Community Care (HACC)

The HACC Program is a joint Commonwealth, state/territory initiative to help people in need. The NSW Department of Ageing, Disability and Home Care administers the HACC Program in NSW.

HACC provides a range of basic maintenance and support services for frail older people, people with a disability and their carers. The overall objective of HACC is to support people who live at home and whose capacity for independent living is at risk or who are at risk of premature or inappropriate admission to long-term residential care. Services provided through the program include:

- respite care – support to carers through the provision of flexible and responsive alternatives to the usual care arrangements
- home modifications or maintenance – assistance to maintain a person’s home, garden or yard to keep it safe
- social support – assistance to meet a person’s need for social contact and participation in community life
- transport – practical assistance with group or individual transport needs
- nursing care – support in the management of particular health problems such as diabetes and incontinence
- case management – a collaborative and person-focused process for managing support to people with chronic, ongoing or complex conditions or situations
- centre-based day care – group activities to assist with social interaction that are conducted in a centre-based setting
- assessment – activities to establish eligibility needs and access to services
- client care coordination – the coordination of activities undertaken to facilitate access to HACC services for people who need help to gain access to more than one.

Other HACC Program services include domestic assistance and personal care such as help with cooking, cleaning, washing, ironing, bathing and dressing; meals and other food services such as the preparation and delivery of meals or other food items which contribute to meeting a person’s daily nutrition requirements; a formal linen service for the provision and laundering of linen; and allied health such as podiatry, physiotherapy, occupational therapy, speech pathology and dietetics.

The HACC Program subsidises costs. Where possible, materials are purchased at a discounted rate for clients.
Information and support for parents of children with a disability in NSW

Fees

HACC services are required to have a fees policy, with the flexibility to reduce or waive fees according to the person's financial situation. The fees policy for personal care, respite and domestic services is set out in the Fact Sheet entitled *Home Care Service Standard Client Contribution Fact Sheet* at [www.dadhc.nsw.gov.au/dadhc/Older+people/Home+Care+Service.htm](http://www.dadhc.nsw.gov.au/dadhc/Older+people/Home+Care+Service.htm). Note that personal care services for children under 16 years is free. A person should never be refused access to respite services due to an inability to pay charges.

Local government, community and voluntary organisations, religious and charitable organisations and commercial organisations, as well as state/territory government agencies, may be responsible for the delivery of HACC services. For information, phone your DADHC Regional office. (Refer to page 10 of this handbook for contact details).

Peer support

Provides social and recreational activities in a group, usually for young adolescents through to young adults. To determine if your local service providers offers a peer support program, contact the Commonwealth Carelink and Respite Centre. Phone 1800 052 222 or the Carer Line 1800 242 636 or the Commonwealth Carers Respite Centre phone 1800 059 059 or speak to the Disability Support Worker in your local council.

**Allowah Presbyterian Children’s Hospital, Dundas**

This is a hospital for children aged 0–16 years who have a developmental disability. Children from throughout NSW are able to stay at Allowah. Allowah is a private hospital, so you need to have private health cover. It has a full medical and nursing staff, physiotherapy, occupational therapy, music therapy and special programs to deal with specific issues. Allowah also provides long-term care and overnight respite services as well as day programs in the school holidays.

Phone (02) 9858 4994.

**Northcott Society**

The Northcott Society provides respite services for children and adults with a disability in NSW including flexible respite programs, leisure access and out of school hours programs. There are also centre-based respite and community recreation programs for school aged children. Northcott has 22 sites located around NSW. For information phone the Northcott Central Office located in North Parramatta. Phone (02) 9890 0100.

**The Spastic Centre of NSW**

The services of The Spastic Centre of NSW include respite care. The Spastic Centre of NSW provides services in the Sydney metropolitan area and regional NSW. Phone (02) 9451 9022 or (02) 9479 7200.

**Centacare Sydney**

This is a non-government, not-for-profit organisation that provides ageing and disability services (including respite), children’s services, and counselling services across NSW. For more information phone the Centacare head office on (02) 9390 5377 or to find the Centacare service closest to you visit [www.centacare.org.au](http://www.centacare.org.au).

**Young Carers Program (Carers NSW)**

Young carers are children or teenagers who care in part or full for a parent, sibling or relative who has a chronic illness or disability. Carers NSW has service programs to meet the needs of young carers. Phone 1800 242 636 or visit [www.youngcarersnsw.asn.au](http://www.youngcarersnsw.asn.au).
Sunnyfield Association

Services include respite care, accommodation, supported employment, day options, recreation and transition to work. Services are available in the Sydney metropolitan area and some of regional NSW. Phone (02) 9451 6999 or visit www.sunnyfield.com.au.

Bear Cottage

Bear Cottage is NSW’s only children’s hospice providing respite and end of life care for children with life limiting illnesses and their families. It is designed as a large beach home situated on Sydney’s Northern Beaches and provides families with 24 hour medical care and bereavement support after the death of a child. Phone (02) 9976 8300 or visit www.bearcottage.chw.edu.au.

Interchange Respite Care NSW

Interchange Respite Care NSW is the peak body for organisations involved in providing respite care and/or social support to families who have a member with a disability, or a family member who is frail aged. It represents 110 respite care and social support providers across NSW, many in the disability sector. A list of member agencies and their contact details across NSW can be accessed through the home page of its website at www.interchangensw.com.au or by phoning (02) 9789 1348.

Vacation Care, NSW Child Care Inclusion Support Subsidy (FaHCSIA)

Through the Inclusion Support Program (ISP) there is funding available for children with a disability to access all forms of child care, including vacation care. You may be eligible for the Child Care Benefit (which is a subsidy to help families pay for Commonwealth approved vacation care services for their children).

Centre based care is combined with outing days for school age children generally up to secondary school age. Local councils operate vacation Care Centres. Vacation care generally welcomes and accommodates children with a disability, by using funding from the Inclusion Support Subsidy.

Once you have secured a place in a vacation care centre for your son or daughter, you will be guaranteed a maximum of 5 days each school holiday period. This helps parents who are trying to remain in paid employment, and your child will be enjoying the company of their school-aged peers, which is a “win-win” situation for all!

Phone your closest Inclusion Support Agency (see contact details on page 12 of this handbook) or Children’s Services Central. Phone 1800 157 818.
Home help

Home and Community Care Program (HACC)

HACC provides basic support services to frail aged people, people with disability and their carers who live in the community. Services include domestic assistance, personal care, home modification and maintenance, food services, in-home respite care, community transport, community allied health services, community nursing and case management. Phone DADHC on (02) 8270 2000 or the Commonwealth Carelink and Respite Centre. Phone 1800 052 222 or visit www.dadhc.nsw.gov.au.

Home Care NSW Service (NSW Department of Ageing, Disability and Home Care)

Home Care assists people to live independently in the community by providing assistance with the following types of services: general housework, personal care (e.g. showering and dressing), respite care, essential home handyman tasks, shopping and personal transport. There is a charge for some services: see page 87. For the Referral and Assessment Centre, phone 1800 350 792 or visit www.homecare.nsw.gov.au.

Au pairs

If you have a spare room (or can free one up), you might like to consider engaging an au pair to help you at home, particularly over the longer January school holidays. In general, an au pair will work 25–35 hours a week for $150–$250 plus their lodgings (including meals).

Duties can include light housework and cooking but au pairs are generally not willing to do heavy housework. Au pairs are usually travellers or students and, due to visa restrictions, can only stay for a limited period. Au pairs can be found through most nanny agencies (see “Nannies” in the Yellow Pages Directory) or on the internet using websites such as:

- www.aupairs.co.uk
- www.familymatch.com.au
- www.sunnyaupairs.com
- www.eaupairs.co.uk

Agencies will require a placement fee and websites require a “matching” fee. Alternatively you can contact the schools in your area offering English language courses and ask if any of the students are requiring a “homestay” (see under “Language Instruction” in the Yellow Pages Directory). There is generally no charge for this service but you need to give the school a couple of months’ notice. For general information on au pairs visit www.peopleforpeople.com.au.
Advocacy

When you have a child with a disability most of the time you will find yourself in the position of advocate for your child. This is not always an easy position to be in. However, as parents you are the ones in the best position to organise the services and help meet your child’s needs. This can sometimes be difficult as you feel you are constantly having to battle for every little thing. However, with the right information, a calm but positive attitude and a little persistence, it is amazing what you can achieve.

In some situations, however, it is desirable to have the support of another person or organisation to represent the interests of your child.

Key elements of advocacy

- Advocacy is on the side of the disadvantaged person/people.
- Advocacy is concerned with the genuine major needs and welfare of the person/people at stake.
- Advocacy strives for the minimum conflict of interest.
- Advocacy engages in vigorous defence and promotion of the welfare and interests of the party at stake.
- Advocacy has fidelity (loyalty).

General principles

Below are listed the general principles of parent or family advocacy.

- Be calm and positive! Be clear on the outcome you want to achieve.
- Gather any relevant facts, figures or documents necessary to argue your case.
- Prepare yourself by thinking about the 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 next time if needed.
- Don’t always expect conflict. Others might agree with you! However, be prepared with a positive strategy if you do experience disagreement.
- Listen carefully and don’t allow others to intimidate you. Counter arguments with facts and don’t get into personal attacks on individuals.
- Ask for important issues and decisions to be formally recorded in writing. Note the issues you’ve agreed on, and try and find a strategy for dealing with disagreements.
- Make sure there is an agreed process for following up and be prepared to do some specific follow up to ensure that the things that are agreed are undertaken.
- You might like to consider taking another person to advocate on your behalf, but if you’re well organised and prepared, the chances are that the best advocate for you and your family is you!
Types of advocacy

Parent/family advocacy
Parent advocacy programs assist families of persons with a disability to represent their interests in the community.

Self advocacy
Self Advocacy Programs help people with a disability to develop skills, knowledge and confidence to advocate on their own behalf.

Citizen advocacy
Citizen advocacy organisations link a person with intellectual disability (for whom there is an existing or potential need for representation) with a typical ordinary member of the community who is independent, unpaid and not linked to human services, who then advocates for this person.

Group/corporate advocacy
Group advocacy describes a group of people who come together to speak up for a whole group of people. Peak bodies practise group advocacy and work to change systems that affect people with an intellectual disability.

Systemic advocacy
Systemic advocacy is advocacy aimed at systems within society. For example, organisations such as NSW Council for Intellectual Disability focus on making changes to government policy. These organisations are practise systemic advocacy.

Legal advocacy
Legal advocacy describes the broad range of methods and activities by which lawyers and other skilled individuals help people to defend their rights. Legal advocacy can play an active part in reforming law and policies that are not in the best interests of people with a disability.

Large advocacy organisations
The next section of this handbook provides an overview of the large advocacy organisations in NSW.

Citizen advocacy groups
Commonwealth Carelink and Respite Centres will be able to provide you with the details of any local citizen advocacy groups in your local area. Phone 1800 052 222.

Carers Wiki
A new concept in this area is the online discussion space WhatCarersNeed, established by two mothers of children with a disability. Visit http://whatcarersneed.wikispaces.com.
Advocacy organisations

The Australian Association of Special Education (AASE)

AASE is a broad-based non-categorical association concerned with all children who have special education needs. AASE aims to:

• advocate on behalf of people with special education needs to ensure provision of and access to quality education services
• provide a range of quality services to members and the wider community
• provide a strong and informed national and state voice for the special education community
• enhance access by students with special education needs to quality educational programs
• promote professional standards of a high order
• foster equitable and effective support for students with special education needs
• support research that informs the delivery of special education in the Australian context.

Any person interested in these goals may be a member of AASE. Members include parents and carers, teachers, therapists, community members, administrators and university lecturers. Visit www.aase.edu.au or email office@aase.edu.au.

Human Rights and Equal Opportunity Commission (HREOC)

The Human Rights and Equal Opportunity Commission was established in 1986 by an act of the Federal Parliament. HREOC’s goal is to foster greater understanding and protection of human rights in Australia, and to address the human rights concerns of a broad range of individuals and groups. HREOC is an independent statutory organisation and reports to the federal Parliament through the Attorney-General. To contact HREOC phone (02) 9284 9600 or phone the Complaints Infoline 1300 656 419. For general enquiries and publications phone 1300 369 711.

People with Disability Inc (PWD)

PWD is a national peak disability rights and advocacy organisation. Its primary membership is made up of people with disability and organisations primarily constituted by people with disability. PWD also has a large associate membership of other individuals and organisations committed to the disability rights movement.

PWD's work is supported in part by grants of financial assistance from both the state and Commonwealth Governments. It provides:

• rights-related information, advice and referral services for people with disability and their associates
• short-term individual and group advocacy assistance to people with disability and their associates
• advocacy for reform around systemic issues that adversely affect people with disability and their associates
• representation of the sector of interest constituted by people with disability and their associates to government, industry and the non-government sector
• coordination of the sector of interest constituted by people with disability and their associates
• disability rights-related research and development around issues of concern to people with disability and their associates
• disability rights-related training and education for people with disability and their associates, service providers, government and the public.

Phone (02) 9370 3100 or 1800 422 015 (regional NSW) or email pwd@pwd.org.au.
The National Disability Abuse and Neglect Hotline (PWD)

The National Disability Abuse and Neglect Hotline is an Australia-wide telephone hotline for reporting abuse and neglect of people with a disability who use government-funded services such as open or supported employment, accommodation, community and respite care services.

Cases of abuse and neglect can include physical, sexual, psychological, legal and civil abuse, restraint and restrictive practices or financial abuse. They can also include the withholding of care and support that exposes an individual to harm. Allegations are referred to the appropriate authority for investigation. The Commonwealth Government funds this service. The Hotline is open from 8am to 8pm across Australia, seven days a week. Phone 1800 880 052 (regional NSW) or 1800 301 130 (TTY) or 1800 555 677 (NRS) or 131 450 (TIS).

Intellectual Disability Rights Service (IDRS)

IDRS is a community legal centre in NSW, working with people with an intellectual disability to exercise and advance their rights. IDRS will help anyone of any age with an intellectual disability to exercise their rights under the law.

Legal advice and information is provided for people with an intellectual disability or others acting on their behalf within NSW. Initial advice is provided over the phone by appointment. Phone (02) 9318 0144 or 1800 666 611 or visit www.idrs.org.au.

Physical Disability Council of NSW Inc (PDCN)

PDCN is the peak body representing people with a physical disability across NSW. It aims to assist and support people to achieve equality of citizenship and full participation. Phone (02) 9552 1606 (metropolitan), toll free 1800 688 831 (regional NSW) or email admin@pdcnsw.org.au or visit www.pdcnsw.org.au.

Multicultural Disability Advocacy Association of NSW (MDAA)

MDAA is the peak organisation and the only specific advocacy service for people from a non-English speaking background (NESB) with disability and their families and carers in NSW.

MDAA aims to promote, protect and secure the rights and interests of this group of people by:

- promoting and safeguarding the rights of people from a non-English speaking background with disability and their family/carers
- working to improve the quality of life for people from a non-English speaking background with a disability and their family/carers
- increasing the participation by people from a non-English speaking background with a disability and their family/carers in community activities.

Phone (02) 9891 6400 or 1800 629 072 or email mdaa@mdaa.org.au or visit www.mdaa.org.au. For Regional Individual Advocacy Offices visit www.mdaa.org.au/contact.html.

The Network of Carer Associations and the Carer Line (Carers NSW)

For information see page 5 of this handbook. Phone 1800 242 636 or visit www.carersnsw.asn.au.

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

This is a national organisation that advocates to government and other decision-makers for improvements to services and support for families of children with a disability. Phone 1800 222 660 or visit www.aafcd.org.au.
Women With Disabilities Australia (WWDA)

WWDA was initially established by a group of women with a disability who felt that their needs and concerns were not being acknowledged or addressed within the broader disability sector or the women’s sector in Australia. WWDA is the peak organisation for women with disability in Australia. It is an organisation made up of women with a disability and associated organisations. The national secretariat is located in Tasmania. Women with a disability run WWDA, for women with a disability.

WWDA seeks to ensure opportunities in all walks of life for all women with a disability. In this it aims to increase awareness of, and address issues faced by, women with a disability in the community. WWDA is unique, in that it operates as a national disability organisation, a national women’s organisation, and a national human rights organisation. Visit www.wwda.org.au or email: wwda@wwda.org.au. Phone (03) 6244 8255. PO Box 605 Rosny Park, Tasmania 7018.

Family Advocacy (Institute of Family Advocacy and Leadership Development Inc.)

Family Advocacy is an independent, community-based social advocacy organisation that works across New South Wales.

Family Advocacy seeks to achieve positive social roles for people who have a developmental disability through the development of advocacy by families. Family Advocacy’s mission is to attain positive social roles for people who have a developmental disability by strengthening the knowledge, role and influence of families in the community. Phone (02) 9869 0866 or visit www.family-advocacy.com.au.

Anti-Discrimination Board

The Anti-Discrimination Board of NSW is part of the NSW Attorney General’s Department. It administers the anti-discrimination laws of New South Wales. Phone (02) 9268 5555 or visit www.lawlink.nsw.gov.au/adb.

NSW Council for Intellectual Disability (CID)

NSW CID represents the rights and interests of people with an intellectual disability and their carers. Phone (02) 9211 1611 or 1800 424 065 (regional NSW).

NSW Council of Social Service (NCOSS)

NCOSS is the peak body for the social and community services sector in NSW. It works towards achieving social justice and represents the interests of disadvantaged people and the community welfare sector to the government. Non-government, not-for-profit organisations based in NSW delivering human services or involved in community development, policy or advocacy are entitled to apply for full organisational membership of NC OSS, as are individuals. Phone (02) 9211 2599.

National Disability Services (formerly ACROD)

This is the peak coordinating and advocacy organisation for providers of services to people with a disability. (The NDS is not an advocacy service for individual people with a disability; it advocates systemic changes for service providers at senior government levels). Phone (02) 9256 3111.

PATH Inc

PATH Inc stands for Penrith Association for People with Disabilities and their Carers, Families and Friends. It is a community-based advocacy, support and information group and also publishes a regular newsletter. Phone (02) 4721 0866 or email path@eftel.net.au.
Complaints

NSW Ombudsman

The NSW Ombudsman is an independent and impartial “watchdog”. Its role is to ensure that NSW Government agencies fulfil their functions properly and improve their delivery of services to the public. If you feel a NSW Government department, community service or agency has treated you unfairly you have the right to complain. The Ombudsman’s office is independent of the government of the day and accountable to the public through the NSW Parliament.

Generally the first thing to do is to discuss your concerns directly with the department, service or agency involved. Sometimes though this is not appropriate or does not solve the problem. If this is the case and you need further help, you can contact the NSW Ombudsman. The Ombudsman handles complaints that fall within the following areas:

- public sector agencies
- local government
- the police
- community services
- workplace child protection
- correctional centres
- freedom of information
- protected disclosures.

The NSW Ombudsman also handles complaints about a range of disability services including:

- residential services, respite care, community access
- community support programs
- day, activity and recreation programs
- Home Care
- HACC services.

If you do not want to make the complaint yourself you can ask someone else, like a friend or relative, welfare worker or advocate, even your local member of parliament, to contact the Ombudsman on your behalf. If for any reason the complaints staff cannot help you they will try to refer you to someone who can help.

The Ombudsman has the power to investigate conduct that is:

- illegal
- unreasonable
- unjust or oppressive
- improperly discriminatory
- based on improper or irrelevant grounds
- based on a mistake of law or fact
- otherwise wrong.

For information on how to make a complaint, and how the Ombudsman’s Office helps parties to reach a resolution, phone (02) 9286 1000 or 1800 451 524 or visit www.ombo.nsw.gov.au/disability.html. You can also make a complaint online by accessing the website.
Translated NSW Ombudsman Publication Information

The Ombudsman’s Office produces many useful publications. Substantial portions of the website are available in Arabic, Chinese, Italian and Vietnamese. The general information brochure about how to make a complaint, what to include in the complaint, and the complaint process is also available in Croatian, Greek, Hindi, Bahasa Indonesia, Korean, Persian, Russian, Samoan, Serbian, Spanish, Tamil, and Turkish.

Phone (02) 9286 1072 or write to the NSW Ombudsman, Level 24, 580 George Street, Sydney NSW 2000. To download the brochures visit www.ombo.nsw.gov.au.

Commonwealth Ombudsman

The Commonwealth Ombudsman’s office investigates complaints about the administrative actions of Commonwealth Government agencies and works to foster good public administration. For information or to make a complaint phone 1300 362 072.

Disability Council of NSW

This is the official advisory body to the NSW Government that monitors the implementation of government policy in relation to people with a disability, their families and carers.

Phone (02) 9211 2866 or email: info.disabilitycouncil@dadhc.nsw.gov.au or visit www.disabilitycouncil.nsw.gov.au.

Disability discrimination legislation

It is against the law to discriminate against a person because of a disability. There are two key disability discrimination laws that relate to New South Wales. These are:

- Federal Disability Discrimination Act 1992
- NSW Anti-Discrimination Act 1977

In pursuing a case of discrimination, consideration needs to be given as to which Act is better to use. To view the NSW Anti-Discrimination Act or the Disability Discrimination Act visit www.lawlink.nsw.gov.au/adb and click on Anti-Discrimination Laws.

- The Anti Discrimination Board handles complaints that fall under the NSW Anti-Discrimination Act. Phone (02) 9268 5555 or 1800 670 812.
- The Human Rights and Equal Opportunity Commission (HREOC) is responsible for complaints lodged under the Commonwealth Disability Discrimination Act 1992 and other anti-discrimination laws. Phone 1300 656 419.

NSW Disability Discrimination Legal Centre

This is a specialist legal service offering assistance to people who have been discriminated against because of their disability. It provides free information, advice and support related to the Disability Discrimination Act, and legal representation for individual and representative complaints. Phone (02) 9310 7722 or 1800 800 708 or visit www.ddlcnsw.org.au.

Community Legal Centres

Australian Community Legal Centres are independent, non-profit community organisations that provide free legal services to the public, covering most areas of the law. Phone the Combined Community Legal Centres Group NSW State Office on (02) 9212 7333. For a list of centres visit www.nswclc.org.au.
Information and support for parents of children with a disability in NSW

Legal Aid Commission of NSW

The Legal Aid Commission of NSW assists socially and economically disadvantaged people to understand and protect their rights. There are 21 offices in NSW. To locate your closest office visit www.legalaid.nsw.gov.au.

Law Access NSW

This is a service that provides help over the phone. It is a free information referral and advice service, on 1300 888 529 or 1300 889 529 (TTY) between 9 am and 5 pm, Monday to Friday.

Law Society of NSW

Pro Bono Community Assistance Scheme

Pro Bono work is legal work done ‘for the public good’. Solicitors who undertake pro bono work do so either without charge or at reduced cost for members of the public who are ineligible for Legal Aid or have limited means to retain legal representation. Solicitors also undertake pro bono work for charitable and other non-profit making organisations.

The Law Society of NSW provides a telephone helpline offering general legal information and referral to private law firms practising in a particular area of law. For information, phone (02) 9926 0333 or visit www.lawsociety.com.au.

Individual Advocacy

This is a free, independent advocacy service for people with a disability or those acting on their behalf. It helps people with a disability who wish to make a complaint. Such complaints can be made about any service the person uses or about infringement of their rights. The service also assists in having complaints acted on, puts people in touch with other appropriate complaints services, helps people to use these services, provides information about rights, and helps people to protect their rights. Phone 1800 422 015.

Complaints Resolutions and Referral Service (CRRS)

The CRRS is a service that helps people with a disability sort out complaints about disability employment and advocacy services funded by the Commonwealth Government. Phone 1800 800 052 or visit www.crrs.org.au.
Support and Information for specific groups

Association of Genetic Support Australasia (AGSA)

If your son or daughter has a syndrome diagnosis, it could help to join a support group for that specific genetic condition. It is helpful to talk with other parents who are working through similar issues and who have similar concerns to your own.

AGSA facilitates support for those affected directly or indirectly by genetic conditions throughout Australasia. The Association has a Contact Register representing over 750 genetic conditions plus over 200 chromosomal abnormalities. It also provides details of associated support groups.

AGSA provides a forum for the exchange of information between support groups regarding available community services, a rural carers program (that includes telegroup counselling), face-to-face counselling, and sibling workshops.

For information on a specific genetic support association phone (02) 9211 1462 or email info@agsa-geneticsupport.org.au.

Examples of support groups in Australia

- Angelman Syndrome Association
- Asthma Foundation of Australia
- Autism Spectrum Australia (Aspect)
- Brain Foundation NSW
- Cerebral Palsy
- Cornelia de Lange Syndrome Association
- Cystic Fibrosis NSW
- Deaf Society
- Defence Special Needs Support group
- Down Syndrome NSW
- Epilepsy Association
- Haemophilia Foundation NSW
- Hyperactivity Attention Deficit Association NSW
- Muscular Dystrophy Association
- Parent Council for Deaf Education
- Prader-Willi Syndrome Association of NSW (Aust) Inc.
- Rett's Syndrome Association
- Royal Blind Society NSW
- Smith Magenis Syndrome Association
- Spina Bifida Group
- SWAN (Syndromes Without A Name)
Information and support for parents of children with a disability in NSW

Large support organisations

Government departments

NSW Department of Ageing, Disability and Home Care (DADHC)
See page 10 of this handbook for DADHC regional and metropolitan contact details.

NSW Department of Education and Training (DET)
To contact the DET office in your area, phone 131 536.
Head Office
GPO Box 33, Sydney NSW 2001
www.det.nsw.edu.au

NSW Health
See page 10 of this handbook for NSW Health regional and metropolitan contact details.

Commonwealth Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA)
NSW Office
GPO Box 9820 Sydney NSW 2001
1300 653 227
www.FaHCSIA.gov.au

Non-government organisations

Autism Spectrum Australia (Aspect)
Autism Spectrum Australia provides information, advice, consultation, referral assessment, family support, home-based early intervention, special schools, community residential care, and vocational training for adults. A new kit Building Foundations – Autism: Your child, Your Family which includes a manual and DVD providing detailed information for parents and families with a child newly diagnosed with autism spectrum disorder is available from Autism Spectrum Australia. Phone (02) 8977 8300.

Association of Genetic Support of Australasia (AGSA)
AGSA facilitates support for those affected directly or indirectly by genetic conditions throughout Australasia. (See page 98 of this handbook for information). Phone (02) 9211 1462 or email info@agsa-geneticsupport.org.au.

Northcott Society
Northcott Society provides a range of services for children and adults with a disability across NSW. Services include early intervention, family support, respite care, recreation, accommodation, employment, equipment and technology. In some areas there are also flexible respite and case management programs available for children and adults with a range of disabilities. Phone (02) 9890 0100.
Royal Institute for Deaf and Blind Children (RIDBC)
RIDBC provides a wide range of educational, diagnostic, assessment and advisory services for children who have or may have, a hearing impairment or visual impairment, as well as additional disabilities. Services include specialist schools, preschools, and early intervention including the Home Start Program. Rural programs are also available. Phone (02) 9871 1233 or 1800 043 411.

The Spastic Centre of NSW
The Spastic Centre of NSW provides services for people with Cerebral Palsy (CP) and their families including early intervention, therapy, employment services, supported accommodation, respite care, technology. Phone (02) 9451 9022 or CP Helpline on 1300 302 920.

Brain Injury Association of NSW Inc.
This Association is the leading advocacy body in NSW for people with an acquired brain injury, their families and carers. The Association provides information, referral, self-help and support groups. Phone (02) 9749 5366 or 1800 802 840.

Centacare Sydney
This is a non-government, not-for-profit organisation that provides ageing and disability services (including respite), children’s services, and counselling services. For more information phone the Centacare head office on (02) 9390 5377 or to locate the Centacare service closest to you. Visit www.centacare.org.
Mental health

The range of people who can be assisted through the mental health system is quite broad. This includes children with major behavioural problems who have not yet been diagnosed. It also includes children who may have mental health issues as well as other disabilities. Families who have a child with severe behavioural difficulties who have not yet been diagnosed should consider requesting a CAMHS (Child and Adolescent Mental Health Services) assessment. To find out more about CAMHS, contact your local area health service (see page 10 for contact details).

For parents concerned about their own mental health, see the chapter on Counselling and Support in this handbook.

Mental Health Information Service

This is an information and referral service on mental health services in NSW, using a comprehensive state-wide database. A telephone information and referral service for crisis intervention, accommodation services, family services, legal and advocacy services is provided. There is also a public resource centre as well as access to support groups for a variety of disorders. Phone 1300 794 991 or visit www.mentalhealth.gov.au.

Association of Relatives and Friends of the Mentally Ill (ARAFMI)

ARAFMI provides information on mental illness and a 24 hour helpline of support and referral for family, friends and carers of those with a mental illness. Emotional support is available through self-help and mutual support groups in different city and country areas in NSW. There is also a drop-in centre. Phone (02) 9805 1883 (Helpline) or 1800 655 198 (regional NSW).

Transcultural Mental Health Centre

This organisation provides mental health care for people from a non-English speaking background and has a list of suitable bi-lingual mental health providers, phone 1800 648 911.

Anxiety Disorders Alliance incorporating OCD/TOPS (Obsessive Compulsive Disorders and Triumph over Phobias)

Information is available on support groups meeting in NSW. Phone (02) 9879 5351; ODC 1800 626 055; TOPS 1800 626 077 or visit www.adamentalhealth.asn.au.

Child and Adolescent Mental Health Service (CAMHS)

CAMHS can be a key source of help for behavioural problems and/or learning difficulties. Children who have not yet been diagnosed may be assessed by CAMHS. Phone 1300 794 991 or visit www.mentalhealth.gov.au.

CAN

CAN is a mental health support group that provides resources, reports, articles and useful links are available online. Visit www.canmentalhealth.org.au.

SANE

This is a mental illness Helpline, phone 1800 688 382.
# Glossary of acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADN</td>
<td>Aboriginal Disability Network</td>
</tr>
<tr>
<td>AGSA</td>
<td>Association of Genetic Support of Australasia</td>
</tr>
<tr>
<td>Aspect</td>
<td>Autism Spectrum Australia</td>
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<tr>
<td>ATO</td>
<td>Australian Taxation Office</td>
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<tr>
<td>CAAS</td>
<td>Continence Aids Assistance Scheme</td>
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<tr>
<td>CAP</td>
<td>Carer Adjustment Payment (FaHCSIA – Commonwealth Government)</td>
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<tr>
<td>CCB</td>
<td>Child Care Benefit</td>
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<tr>
<td>CID</td>
<td>NSW Council for Intellectual Disability</td>
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<tr>
<td>CRC</td>
<td>Community Relations Commission</td>
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<tr>
<td>DADHC</td>
<td>Department of Ageing, Disability and Home Care (NSW Government)</td>
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<tr>
<td>DEEWR</td>
<td>Department of Education, Employment, Workplace Relations (Commonwealth Government)</td>
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<tr>
<td>DET</td>
<td>Department of Education and Training (NSW Government)</td>
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<tr>
<td>DIRC</td>
<td>Disability Information Resource Centre</td>
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<tr>
<td>DoCS</td>
<td>Department of Community Services (NSW Government)</td>
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<td>DSP</td>
<td>Disability Support Pension</td>
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<td>ECIS</td>
<td>Early Childhood Intervention Services</td>
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<tr>
<td>EPCP</td>
<td>Enhanced Primary Care Program</td>
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<tr>
<td>FaHCSIA</td>
<td>Department of Families, Housing, Community Services and Indigenous Affairs (Commonwealth Government)</td>
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<tr>
<td>HACC</td>
<td>Home and Community Care Program</td>
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<tr>
<td>HMMS</td>
<td>Home Modification and Maintenance Services</td>
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<tr>
<td>HREOC</td>
<td>Human Rights and Equal Opportunity Commission</td>
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<tr>
<td>ILC</td>
<td>Independent Living Centre</td>
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<tr>
<td>IPTAAS</td>
<td>Isolated Patients Travel and Accommodation Assistance Scheme</td>
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<tr>
<td>IDRS</td>
<td>Intellectual Disability Rights Service</td>
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<tr>
<td>IRI</td>
<td>Information, Referral and Intake service (DADHC)</td>
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<tr>
<td>ISA</td>
<td>Inclusion Support Agency (FaHCSIA)</td>
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<tr>
<td>ISP</td>
<td>Intervention Support Program (DET)</td>
</tr>
<tr>
<td>ISS</td>
<td>Inclusion Support Subsidy (FaHCSIA)</td>
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<tr>
<td>MDAA</td>
<td>Multicultural Disability Advocacy Association of NSW</td>
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<tr>
<td>NCA</td>
<td>Network of Community Activities</td>
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<tr>
<td>NCOSS</td>
<td>NSW Council of Social Services</td>
</tr>
<tr>
<td>NDS</td>
<td>National Disability Services (formerly ACROD, Australian Council for Rehabilitation of Disabled)</td>
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<tr>
<td>NES</td>
<td>Northcott Equipment Solutions</td>
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<tr>
<td>NICAN</td>
<td>National Information Communication Awareness Network</td>
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<tr>
<td>OPC</td>
<td>Office of the Protective Commissioner (and of the Public Guardian)</td>
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<tr>
<td>PADP</td>
<td>Program of Appliances for Disabled People</td>
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<tr>
<td>PARAQUAD</td>
<td>Paraplegic and Quadriplegic Association of NSW</td>
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<tr>
<td>PDCN</td>
<td>Physical Disability Council of NSW</td>
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<tr>
<td>PWD</td>
<td>People with a Disability</td>
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<tr>
<td>SDT</td>
<td>Special Disability Trusts</td>
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<tr>
<td>TAD</td>
<td>Technical Aid to the Disabled</td>
</tr>
<tr>
<td>TASC</td>
<td>Technology Solutions for Computer Access, Seating and Communication</td>
</tr>
</tbody>
</table>
Reading Resources

Follow Your Instincts  Cunnins, R and Bratel, J
2005, The Spastic Centre NSW
Download, order or view online at
www.thespasticcentre.org.au/about_cp/follow_your_instincts.htm

Operation Adoption Guide
2008, Families Supporting Families Inc
Download or view online at

Paper Cranes  Cheryl Koenig
2008, Exisle Publishing, NSW

Lessons from my Child – Parents’ experiences of life
with a disabled child
Cindy Dowling, Neil Nicoll, Bernadette Thomas
2004, Finch Publishing, NSW

Married with Special-Needs Children
L.E. Marshak, Ph.D. and F.P. Prezant, M.Ed., CCC-SLP
2007, Woodbine House, USA

From the Heart: On Being the Mother of a Child with
Special Needs  J Marsh
1995, Woodbine House, USA

It Isn’t Fair!  Klein, S.D. and Schleifer, M.J.
1993, The Exceptional Parent Press, USA

Siblings  Kate Strohm
2002, Wakefield Press, SA

There’s No Such Thing as a Silly Question
2007, interACT
For a free copy email –
secretary.interact@gmail.com

The Other Country  Michael Whelan
2008, Macmillan, Australia

Special Children, Challenged Parents: The Struggles and
Rewards of Raising a Child With a Disability
Robert A. Naseef
2001, Paul H. Brookes Publishing Co, USA

Building Foundations. Autism: Your Child; Your Family
ASPECT, available by contacting (02) 8977 8377

Regional Publications

Blueprint Directory
Blueprint Family Support Project offers information,
resources and support to families living in the
Hawkesbury, Blue Mountains and Penrith areas who
are caring for a child with complex disabilities and
fragile health conditions. The Project has produced
a Directory of Services which is available at no cost by
contacting Blueprint on 02 4784 2323. Blueprint’s
revised website www.blueprintproject.org.au also
provides links to information for carers on planning,
self-care, advocacy, services and websites where
carers and siblings can connect and network.

Early Intervention Directory
For families in the Queanbeyan District
2006, ECICP Committee
Download or view online at www.acdnsw.org.au
## Index

### A
- Aboriginal support services ........................................... 58
- Aboriginal Carer Support Groups (Carers NSW) ............. 58
- Aboriginal Disability Network (ADN) NSW .................. 58
- Active Air Sports ......................................................... 77
- Adolescence ................................................................... 26
- Advocacy ........................................................................ 90
  - General Principles ...................................................... 90
  - Organisations .......................................................... 92
- Types ............................................................................. 91
- AGSA (The Association of Genetic Support Australasia) .. 7, 99
- Aids and equipment ........................................................ 42
  - Communication aids .................................................. 44
  - Equipment hire ......................................................... 50
  - Equipment loan pools ............................................... 50
  - Hearing impairment .................................................. 46
- Northcott Equipment Solutions (NES) .......................... 49
- Portable ramps ............................................................. 53
- Second hand equipment ................................................. 50
- TAD – Technical Aid for the Disabled ............................ 45
- TASC – Technology Solutions for Computer Access, Seating and Communication .............................. 46
- Vision Australia ........................................................... 46
- VisionCare NSW .......................................................... 46
- Aids for Personal Care .................................................... 47
- Allowah Presbyterian Children's Hospital ........................ 87
- Animals, assistance ...................................................... 52
  - Assistance Dogs for Independence Australia ............... 52
  - Australian Support Dogs .......................................... 52
- Guide Dogs NSW/ACT – Mobility services .................... 52
- Guide Dogs NSW/ACT – Pets as therapy ......................... 52
- Anti Discrimination Board .............................................. 94
- Apprenticeship and Traineeship program ......................... 32
- Au pairs ........................................................................ 89
- Australian Association for Families of Children with a Disability (AAFCD) ........................................ 93
- Autism Spectrum Australia (Aspect) ............................... 99

### B
- Beach/Snow Chairs ........................................................ 78
- Bear Cottage .................................................................. 88
- Bikes ............................................................................. 80
- Brain Injury Association .................................................. 100

### C
- Camps .......................................................................... 82
- Carer Adjustment Payment (CAP) (FaHCSIA) ................. 82
- Carer Payment .............................................................. 65
- Carers NSW ................................................................. 62
- Carer Line ..................................................................... 6, 8
- Case workers, community nurses and social workers ....... 17
- Centacare Sydney .......................................................... 100
- Centrelink ..................................................................... 27, 62
  - Identification .............................................................. 27
  - Payments ................................................................. 27, 62
- Child Abuse Prevention Service ..................................... 8
- Child and Adolescent Mental Health Service (CAMHS) .... 101
- Child Care Access Hotline ............................................ 12
- Child care and preschool support ................................... 12
- Child Care Benefit (CCB) ............................................ 70
- Child Care Tax Rebate .................................................. 70
- Child care types ........................................................... 13
- Child Disability Assistance Payment .............................. 62
- Children's Services Central .......................................... 13
- Citizen Advocacy Groups ............................................ 91
- Clothing .......................................................................... 43
- Commonwealth Carelink and Respite Centre ................. 85
- Commonwealth Carelink Centres .................................. 85
- Commonwealth Carers Respite Centres ....................... 85
- Community Housing Association .................................. 41
- Community Legal Centres ........................................... 96
- Community Participation Program ................................ 29
- Community Relations Commission (CRC) ...................... 61
- Community transport (Ministry of Transport) ................ 56
- Complaints ..................................................................... 95
- Companion Card .......................................................... 77
- Compounding chemist .................................................. 4
- Consent Medical and dental ............................................ 75
- Continence aids
  - Continence Advisory Service (ParaQuad NSW) ............ 47
  - Continence Aids Assistance Scheme (CAAS) ............... 47
  - Continence Foundation of Australia ............................ 47
  - Discount nappy companies ......................................... 47
  - PADP – Program of Appliances Disabled People ........ 42
  - Product suppliers ....................................................... 47
- Counselling and support ................................................ 5
- Dalmar Child and Family Care (Wesley Mission) .............. 7
- Dentistry ........................................................................ 3
- Dependent Rebate ......................................................... 68
- DET Intervention Support Program (ISP) ......................... 12
- Diagnosis ........................................................................ 2
- Disability Complaints Service of NSW ......................... 96
- Disability Council of NSW ............................................ 96
- Disability Discrimination Laws ....................................... 96
- Disability Services Act (DSA) and Disability Services Standards ......................................................... 34
- Disabled Surfers’ Association of Australia ....................... 77
- Disability Support Pension (DSP) .................................. 63
- Driver Rehabilitation and Fleet Safety Services ............... 57

104 Through the Maze
Information and support for parents of children with a disability in NSW

E

Early Childhood Health Centres ........................................ 9
Early Childhood Intervention Co-ordination Program .... 9
Employment
Centrelink Vocational assistance ...................................... 31
Commonwealth Rehabilitation Service .............................. 34
Deaf Society of NSW ....................................................... 33
Disability Employment Assistance Program ...................... 33
Disability Employment Services ....................................... 33
Employers Making A Difference ....................................... 33
Employment Incentive Programs ....................................... 33
Employment programs .................................................... 31
HREOC ........................................................................... 33
Job applications and interviews ..................................... 36
Job Network ........................................................................ 33
NSW Department of Education and Training Industry Programs ..................................................... 32
Open Employment (Commonwealth Department of Employment and Workplace Relations (DEEWR)) ........................................................... 32
Open Employment Services .............................................. 32
Rights at work, wages and conditions of employment ................................................................. 34
Supported Employment Business Services ...................... 34
Supported Wage System .................................................... 35
Wage Subsidy Scheme ........................................................ 35
Workplace Modifications Scheme ...................................... 36

F

FaHCSIA – Families and Housing, Community Services and Indigenous Affairs ................................................. 99
Family Advocacy (Institute of Family Advocacy and Leadership Development Inc) .................................................... 94
Family Assistance Fund (DADHC) .................................. 66
Family Day Care ................................................................ 13
Family Tax Benefit ............................................................. 64
Part A ................................................................................ 64
Part B ................................................................................ 64
Financial ............................................................................ 62
Clubs NSW ........................................................................ 67
Service clubs ..................................................................... 67
Smith Family – Learning for Life ........................................ 67
Variety the Children’s Charity ............................................ 67

G

General practitioners .......................................................... 2
Genetic counselling ............................................................. 7
Girl Guides NSW and ACT .............................................. 79
Glossary of acronyms ......................................................... 102
Gowrie Child and Family Information – Referral Service ................................................................. 6
Guardianship and financial managers .............................. 75
Management ..................................................................... 76
Medical and dental consent .............................................. 75

H

Health Care Interpreter Services (HCIS) ......................... 61
Holidays and travel ............................................................ 81
Accessible accommodation .......................................... 81
Air travel ........................................................................... 83
Qantas Carer Concession Card ......................................... 83
Home and Community Care Program (HACCP) ............ 86, 89
Home Care NSW Service (NSW Department of Ageing, Disability and Home Care) ........................................... 89
Home Care Service of NSW ........................................... 85
Home help ........................................................................ 89
Home modifications ........................................................ 53
Hospital Ward Grandparents Scheme (AWCH) ................ 2
Hospitals ............................................................................ 2, 18
Human Rights and Equal Opportunity Commission (HREOC) ................................................................. 92

I

Inclusion Support Agencies
NSW (ISA) (FaHCSIA) .................................................. 12
Inclusion Support Subsidy (FaHCSIA) .............................. 13
Income taxation of minors .............................................. 69
Independent Living Centre (ILC) ...................................... 43
Information Kit, FaHCSIA .............................................. 74
Information sources ......................................................... 37
In-home care (Family Day Care Service) ........................ 13
Intellectual Disability Health Assessment ............................ 65
Intellectual Disability Rights Service (IRDS) .................... 93
Intensive Family Support Options (IFSO) ......................... 6
Interchange Respite Care NSW ....................................... 88
Interpreting and Translation Services ............................. 60
Interrelate .......................................................................... 7
Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) .................................................. 66

K

Karitane Care Line .............................................................. 8
Kids Helpline ...................................................................... 8

L

Language assistance ........................................................ 60
Large Advocacy Organisations ........................................ 92
Law Access NSW ............................................................ 97
Law Society of NSW ......................................................... 97
Learning Assistance Program ........................................ 21
Learning Links ................................................................... 11
Legal advocacy ................................................................. 91
Legal Aid Commission of NSW ...................................... 97
Legal and financial planning ........................................... 72
Legal guardian ................................................................... 75
Libraries Australia ........................................................... 38
Lifeline ............................................................................... 8
Local councils
Disability support worker ............................................... 11
Local Government Access Committees ......................... 57
Long Day Care Centres .................................................... 15

Through the Maze 105
<table>
<thead>
<tr>
<th>M</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical and dental consent .............................................. 75</td>
</tr>
<tr>
<td>Medical Appointments .......................................................... 37</td>
</tr>
<tr>
<td>Medical Expenses Rebate ....................................................... 68</td>
</tr>
<tr>
<td>Eligibility ............................................................................. 68</td>
</tr>
<tr>
<td>Reimbursements ..................................................................... 69</td>
</tr>
<tr>
<td>Medicare:</td>
</tr>
<tr>
<td>Dental Provisions .................................................................. 65</td>
</tr>
<tr>
<td>Health Assessments – Enhanced Primary Care Program (EPCP) ........... 65</td>
</tr>
<tr>
<td>Melatonin .................................................................................. 4</td>
</tr>
<tr>
<td>Mental Health .......................................................................... 101</td>
</tr>
<tr>
<td>Mobility ...................................................................................... 49</td>
</tr>
<tr>
<td>Mobility Allowance ................................................................... 63</td>
</tr>
<tr>
<td>Mobility Parking Scheme .......................................................... 55</td>
</tr>
<tr>
<td>Moving from School to Adulthood ............................................. 29</td>
</tr>
<tr>
<td>Multicultural Disability Advocacy Association of NSW (MDAA) ......... 60, 93</td>
</tr>
<tr>
<td>Multicultural Support Resources ............................................. 60</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Disability Abuse and Neglect Hotline (PWD) ..................... 93</td>
</tr>
<tr>
<td>National Disability Coordination Officer Programme (DEEWR) .......... 30</td>
</tr>
<tr>
<td>National Disability Services (formerly ACROD) ................................ 94</td>
</tr>
<tr>
<td>National Relay Service .................................................................. 46</td>
</tr>
<tr>
<td>Network of Carer Associations .................................................. 5</td>
</tr>
<tr>
<td>Network of Community Activities (NCA) .......................................... 16</td>
</tr>
<tr>
<td>Networking ................................................................................... 37</td>
</tr>
<tr>
<td>NICAN ........................................................................................... 77</td>
</tr>
<tr>
<td>Northcott Equipment Solutions ................................................. 49</td>
</tr>
<tr>
<td>Northcott Society ......................................................................... 49</td>
</tr>
<tr>
<td>NSW Area Health Services .......................................................... 99</td>
</tr>
<tr>
<td>NSW Council for Intellectual Disability (CID) ................................. 94</td>
</tr>
<tr>
<td>NSW Council of Social Service (NCOS) .......................................... 94</td>
</tr>
<tr>
<td>NSW Department of Education and Training (DET) ............................... 19</td>
</tr>
<tr>
<td>NSW Department of Housing Home Purchase Advisory Service .......... 53</td>
</tr>
<tr>
<td>NSW Department of Sport and Recreation (DSR) .................................... 79</td>
</tr>
<tr>
<td>NSW Department Ageing, Disability and Home Care (DADHC) .......... 10, 84</td>
</tr>
<tr>
<td>Camps ......................................................................................... 82</td>
</tr>
<tr>
<td>Holiday programs ......................................................................... 86</td>
</tr>
<tr>
<td>Overnight respite ......................................................................... 86</td>
</tr>
<tr>
<td>Recreation team ........................................................................... 85</td>
</tr>
<tr>
<td>NSW Disability Discrimination Legal Centre ...................................... 96</td>
</tr>
<tr>
<td>NSW Family Services .................................................................... 7</td>
</tr>
<tr>
<td>NSW Home Modification and Maintenance Services (HMMS) .................. 53</td>
</tr>
<tr>
<td>NSW National Parks and Wildlife Service ....................................... 79</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>O</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occasional care centres .......................................................... 14</td>
</tr>
<tr>
<td>Occupational therapist ............................................................... 17</td>
</tr>
<tr>
<td>Ombudsman:gadooba</td>
</tr>
<tr>
<td>Commonwealth Ombudsman .......................................................... 96</td>
</tr>
<tr>
<td>NSW Ombudsman .......................................................................... 95</td>
</tr>
<tr>
<td>Operation Adaption Handbook ..................................................... 7</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>PADP – Program of Appliances for Disabled ................................. 42</td>
</tr>
<tr>
<td>People ......................................................................................... 42</td>
</tr>
<tr>
<td>Paediatricians ............................................................................ 2</td>
</tr>
<tr>
<td>Parent Line .................................................................................. 8</td>
</tr>
<tr>
<td>PATH Inc ....................................................................................... 79, 94</td>
</tr>
<tr>
<td>Peer support ............................................................................... 87</td>
</tr>
<tr>
<td>AGSA ............................................................................................. 7</td>
</tr>
<tr>
<td>My Time – Peer Support Group ..................................................... 6</td>
</tr>
<tr>
<td>Pensioner Education Supplement .................................................. 64</td>
</tr>
<tr>
<td>Person responsible ........................................................................ 75</td>
</tr>
<tr>
<td>Physical Disability Council of NSW (PDCN) ................................. 77, 93</td>
</tr>
<tr>
<td>Physiotherapist ........................................................................... 17</td>
</tr>
<tr>
<td>Playgroups .................................................................................... 11</td>
</tr>
<tr>
<td>Post school options – NSW Government ......................................... 29</td>
</tr>
<tr>
<td>Power of attorney ........................................................................ 75</td>
</tr>
<tr>
<td>Preschools and long day care centres ........................................... 14</td>
</tr>
<tr>
<td>Private therapy services ............................................................ 18</td>
</tr>
<tr>
<td>Pro Bono Community Assistance Scheme ....................................... 97</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>R</th>
</tr>
</thead>
<tbody>
<tr>
<td>Raising Children Network ....................................................... 8</td>
</tr>
<tr>
<td>Regional Student Service Teams ................................................ 21</td>
</tr>
<tr>
<td>Rent Assistance (Centrelink) ...................................................... 62</td>
</tr>
<tr>
<td>Respite ......................................................................................... 84</td>
</tr>
<tr>
<td>Riding for the Disabled (RDA) ..................................................... 77</td>
</tr>
<tr>
<td>Roads &amp; Traffic Authority ........................................................... 27</td>
</tr>
<tr>
<td>NSW Photo Card ........................................................................... 27</td>
</tr>
<tr>
<td>Royal Institute for Deaf and Blind Children (RIDBC) .................... 100</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>S</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sailing ....................................................................................... 79</td>
</tr>
<tr>
<td>Salvo Care Line ........................................................................... 8</td>
</tr>
<tr>
<td>School:</td>
</tr>
<tr>
<td>Advocacy ..................................................................................... 23</td>
</tr>
<tr>
<td>Catholic schools ........................................................................ 22</td>
</tr>
<tr>
<td>Choosing a school ........................................................................ 24</td>
</tr>
<tr>
<td>Communication with the school .................................................... 24</td>
</tr>
<tr>
<td>Counsellors .................................................................................. 19</td>
</tr>
<tr>
<td>Disability Standards for Education ............................................. 19</td>
</tr>
<tr>
<td>Disability Program Consultants .................................................... 21</td>
</tr>
<tr>
<td>Home schooling ........................................................................... 22</td>
</tr>
<tr>
<td>Independent schools ..................................................................... 21</td>
</tr>
<tr>
<td>Learning Assistance Program ...................................................... 21</td>
</tr>
<tr>
<td>Mainstream classes ..................................................................... 20</td>
</tr>
<tr>
<td>Meetings ....................................................................................... 25</td>
</tr>
<tr>
<td>Options ......................................................................................... 19</td>
</tr>
</tbody>
</table>
Information and support for parents of children with a disability in NSW

**S**
- Publications ................................................. 23
- Regional Student Service Teams .................. 21
- School Student Special Transport Scheme (DET) .... 22
- Special school (School for Specific Purpose) ...... 21
- Sport/excursions .......................................... 22
- Support class within a regular school ............. 21
- Support for students with a disability .......... 19
- Scouts Australia ........................................... 79
- Showering and toileting ................................. 48
- SIBS (Sisters, Individuals, Brothers) ............... 6
- Sleep disorders .............................................. 3
- Smith Family ................................................. 67
- Spastic Centre of NSW ................................. 100
- Special Olympics .......................................... 78
- Special Taxation Provisions ......................... 69
- Speech pathologist ........................................ 17
- SPELD (Specific Learning Difficulties Association) ...................................................... 7
- Spinal Cord Injuries Australia (SCIA) ............... 53
- Sport and leisure .......................................... 77
- Sunnyfield Association .................................. 88
- Support and information for specific groups .... 98
- Supported accommodation .......................... 39
- Supported living .......................................... 40
- Supported wage system ................................ 35
- Swimsafe Program (NSW Department of Sport and Recreation) ......................... 79
- Systemic advocacy ....................................... 91

**T**
- TAFE NSW .................................................. 30
- Disabilities Services.................................... 30
- Taxation ...................................................... 68
- Taxi Transport Subsidy Scheme .................... 56
- Teenagers, puberty and sexuality .................. 26
- Telstra services .......................................... 46
- The Network of Carer Associations and the Carer Line (Carers NSW) .................. 5, 93
- Therapists, types of .................................... 17
- Therapy ...................................................... 17
- Therapy for school aged children .................. 18
- Toilets ....................................................... 48
  - Public toilets ........................................... 48
  - Wheelchair Accessible Toilets ................... 48
- Toy Libraries ............................................. 11
- Transition Care Website – NSW Health .......... 28
- Transition to secondary school .................... 24
- Transition to Work Program ......................... 29
- Transport ....................................................
  - Community transport ................................ 56
  - Private transport ..................................... 54
  - Public transport ...................................... 56
- Tresillian Family Care Centres ..................... 8
- Trusts ....................................................... 72
- Special Disability Trusts .............................. 73
- Turning 16 Years ......................................... 27

**U**
- University .................................................. 31
- Disability Advisers ...................................... 31

**V**
- Vacation care ............................................. 14
- Vacation Care, NSW Child Care Inclusion Support Subsidy (FaHCSIA) ............. 88
- Vehicles ..................................................... 71
- Vehicles and vehicle modifications ............... 54
- Lifts and hoists ........................................... 54
- Suppliers .................................................... 55

**W**
- Wheelchair Sports NSW .............................. 77
- Wheelchair swings ...................................... 80
- Wheelchairs .............................................. 49
- NRMA Road Service ................................... 49
- ParaQuad Engineering NSW ......................... 49
- Wheelchair Accessible Taxi Service ............... 56
- Wheelchair Accessible Toilets ...................... 48
- Wheelchair Accessible Restaurants ............... 81
- Wills and Testamentary Trusts ....................... 72
- Women With Disabilities Australia ................. 94
- Working Carers Support Gateway .................. 7

**Y**
- Young Carers – Carers NSW ......................... 6
- Young Carers Program (Carers NSW) .............. 88

*Through the Maze* 107