Shoulder to Shoulder

Information for Aboriginal families who have a child or young person with a disability

An Initiative of the NSW Government

A new direction for disability services in NSW 2006–2016

Department of Ageing, Disability & Home Care
# GETTING THE FACTS

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About this booklet

In this booklet you’ll find all sorts of information about disability services, respite services (to give you a rest), and Aboriginal organisations that can support you if you have a child with a disability. You’ll also read about how other Aboriginal families have been able to cope with caring for a child with a disability.

The term “child” is used throughout this booklet to also include “young person”.

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What is a disability?

If your child has a medical, physical or intellectual condition that means it might not be possible to do everyday activities without some type of help, then this is known as a disability.

**WHY DOES MY CHILD HAVE A DISABILITY?**
Disabilities can happen at different times in our lives. Children can be born with a disability or they may develop a disability because of an illness or accident.

**HOW COULD A DISABILITY AFFECT MY CHILD?**
Having a disability may affect your child’s learning, development and behaviour. For example, a disability could affect the way your child:

- learns to talk/communicate and understand things (language)
- can move around (movement)
- plays and forms relationships with others (social skills).

The frustrations that a child with a disability may experience can also result in behaviour such as:

- physical aggression such as hitting, kicking and hurting others
- hurting themselves by biting
- being fearful for example in noisy situations, or
- withdrawn behaviour when your child may not want to communicate with others.

If you have concerns about your child you should visit your doctor or an Aboriginal Medical Service (AMS).

If your doctor says your child has a disability don’t worry because you won’t have to cope alone. It is important to know that you have the right to receive support in understanding your child’s disability and how to best care for your child. You can also get financial support for your family.

Remember:

- disability can affect your child in different ways, so the amount and type of support will vary
- you need to ask the right people and you might have to ask more than once
- the most important thing is to get practical information and support.
Learning about your child’s disability

When you have a child with a disability, it is important that you and the other members of your family learn about the disability. When you understand more about your child’s disability you will find it easier to cope because you will know what to expect. You will also be able to help other members of your family understand why your child will sometimes need extra attention.

WHERE TO GET INFORMATION
The first time you question your child’s ability it is important to ask lots of questions from a professional such as a doctor. It is okay to take a support person with you when you talk to your doctor.

If you are still unsure, there are other groups or people who can help such as your local Aboriginal Medical Service, local playgroups, other parents, or your family and friends.
If your child has a disability you will probably talk to several doctors. If you don’t get on with your doctor it is okay to try and find another doctor who you feel understands what you are saying and will listen to you.

Another good way to learn about your child’s disability is from the parents or grandparents of other children with a disability. There are several Aboriginal and non-Aboriginal parent support groups where you can get together, have a yarn and a cuppa and talk about what you have learned about your child. Contact the Commonwealth Carelink Centre for a Parents’ or Grandparents’ Support Group in your area for advice.

The internet is also a good way to find out about your child’s disability. Some sites are listed at the back of this booklet.

WHAT ABOUT YOUR OTHER CHILDREN?
If you have other children, sometimes they might feel confused, sad or jealous of their brother or sister with a disability because they take up so much time. It is important not to be mad at them for this. Instead try to talk to them about why their brother or sister needs more help and if you can, try and spend some special time with them.

Brothers and sisters of children with a disability may need extra time and attention to make up for the things they miss out on. Sometimes they may feel embarrassed, guilty, confused, shamed, over-protective, sensitive or like they have too much responsibility.

There are support groups to help Aboriginal brothers and sisters of people with a disability and these are called sibling support groups. You can contact the Commonwealth Carelink Centre for more information.

DISABILITY SUPPORT GROUPS
There are also some groups that specialise in helping people who have specific disabilities. For example, there are groups that focus on helping children with intellectual and physical disabilities as well as hearing and vision impairment.

Contact the Commonwealth Carelink Centre to find a group in your area that specialises in your child’s disability.

YOUNG CARERS
There are many young people who also help to care for a child with a disability. Young carers often feel proud of the job they do but they can also sometimes need a rest to concentrate on doing the things young people do - like having fun or even doing some homework. Contact the Young Carers Association for more information.
It is important to look out for any problems your child might be having so that you can get help as soon as possible. Children grow very quickly especially when they are young. Problems that are not discovered early can lead to difficulties later in life.

As a parent, you are the best person to keep track of your child’s growth and development as you know your child better than anyone else. Even if you’ve known about your child’s disability for some time, things will change as your child grows up.

The Personal Health Record, (also called the Blue Book), that you were given in hospital when your baby was born, has information on the ages children should go to their doctor or nurse to have their health checked.

This book also has information about vision and hearing and a section for you
to write notes about your child’s learning, language, development and behaviour.

0-FIVE YEARS
If you have noticed that your child is slow to sit up, walk, follow directions, learn new things or has difficulty playing alone or with other children, seek help as soon as possible.

Also, if your child is having trouble making eye contact, swallowing, chewing or has some behaviour problems or any bad fears or worries, then you should contact your doctor.

IT IS IMPORTANT TO GET HELP
When your child is young you need to start getting help straight away. This is called early childhood intervention. People may say things like “he/she will probably grow out of it”, but it is important that you get help as soon as you notice a problem. Getting help early often makes the biggest difference because when your child is young it is easier to learn things that will be helpful throughout life.

There are several organisations that can help with your child’s health and therapy and they can also help you understand what is best for your child.

You may also be able to send your child to playgroups, preschools and other children’s services that meet the needs of your child. For more information contact the DADHC Early Childhood Intervention Infoline NSW, the DADHC Information, Referral and Intake Service (IRIS), your local Aboriginal Medical Service or your local disability support services.

SCHOOL YEARS
Just because your child has a disability doesn’t mean he or she can’t or shouldn’t go to school. The public school system is there for all children and young people. In fact there are many schools with education programs designed for students with a disability.

Students with a disability in government schools may be enrolled in a range of places which include regular classes, support classes in regular schools and special schools. Your local school can help with information. Remember, all children in NSW must go to school (unless they are registered for home schooling) from age 6 to 15. You can ask questions about enrolment at the local regional office of the Department of Education and Training (DET). They will also be able to put you in touch with Aboriginal support staff.

There are also organisations to help you with after school care and looking after your child during the school holidays such as the Commonwealth Carelink Centre or your local DET regional office. Your local school can help you with this information.
TEENAGERS AND TOWARDS ADULTHOOD

Some problems may not develop until teenage years start. For example, you may be concerned if your child:

- has sleeping problems
- appears very worried or withdrawn
- is hurting him or herself, for example by biting or cutting
- is not mixing well with family or friends
- is often angry or aggressive, or
- is having problems with drugs or alcohol.

If you are worried contact your local Aboriginal Medical Service.

TEENAGERS AND SEX

As your child grows older he or she will have different needs particularly when going through puberty. It is important to be prepared for how things will change and to talk to someone about how best to talk with your child about issues such as sexuality and family planning.

Sexual expression is a natural part of life and as your child becomes a teenager it is important to make sure they receive sex education and information about sexual health. Your local Aboriginal Medical Service will be able to answer questions you may have. Even if you feel shy, it is important to talk about these issues with your doctor and your child. You can also contact the Family Planning Association Healthline for advice.

TURNING 16

Before your child turns 16 it is important that you visit Centrelink as the payments for your child may change. You will still receive payments but the names of the payments will be different. You will no longer receive a child allowance but will be assessed for an adult allowance.

When your child turns 16 you should also ask Centrelink if your child can apply for the disability support pension. Remember to make an appointment with a Centrelink disability officer when your child turns 15 so you have plenty of time to make sure you get the right payments.

AFTER LEAVING SCHOOL

Often people with a disability are able to complete community education courses, further education and training courses through TAFE NSW and, in some cases, university courses.

The Commonwealth Carelink Centre has Aboriginal employees who can help you find out what college or university can best help your child, including information such as the specialised equipment and facilities they provide, accommodation and personal care facilities, learning support details and any educational allowances available.

For information on TAFE courses, you can contact your local TAFE college direct and speak to the Aboriginal Development Officer.
WORK AND COMMUNITY PROGRAMS

If your child with a disability needs help to get a job or to take a more active role in the community then the Department of Ageing, Disability and Home Care (DADHC) can help you. DADHC offers two programs for young people with a disability after they leave school.

The first program, Transition to Work, is designed to help your child develop skills that will help to get and keep a job. It is a two year program that provides several days of support each week.

The second program, Community Participation, provides support for young people with a disability to help them live a full and active life in their community. It can also help them to live independently or in a group house with other young people with a disability.

To find out more call the DADHC Post School Programs Information Line or go to the DADHC website and follow links to the People With a Disability Post School Programs.

DADHC can also help your child to find work or join in with other social and community activities. If your adult child is not ready or able to live alone, DADHC may also be able to find them a place with a suitable family in the community.

ADULTHOOD

With the right help, many people with a disability can live by themselves when they become adults. There are many services out there that can help your adult child find accommodation either on their own or with other people who have a disability.

There are also organisations that visit and assist people with a disability to help them live an independent life.
When your child feels bad

Not all pain is physical. Sometimes your child may feel angry, sad, lonely or frustrated. It is normal for your child with a disability to sometimes feel upset about not being like other children. If you don’t always know what to say to make your child feel better, don’t worry because there are people and organisations that can help your child to cope better when upset.

Most schools have a school counselling service or support people who can speak to you about good sources of help. Community health services and hospitals can also help you find a child counsellor or social worker. Your doctor may also recommend you take your child to see a child psychologist who is trained to listen to your child and who can help to work out ways for them to feel better. If you are not happy with the person your child is seeing it is okay to ask to see someone different. Contact the Aboriginal Disability Network or the Indigenous Disability Advocacy Service for more information.

WORK OPPORTUNITIES

Many people with a disability will be able to work in the general community or in supported employment and there are a number of organisations that can help.

Business services help people with a disability to get a job and they also provide a support worker to train them and help them keep the job. People with a disability receive a wage from their employer through the Supported Wage System. Call Centrelink and speak to a disability services officer for more information.

WHAT DECISIONS SHOULD YOU MAKE?

Once your child becomes an adult you may also need to consider getting what is called a Legal Power of Attorney. This is where you continue to take care of financial matters, medical decisions and care decisions even after your child turns 18.

To find out if you should get Legal Power of Attorney, contact the Indigenous Disability Advocacy Service (IDAS), the Aboriginal Legal Service NSW/ACT Limited or the Guardianship Tribunal.