



Shoulder to Shoulder

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

An initiative of the NSW Government

stronger together ::

A new direction for disability services in NSW :: 2006-2016



New South Wales
Government

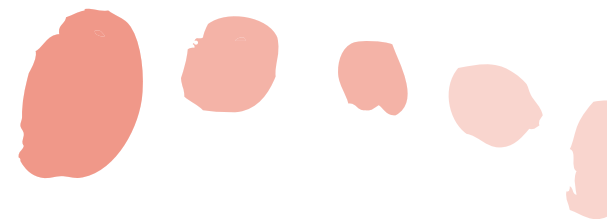


Department
of Ageing,
Disability &
Home Care



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Cover:
 From left to
 right Dominic,
 Nita and Corey
 Lyons with
 Aboriginal
 Education
 Assistant
 Schauntele
 Sagigi.

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- withdrawn behaviour when your child may not want to communicate with others.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.

Some children with disabilities may need support to carry out everyday activities





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.

Brothers and sisters can play an important role in the life of a child with a disability

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.



From baby to adult



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

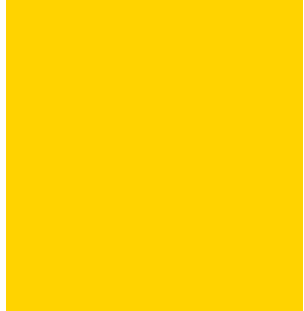
disability officer when your child turns 15 so you have plenty of time to make sure you get the right payments.

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.

Nita knows how important it is for her son Dominic to be prepared for an active role in the community

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

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.

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.



Caring for kids - Nita's story

Nita has two sons who have learning difficulties, Corey aged 15 and Dominic aged 18. Corey also has an acquired brain injury.

“Corey and Dominic were both premature babies but I didn't find out they had a learning difficulty until they were at preschool,” says Nita. “Corey got his acquired brain injury when he was eight years old and fell off a train.”

Nita says back then the first place she turned to for help was her own Aboriginal community and says that today her Aboriginal Medical Service (AMS) is still the first place she turns to when she needs advice about medical help for her sons.

“You just have to trust them to find someone for you,” says Nita. “After I went to my AMS, we had to go and see a psychiatrist because Corey was going through a lot of anger issues after he had the plate put in his head.

But when I saw the psychiatrist he suggested he had ADHD (Attention-Deficit Hyperactivity Disorder) and that he should be put on Ritalin. I thought that wasn't right so I said to him, ‘that's a quick solution to your problem but it's not going to help my problem’.”

Nita says when you have a child with a disability you have to trust your own knowledge of your child and that you need to learn to speak up and to not worry about feeling shame. She understands that sometimes even your AMS might send you to a doctor that you don't agree with.

“You have to keep looking until you find the right person that cares about what happens to him,” says Nita. “I'm past shame now, I can't have that word because if I used that word I would never have got anywhere with my boys. I just had to stand up and be strong. As a young Aboriginal woman I left school

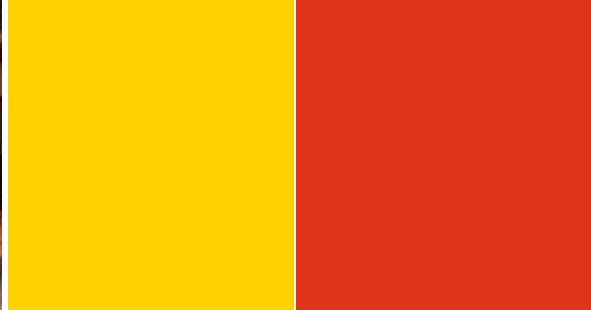
at 14 and I wanted something different for my kids. My eldest two went through school and finished and now I've got to fight for Corey's rights to be educated.”

Nita says she has had to fight for her children's needs throughout primary and high school. She says that while Dominic is now in a small, special class, Corey continues to struggle in the mainstream school system.

“The only way Dominic's coped is because he's not in the mainstream high school, but because Corey's IQ is high, he's not entitled to be in the same situation as Dominic.”

Apart from trying to get the best help for her children at school, Nita says she has also visited a lot of doctors, social workers, psychiatrists and speech pathologists to help her sons. But she says it can sometimes be easy to give up.

Nita believes in speaking up when it comes to getting an education for her sons Dominic and Corey



“I stopped looking for help for a while because a lot of them were saying there was nothing more they could do to help,” admits Nita. “Sometimes after you talk to them you get disillusioned, but my mum is out in the community and she sometimes gives me contacts and then I start talking to people again. You just have to try again.”

Dominic will soon be finished school, but Nita says as your children grow they have different needs that you need to be aware of.

“Dominic wants to start working when he leaves school but wherever he works he’ll need a lot of support because he still has a learning difficulty,” she says. “They will need to speak clearly to him and explain exactly what his jobs are, and give him one job at a time otherwise it will be too overwhelming for him.”

When you need a rest

If you are looking after a child with a disability it is important that you get a break to take care of yourself. You can ask friends or relatives such as your aunty or grandmother to help or you can use an Aboriginal respite care service. Don't feel guilty about taking a break. If you get sick because you are too tired or stressed then you won't be able to care for your child as well.

WHAT IS RESPITE CARE?

Respite care is when someone takes over caring for your child to give you a rest. Respite care can be a regular few hours a week, an overnight break or anything from a weekend up to a week or longer if necessary.

WHEN CAN YOU HAVE A BREAK?

You can plan to have regular or occasional breaks throughout the year. As respite care can be hard to get, it is best to plan ahead. If you haven't

planned a break and you feel like you need one, don't worry, you can still call your regional Carer Respite Centres to help you with respite care at short notice if you get sick or there is an emergency. So remember, you are not alone.

DO I QUALIFY?

Respite care is for anyone who looks after a child or adult with a disability. Whether you are a parent, sister, brother, husband, wife, partner, foster parent, grandparent, son, daughter or carer, you are able to ask for a break.

WHERE CAN I GET RESPITE CARE?

You can ask for help in your own home and also get respite care outside of your home.

There are retreats for carers where you get to go away and have a rest and there are also opportunities for your child to be cared for away from home. For example, your child with a disability could go on a

camp, holiday or weekend away, or might visit somewhere with special facilities for the day or for a few days. It can be good for your child to get to do things that can't always be done at home. It can also be good for the rest of the family who also need a rest. When your child is away this can be a good opportunity to spend special time with your other children or your partner.

TALKING CAN HELP

While caring for those you know and love can be very rewarding, most people who care for a child, young person or adult with a disability will at times feel angry, sad, frustrated, guilty, afraid or lonely. Sometimes it can help to talk to other parents who are going through the same thing. There are a number of Aboriginal parent and grandparent support groups throughout NSW. Contact the Aboriginal Disability Network or the Indigenous Disability Advocacy Service and ask

As a full time carer to her granddaughter Kayla, Ann knows the importance of respite care





for the number of your regional Parent Support Co-ordinator to find out about meeting up with other Aboriginal parents or grandparents of children with a disability.

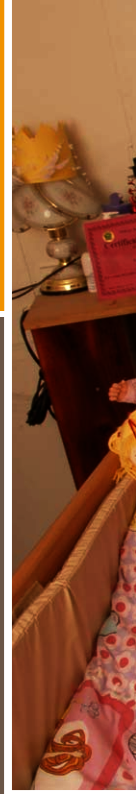
WHEN YOU NEED A CHAT

It can often help to have someone who will listen to you so if you are feeling sad or tired talk to your doctor, counsellor or call Lifeline.

You can also call Carers NSW and ask to speak to the Aboriginal Carer Support Officer.

TAKE CARE OF YOURSELF

Apart from finding someone to talk to, it is also important to take good care of yourself. Eat good food (lots of fruit, vegetables and whole grains) and drink at least eight glasses of water a day. It is also a good idea to get plenty of sleep and take some time out to exercise every day, even if it's just to go for a walk.



Finding a way through - Ann's story

Ann is the grandmother and full time carer of her granddaughter Kayla- Marie. Diagnosed with a terminal illness, Kayla-Marie has been paralysed since she was a baby.

“She was struck down with her illness at the age of four months. It’s called Glutaric Acaduria Type One,” says Ann. “It happened in a matter of 15 minutes, one minute she was our normal girl and then she was twisted up like a little withered tree.”

After she was diagnosed with the illness Kayla-Marie spent seven months in Westmead hospital before she was allowed to go home. Kayla-Marie is now six and a half and for the last three years Ann has been looking after her seven days a week around the clock.

“I look after her on my own, I have to feed her and medicate her through a tube in her stomach,” says Ann. “I have to wash her, lift her and do everything

for her that any normal child would need when they’re sick. I do all the very basic, daily things she needs because she’s totally dependent on me.”

Ann says children with Kayla-Marie’s disease usually have a short life expectancy. In order to make their life as enjoyable as possible they need a lot of really good care and Ann admits it can often be heartbreaking work.

“Sometimes it’s very emotional especially when she’s sick and you can’t do anything for her. I always try and look on the positive side. When I look down and see that beautiful little face smiling back at me, then I keep going for her sake.”

When Ann first started looking after Kayla-Marie she had no one helping her, but now she gets a small amount of respite care to help her rest and stay strong.

“I get three hours a week of respite care but now they’re going to try and

get some overnight respite care for me. My day doesn’t end at five. It goes all through the night because Kayla-Marie can’t bring her saliva up on her own and I have to help her to make sure she doesn’t choke.”

Ann says that when she gets respite care she uses it to catch up on her sleep as it is very important she gets her rest. Ann didn’t always have respite care. In fact, for many years she didn’t know who to turn to for help. However since finding the Indigenous Disability Advocacy Service she says things have improved for her.

“When I feel down I usually ring up the Indigenous Disability Advocacy Service” says Ann. “They’re like family there and sometimes I ring them and I say, ‘I’m feeling sorry for myself’ and when I let it all out then I feel better and I can start again.”

Kayla is cared for by Ann who makes use of all the services available to her



Ann says sometimes she feels self-centred when she complains, especially when her granddaughter is suffering so much, but she knows it is important to talk about her feelings.

“If you could see my girl and see the way she suffers then you’d know my suffering is only minute compared to hers. I sometimes think, ‘how can I be so selfish when this little girl is suffering?’ They tell me you shouldn’t feel guilty but you just can’t help it sometimes.”

Kayla-Marie needs a lot of equipment to help with her condition and Ann says that at the beginning she didn’t know who

could help her buy the equipment, so initially she paid for a lot of the equipment herself.

“I did garage sales and made the money to buy a lot of the equipment. You get so frustrated because the child needs these things and that’s where most of your frustrations come in.”

Ann says connecting up with other people who are in a similar situation can help you to feel better and also to better understand how the system works.

“The only advice I can offer is to talk with your friends and family or to go to a carer’s group and put your problems on the table,” says Ann. “A lot of people find it easier once they find out there is someone else in their situation who can guide them.”



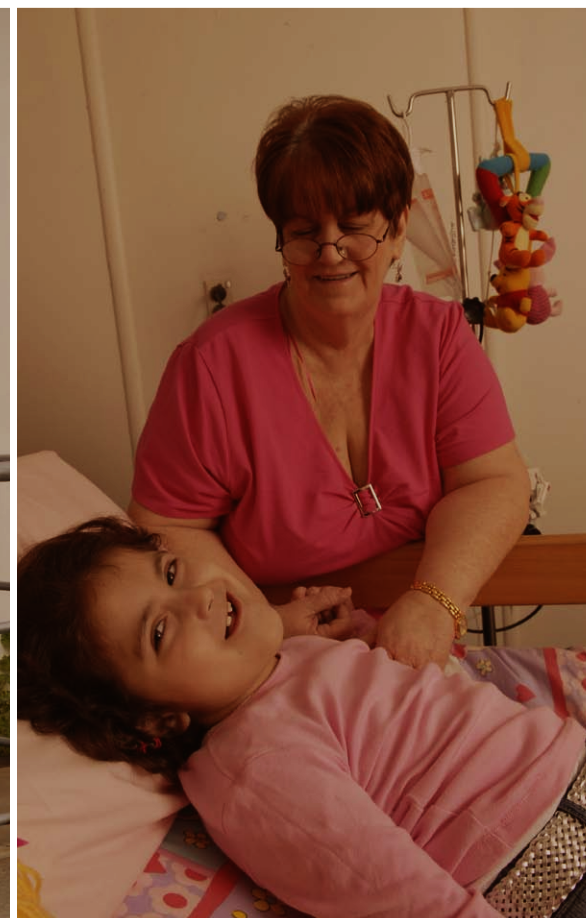
TAKING TIME TO HAVE FUN

Having a child with a disability can sometimes be difficult but that doesn't mean you can't have happy times together. It doesn't all have to be hard work. It is important that you recognise your child for all the things he or she can do instead of just thinking about what can't be done.

Depending on the kind of disability your child has, activities your family can get involved in may include art, craft, dance, singing karaoke, support groups, outings like going to the park or swimming, riding a bike or a horse, going to the movies and playing outdoors.

There are several groups that can help you have fun with your child in a safe environment. Contact the National Information Communication Awareness Network for information on recreation, accessible accommodation, tourism, sport and the arts for people with a disability.

Ann makes sure she takes time to have fun with Kayla, playing at home or going for walks





LET'S GET PHYSICAL

Physical activity and exercise is important for good health for everyone. Children with a disability should be encouraged to do whatever exercise they can manage.

Apart from fun activities and exercise, doing everyday activities such as sweeping, washing, watering the garden, hanging clothes on the line and walking to the shops can help your child be healthier and feel happier. It can also lighten your load and help your child to learn important living skills. Speak to your doctor or therapist about activities that will best suit your child.

It doesn't matter what other people think - Nikki's story

After ten years of caring for her son Brady who has a disability, Nikki has learnt to trust her own feelings to do what is best for Brady and her family.

Brady, who has an intellectual disability, epilepsy and some of the features of autism was first diagnosed at age three.

"When he was diagnosed with an intellectual disability they said he was born with it but I'm not sure about that. I think the seizures he's had slowed him down. We had to teach him to talk and walk again at the age of four but before that he was reaching all his milestones for his age - yet they kept telling us he was born with it. Sometimes they look at you as if to say 'you don't have a degree' but I know about Brady because I'm his mum and I'm with him around the clock," she says.

In order to get as much information as possible, it is a good idea to ask as many

questions from your doctors as possible. Nikki believes you shouldn't be shamed if you don't understand everything at first.

"If I don't know something I'll get my doctor to explain it to me until I do," says Nikki. "Even if they have to tell me 24 times, I'll keep asking questions until I know what they mean. I'll also ask about the medication they are putting him on because I need to know exactly what medicine he's taking, what it does and what it's going to do to him."

The medication is helping Brady and Nikki says he just looks like any normal kid. However, while that has its benefits, it can also make life more difficult for his mum when they go out in public.

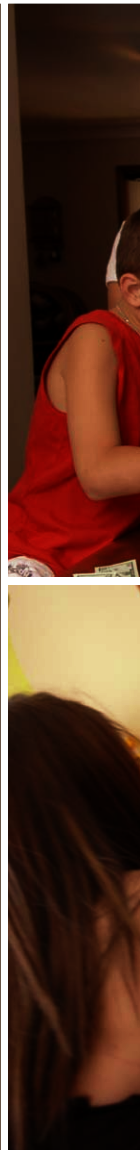
"You look at him and you would think he's a normal kid. There's a stigma there that everyone with a disability should look like they have a disability," says Nikki. "He doesn't like crowds and when he

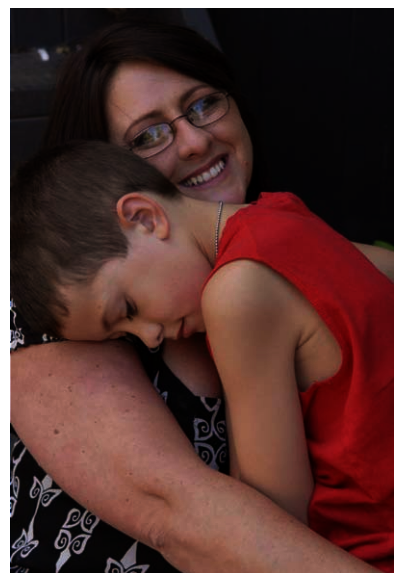
gets in a crowd he has a panic attack and will sometimes chuck a tantrum. Because he looks normal people will give you a look, as if to say control your kid, but it's not that, he's just not comfortable in his surroundings."

Nikki explains that talking with 10 year old Brady is like talking to a three year old and because of this he finds it difficult to play with children his own age.

"We went camping a few years ago and this young boy about the same age as Brady came up to talk to him and because Brady was so excited he couldn't get out what he wanted to say. The boy walked away and it broke my heart. When he's with younger kids he talks their language and he's the bigger person for a change. With older kids he mainly plays with his brothers and sisters and their friends and they take him to the movies which he thinks is fantastic."

Brady enjoys fun times with his mum, dad brother and sisters





Nikki's other children are aged 17, 15 and 13 and while they love their brother, she admits they have had to make some sacrifices.

"When they were younger and they wanted to have sleep overs it was hard for them because we never knew when we would need to get up and go to the hospital, so they couldn't have sleep overs at home," says Nikki. "Their sleepovers were always at their friend's house but I felt like the nasty mum who was always sending my kids away, so I had to explain it to the other parents."

Despite Nikki trying to compensate for the extra time she had to spend with Brady, she says it was still sometimes difficult for her other children to understand the extra attention he needed, especially when they were younger.

"My eldest son was seven when Brady was diagnosed so he was more

understanding whereas my youngest daughter was much younger so she always felt like Brady was the favourite. As she got older she realised he wasn't the favourite, he just needed more attention."

Despite the difficulties though, Nikki says that Brady and her family still have a lot of fun together.

"We have a ball. He loves music and Saturday mornings consist of everyone dancing and singing and he has his own little microphone. At the moment he's singing Advance Australia Fair and he's just told me I have to stand up," she laughs. "There are a lot of downs but there are always a lot of ups. He's our boy, we can't change him and you've got to enjoy what you've got. Right now he's sitting there in his spider man outfit ready to web somebody," she laughs.

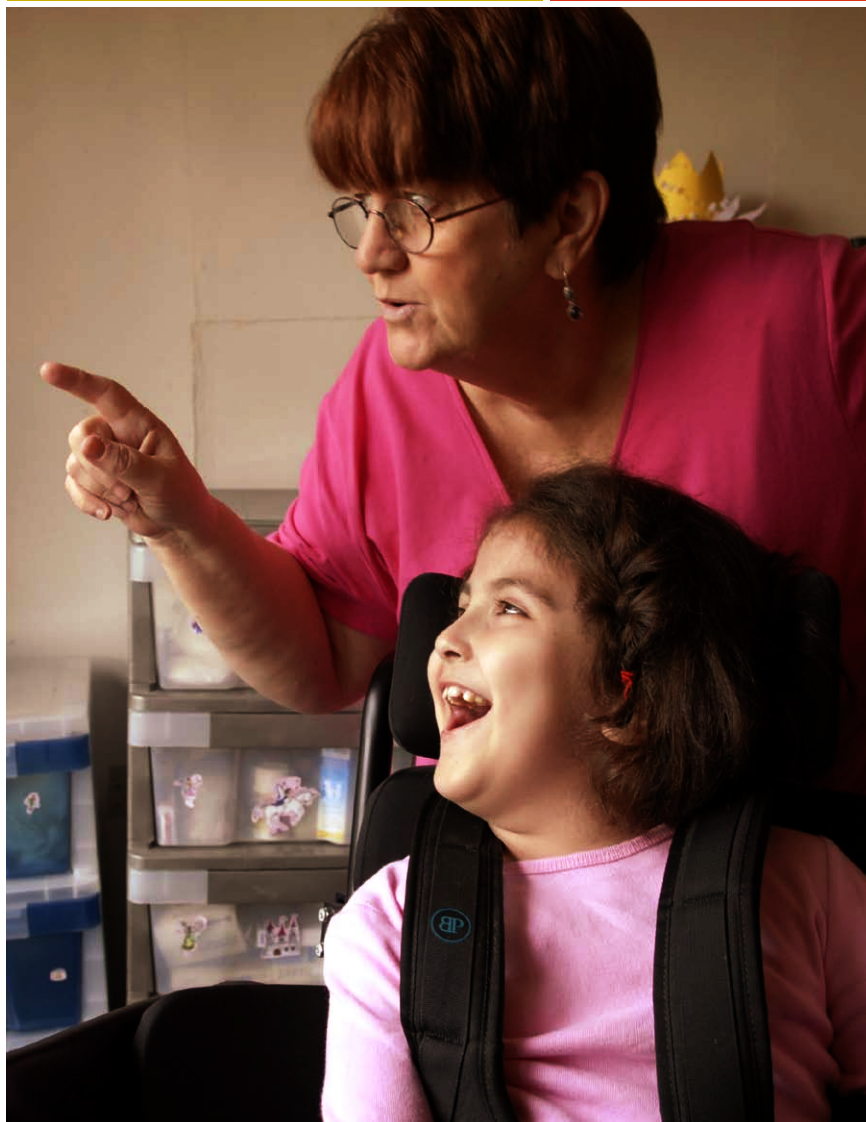
People who can help

Getting help with money

If you have a child with a disability you have the right to get help but you have to ask. It is important you know that you can receive the money and services you need in order to keep you and your child strong and healthy.

CENTRELINK

Centrelink has funds to help people with a disability and their family. Your Centrelink social worker or disability services officer can help you with advice on what pensions you and your child can receive from the government. For example, if your child has a disability and is being looked after by you full time, you can receive a carer's allowance. You may also be able to get travel allowance, rent assistance, special activity assistance, telephone allowance, remote area allowance or mobility assistance.



Getting help when you need it can help you to better enjoy your time with your child with a disability

Equipped for anything

Depending on your situation, you might be able to get help in making sure your house is easy for your child to live in. If your child uses a wheelchair for example, you may be able to get some money to build a ramp to your house.

As your child gets older there are also people who can help them with money so they can live on their own and find work.

CONCESSION CARDS

Concession cards are provided by Centrelink to give you discounts that help you and your child with a disability. Make sure you also ask if you can get a Health Care Card which gives you cheaper medicine and a travel concession card for discounts on public transport.

For more information call the Centrelink Indigenous Call Centre or the Centrelink Disability, Sickness and Carer's line.

To help your child to be able to do as many things as possible, it might be a good idea to see if there are any special aids or equipment that can help.

If your child needs special equipment you can apply for this equipment. Some equipment that can help includes:

- mobility equipment to help move about such as wheelchairs, walking frames, splints and surgical footwear, hoists and transfer boards
- bed equipment such as bed rails and bed levers to help your child in and out of bed
- personal care equipment such as commodes and portable toilets to help with bathing and toileting
- orthotics such as artificial legs, splints and surgical footwear to help with problems with feet, legs and arms

- communication equipment such as personal alarms and switches to assist with speaking and contacting others
- continence aids including pads for if your child is incontinent (wets him or her self).

WHO CAN HELP

You may be eligible to receive money from the DADHC Family Assistance Fund to buy equipment or services. This money can help to make practical changes at home and make it easier for you to care for your child with a disability. To find out more about the Family Assistance Fund call your DADHC regional office.

NSW Health also provides equipment and aids to help people with disability. The Program of Appliances for Disabled People (PADP) is designed to help people with a long-term disability take part in their community. Ask your local hospital for the phone number of your NSW

Getting the best health support for your family

Health Lodgement Centre which can help you apply for PADP support.

When you have a child with a disability you will probably have to visit a lot of different health support workers. At first it might seem like there are too many people to go and see, but once you understand what they all do then it will be easier to understand why it is important to keep your appointments and to get the right person to treat your child.

Your local Aboriginal Health Worker or Aboriginal Medical Service will probably be the first place you go when you have a child with a disability. They can help you by sending (referring) you to see other doctors who specialise in helping children with the particular disability your child has. Here are a few of the health professionals you may be sent to.

PAEDIATRICIAN

A paediatrician is a doctor who is trained

to treat infants, children and teenagers. Paediatricians have to study for six years more than a general doctor and there are different types of paediatricians. Some also specialise in other areas such as treating children's hearts or working with developmental delay in children. So you may see more than one paediatrician. Your doctor has to refer (send) you to a paediatrician. If your doctor doesn't refer you then you won't get a refund from Medicare. If you visit a paediatrician at the hospital outpatient clinic it does not cost you anything.

SPEECH PATHOLOGIST

A speech pathologist is a health worker who works with people who have problems communicating. Communication problems are when someone either has difficulty understanding language or being understood. Speech pathologists can help people with their speech, reading,

writing, and also with understanding signs, symbols and gestures. They can help people who have difficulty swallowing food or drink. They work in a number of different places including kindergartens, primary and secondary schools, hospitals, universities, rehabilitation services, mental health services, community health centres and their own private practice.

PHYSIOTHERAPIST

A physiotherapist is a health worker who treats people with a range of physical problems. These problems may include spinal injuries, joint problems and chest conditions as well as problems in moving, coordinating or balancing. Physiotherapists use treatments to help control pain and improve your child's condition. These treatments include mobilisation (moving), manipulation of joints, massage, therapeutic exercise, electrotherapy, hydrotherapy and hot and

cold packs. Physiotherapists work in hospitals, rehabilitation units, community health centres, schools or in private practice.

OCCUPATIONAL THERAPIST

An occupational therapist helps people with the skills they need to function in their day to day life. They can help with basic physical movements of the small muscles or larger muscles (motor function). They can also help people to be able to reason or think better. Occupational therapists help people to do a range of activities from using a computer to daily needs such as dressing, cooking and eating, budgeting, shopping or the use of public transport. They may use physical exercise to help them increase their strength or use memory or visual exercises to help with problem solving and thinking. They can also recommend the kind of equipment people with a disability might need to help them at work or home.




Don't go it alone: Places to find help

When you have a child with a disability there are going to be times when you need some help. The important thing is to not give up and to not be too shamed to ask for help.

There are plenty of organisations out there that have been set up to help people who have a child with a disability. Sometimes you might have to ask more than one person but keep asking because there is someone out there who can help you and your child get the care you need.

Aboriginal Disability Network NSW (ADN)


Provides Aboriginal people with individual and group advocacy support.

 **1800 611 889** or **TTY 02 9318 2138**

 or email: **adnsw@pwd.org.au**

Access to Accessible Toilets

Helps people with a disability to have 24 hour access to public accessible toilets.

 **1800 990 646** or

 **www.toiletmap.gov.au**


Aboriginal Community Liaison Officers

Many hospitals now have Aboriginal Liaison officers or social workers that you can talk to about such things as concerns about your child or problems you are having with the health system. You can also talk to them if you are not coping, are feeling bad or if you or your child have any mental health concerns.

They can be contacted through your local hospital.

Carers NSW

Provides advice if you are looking after a child with a disability and just need someone to talk to or to give you information. Ask for the Aboriginal Carer Support Officer.

 **1800 242 636** or

 **www.carersnsw.asn.au**

Carer Respite Centres (regional)

Can arrange for short term and emergency respite (rests). The number will go through to the respite centre that is nearest to where you live.

 **1800 05 9059**


Centrelink

Can help if you need advice about getting a job for a young person with a disability. Ask to speak to your nearest disability employment network.

 **132 717** or **www.centrelink.gov.au**

Centrelink Indigenous Call Centre


Provides information about what money and services you and your child with a disability should be receiving.

 13 63 80

Children's Hospital at Westmead

For information fact sheets on disability issues.

 9845 0000 or

 www.chw.edu.au/parents/factsheets

Commonwealth Carelink Centre

Provides information about what services the government has for you and your child with a disability.

 1800 052 222 or

 www.commcarelink.health.gov.au

Criminal Justice Support Network

Operates a 24 hour information, referral and support service to help people with intellectual disabilities who are in trouble with the police or the law.


 1300 665 908 or

 cjsn@idrs.org.au


Department of Ageing, Disability and Home Care (DADHC)

Offers a wide range of services for people with a disability and their families including help with respite care, funding for equipment and support for families in crisis. Call and ask for the Intake Information and Referral Service.

www.dadhc.nsw.gov.au

 Metro North Region
8855 4200

 Metro South Region
9334 3700


 Western Region
1300 134 450

 Northern Region
1300 364 563

 Hunter Region
4908 5229


 Southern Region
6200 7300

There are 8 Aboriginal Home Care Branches with 23 outlets as part of the Home Care Service of NSW providing services to Aboriginal people with a disability and also older people and their carers. To access Aboriginal Home Care call the Aboriginal Access and Assessment Team who can also refer you to other providers if needed.

 1300 797 606 or

 aboriginalrac@dadhc.nsw.gov.au

For information about post-school programs call the DADHC Post School Programs Infoline.

 **1800 761 030**

Department of Education and Training (DET)

For advice about services available from government schools call the regional office. You can get information about enrolling your child with a disability in a school and they can put you in touch with Aboriginal support staff. They can also advise you about pre-school and early childhood intervention classes.

 www.schools.nsw.edu.au/gotoschool/enrolment/index.php

 www.schools.nsw.edu.au/studentssuppot/studenthealth/index.php

There are plenty of organisations out there who can help children like Kayla


Contact numbers for the NSW Department of Education and Training (DET) regions are:


 Sydney **9217 4877**

 Sydney South West **9796 5446**


 Western Sydney **9208 9359**


 Northern Sydney **9886 7690**

 Hunter/Central Coast **4924 9999**

 Illawarra and South Coast **4222 2929**

 New England **6755 5934**


 North Coast **6652 0500**

 Riverina **6937 3871**

 Western NSW **6841 2110**


Disability Complaints Service (DCS)

Can help you if you have called somewhere for assistance but feel like they haven't listened to you or have treated you badly.

 **1800 422 015**

Disability Discrimination Legal Centre


Gives help if you think someone isn't treating you or your child equally because of their disability.

 **1800 800 708** or

 www.ddlcnsw.org.au

Early Childhood Intervention Infoline NSW


Provides useful information about what services are available if you are concerned that your young child may have a disability.

 **1300 656 865**




EnableNSW (NSW Health)

Provides equipment and aids to help people with a long-term disability through its PADP program (Program of Appliances for Disabled People). This includes assistance with continence pads.

 1800 362 253

Family Planning Association Healthline


Can provide information about relationships, health and contraception.

 02 8752 4300 or

 www.fpahealth.org.au

Guardianship Tribunal

Can help you with information about Legal Power of Attorney.

 1800 463 928 or

 www.gt.nsw.gov.au



Independent Living Centre NSW Inc.

Helps with information on how your house can be changed to make living with a disability easier.

 **1300 885 886** or
 **www.ilcnsw.asn.au**

Information on Disability Equipment Access Services (IDEAS)

Provides information about disability equipment.


 **1800 029 904** or
 **www.ideas.org.au**

Indigenous Disability Advocacy Service (IDAS)

IDAS provides short and long term individual advocacy, advocacy training and an information service to Aboriginal people with a disability and their families.



 **1300 114 327**

John Hunter Children's Hospital

 **www.kaleidoscope.org.au/parents/factsheets.htm**



Kids Help Line

Provides a free 24 hour telephone number that kids aged five to 18 can call if they want to speak to someone about feeling bad.

 **1800 55 1800** or
 **www.kidshelp.com.au**

Lifeline

Provides 24 hour support if you need to talk to someone because you are feeling very upset.

 **131 114** or
 **www.lifeline.org.au**

National Disability Services (NDS)

Provides advice about quality services and life opportunities for people with a disability.

 **9256 3111** or
 **www.nds.org.au**

National Information Communication Awareness Network

Can give you advice about activities for you and your child including sport, art, things to do and holiday accommodation that is easy for people with a disability to access.

 **1800 806 769** or
 **www.nican.com.au**



NSW Health

Has a useful website with local service information for people with a disability and their families.

 **9391 9000** or
 **www.health.nsw.gov.au**

Parent Line

Can help you if you are worried and want to talk to someone about your child. Now open 24 hours a day, 7 days a week, 365 days a year.

 **13 2055** Or
 **1300 130 055**


Raising Children Website

Provides help for parents raising a child and has a useful section for parents of a child with a disability.

 www.raisingchildren.net.au

Relationships Australia


Can help if you need to talk to someone about your partner, husband, wife or family.

 1300 364 277

Royal Far West Children's Health Scheme


Provides support to families who live in country NSW and more than 50 kms from Sydney. Can give your child free medical and other care with free transport to the hospital as well as accommodation. If your child has a severe disability they also offer a respite (rest) service.

 8966 8500 or

 1800 500 061 or

 admin@royalfarwest.org.au

Sydney Children's Hospital

 9382 1111 or

 www.sch.edu.au/health/factsheets

Sydney Dental Hospital, Paediatric Dentistry Department


Provides dental help for children with a disability.

 9293 3230

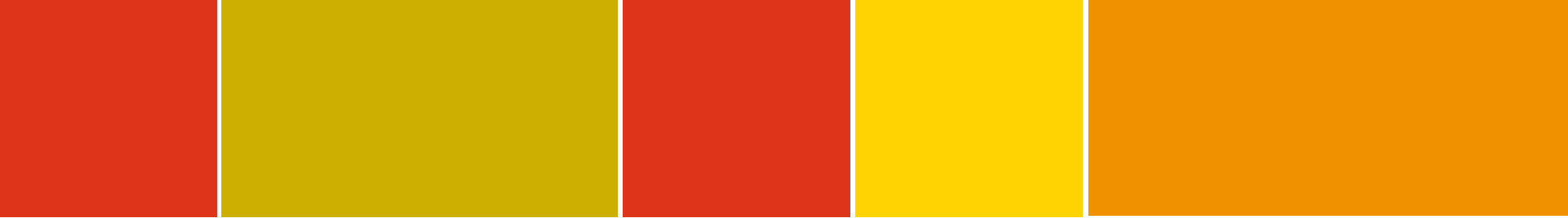
YOUNG CARERS

The Commonwealth Carer Resource Centre

Can help if you are a young person caring for a brother, sister, mother or father with a disability.

 1800 242 636 or

 www.youngcarersnsw.asn.au



NSW Department of Ageing, Disability and Home Care

Level 5, 83 Clarence Street
Sydney NSW 2000

Ph 02 8270 2000

TTY 02 8270 2167

www.dadhc.nsw.gov.au

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