

Caring Together
Raising them strong
Caring for kids with a disability



**This book is dedicated to kinship and foster carers
across NSW and the amazing children and young people
in their care.**



This book is part of the *Raising Them Strong* carer support project that includes the booklets on *Raising Them Strong*, DVD and topic cards. Developed with Aboriginal kinship and foster carers, carer support groups, carer support workers and the Aboriginal Child, Family and Community Care State Secretariat (AbSec).

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What is this book?

This book is for kinship and foster carers who care for an Aboriginal child or young person with a disability.

Looking after kids of any age can be both a real challenge and lots of fun. As a carer you can watch the child learn and grow, see when they shine and be part of each step. At the same time, when a child has a disability it can mean a lot of extra challenges. Having support can make a big difference.

This book has information, advice and ideas to help you as a carer.

It's important to ask for help when things aren't going well and to talk about any worries you have. Talk to the caseworker, your doctor, support worker or join a carer support group.

Having a disability can affect the way kids learn, behave and how they grow. They may struggle with everyday things like eating, having a bath, following rules and learning at school. They often feel that people do not listen to them especially if they cannot communicate very clearly. Try to work out their likes and dislikes – otherwise it can be frustrating for everyone!

Each child is different and as they grow their needs will change. Don't go it alone, form a team who can help out – like doctors, teachers, psychologists, paediatricians, early intervention workers, family, community and friends... caring together.

This book includes:

- ▶ **settling in and talking about disability**
- ▶ **health and types of disabilities**
- ▶ **challenging behaviour**
- ▶ **education**
- ▶ **looking after yourself**
- ▶ **support and financial help.**

“ We have to help our kids to aim high. ”



“ Find out as much information as you can. ”

Settling in

Talk to the caseworker about the child's disability and their needs. Find out as much as you can and ask questions. Ask about medicines, equipment, behaviours, diet, likes and dislikes.

- ▶ Take the child to the doctor, paediatrician and dentist for a check-up – ask about any specialist help the child may need. This might include an occupational therapist, speech therapist, physiotherapist or early intervention support services.
- ▶ Talk to the caseworker about day-to-day support. Depending on the child's age or needs this might include enrolling the child into preschool or early intervention programs, adjustments to your home or special equipment, or assistance with transport.
- ▶ Watch the child and listen to what they say. Children communicate through behaviour, gestures, sounds and art. Work out how the child is communicating 'yes' and 'no'.
- ▶ Try to include, where possible, a range of objects that they will recognise such as their toys and photographs.
- ▶ Try to talk to the child about your home, family life and routines. Keep things settled and calm, especially when you're getting to know each other.
- ▶ Tell the child who to talk to (and wake) if they feel sick, wet the bed, have a bad dream or feel worried. Placing something on your door like a photo or picture may help remind them where to find you. Tell them you are there for them.

Ask for a copy of the child's personal health record (the Blue Book) and talk to the caseworker about what health assessments have happened or what might be needed.



Talking about disability: feelings and reactions



Talking about feelings helps kids understand disability and deal with their and others' reactions. Find a quiet time to have a yarn about feelings, including any other children you care for.

Help kids understand and deal with the challenges of having a disability.

- ▶ Help the child talk about their disability and how they feel. Let them go at their own pace, not all kids are ready to talk about these things. Ask them how they are going every day and give them lots of praise. Tell them they're deadly!
- ▶ Encourage questions, and answer them honestly and in a way the child can understand.

- ▶ Give the child ideas about how to handle questions from other kids and grown-ups. Talk about what to say and what not to say!
- ▶ Teach children to tell you, a teacher or trusted adult if they are being teased or bullied.
- ▶ As kids get bigger, talk about the future. Be positive and realistic about the future.
- ▶ Remind the child (and others) about their strengths and capabilities.
- ▶ Understand the child's limitations, talk about what's realistic.
- ▶ Find activities they like to do and where they can feel good about themselves.

Siblings/other children in your home: Talk about disability with other children in your home – this will help them understand and explain the disability to other people. Try to be reassuring and stick to simple language. Sometimes they may feel shame, guilty or like they have too much responsibility. Talk about how other people react and how to respond. Explain that sometimes people say hurtful things because they don't understand. Make some special time together.



“ We found a child psychologist that we liked, that we're comfortable with. It's really helping our boy, he's had it tough. ”



“ Talking about feelings helps kids understand disability and deal with reactions. Find a quiet time to have a yarn about feelings. ”



Health – caring together

Take the child to visit the doctor or a paediatrician. If your child has a disability you may need to see several doctors and visit a specialist doctor. You can go to your local doctor or the local Aboriginal health service, use community health or get a referral to see a specialist.

If you don't get along with a doctor, it's okay to find another doctor. Ask other carers and parents for recommendations for good local doctors or specialists.

Make sure the child has a health check (assessment) and ask questions so you really understand the disability. Your caseworker will tell you if the child in your care is eligible for or (or is already part of) the "health pathway" a shared pathway with Health to coordinate the assessment and meet the health needs of your child.

Many specialist services have a **waiting list**. Get help early so you can put your child's name down on the waiting list. You may need to make a few calls to get in. Explain your child is an Aboriginal child with a disability or special needs. Ask for help and support from the caseworker if things get stressful.

Ask for help and advice if you are overwhelmed about **medical appointments**, forms or processes. It can be frustrating and confusing! Contact the caseworker, disability support worker or carer support if you are stressed out.



“ Our local AMS helped with everything – psychologist, eye tests, new glasses and even braces. So we always go there. ”

Health – getting in early

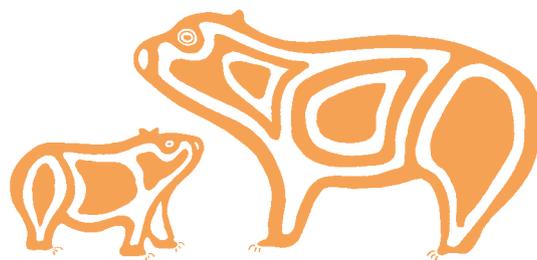
Early intervention is about supporting young children with a developmental delay or disability with special help and services as soon as possible. An early intervention specialist can work with you and the child with a disability to develop a plan to support the child to be the best they can be.

The plan may include:

- ▶ developmental and learning activities
- ▶ opportunities to interact with other children
- ▶ play based activities to develop new skills.

The early intervention worker can also help you to connect with psychologists, speech pathologists, educators, physiotherapists and occupational therapists if needed. They can also help you find out about local preschools or early intervention programs for your child.

Some early intervention services run preschool programs and supported playgroups. Ask about your local early intervention service.



Working with doctors, health workers and specialists



Working together with health services means you are part of a team supporting your child. Sometimes you may feel overwhelmed by all the people involved, but remember you're the person who knows your child best – so don't forget your role is important!

If you're not happy with something, ask questions or get a second opinion or talk to the caseworker.

When talking to the doctor, nurse or health workers you should be able to talk freely about your child's condition and needs, about your needs and feelings, and about the situation.

The doctor or specialist should be able to explain things in words that you can understand.

Make a list of any worries and take the list with you when you go to see the doctor. Take a support person (like Aunty or another carer) to help in the discussion.

What if I don't agree? Sometimes you'll disagree with the health professionals you work with. Stay calm. Speak to your caseworker or the disability support worker or call carer support. Most of the time you'll be able to figure things out between you. Make a **special appointment** to discuss any worries without your child there.

Complex and challenging needs

As the carer you can benefit from having a good understanding of the child's intellectual disability or developmental delay (when they are not doing the things that other kids their age are doing).

It's important to get a **full assessment and diagnosis**. This usually happens when kids are young but can also be useful in the teenage years. Get in early for a health assessment if you have any worries or concerns about the child in your care.

Usually if a child has a disability referrals are made to the **Information, Referral and Intake team (Ageing, Disability and Home Care)**. The caseworker will work with the team in your region to ensure the child's needs are met. Talk about what goes in the case plan and the health plan.

School counsellors and psychologists can also do assessments to identify an intellectual disability. Sometimes problems are not easy to pick up. If you're worried talk to someone – like the health professionals, teachers, support worker or ask the caseworker for a referral to a psychologist.

www.physicalanything.com.au has good information and ideas about helping kids with disabilities. The site includes **great videos** with families telling their stories. There are videos about how to work with the school to support kids and to help kids feel good about themselves.

Enable NSW provides access to equipment to help kids with a disability. Visit www.enable.health.nsw.gov.au to see guidelines and get an application form for:

- ▶ aids and equipment request forms
- ▶ footwear and orthotics
- ▶ home enteral nutrition
- ▶ home respiratory program
- ▶ mobility and self care
- ▶ pressure care and seating
- ▶ prosthetic limbs
- ▶ communication
- ▶ continence.

“ **Ask the doctor to explain again if you don't understand. There's no shame.** ”

Different types of disability

There are lots of different types of disabilities – and some children have more than one disability. Here is some information but you can find out more by looking at the back of this book, going on the internet, or talking to a health worker or caseworker.

Autism

Autism is a spectrum disorder which means a child can have a range of autistic features from mild to severe.

Autism is a different way of thinking and affects how people make sense of the world around them. But it can also come with many talents.

People with autism have problems with how they interact and communicate with others and often have restricted and repetitive behaviours. Some of the signs of autism in very young children include:

- ▶ no big smiles or warm, joyful expressions by six months or thereafter
- ▶ no copying sounds, smiles, or facial expressions by nine months or older
- ▶ no babbling by 12 months, or words by 16 months
- ▶ no back-and-forth gestures, such as pointing, showing, reaching or waving.

Routine and keeping kids safe

Stick to a schedule for meals, bath-time and bedtime, therapy and school. If there is going to be a change, prepare your child – talk to them, use stories or pictures to prepare them for the change.

Be consistent to help children adapt what they've learned in one setting (such as at therapy) to others, including the home. Creating consistency is the best way to reinforce learning. Find out what the therapists are doing and do this at home. Be consistent in the way you talk and deal with any challenging behaviours.

Slow down and give the child a chance to communicate. Caring for a child with autism can be hard work and time consuming. You might feel like rushing the child when they are doing daily tasks such as eating breakfast and getting dressed. Give them some extra time. Be patient. This gives kids extra time to help understand what is happening around them and to talk about these activities.



“ Find out about early intervention programs and preschools in your area. ”

Create a safe home so the child can relax and feel secure. You may need to organise and set boundaries your child can understand. For example coloured tape to mark areas that are off limits, labelling items in the house with pictures. You may also need to safety proof the house – particularly if your child has tantrums or can injure themselves.

Reward positive behaviours and praise them when they do something positive or learn a new skill. Be specific about what you are praising them for e.g. “I liked the way you tidied your toys.” Look for ways to reward them such as giving them a sticker or letting them play with a favourite toy.

Look for non-verbal signs. If you are aware, you can pick up on the non-verbal cues that kids with autism use. Pay attention to the sounds they make, facial expressions, and the gestures they use when they’re tired, hungry, or want something. You also communicate by the way you look at the child, the way you touch him or her, by the tone of your voice and body language.

Figure out what’s behind the tantrum. It’s only natural to feel upset when you are misunderstood or ignored, and it’s no different for kids with autism. When they act out, it’s often because you’re not picking up on their non-verbal cues. Throwing a tantrum is their way of saying how they feel. Try and work out what’s set it off.

Give things to the child gradually. If the child is given everything they want they will have no reason to ask you for anything else. For example, if the child wants a biscuit, break it into small pieces, give

them one piece and then gradually give them more once they have asked for it in whatever way they can. Give the child a chance to show and tell you what they want or need.

When playing with the child take on the role of a partner rather than a leader. As the child becomes more capable at communicating, they need less direction. If they are given too many questions and suggestions it can become difficult for them to start their own conversations. Follow the child’s lead and respond to what they do.

Let the child decide when to end an activity. Look out for facial expressions or the child pushing away the activity. This way, the child is forced to communicate that they are ready to finish. If they don’t use language, then you say words ‘had enough’ or ‘stop’ with whatever communication they use – this will help language development.

Work out sensory responses. Some children may be sensitive to light, sound, touch, taste, and smell. Work out what sights, sounds, smells, movements, and textures trigger their likes and dislikes. If you understand them, then you’ll be able to prevent situations that cause them to act up or feel upset.



Asperger syndrome is part of the autistic spectrum. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties understanding and processing language.

Kids with Aspergers often have trouble communicating with other people and understanding what they mean. At the same time, they might have good language skills, talk easily on their favourite topics and like yarning.

Kids with Aspergers sometimes have challenging behaviours and don't always understand what people mean or feelings. Find out what works for your child and talk to their teachers about how they can learn best.

Make time for fun. A child with autism is still a kid. For everyone in your family there needs to be more to life than therapy! Work out good ways to have fun together. What makes your child smile, laugh, and come out of their shell.

Foetal alcohol spectrum disorder is when a pregnant woman drinks alcohol (including binge drinking) and this causes problems in her unborn baby. Alcohol crosses the placenta into the baby's bloodstream. This can harm the nervous system, including the brain. Signs at birth include low birth weight, small head circumference and small eyes. Other signs include:

- ▶ underdeveloped vertical ridges that run from the nose to the upper lip
- ▶ upper lip is thinner than normal.
- ▶ small lower jaw
- ▶ heart defects.

Sometimes it doesn't get picked up until later, when the child is having problems with learning or behaviour. The child may also experience developmental delays, behaviour problems such as difficulties with attention, learning difficulties and memory problems, clumsiness and language delays.

There is a great deal carers can do to help. Teach them songs and rhymes and read to them to improve their language and memory. Speech therapists can help children improve their language skills and work with the carer to give ideas for developing language skills at home. Occupational therapists can teach many games and activities to help them become less clumsy. Many playground games help a child learn to pay attention.

Down syndrome is a chromosomal disorder and is one of the better known intellectual disabilities. Kids with Down syndrome all look different, but they do have some similar characteristics such as a slightly flatter profile and slanting eyes. Other features include small ears, hands and feet. Physical problems such as heart defects and low muscle tone are common. They may also have a developmental delay and intellectual disability. Early childhood intervention services can help younger children with Down syndrome get ready for school and some children can attend regular schools. With help and support, some children with Down syndrome can successfully learn to read, write, manage everyday tasks, and find useful employment when they grow up.

Epilepsy is a common neurological condition where children may have a seizure. This can be scary for the child and for you so it's important to get a diagnosis and understand what might trigger a seizure such as tiredness. Many children and adults with epilepsy can become seizure-free by taking medication and keeping healthy. As part of diagnosis, the doctor will do routine physical and neurological examinations which may include blood tests. There are several brain tests such as an EEG that may help to diagnose the condition and find the cause.

Ear problems, hearing impairment and deafness can be inherited or caused by infections or repeated exposure to loud noise. Some Aboriginal kids have 'glue ear' and if it wasn't picked up early it can cause delays in speech, language and learning. This all depends on when the hearing problems were diagnosed and treated. Today, early intervention services provide support and teach children so they can learn and be the best they can be. Sometimes hearing aids can help and in some cases Cochlear implants or corrective surgery can also help. Specialists who can help include an audiologist, specialist teacher and speech pathologist.

Hearing loss can affect development of listening, speech and language skills. Some children with hearing problems can learn to use sign language (AUSLAN). Children with deafness and special needs can also learn to sign because there are different types of sign language that can assist kids.



“ If you can, use the internet as a resource – but not a diagnosis. ”

Eye problems: if your child has a serious visual impairment or can't see well, make your home is safe by checking for things that could cause accidents.

As your child gets older, they may need a special school that will support their learning and development. As they mature, children with low vision generally have fewer opportunities to run, jump and climb. This makes it hard for them to play with others and they may feel lonely. Talk to the teachers about how they can help.

Get involved in helping the child to make best use of other senses like hearing and touch for learning. Some kids are able to read large print books. Others learn Braille or learn from audio-tapes and 'talking books'. Help the child become as independent as possible.



Tips from carers of kids with a disability

"Find out about early intervention programs and preschools in your area."

"Be the voice for these kids."

"When you have a medical appointment, take their favourite toy to keep them occupied while you're waiting."

"Try to be aware of your child's fears – get a handle on that."



Physical disabilities

There are many different types of physical disabilities and a range of services (see the back of this book) that can help children get moving, be mobile and try new things. Some of the main ones include:

Muscular dystrophies means that the muscle fibres in the body gradually weaken over time. Children can have different types of muscular dystrophy. The most common type is Duchenne Muscular Dystrophy, which occurs only in boys. All types of muscular dystrophy are genetic even though other family members may not have the condition.

Acquired brain and spinal injuries Physical disabilities may result from permanent injuries to the brain, spinal cord or limbs that prevent proper movement in parts of the body.

Spina bifida Sometimes, a baby's spinal cord (the nerves that run down the spine) does not develop normally during pregnancy. When this happens, the child can have spina bifida. The amount of disability caused varies. Children with spina bifida may have partial or full paralysis

of the legs and/or difficulties with bowel and bladder control.

They may also have pressure on the brain (because of fluid not being drained away as normal), learning difficulties, bone and joint deformities (they may not grow normally) and curvature (bending) of the spine.

Cerebral palsy is caused by damage to parts of the brain which control movement during the early stages of growing (development). In most cases, this damage happens in pregnancy. However, damage can sometimes happen during birth and from brain injuries in early infancy (such as lack of oxygen from near drowning, meningitis, head injury or being shaken). Most kids with cerebral palsy do not have an intellectual disability. They can learn as well as other kids but may have trouble communicating.

Kids with cerebral palsy may have problems with:

- ▶ posture and moving parts of their body or whole body
- ▶ muscle weakness or tightness
- ▶ spasms (involuntary muscle movements)
- ▶ balance and coordination
- ▶ talking and eating.

Multiple disabilities Some children have several disabilities, such as intellectual, physical, visual or hearing impairments. They may also have communication difficulties or other medical conditions such as epilepsy or asthma. When a child has several different types of disability, professionals talk about multiple disabilities rather than listing separate conditions.



Caring for kids

Toilet training for most kids will begin by the time they are three years old. For some kids with a disability they may be older. You can tell if they are ready if they pull at wet and dirty nappies or tell you their nappy is wet or that they don't want to wear nappies anymore. Talk to your agency about equipment like padded toilet seats or portable toilets.

- ▶ Teach your child the words such as wet, dry, wee, poo, it's coming (or try pictures).
- ▶ Choose a potty, or a special toilet seat with a step so they can get up and feel safe.
- ▶ Make sure the toilet area is safe. Keep cleaners, deodorants and toiletries out of reach.
- ▶ Give praise for small steps. Toilet training takes time, accidents happen, be patient!
- ▶ Pull-ups may assist in the toilet training process.
- ▶ For some kids with disabilities timed toilet visits may help e.g before bed.

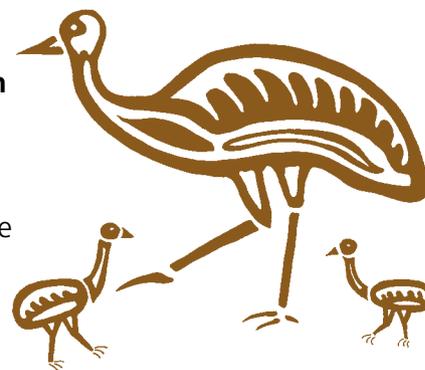
Bed wetting and waking up in a wet bed can make children feel sad or worried. Explain that sometimes the brain doesn't send the message to the body to get up for the toilet. Change the sheets and don't make a big fuss. Make sure they have a wash in the morning to feel fresh.

- ▶ Try leaving a potty in the room at night.
- ▶ Use a mattress protector if it's happening a lot (place sheet on top).
- ▶ It may help to get them to go to the toilet before bed.

Incontinence (can't control wees and/or poos) can have many causes in children who have particular physical disabilities. Developing an **individual health care plan** may be needed to help request the specific support needed when a child is going to school. Some students will require additional support for toileting.

For serious bed wetting that goes on for a long time you may need to discuss using nappies and incontinence pads as the child grows. Get advice about costs for paying for these items.

Sleep disturbance Many kids with disabilities have problems sleeping. They may cry or shout out when they wake several times a night. Sometimes this is because of physical problems and sometimes because they have got into bad habits. Your GP or paediatrician can assess the problem and help you with a safe sleep program.





Keeping kids healthy

- ▶ All kids need a healthy balanced diet with lots of fresh fruit and vegies and plenty of water.
- ▶ Kids need rest, so notice when they are tired and let them have plenty of sleep.
- ▶ Turn off the TV and keep kids active. Help kids to try new things.
- ▶ Encourage them and talk to the teacher about how they can be involved and 'join in'.
- ▶ If the child has a physiotherapist or speech therapist, ask about exercises for doing at home.
- ▶ Talk to them, tell them stories, sing songs together. Children often take in more than you think.

“ Our kids are amazing. It’s important to celebrate when kids are doing well. Tell kids they come from one of the oldest surviving cultures. ”



Challenging behaviour

Ways to prevent challenging behaviour:

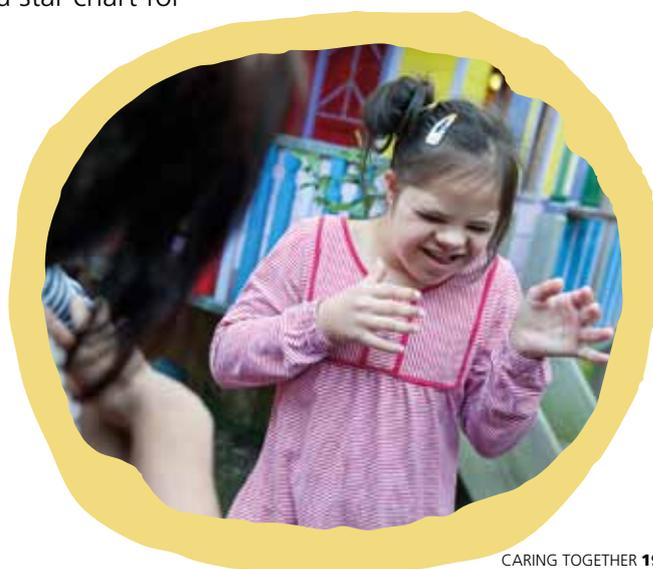
- ▶ Let the child know the house rules and stick to routines. Make life settled.
- ▶ Teach children the rules. Break them down into small steps. Reward and praise them when they get them right.
- ▶ Give them lots of praise – show them you notice good stuff.
- ▶ Let them know you are there for them – talk about feeling sad or angry.
- ▶ Encourage kids to be social and active. Some organisations (see the websites in this book) offer special programs, supported camps and activities for kids with a disability.
- ▶ Make sure kids get plenty of sleep and always talk to the doctor about diet and medication.

Ways to deal with challenging behaviour:

- ▶ Think about what triggers tantrums or bad behaviour e.g. change in routine, tiredness.
- ▶ Be clear about what you want – talk about positive and problem behaviour.
- ▶ Let your child know how their bad behaviour makes people feel upset and sad. Talk about saying sorry and how to make things right.
- ▶ Use positive rewards such as a trip to the park together, or a dedicated time together playing a game. Some children may respond to a star chart for good behaviour.

Violent behaviour

If your child is violent, hurts you or other people, don't be shamed – ask for help. Talk to the caseworker/agency or a teacher or doctor.



Growing up and changes

- ▶ Talk about growing up and body changes as children enter puberty. Remind them that growing into an adult is a special time that we all go through.
- ▶ It's important for you (as the carer) to be prepared for how things might change. Sexual expression is a natural part of life and as your child becomes a teenager it's important they have education and information about sexual health. There are good books and resources to help you talk about it with the young person if they have an intellectual disability or learning delay. These often have pictures to help kids understand. Ask the doctor or health worker about these.
- ▶ Teach them skills for life – focus on what they are good at. Try teaching them how to cook simple meals, make a doctor's appointment, fix simple injuries and save money for something. All kids like to feel grown up!
- ▶ Talk about relationships and peer pressure. When friends push you into things, how do they handle it? Remember the young person may have been abused and reluctant to talk about sex or their body so don't push the conversation on them.

Periods and girls with special

needs: If your child has an intellectual disability or difficulty with speech, she might not understand changes to her body and mood that are part of growing up. She still needs to know about periods at a level she can understand. Talk to your GP or health worker about any questions. You could also speak to your child's school and get the support of a teacher aide. Using pictures might help to explain changes so ask workers about resources/books.

“ **Ask for help if you are worried about the young person's mental health and wellbeing. They may need counselling or extra support.** ”



Education

Preschool and child care

Ask your caseworker about access to a local preschool or child care centre. This will be free or very low cost. This will help your child make friends and get them ready for primary school. Many preschools offer extra support for children with a disability. Sometimes there is a special teacher to support children with special needs. There are also centres and early intervention playgroups just for kids with autism and complex disabilities.

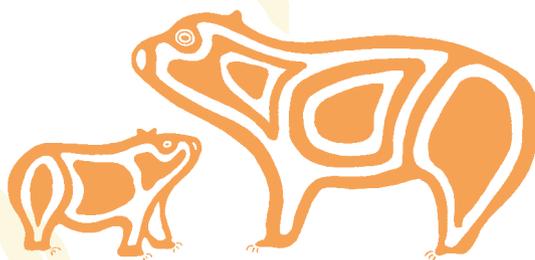
What to ask:

- ▶ **Can my child have access to a preschool or early intervention program?**
- ▶ **How will my child be supported e.g. a support teacher?**
- ▶ **How will the centre work with me to help my child learn?**

It's important to talk to the early childhood staff or early intervention workers about what works for your child and any problems. These staff will also have ideas to help you at home.

School

There are many schools with education programs for kids with a disability. Some kids go to **regular classes or support classes in regular schools or attend special schools**, or a mix of these. The principal of your local government school may contact the Disability Programs Consultant from the regional office to discuss the help and services available. This may include a specialist teacher or teacher's aide, making changes to a classroom or the desk, assisting with eating and using the toilet or help with travel to and from school. Ask the principal what services will be available.



“ I found I had to follow up with the school a lot. You need to go and ask. Be involved. That's what I do. ”



Starting school

Meet your child's teacher together and ask about an **education plan** and talk to the school principal about support and what you can do to help. Visit the school together and talk about where things are like the drink taps, toilets, school office and classroom.

- ▶ Try on the uniform and shoes – make sure everything fits!
- ▶ Play schools with your child. Play is the way children learn best
- ▶ Make sure your child can open their lunch box and drink
- ▶ Explain the basic school rules, such as putting up your hand, asking before going to the toilet, listening quietly, taking turns and doing what the teacher asks.
- ▶ Make time for homework and readers – encourage your child to do their best.



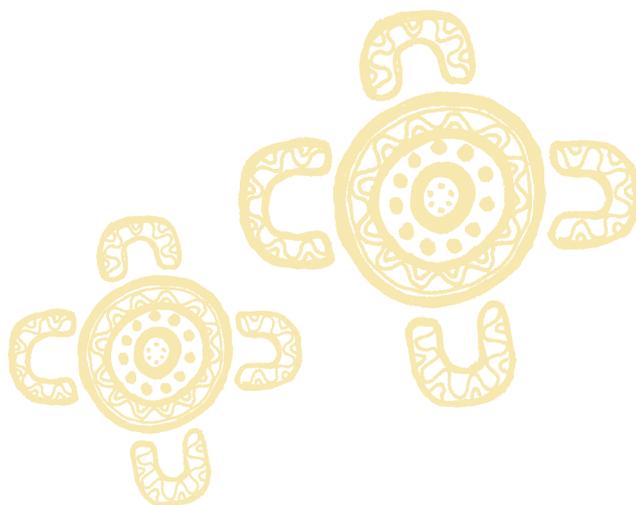
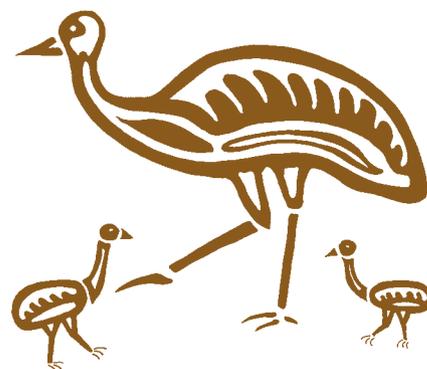
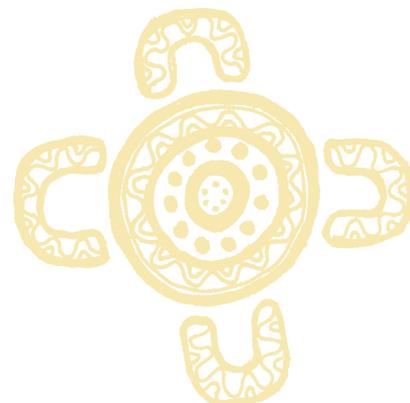
Starting high school is a big change so be ready for the ups and downs. Help young people feel strong and and be positive about learning.

- ▶ Get to know the school and keep an eye on how they're going so you can spot any problems.
- ▶ Talk to your teen about school and notice how they talk about it. Ask them how is the school? Do you see your friends? What are you learning?
- ▶ Go along to the parent-teacher interviews, read school reports and keep track of what they are learning. Talk to the caseworker or teacher if you think there is a problem. There are many special programs to help with learning.
- ▶ Let your child know if school mates are welcome at home.

Assisted School Travel

Program is available to some students with a disability under the Department of Education and Communities' Assisted School Travel Program. This offers door-to-door transport assistance between home and school at no cost to families when carers are unable to provide transport. All applications are assessed. Visit www.schools.nsw.edu.au or call 1300 338 278.

Family Advocacy is an independent service that can give information about the school system and services for kids with a disability, call **Family Advocacy 1800 620 588**.





What other carers say about school

“Give as much information as possible to the teacher and principal.”

“Think about helping out in the classroom – that’s what I do. Then I can show the teacher things that work (for my child).”

“I have contact with the school every day. I can’t just leave my boy at the gate. I’m always talking to his teacher.”

“Use the internet to learn about teaching styles for kids with specific learning problems. There are heaps of ideas to help.”

Challenges for children with disabilities

Children with disabilities can have trouble making friends because of:

- ▶ **physical challenges** that make it hard to follow friends around or play games that require good coordination
- ▶ **learning challenges** that make games too complicated for them to play
- ▶ **behaviour challenges** that make it hard for them to share or wait
- ▶ **communication challenges** that make it hard for them to express themselves or understand other children.

Kids with disabilities are less likely to play with others. They're also less likely to approach other children to play because they do not know how to ask if they can join in. Sometimes they may have trouble understanding the rules of the games. You can teach them what to say and how to play. They love playing with other children and play helps them develop their skills.

Children with autism are more likely to play alone or alongside other children.

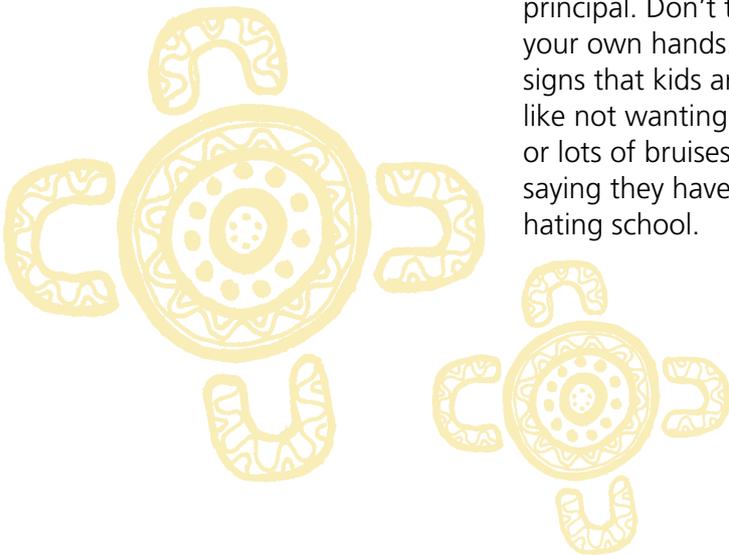
Bullying – don't ignore it. If kids aren't settling in at school and say they are being teased or bullied, make sure you speak to the teacher or the school principal. Don't take matters into your own hands. Look out for signs that kids are being bullied – like not wanting to go to school or lots of bruises and cuts, or saying they have no friends and hating school.

Learning problems

Some kids really struggle with learning and this makes going to school hard. They may find it hard to pay attention, remember things, talk to you or others or deal with homework.

A child with a **learning difficulty** can have delays in their development – they might be late in talking or using a spoon and fork. Learning difficulties happen for lots of different reasons – like an intellectual disability, physical and sensory disabilities, emotional problems, not going to school, an illness or stress from what they've been through. It's good to spot problems early and get help.

A child with a **developmental disability** has problems thinking, speaking, moving about (motor skills – like holding a spoon) or with social skills, which is likely to continue as they grow up.





Attention Deficit Hyperactivity Disorder

(ADHD) Kids with ADHD may have trouble paying attention for long and find it hard to be settled. They are always on the go. They might be easily distracted, do things without thinking, argue a lot, lose their temper and find it hard to follow rules. Sometimes children with ADHD may need medication.

ADHD must be professionally diagnosed so that normal behaviour is not mistaken for it and vice versa.

Dyslexia is where the child has problems understanding written words. It is the most common of learning disabilities. It varies in severity and often improves with age and good teaching.

The sooner kids get help the better. So if you're worried talk to someone. People who can help:

- ▶ teacher, school counsellor or Aboriginal Education Officer
- ▶ caseworker, support worker or your agency
- ▶ child psychologist or family counsellor

- ▶ doctor, speech therapist, occupational therapist or physiotherapist
- ▶ school – ask about literacy and reading recovery programs
- ▶ Aboriginal Health Service/Child Health Clinic
- ▶ other carers and parents in your community
- ▶ tutor – who can visit your home and help one-on-one.

Leaving school

There are a range of support services for kids with a disability when they are ready to leave school, depending on their needs and abilities. Children with a disability are able to complete community education courses, further education and training courses through TAFE NSW and university. For more information on TAFE and support for students with a disability visit www.tafensw.edu.au.

Disability employment services Centrelink can help young people with a disability look for work and refer them to a disability employment agency or provider. Some young people with a disability can take up jobs in everyday employment settings. Some young people might need extra help to go to work. Supported employment services, also known as Australian Disability Enterprises, provides young people with a disability with help like job coaches, transport, technology, job training and individual supervision. Call Centrelink and ask about disability employment services or visit www.australiandisabilityenterprises.com.au.

Leaving care

Preparing to leave foster or kinship care usually begins when a child is turning 15. By this age, they can start learning skills like cooking, budgeting, looking after their health and how to apply for a job. You can play a big role in preparing them by teaching them life skills.

For kids with a disability this planning should begin earlier – at least three years before the young person leaves care to make sure that any special supports are in place. The caseworker or agency will talk to the young person and you about preparing a written **leaving care plan**. This plan covers things like:

- ▶ where they will live
- ▶ where they will work or study
- ▶ where money will be coming from
- ▶ any health issues to be managed
- ▶ who they can turn to if there are any problems.

For young people with complex disabilities the caseworker will refer them to Ageing, Disability and Home Care (ADHC) Leaving Care Program and will work with ADHC to prepare the leaving care plan. The plan is about making sure the young person gets the help and support they need.

For more information go to www.community.nsw.gov.au/leaving_care
www.create.org.au



“ Be honest if things aren’t going well. Talk to someone – caseworker, doctor and other carers. ”

Feeling safe and connected

The impact of abuse can last forever but you can help a child become a survivor. Making kids feel safe and secure is important. They can feel really hurt and not trust anyone – this stops them from accepting love and support.

- ▶ **Stick to routines – be consistent.** A familiar routine can provide comfort, especially during times of change. If your family's schedule is going to change, talk about it with the child in your care.
- ▶ **Know your child's strengths.** All children with disabilities have strengths. Build on their strengths to help them grow.
- ▶ **Make sure your child** knows they are loved and their importance to the family.
- ▶ **Consistent, loving boundaries** make the world seem predictable and less scary for children with attachment problems. Let the child know the house rules are for everyone. They keep everyone safe and teach respect.
- ▶ **Take charge but remain calm when your child is upset or misbehaving.** Remember the child doesn't know how to handle their feelings. You need to stay calm and show them how to handle emotions.
- ▶ **Hugs, cuddles, rocking.** It's important for kids to feel closeness and warmth but be aware that for some kids touch is associated with pain or abuse. Be aware of their reaction – change your actions accordingly.
- ▶ **Try to understand behaviours,** for example, when a child hoards food, it should not be viewed as stealing, but as a possible response to deprivation in the past.
- ▶ **When they act younger.** Some children may act younger than their age when upset or sad. If they are tearful and frustrated, (like a two year old) then it's best to comfort by holding or rocking (like a younger child).
- ▶ **Read to them** and tell them stories. Kids with disabilities need to hear the many stories of heroes who were overlooked as children.

Be honest if things aren't going well. Talk to someone – caseworker, doctor and other carers.

Grief and loss can be hard for kids with disabilities. Some people think that children with intellectual or learning disabilities can't understand death or sorry business. But children with a disability can feel sad and may have trouble talking about their feelings or expressing their sadness. They need your help to talk about loss and for you to explain death in a way they can understand. There is also a feeling of loss and sadness for some children with disabilities when they realise they are not the same as their friends. This can sometimes happen when they enter the teenage years. They need a lot of support at this time.

Family contact – why contact is important

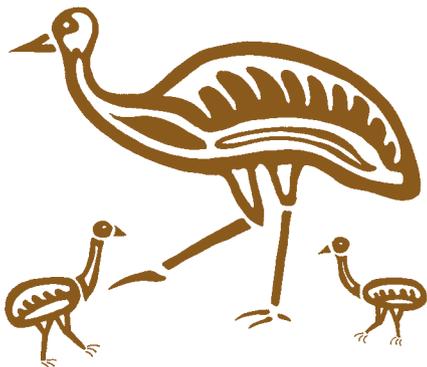
Children in care need contact with their families to keep them connected to who they are and to give them a feeling of identity. Kids need to be able to love their family and be with their kinship or foster family without feeling guilty.

Family contact can help kids feel stable and secure. For example, they may see that their mother is safe and this helps them feel better about living apart. Contact can help them build family relationships in a safe place and with support.

Family contact needs to be safe and might be supervised where the child is not left alone with the parent or family member. Or it can be unsupervised. Contact may include visits, phone calls, sending photos and letters, email or texting.

- ▶ Ask the family about the child's care and speak positively.
- ▶ Tell the parents about some of the things you're doing at home to help the child. They might be able to try these things too at contact.
- ▶ Keep the parents informed about the child's life, such as school sports days and achievements.

Contact can stir up a lot of mixed feelings for kids – it's good for them to talk about how they feel.



What carer's say about contact

"I've had parents who won't believe there is anything wrong with their child or won't acknowledge the cause. That can be tough. As a carer you need to be able to deal with that."

"Sometimes the birth parents can also have disabilities or mental illness. This might mean talking with the caseworker about how to work with the parents. It can mean more supervised contact where you need to stay."

Looking after yourself – the carer!

If you care for a child with a disability it is important you take a break and care for yourself. Don't be ashamed – you need a break to stay strong!

- ▶ Ask for help from family and friends and other carers.
- ▶ Join a carers' group – share your feelings and worries with people who really understand!
- ▶ Ask the caseworker about a break from caring – this is called respite.
- ▶ Do something nice for yourself – go swimming, see a movie, or have a cuppa with a friend.
- ▶ Eat plenty of fruit and vegetables. Don't skip meals or eat lots of take-away.
- ▶ Enrol younger children into preschool or playgroups.
- ▶ Watch your back when carrying and lifting kids.
- ▶ Call Carer Support if you need to talk and get help.

Having a break – respite care is when someone takes over caring for your child to give you a rest. It can be for a few hours, overnight, for a weekend each month or even a week. You can also ask for help in your home or can get respite care outside of your home. Find out what's available. You can use an Aboriginal respite care service and there are foster carers who offer respite breaks to other carers. **Don't feel guilty about asking for help.**

Centre-based respite care is a special centre that looks after children and young people with a disability – usually kids with an intellectual disability, autism or a physical disability. Children can stay overnight or for a short stay. **Home-based respite** is where a support worker can come to your home and look after the child while you take a break.

Respite camps for teens with a disability are provided by Sport and Recreation and Ageing, Disability and Home Care. The camps offer teenagers (13 to 17 years) with an intellectual disability the chance to experience new activities, make new friends and feel good about themselves. Some weekend camps are also available for siblings. Visit **www.dsr.nsw.gov.au/camps/respitecamps.asp**

There are also retreats (for carers!) and special camps and holiday programs for kids with disabilities. Kids meet new friends and try new things!

Build your own network of support. This is important for when things might not be going too good. It's good to talk to someone.



Support and training

What carers say about support

"I go to a meditation class every week. That's what helps me."

"I come to this group – before I joined this carer group I didn't know anything."

"I went to Triple P parenting course. It really helped and reminded me of some things I can do. Grab the training, it does help."



Talk to your caseworker or agency

Keep in touch with people who can help – either the caseworker, support worker or call AbSec or Connecting Carers or Carers NSW, see page 36. Talk about education, health, family contact and ask if you have any concerns or changes relating to the child and their care. AbSec provides support for Aboriginal kinship and foster carers.

A **case plan** is a plan for the child between the caseworker/agency and the approved carer. This plan includes important decisions about the child's health, education, family contact and any payment information. It should include if the child has special needs. **Talk about the case plan.** A child with a disability may also have an **early intervention plan** and a **health plan.**

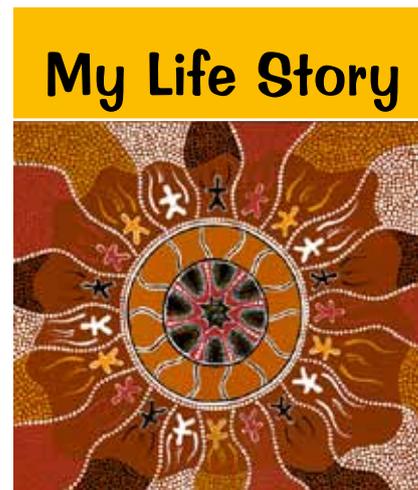
Join a support group. These groups offer friendship, support and great ideas for raising kids. Across NSW there are a number of foster and kinship carer support groups and Aboriginal carer groups too. **Find out about your local group or start your own! Ask about your local group.**

Join a supported playgroup or a disability carer group to meet other families with children who have a similar disability. That way you can share concerns and advice. Ask about supported playgroups if you have a younger child. Visit www.carersnsw.asn.au or try some of the organisations listed in this book.

Free training Try going to some training. There are free training sessions to help carers in their caring role. **Check out** www.connectingcarers.org.au and www.carersnsw.asn.au or talk to the caseworker about what you need. Lots of disability organisations offer free training or information sessions about particular disabilities.

Keep kids connected – Aboriginal *My Life Story* book

This is a way of recording the story of a child's life in words, pictures and photos. The child or young person makes this book with help from you or another trusted adult. *My Life Story* book helps kids connect with who they are. The book helps Aboriginal kids understand more about their culture, family and community. It helps them feel pride. Ask for a copy of the Aboriginal *My Life Story* book.



Other resources to help carers:

- ▶ *Raising Them Strong* (booklets and DVD)
- ▶ *Caring for kids* – a guide for foster, relative and kinship carers
- ▶ *Case management*
- ▶ *Supporting deadly behaviour.*

“ Remember we’re all part of a team, we’re not alone. None of us alone has all of the answers. ”



Financial assistance

The statutory carer payment for a child with a disability is set at a higher rate than the general allowance. An assessment of the child's needs helps to work out what level of extra payment is needed.

These payments help to cover general costs of care like food, clothing, haircuts, hobbies, holidays and schooling. They will also assist with general pharmaceuticals, hygiene needs and medical costs. Additional financial support may be available to cover one off or extra items that are needed because of the child's special needs.

Always talk to the caseworker about what is needed and any changes to the costs for caring for your child. You can also talk to disability services and Ageing and Disability teams in your region to find out about local support and special assistance.

Centrelink

www.centrelink.gov.au
(or visit a Centrelink near you)

Family Assistance Office

www.familyassist.gov.au
Phone 136150

Family Tax Benefit: helps carers with the cost of raising children and is income tested. This payment is made up of two parts – part A and part B. Payments are fortnightly or annually.

Parenting Payment: You may qualify if you're single and the primary carer of at least one child under eight, or you're partnered with at least one child under six or you and/or your partner's income and assets are below a certain amount.

Work participation requirements exemption:

Authorised carers who receive the Parenting Payment or Newstart Allowance are eligible to apply for an exemption from Centrelink's work participation requirements. Contact your agency.

Other payments you and your child may be eligible for:

- ▶ **Child Care Benefit**
- ▶ **Child Care Rebate**
- ▶ **Education Tax Refund**
- ▶ **Grandparent Child Care Benefit**
- ▶ **ABSTUDY**
- ▶ **Baby Bonus**
- ▶ **Carer Allowance (child)**
- ▶ **Teenage Education Payment**
- ▶ **Assistance for isolated children.**

Health Care Card: All children/young people in care are eligible. Concessions include cheaper prescription medicines, bulk-billed doctor appointments and reduced out-of-hospital medical expenses.

Immunisation allowance: Is paid in two separate amounts – the first if the child is immunised between 18-24 months of age and you have lodged your claim before the child's second birthday. The second is paid if the child is fully immunised by five years old.

Healthy Start for School check: This check will help to make sure children are healthy, fit and ready to learn when they start school. If you and/or your partner receive an income support payment from Centrelink (e.g Parenting Payment, Newstart Allowance) at any time during the financial year in which the child in your care turns four, then you need to take your child for a health check. The health check will assess physical health and include height, weight, hearing and vision tests. Health checks may be organised through your agency or you can visit your doctor or Aboriginal health service. Don't forget to tell the Family Assistance Office. If the health check is not done, then part or all of your Family Tax Benefit Part A Supplement for your child will be withheld.

Better Start: Helps to pay for early intervention services and treatments for eligible children (aged under six who have been diagnosed with Down syndrome, cerebral palsy, Fragile X syndrome or have a moderate to serious vision or hearing impairment). Families can register for up to \$12,000 (maximum of \$6,000 per financial year). This helps cover services such as speech pathology, occupational therapy, physiotherapy, and orthoptics. Better Start also includes a one-off payment of \$2,000 for eligible families living in rural/remote areas. Visit www.fahcsia.gov.au/betterstart or call **1800 989 530**.

Cleft Lip and Cleft Palate Scheme: Helps families meet treatment costs for specialised services for cleft lip and cleft palate conditions. Call Medicare on **132011**.



Help and support

Aboriginal Statewide Foster Care Support Service

1800 888 698 or 9559 5299

Connecting Carers NSW

1300 794 653

Ageing and Disability Community support teams

(Information, Referral and Intake teams)

02 8270 2000 or TTY 02 8270 2167

Metro North Region – 02 9841 9350

Metro South Region – 02 9334 3700

Western Region – 1300 134 450 or (02) 6841 1594

Northern Region – 1300 364 563 or (02) 6621 1400

Hunter Region – 1300 205 268 or (02) 4978 6222

Southern Region – 1300 841 566 or (02) 6128 9200

Parent Line 24 hours

1300 1300 52

Foster Parents Support Network

1800 262 445 (24 hours)

Early Childhood Intervention Infoline

1300 656 865

Helpline (child protection)

132 111 (24 hours)

Department of Education & Training (Disability Programs)

02 9244 5085 / TTY: 02 9266 8189

CREATE Foundation

1800 655 105

1800 637 357 (NSW)

Useful websites and contacts

www.absec.org.au – support and advice for Aboriginal kinship and foster carers

www.connectingcarersnsw.com.au – support and training for all NSW foster and kinship carers

www.mytime.net.au – support for carers of kids with disabilities

www.raisingchildren.net.au –

lots of good info about raising kids

www.create.org.au – support, workshops and events for kids in kinship and foster care

www.adnsw.org.au –

First Peoples Disability Network (Aboriginal Disability Network)

www.community.nsw.gov.au – foster & kinship care, Community Services

School and child care/preschool

www.det.nsw.edu.au/parents – for families with school age kids

www.physicalanything.com.au – information about disability and learning and working with teachers

www.mychild.gov.au – find child care and preschools /Child Care Access Hotline 1800 670 305

www.det.nsw.edu.au – education information or call the Aboriginal Education Unit 02 9582 5800

www.aecg.nsw.edu.au – NSW Aboriginal Education Consultative Group 02 9550 5666

Health and disability

www.ahmrc.org.au – locate Aboriginal health services in NSW 02 9212 4777

www.adhc.nsw.gov.au – Ageing, Disability and Home Care

www.nswcid.org.au – NSW Council for Intellectual Disabilities

www.enable.health.nsw.gov.au – information about equipment and aids

www.healthdirect.org.au – healthdirect Australia 1800 022 222 or if for speech/hearing impairment 1800 555 677

www.chw.edu.au – The Children's Hospital, Westmead 02 9845 3585 (Kids Health) has a range of parent fact sheets on disabilities.

Organisations and services

www.aspect.org.au – Autism Spectrum Australia (ASPECT) for information about autism 02 8977 8377

www.cerebralpalsy.org.au – Cerebral Palsy Alliance provides therapy and support 02 9451 9022

www.dsansw.org.au – Down Syndrome advice and support 02 9841 4444

www.epilepsy.org.au – Epilepsy information and support, call 1300 EPILEPSY – 1300 37 45 37

www.deafsocietynsw.org.au – support and advice 1300 555 727

www.ridbc.org.au – Royal Institute of Deaf and Blind Children helps blind and deaf children 02 9871 1233

www.hearing.com.au – Australian Hearing 02 9412 6800 or TTY 02 9412 6802

Health people – who does what?

www.paraquad.org.au specialises in modifying vehicles, building and repairing wheelchairs. 02 8741 5600 or 1300 788 855

www.tadnsw.org.au – Technical Aid to the Disabled can make custom-designed equipment 02 9912 3400 or 1300 663 243 (outside Sydney)

www.northcott.com.au – Northcott Society provides support, therapy, respite services, assists with accessing equipment and offers programs

02 9890 0100 or 1800 506 071

www.daisi.asn.au – Disability and Aged Information Service Inc (Lismore) 02 6622 8002 or 1800 800 340

www.nswtaxi.org.au – Wheelchair accessible taxis 02 8332 0200 or for country areas call 02 9332 1266

www.rta.nsw.gov.au – to apply for the NSW Mobility Park Scheme when you care for a child with mobility disabilities. Visit site to find out if you're eligible and how to apply.

There are many more organisations that offer help and advice so talk to your caseworker or health worker about what services are available where you live.

- ▶ **Paediatrician** – looks after kids health, has special knowledge about children's health and growth
- ▶ **Dietician** – advises about diet, including healthy food choices.
- ▶ **Occupational therapist** – helps make every day activities easier for you and the child and may advise on equipment like wheel chairs or changes to the home environment.
- ▶ **Early Intervention Worker (Early Educator)**– works with the child and family to support early development and learning.
- ▶ **Speech pathologist** – helps with communication, speech and swallowing problems.
- ▶ **Physiotherapist** – helps with physical development and how the child moves.
- ▶ **Podiatrist** – treats foot and toenail problems, and can recommend footwear.
- ▶ **Optometrist** – checks vision and provides glasses, eye examinations are covered by Medicare.
- ▶ **Ophthalmologist** – eye specialist.
- ▶ **Audiologist** – tests hearing and provides hearing aids. Australian Hearing Services provides free hearing assessments and hearing aids for children.
- ▶ **Women's health services** – specialist health services for women.
- ▶ **Child and Family Nurses** – provide primary health care for children 0-5 years.

We always need more carers to look after kids with a disability. If you know someone who can make a difference tell them to apply www.fosteringnsw.com.au



FOSTERING NSW
Growing together

Note: This book provides general information only from a range of good places and we have shared these with you on pages 36 and 37. This book is not intended as medical advice or as a disability assessment guide. Some of the information covered can be found at: raisingchildrennetwork; physical as anything; and Ageing, Disability and Home Care as well as from the websites listed. We encourage you to visit these sites for more detail and to look at the videos.

