THE VISION BOOK

MY CHILD, OUR JOURNEY

— TE PUKA MOEMEOA: TÔKU TAMAITI, TÔ TÂTOU HUARAHI

Information for families and whânau about children who are blind, deafblind or have low vision.

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Thank you


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Thank you also to the following organisations who provided feedback:

*Parents of Vision Impaired*

*Ngāti Kāpō O Aotearoa*

*Deafblind (NZ) Incorporated*

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Provide feedback on this book by emailing specialeducation@minedu.govt.nz.

For extra copies of this book, please contact the Blind and Low Vision Education Network NZ (BLENNZ) on 09-266 7109 (Auckland) or the Blind Foundation on 0800-243 333.


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This book is for the parents, caregivers, and families and whānau of children and young people who are blind, deafblind or have low vision. It gives you information about the people, support and services you and your child may need in your journey through life.
Introduction

Welcome to The Vision Book: My Child, Our Journey.

The Vision Book: My Child, Our Journey starts by looking at a child in their early years, at the time of diagnosis, and covers their experience at school and into early adulthood. It also features stories from people who have parented or supported a blind or low vision child or have lived with a vision impairment themselves.

The book gives readers a general idea of what to expect, recognising that your own experience may look quite different to what is represented here. We hope, however, it will give you confidence and reassure you that there are many people and organisations available to support you and your child. We also hope that it will give you an idea of how the services available are likely to change, depending on your child’s needs, age and where your child is at in life. You will see that education is a central theme of this book, but we hope it also weaves in enough information about the parent, health and disability services available to be useful in a broader sense.

The book is not intended to be read in one go, but rather dipped into as and when needed, over time. Readers wanting quick access to information about a particular topic are encouraged to use the indexed glossary at the back.

The Vision Book: My Child, Our Journey is the first book of its kind developed by the Ministry of Education and its partners. The idea is to add to what is here and develop more materials for the blind, deafblind and low vision community over time. To help us, please tell us what you think of this book. Is it useful? What parts work well? What could be improved? Your feedback is important and will play a key role in any further information. Thank you. Please contact us at: specialeducation@minedu.govt.nz.

A note about the terms used in this book

In this book, we refer to children and young people who are blind, deafblind or who have low vision.

We recognise that this is a diverse group of children and young people – and that some of them may also have physical, intellectual and/or developmental needs or conditions that improve, deteriorate or change over time.

However, we have chosen to use the following definitions of blind, deafblind and low vision (thank you to the Blind Foundation for help with these definitions).

Blind – having either no vision at all or very low vision. Some blind people will be able to see shadows and movement, but they get most of their information about the world from senses other than vision.

Deafblind (also called dual sensory) – having a combined loss of hearing and vision, affecting the ability to do everyday things, especially communicating with others and accessing information.

Low vision – having a loss of vision that affects someone’s ability to complete everyday activities such as reading, looking at pictures, playing games or moving about. People with low vision have some useful vision, but their ability to use that vision may vary from day-to-day and task-to-task.
SECTION 1

EARLY YEARS
Early diagnosis is good news! – it is important to pick up a child’s vision impairment early. That way you can get the help you need as soon as possible.

Your child’s diagnosis

Finding out your child is blind, deafblind or has low vision can be a difficult time for families and whānau. It is natural to feel apprehensive about your child’s future and anxious about what is in store for you.

If your child’s condition wasn’t picked up at birth and has been diagnosed in hospital or identified later, the news may be a total shock.

You may also have found out your child has hearing loss or other needs. There may be no history of blindness or low vision or any other disability in your family.

If you are a parent who was concerned about your child’s recent development, it could be a relief to get this diagnosis because it answers some of your questions.

Whatever your situation, it is okay to experience feelings of sadness, guilt, anger or denial and to worry about how you will cope and how your child’s diagnosis impacts on the future.

“We are still grieving in many ways. But it does lessen with time. For me, it was the not knowing what he would do, what would happen to him in life. That was hard. But now I see that he will be fine – he just goes about things differently, in his own way.”

Parent

Your feelings are personal and highly individual. How you feel will depend on many factors – your personality, your life experience, your coping style and how much support you have around you. Give yourself time to come to terms with your child’s diagnosis. Be patient with yourself and reach out for support when you need it.
Talking can help

It helps to talk about your situation and how you are feeling with someone you trust and respect. You may want to talk to parents who have gone through something similar or professional counsellors (eg, a Blind Foundation counsellor) with knowledge about vision loss.

“Gary from the Blind Foundation and the BLENNZ Visual Resource Centre staff have become part of our family, part of our lives. They’ve been an absolute lifeline. I don’t think we’d have survived without them, especially in those early years.”

Parent

“Be open if you can. The more open you can be, the easier things will become over time.”

Parent

Talk to other parents – it’s good to talk. Many parents say one of the things that really helped was talking to other parents who’d been through the same thing.

The Blind Foundation counselling service

The Blind Foundation (legally known as the Royal New Zealand Foundation of the Blind) provides a free, nationwide counselling service to children and their families from fully qualified counsellors. Counsellors will come to your home or you can visit them at the Foundation’s offices – whatever works for you.

See: www.blindfoundation.org.nz
Freephone 0800-243 333

Ngāti Kāpō O Aotearoa Inc

Ngāti Kāpō O Aotearoa Inc is a national kaupapa Māori information and support service for people of all ages who are blind, deafblind or have low vision and their families and whānau. They run regional support groups and programmes focused on strengthening and sustaining the well-being of whānau.

See: www.kapomaori.org.nz
Freephone 0800-770 990
Parent2Parent

Parent2Parent is a nationwide parenting network for parents of children with disabilities. The organisation can put you in touch with parents of children who have similar disabilities to your child. They also offer training and information.
See: www.parent2parent.org.nz
Freephone 0508-236 236

Parents of Vision Impaired

Parents of Vision Impaired (PVI) is a national parent support group. It offers parents advice, information and opportunities to meet other parents. The group also has parent support workers who can give you one-on-one help and support. PVI publishes a regular magazine and has a members-only Facebook page for families and whānau to share information and network.
See: www.pvi.org.nz
Freephone 0800-312 019

Deafblind (NZ) Incorporated

Deafblind (NZ) Incorporated works closely with the Blind Foundation to offer support to children who are deafblind and their families. The organisation runs support groups across the country as a way to help coordinate services and provide families and whānau with the opportunity to meet and support one another. Deafblind NZ can also put parents in touch with the Blind Foundation’s three regional deafblind coordinators.
See: www.deafblindnz.org.nz
Email deafblind@clear.net.nz

Blind and Low Vision Education Network NZ (BLENNZ)

BLENNZ is an education service provider for children from birth until they are 21. BLENNZ employs Resource Teachers: Vision (RTVs) and Developmental Orientation and Mobility (DOM) specialists who work across New Zealand from a main campus, Homai Campus School, in Auckland and regional Visual Resource Centres throughout the country. They offer children and their families and whānau throughout New Zealand a wide range of services, information and advice. They will come to you at home at the time of your child’s diagnosis or visit you at your child’s early childhood education service or school – wherever suits you best.
See: www.blennz.school.nz
Phone 09-266 7109 (Auckland)

Ministry of Education, Special Education

Ministry of Education employs a wide range of education specialists who visit families and whānau at home (or at a place that suits) in the early years and who work with children throughout early childhood and school as a child develops and grows older. Specialists include early intervention teachers, physiotherapists, occupational therapists and educational psychologists.
See: www.minedu.govt.nz (look for information about special education)
Freephone 0800-622 222
Ministry of Health

The Ministry of Health funds a range of disability services for children and their families and whānau who meet specific eligibility criteria and are assessed as needing such services. Needs Assessment and Service Coordination (NASC) organisations coordinate access to Ministry of Health funded support and respite services while District Health Boards provide access to developmental and therapy support for children through child development teams. In some cases, equipment such as glasses, hearing aids and wheelchairs may be funded through the Ministry of Health.


The Ministry of Health’s Well Child programme is a series of 13 health checks offered free to all New Zealand families and whānau for children from birth to five years. The programme includes a GP check at six weeks (linked to the six-week immunisations), as well as a health check before a child starts school.


Your child’s vision team

It is likely you will find yourself involved with a wide range of people throughout your child’s life. At times, you might find yourself working closely with people in the health sector whose focus will be long term but may come and go depending on your child’s age, diagnosis and overall needs. These people are also likely to be more involved with the diagnosis and assessment of your child’s medical needs.

These people might include:

- family doctor (or GP) – a health professional who looks at the general health of your child and can refer you to specialists for a clinical assessment
- ophthalmologist – a specialist eye doctor who checks the health of the eye and can provide information about diagnosis and treatment
- orthoptist – a health professional who diagnoses and treats eye problems related to eye movement and coordination
- optometrist – someone professionally trained and registered to examine the eyes for visual defects, diagnose problems or impairments and recommend glasses or other corrective lenses or provide other types of treatment
- paediatrician – (a medical professional doctor) specialising in children’s health and development
- visiting neuro-developmental therapist – a specialist in child development who works with very young children.
At the same time, you may find yourself involved with parent group representatives and people who work across the education and disability sectors. Your relationship with these people may be more consistent, long term and cover a wide range of health, education and disability services. These people might include:

- BLENNZ teachers or Resource Teachers: Vision-qualified teachers who support children and their parents and caregivers, providing general advice, teaching and development support
- Blind Foundation life skills specialists – key workers who support children and their parents and caregivers, providing general advice, counselling and support
- other Blind Foundation specialists – eg, deafblind coordinators and recreation advisors who provide advice and support related to their area of expertise
- Ngāti Kāpō O Aotearoa national field coordinators – specialist support workers who use a kaupapa Māori approach to help children and their whānau to access education, health and disability services
- Ministry of Education early intervention teachers – education sector specialists who provide advice and support related to a child’s learning and development
- other Ministry of Education specialists – eg, educational psychologist, physiotherapists and occupational therapists who provide advice and support related to their area of expertise

- early childhood education and school staff – your child’s teachers, education support workers and teacher’s aides who are there to help your child develop and learn within the early childhood and school environments
- health professionals from a Ministry of Health child development team.

In this book, we refer to the group mentioned above as your child’s vision team, as their ongoing support role will help you access all the support you need throughout your child’s life.

"Having to meet so many people in the early days can be overwhelming. My advice is to take them as they come, don’t try to remember everyone’s names and, remember, they are there to help."

Parent

It’s important to know your child’s vision team is there to help you – regardless of who they are or which organisation they represent.

Their aim is to work as a team to build a strong relationship with you on your journey.
How the eye works

Understanding how the eye works and how we see is a good first step to understanding your child’s vision and the assessment process.

To see, three things need to work properly: the eye, the optic nerve (the nerve that takes information from the eye to the brain) and the brain.

It takes about six months for babies to develop much of their vision (none of us is born with fully developed vision). In this time they begin to focus, develop eye muscles, learn to scan and track, coordinate their eye movements and see the full range of colour. By the age of seven, most children have developed normal adult vision.

Share anything you notice about your child’s sight with the professionals you meet – you know your child best and you will have information that is often invaluable to others outside the home.
Why a child's vision is assessed

Assessments are an important way for you and the people you work with to understand how your child’s vision is influencing their overall development.

Most blind children will have some degree of vision – total blindness is rare.

Overall, an assessment will help you to:

- understand how your child is using vision to gather information about the world
- share information about your child with family and whānau and others
- understand how to support your child to develop and grow
- identify the services and support your child is eligible for and the team of specialists available to support you.

How children are assessed

The initial assessment will give you some information about what your child can see. But it often takes time to establish the full picture.

It might take months, even years, and several assessments to find out the full extent of what your child can see.

That is why it is common for specialists to use more than one method to assess a child’s vision and why they may want to see your child several times and seek the input of you and others as your child grows and develops.

Assessments can involve observation of your child in familiar and unfamiliar settings, note taking, interviewing family and whānau, as well as specialist examinations and tests.

It is a good idea to get copies of all assessment reports – keep them handy and share them with others.

Most assessments include a short report noting the specialist’s findings and things that can be done to help your child develop.
Types of assessments

Generally speaking, there are two main types of vision assessment: clinical assessments and functional assessments.

Clinical assessments

Clinical assessments usually involve visiting an eye specialist (eg, an ophthalmologist) at hospital. They will:
- identify what your child likes to look at
- ask questions to understand your child’s medical history
- examine your child’s eyes
- carry out a clinical vision test (depending on how old your child is).

Clinical assessments often lead to a diagnosis and the identification of possible treatments. Clinical vision assessments are typically done:
- in hospital by specialists, including paediatricians, ophthalmologists and orthoptists
- at your local child health clinic or by someone from the Child Development Services specially trained in the development of very young children and in identifying problems early
- at the BLENNZ National Assessment Service in Auckland by an ophthalmologist and optometrist.

Functional assessments

Functional assessments involve observing how a child uses vision to learn, move around, gain information about their surroundings and interact socially.

These types of assessments will be carried out by many of the specialists you work with to help them to develop programmes and strategies you can use at home, in an early childhood education service or out in the community.

They will:
- look at how your child uses vision
- look at how your child holds their head to look at things
- look at your child’s movement and physical response to objects.

Functional assessments often help to understand how your child is using vision, the lighting they might require, how to position things near and around your child and the sort of objects your child is able to see. As your child grows older and develops, these assessments will change as well.

Functional vision assessments are typically carried out at home by:
- visiting neuro-developmental therapists
- Resource Teachers: Vision
- Blind Foundation life skills specialists.

Health of the eye – an assessment of the health of the eye is critical to helping eye specialists diagnose visual conditions and to determine the need for medical or surgical treatment.

It is important your child has regular check-ups and that you notify your specialist if you notice any changes.

If your child’s vision loss resulted from an accident you can contact the Accident Compensation Corporation (ACC) to receive support. Ask anyone in your child’s team to help you if you don’t know what to ask for.
How parents can take part

Distance vision is the ability to see objects at a distance, while near vision is the ability to see things such as text up close. Your visual field is what you can see above, below and to the side of you.

You are the people closest to your child. You know your child best. That means you have the most to contribute to an assessment. Share anything you notice about your child’s vision and how they use their vision. Talk to specialists about what you observe. Talk to your child’s vision team about having their guidance and input throughout the assessment process.

Before any assessment gets under way, sit down with a member of your child’s vision team to find out:

- why the assessment is being done
- how the information will be used
- where you can learn more about the assessment method
- how to get a copy of the findings
- if you need to give your permission in writing.

After a clinical assessment, you and your child’s vision team might want to discuss:

- the cause of your child’s condition (in language that is easy to understand)
- the name of the condition and how it is spelled
- if the condition will stay the same or is likely to change over time
- if the condition can be treated
- if glasses or contact lenses might help when your child gets older and what, if any, role an optometrist might play as your child gets older
- any specialist treatment and anything you can do to help
- if your child’s eyes are sensitive to light
- where you can find out more about your child’s condition
- the inherited nature of the condition and if you should talk to a genetic counsellor.

After a functional assessment, you and your child’s vision team might want to discuss:

- if there is anything you can do to help your child use their vision
- if there are things you can do at home to help your child learn about the outside world
- ways to connect and communicate with your child
- different ideas for helping your child to move and develop physically.

“I say to parents you have the right to ask questions, challenge decisions, get answers and be heard – you really are your child’s best advocate.”

“I say to parents you have the right to ask questions, challenge decisions, get answers and be heard – you really are your child’s best advocate.”

“Parent”

“When my daughter was 16 months old, we had our first BLENNZ assessment up at Homai in Auckland. It was such a help and the specialist made me feel confident in what I was doing with my child – it put my mind at ease and helped me believe things would be okay.”

“Parent”
Visual acuity is a measurement used internationally by eye specialists to describe the ability of the eye to perceive the size and shape of objects in a direct line of vision. Reduced visual acuity means reduced clarity of images and fine detail. Normal visual acuity is expressed as 6/6 – this means a person with normal vision can detect a shape or letter approximately one centimetre high from six metres away. Someone with a visual acuity of 6/24 needs to be six metres from an object to see what a person with normal vision can see from 24 metres away.

At times, you may find it hard to cope with the number of people who are involved with your child – particularly if your child has several different needs, as well as a visual impairment. If you do feel overwhelmed or need some time out, just say so. You can also say if you would like to see fewer people or would prefer to work with one person as a central point of contact. Your child’s vision team is trained to work in a way that works best for you and your family’s needs. All you need to do is let them know where you are at.
Communicating with your child

Every arm or leg wave, every coo, babble or smile – these are your child’s ways of communicating with you. It is important that you always try to respond – through talking and touch particularly.

Talking and touch will give your child valuable information about the world and provide them with some of the basic skills they will need to communicate.

Help your child to develop hearing and tactile (or touching) skills by:

- drawing attention to your child’s hands as you feed them (hands are precious parts of your child as givers and receivers of information) – touch them, hold and caress them, pat them, trace your child’s fingers and thumbs and (if your child is open to it) rub your child’s palms
- beginning to explore some things with your child, eg, their bottle – its shape (rounded), texture (hard), weight (light), size and temperature
- telling your child what you are doing together as they sit on your lap to give them clues about your voice and the way you move your body.
At home with your child

Making sure your home environment is safe and welcoming and that your child has opportunities to form an attachment with you and experience the joys of childhood is vital.

You might find these tips useful for connecting with your child and helping them learn about the world.

- Whenever you can, hold your baby (e.g., in a front pack or sling) to help your baby relate to you through touch and learn about your daily routines.
- Limit background noises as much as possible to help your child identify important sounds and language spoken nearby.
- Tell your child who is in the room and use touch signals to identify familiar people (grandad’s glasses or their brother’s hand).
- Create a regular daily routine to help your child learn to anticipate events and understand what’s coming up.
- Put toys and objects that make sound near your child’s hands so they can learn to reach for them.
- Talk to your child about what you’re doing and what is happening from their perspective, “Now you are leaving the bedroom and going outside; isn’t it warm today?”
- Once your child is mobile, keep the floors in your home as uncluttered as possible and set out the furniture to give your child room to move as easily as possible.

Talk to someone in your child’s vision team (your Resource Teacher: Vision or a Blind Foundation counsellor or life skills specialist) for ideas and advice about developing independence.

Talk to them about the different ways you can communicate with your child and help them to move about and learn about textures and temperatures, toys and play.

The Blind Foundation and BLENNZ have staff who can come to your home and talk with you about how to:

- support your child to move about and understand the world they live in
- help your child learn to do everyday activities such as eating, drinking and dressing
- check and assess your child’s vision at home
- organise vision assessments and understand reports
- develop a plan and discuss ideas that will help your child grow and develop in early childhood
- introduce you to programmes such as the Blind Foundation’s PACE programme (see opposite page for more about the PACE programme).

“We had our first BLENNZ immersion course at Homai when my daughter was just 18 months old. I met four or five different families with kids like mine, about the same age and with similar conditions. Even now, years later, we all keep in contact and give each other advice.”

Parent
A Resource Teacher: Vision can help you set up what they call a LITTLE ROOM in your home – a box-like structure with everyday objects hanging from the roof and attached to the sides. Little rooms give children the opportunity to explore objects from a lying or sitting position, without interruption.

The Ministry of Social Development runs a parenting education programme called Parents As First Teachers. The programme gives parents support and ideas about parenting. Ask someone in your child’s vision team for more information. Or check out the Ministry’s website.

Go to: www.familyservices.govt.nz

Ask the Blind Foundation about their PACE (Parent and Child Enrichment) programme. The programme helps babies and toddlers with vision impairments to develop and learn skills such as moving, playing, eating and dressing.
Growing up Robert's way

Robert Hunt wasn’t one to roll over as a small baby. He didn’t really crawl either. But he’s taken to walking with great gusto.

Meredith, Robert’s mum, says: “He’s really doing it all his way. He’s growing up entirely on his own terms. It’s wonderful, really. Just watching him reassures me he’s going to be fine.”

Robert has a rare eye condition called Familial Exudative Vitreoretinopathy (or FEVR, for short), severely limiting his vision in both eyes.

His condition was first picked up when Robert was about three months old.

Meredith noticed he’d startle easily and wasn’t focusing his eyes during breast feeding. Family members noticed his eyes flickered.

After a series of specialist tests Robert was diagnosed with FEVR.

“We felt devastated. One of the hardest things has been not knowing how life will be for him, because none of the usual milestones apply.

“Now he’s a little older I can see things will work out, just in a different way – in Robert’s way.”

As a baby, says Meredith, Robert didn’t smile.

“It was heartbreaking at first. But he wasn’t getting the visual cues most babies get from the people around them.”
“So, I started to play a game with him. I’d use a soft toy to tickle his feet. Then I’d tickle his arms. I’d put his hands on my mouth and we’d giggle together – so he could feel it was okay to laugh.

“It was a lovely way to play together and bond. Robert smiles a lot now.”

At crèche, they’ve had to think outside the square too, says Meredith.

“Initially he was getting upset in the sleeping room. It was unfamiliar and confined. It was scary for him.

“The staff there are wonderful. They thought about it and set up a special area close to them, where he can hear their voices and feel more settled.”

They also designed a separate, safe corner for Meredith to use to get Robert familiar with standing, walking and using his hands to find his way around the crèche.

“It was a great idea for about half an hour,” says Meredith. “After that, Robert began reaching out to the other kids and the other kids were literally busting down the walls to get to him.

“Kids at this age just want to explore and play – and Robert’s no exception.”
Getting involved in the blind community

There are many ways you and your family and whānau can get involved with and develop friends within the blind, deafblind and low vision community.

You’ll find there are many benefits in doing so. For parents, getting involved offers the opportunity to share information and get support. For children who are blind, deafblind or have low vision, socialising with other children like themselves can give them confidence, a feeling of belonging and the opportunity to meet children just like them.

"The best support you can get is from other parents of disabled kids. They’ve walked the walk and can talk the talk. For me, they’ve been invaluable. We share information; we encourage one another. They’ve been crucial to my survival, to be honest. Absolutely crucial."

Parent

Parents of Vision Impaired (PVI) offer a range of opportunities to join in and be part of the blind community. Contact PVI by phoning 0800-312 019 or check out their website at: www.pvi.org.nz.

Ngāti Kāpō O Aotearoa is another organisation offering community programmes to children and young people and their families and whānau. Programmes range from first aid training and communication to Māori tikanga and peer support. Contact Ngāti Kāpō by phoning 0800-770 990 or check out their website at: www.ngatikapo.com.

Paying for services

Understanding the services available to you and your child and who pays for what can be a challenge for anyone. As a general rule, you will find that most services to support your child’s vision are free until your child leaves school. In New Zealand, most parents make use of the free public health and education systems. Some parents choose to pay for private professional support such as the services of a private opthamologist. Other parents prefer to do both.

"We’re looking at the carer’s subsidy. It’ll give us time out just to talk – to talk about our baby, to talk about the family and, maybe, to talk about anything ‘but’ those things...”

Parent

Needing time out

Caring for a child who is blind, deafblind or has low vision can be hard work. At times, you may find you need a break. That is where the Ministry of Health funded respite service may be able to help. Available through the Needs Assessment and Service Coordination (NASC) service (following an assessment), it offers parents and carers regular time out, time out during an emergency or time out in a one-off situation simply because you need it. Work and Income also offers the Child Disability Allowance to the main carer of a child who needs constant care and attention because of a disability. Talk to your child’s vision team or your GP to find out more about these services.
Other support

If your child has a complex needs, you may be able to get funding from the Ministry of Health for equipment such as a wheelchair or standing frame your child might need at home.

To find out more, contact your GP or your local Child Development Services to ask about getting an assessment with an Equipment and Modification Services (EMS) Assessor. You can also find out more from the Ministry of Health’s website. Go to: www.health.govt.nz (search using the terms ‘equipment and modification services’).

Ministry of Health funding is also available for travel assistance to and from hospital, specialist appointments and your child’s early childhood education service. Talk to someone in your child’s vision team to find out what is available. Visit the Ministry of Health’s website (search using the terms ‘National Travel Assistance’).

Preparing for early childhood education

Preparing yourself and your child for an early childhood education service can be hard for many families and whānau. It can trigger feelings of sadness and apprehension about the future.

These feelings are perfectly natural. It can help to take time out at times like these – even a gentle walk can be good for clearing the head. It can also help to talk about how you’re feeling with a Blind Foundation counsellor.

Government funding for 20 hours of early childhood education – all services offer 20 hours to children from the age of three. Talk to your child’s vision team to find out more.

A glasses subsidy from the Ministry of Health is available to children 15 years and under with a Community Services Card or High Health Use Card. Funding contributes to assessment, lenses and frames. For more information, contact 0800-171 981, talk to someone in your child’s vision team or check out the Ministry’s website. Go to: www.health.govt.nz (search using the terms ‘spectacle subsidy’).

A Contact Lens Subsidy is available from the Ministry of Health to children who for medical reasons cannot wear glasses (and who meet criteria). For more information, check out the Ministry’s website. Go to: www.health.govt.nz (search using the terms ‘contact lens subsidy’).
Will your child be okay?

Every child is different, so it is hard to tell just how your child will respond to the experience of going to and starting early childhood education.

For most children, however, it provides an opportunity to learn to play with other children and get used to moving about confidently in a different environment. All these skills and knowledge are valuable and will help your child grow, develop.

Your love, acceptance and support as your child makes the transition out into the world will help.

“The great thing about places like kindy is that kids don’t care or notice disabilities. Chances are your child will be simply accepted as one of the gang …”

Parent

Choosing an early childhood education service

New Zealand has many types of early childhood education services to choose from. Each type has its own way of working with children and with families and whānau.

Some offer all-day education and care; some offer only a part-day service.

Generally speaking, services fall into two main categories.

- Teacher-led – where registered teachers provide the education and care, eg, kindergartens and early childhood education centres.
- Parent-led – where parents, families and whānau provide the education and care for their own and other children, eg, playcentres and kōhanga reo.

If you’re not sure about the service best suited to you and your child, talk to someone in your child’s vision team for advice and guidance. You might like to visit a few services before deciding on the right one. Talk to the service and your child’s vision team and book a time to go. Ask for time with the people in charge so they can answer any questions you may have.

*Te Whāriki is the Ministry of Education’s early childhood curriculum policy statement. Te Whāriki is a framework that focuses on learning partnerships between the child, teachers and whānau based on the child’s needs and sociocultural context.*
Settling in

Although many children settle happily into a new environment, being away from you and other family can be difficult for some children. Here are some of the things you can do to help your child settle in.

Visit the service several times before you leave your child for the first time. Give yourself the chance to observe how teachers relate to your child and other children, what the routines are and how their programme works.

Don’t hesitate to ask if someone in your child’s vision team can go with you.

Someone from your child’s vision team will support you to talk to your child’s teachers about:

- your child’s vision loss – from the diagnosis, through to what your child can see and how it impacts on your child’s ability to move about and relate to others
- areas of development, such as encouraging independence
- tips on communicating with your child and making them aware of what is happening around them using speech and touch
- the equipment and technology your child uses (if any) – show them how it works, how it needs to be maintained and give them any troubleshooting tips they might need
- the important people in your child’s life and any important things going on right now that are having an impact on them
- things your child likes, dislikes, is good at, finds a challenge, needs help with, can get upset about and can do independently
- the need for good lighting and tidy, clear pathways your child can use to move safely from place to place.

“It’s tempting to keep young ones wrapped up in cotton wool – particularly when they’re little. My advice is don’t do it. Resist the temptation. The best thing you can do is to encourage and support them to get out and explore the world.”

Deafblind adult
Getting the right support

The main organisations available to give you help and support while your child is in early childhood education are:

- **BLENNZ** – they will help you choose a service and help your child make the move from home to early childhood education. They will support the parents and teachers working in the service to know and understand your child’s learning and development needs. BLENNZ Resource Teachers: Vision may also teach your child additional skills related to understanding concepts, communication, vision, living, movement and social development to support your child's growth and development.

- **Blind Foundation** – they will help your child learn to do everyday living tasks and develop strong relationships with others in their new environment. They are there for you, as well, to help you adjust to the changes occurring for you and your child.

- **Ministry of Education** – the Ministry’s early intervention specialists will work with you (depending on the needs of your child), the Resource Teacher: Vision and your child’s early childhood educators to help your child to develop and learn alongside their peers. Early intervention specialists know about child development and how to support teachers to include children who are blind, deafblind or have low vision in the early childhood programme.

How will you know if things are working well?

Take time to talk to people at your child’s early childhood education service. Raise any concerns you have about your child’s learning and development. Have a chat with your child’s teachers about the different strategies they use and the different things they emphasise for your child. Pick up the phone or email them or ask someone in your child’s vision team to organise a meeting where you get together and discuss what is happening.

Helping your child to develop and learn

There are many ways you can keep up with your child’s learning and development. You and your child’s vision team can talk about:

- keeping a written or digital home to early childhood service diary that describes what your child did during the day and how they responded (completed by staff at your child’s service) – you then add information about what happened at home and share it with staff the next day

- developing a written plan for your child that identifies their learning and development goals and sets out how the goals might be achieved, by who and with what support (these are sometimes called individual development plans)

- reading learning stories created by your child’s early childhood education service teachers that show what your child is learning and how they are developing. These can be a wonderful tool for thinking about what your child is achieving and helping your child develop confidence.
Section 1: Early years

“Don’t be surprised if you feel quite emotional at times. School life can be a trigger in my experience. Just when you think you have it all sussed, those old feelings can sneak up and bite you again …”

Parent

“Making that change to school isn’t easy. This is when you part company with your child and let them loose in the world without you. It is a scary time and it can be a time when problems surface. Make sure you have support around you and someone you can talk to.”

Parent

B4 School Check

B4 School Check – is a nationwide programme offering a free health and development check for four-year-olds. The programme includes vision and hearing screening.

See: www.wellchild.org.nz
Freephone 0800-933 922 (PlunketLine)

Preparing for school

Getting ready for school is another big step in your child’s life and another big step for you and your wider family and whānau. Some of those familiar feelings of sadness and apprehension may resurface. You may start feeling anxious about how your child will cope at school. Naturally, you want the best for them – but will they be happy?

The best thing you can do is talk to and plan with your child’s vision team – they know this can be a tricky time and they will know how to support you.

Give yourself and your child’s vision team 12 to 18 months to plan.

Together, think about:

- how to plan for your child’s transition
- choosing a school (it is a big decision)
- where to find out more about a school (eg, by looking at their website, the latest Education Review Office (ERO) report and by talking to other parents)
- the Ongoing Resourcing Scheme (ORS), which provides additional time and assistance from a specialist teacher and a teacher’s aide, and ongoing specialist support or oversight from the Ministry or Ministry funded providers. There are two levels of ORS support, high and very high
- changing school property (the earlier you, your child’s vision team and your child’s school think about any changes, the better)
- meeting with the school to share information, discuss your child’s strengths and needs, and identify any additional support they can offer
- applying for any assistive technology your child may need.
Parent Justine Edwards says it’s hard to single out the one specialist who’s made the biggest impact on her young six-year-old daughter’s life.

There’ve been so many. And each one has had an important role to play – albeit in a relatively short period of time.

Justine’s daughter, Giana, is blind. Her formal diagnosis, revealed through an MRI scan at 11 months, is ‘bilateral optic nerve hypoplasia, septo optic dysplasia, with an absence of a septum pellucidum’.

“It’s a mouthful to say, I know,” says Justine, “but essentially it means Giana’s optic nerve didn’t form properly as a baby, causing blindness. It also means she takes a little longer to learn things and to communicate.”

When Giana was six weeks old, Justine and her Plunket nurse noticed Giana’s eyes weren’t fixing on or following things as they should.

A referral to an eye clinic led to a visit to a hospital ophthalmologist, which, in turn, led to referrals to the Blind Foundation and the Blind Low Vision Education Network NZ (BLENNZ).

Over the past few years, Justine and Giana have seen counsellors, orientation and mobility instructors, early childhood education and hydrotherapy specialists, paediatricians, a Resource Teacher: Vision (RTV) and the BLENNZ Homai assessment team in Auckland.

Justine has signed up with Parents of Vision Impaired (PVI), attended PVI conferences and is a frequent attendee of BLENNZ immersion courses.
“When I think of all the people we’ve met, it can seem overwhelming. I’d say Giana and I would’ve seen more than 20 different specialists over the past six years.

“Yet, to me, I’ve been so grateful to have the support. Yes, I’ve got my own whānau, which is fantastic. But all this additional support that I can tap into is amazing.

“I don’t know how I would’ve survived without Giana’s Resource Teacher: Vision. And through PVI, I’ve met incredible parents who’ve helped me accept things and have become my support network.

“At my first BLENNZ immersion course, when Giana was 18 months old, I met four or five families with kids around the same age as Giana, with the same condition. Even now, we all keep in contact and give one another advice.”

Justine says the benefits for Giana have been huge, too.

“She’s a wonderful wee girl and she’s progressing well thanks to all the support around us.”

What are some of the stand-out milestones?

“Well, she’s overcome a resistance to touch, new people and unfamiliar surroundings. That’s a biggie. And she’s gone from crawling to walking, while starting to play and develop friendships.

“These days I feel much more confident about what the future holds for Giana. Yes, things are challenging, but there are some incredible people there to help her succeed and that means a lot.”
Choosing a school

Local schools
Most children who are blind, deafblind or have low vision attend regular classes within their local school and get access to extra help provided by their school.

If your child is deafblind or has a complex range of needs, the school will approach the Ministry of Education for extra support.

The most important thing is that you and your child are made to feel welcome at enrolment time.

If you feel a school is being unwelcoming or is reluctant to enrol your child, then talk to someone in your child’s vision team. It is likely they will suggest calling the Ministry of Education, Special Education and getting advice from a district manager who will know what to do.

You have a range of choices when it comes to enrolling your child at school. Discuss your child’s needs with their support team. Listen to the team’s advice – but, remember, you know your child best.

“During our child’s time at school, when it all went well, it was great. But when it turned bad, it was awful. If things get tense, reach out for support. Failing that, chocolate cake definitely helps. Who can remain angry when there’s chocolate cake involved?”

Parent

Special schools, satellite classes and special units within regular schools
If your child has high or complex needs, you may choose to enrol them in one of the 28 special day schools around the country.

Some children with high needs go to special classes known as a satellite classes. These classes are run by special schools but are located on the grounds of a regular school – BLENNZ’s James Cook High School’s satellite class in Auckland is an example.

Some special schools also offer a special education mobile teaching service where children with high or complex needs can be enrolled in their local school but are taught by specialist teachers from the special school.

If you’re interested in enrolling your child in a special school, you will need to have what is known as a Section 9 Agreement – Section 9 of the Education Act covers enrolment at special schools.

Some regular schools also have units that provide specialist support for children who are blind, deafblind or have low vision. Your child can move between regular classes and the unit.
Te Aho o Te Kura Pounamu – The Correspondence School and home schooling

Te Aho o Te Kura Pounamu – The Correspondence School offers distance learning in certain circumstances. You can choose to home school your child and there might be extra support available to help you. Talk to someone in your child’s vision team if this is an option you would like to look into.

BLENNZ students can be assessed by a national assessment team. Assesments involve an ophthalmologist, optometrist, a functional vision assessor, a physiotherapist, an occupational therapist, developmental orientation and mobility specialists, music therapists, psychologists and others.

BLENNZ

BLENNZ is New Zealand’s very own school for children who are blind, deafblind or who have low vision. In practice, this means every child with a diagnosed visual impairment who meets BLENNZ criteria can enrol in whatever school he or she chooses and can be enrolled with BLENNZ at the same time.

Doing this means you and your child will have access to everything available from the education system, as well as what is available from BLENNZ.

The range of services and support you might access from BLENNZ include:

- advice and support for families and whānau
- teaching expertise from BLENNZ’s network of Resource Teachers: Vision based in Visual Resource Centres across the country
- Homai Early Childhood Centre and Campus School
- residential services and satellite classes
- assessment from the National Assessment Service
- access to The Expanded Core Curriculum, which will give your child the extra skills they need to learn and participate in class and outside the classroom
- specialist services, including orientation and mobility services
- technology expertise from teachers who know about using assistive technology
- immersion courses on topics such as using assistive technology, learning braille, adapting the curriculum and daily living skills.
“We’ve seen a real growth in confidence in our child recently. I’m not sure why. But he does have an awesome teacher this year. He’s talking more, he gets up earlier and he’s dressing himself for the first time …”

Parent

“Our daughter’s teachers are amazing. They love her to bits and they go that extra mile to make sure she has what she needs to stay ahead – it’s a lot of extra work.”

Parent

Starting school

Starting school can be an exciting time for your child. School provides wonderful opportunities for a child to grow and learn about the world. Your child will have the opportunity to:

- make new friends
- learn new skills
- become more independent, as well as be part of a group
- explore new environments
- think about and plan for their future
- develop confidence, self-esteem and a positive identity.

Give your child lots of encouragement and be enthusiastic about starting school. Your involvement and the involvement of your wider family and whānau are important and valuable.

Starting school involves change – you and your child will be leaving a familiar environment with people you know and stepping into a bigger world with different routines and new people.

You will also notice that services and support are different from what is provided in early childhood.

Teachers and staff at your child’s new school will need to get to know your child. They will need to learn and use different strategies in class to help your child develop and succeed.

They will also need a shared understanding about what your child needs and it will be important for everyone to communicate and work together.

When your child starts school, you also become part of the school community. It’s a great opportunity to get involved in school activities and meet other families whose children will move through school with your child.
Succeeding at school

To succeed and enjoy their time at school, your child needs:

- a high-quality learning environment – where both the school and classroom are well set up and are safe for your child to access and get around. Resource Teachers: Vision are there to support learning and teaching and can give practical advice on classroom design, lighting and storage for your child’s technology and equipment

- every opportunity to learn, participate and engage in the school curriculum – that means your child can access information and has the opportunity to contribute and express what they know and can do. Your child may need their learning resources produced in large-print format or braille. They may need their teacher to verbalise different aspects of the lessons and classroom activities more. Again, Resource Teachers: Vision are there to help and advise teachers on what to do

- teachers with high expectations of what your child can achieve and the skills to change their approach to suit your child’s needs – a Resource Teacher: Vision will know what to do

- opportunities to form relationships, develop independence, learn alongside their peers and develop a positive sense of self. Your child’s teachers may need to take extra steps to stimulate interaction and communication in class and promote your child’s self-esteem, self-confidence and self-respect.

“In my experience, a good teacher can make all the difference. I remember one of mine coaching my sighted peers on using concrete language and verbalising things more, so I could understand what was going on.”

Blind adult

“Making friends gets harder and harder as kids get older – which can be heart wrenching as a parent. But this year our daughter’s made a wonderful friend. They text each other every day, hang out in the weekends – a couple of typical teenage girls doing typical teenage stuff, it’s just lovely.”

Parent
Assistive technology – options for learning

Any equipment and technology your child uses at school will depend on your child’s learning needs and school environment.

In general:
• children who are blind or deafblind and cannot use their vision for learning use braille technology such as braille note takers or refreshable braille (where text from a computer is converted to braille using small plastic or metal pins that move up and down to display the braille characters) and screen readers
• children with low vision can use large-print software and print magnification and scanning technology.

This equipment and technology is called assistive technology. It aims to remove any barriers to achieving and reaching learning goals.

Selecting and using assistive technology

Once your child’s needs have been identified and the best assistive technology for your child selected, your child will be encouraged to:
• become familiar with it to make sure it is the right technology for your child and that it works as expected
• develop the skills needed to use it for specific learning tasks and activities
• use it across a range of situations and tasks
• become independent in its use and care.

Applying for assistive technology

Schools, with help from a Resource Teacher: Vision, can apply to the Ministry of Education for assistive technology using an assessment framework that looks at:
• your child and their abilities
• your child’s learning environment
• the classroom tasks your child needs to complete
• the tools best suited to your child, the learning environment and the tasks your child needs to complete.

Equipment for mobility

There are several options available to children who need mobility equipment to move around safely and independently at school – a cane is one.

There are three types of canes:
• A long cane (that extends to chest height) with a Teflon tip for identifying surface changes, curbs and other obstacles.
• A thinner symbol cane (measuring around 70cm in length) used only to indicate the user has a vision impairment (it doesn’t give the user any information about the environment).
• A support cane for extra support when walking that also indicates the user is blind or has low vision.

Talk to someone in your child’s support team (such as a Resource Teacher: Vision or developmental orientation and mobility instructor) or the Blind Foundation for more information.
Planning and monitoring your child’s education

Your child’s vision team will play a key role in helping you to plan and monitor your child’s education. It is important you know what is going on and how to support your child when you need to.

This means maintaining a strong partnership with your child’s vision team and working with the school to decide on the best approaches and learning programmes. As part of their planning the team may develop an Individual Education Plan for your child.

“Along the way, you and your child will meet some fantastic educationalists – be they teachers, teachers’ aides or canteen staff. I like to make sure I tell them how valued they are. Never presume they know.”

Parent

The relationship you have with your child’s vision team and school will work best when everybody:

- creates a supportive environment
- accepts responsibility for meeting the learning needs of your child
- has a view on how these needs should be met
- works together to find answers
- works with others in ways that concentrate on your child’s needs
- presents their views openly, sensitively and honestly
- respects the knowledge and views of others
- understands and respects the cultural needs of your child
- shares information
- deals with problems as they arise
- keeps in regular contact.

The Individual Education Plan

An Individual Education Plan or IEP is a written plan that shows how the school and classroom programme will be adapted to fit your child.

For example, your child may need their learning materials provided in large-print format or braille. They may need additional computer use and keyboard lessons integrated into their classroom programme with help from an Resource Teacher: Vision.

An IEP involves you, your child’s Resource Teacher: Vision (as well as other members of your child’s vision team) and your child (if appropriate) and is typically reviewed twice a year.

Tips for families and whānau

- Before the meeting, talk to someone from your child’s vision team (eg, the Resource Teacher: Vision) and make a list of what you want to talk about and who else should be there.
- Ask your support person to make sure everything noted is covered.
- Ask questions if you don’t understand something.
- Take your time making big decisions – don’t be rushed.
- Make sure the goals agreed to are important to you and your child too.
- Before you leave, check in with your child’s vision team to make sure you clearly understand what has been agreed to, including your role.
- Check the date, time and place of the next meeting.
- Remember that you can ask for a meeting at any time.
What you can expect your child to learn at school

Teaching in schools is guided by the national curriculum, which is made up of two documents, *The New Zealand Curriculum* for English-medium schools and *Te Marautanga o Aotearoa* for Māori-medium schools.

Children in English-medium schools learn a range of skills and understanding related to English, the arts, health and physical education, learning languages, mathematics and statistics, science, social sciences and technology. *The New Zealand Curriculum* is also designed to encourage enjoyment of learning and the ability to think critically, manage self, set goals, overcome obstacles and get along with others – the attributes we all need to succeed as children and adults.

Children in Māori-medium schools (schools that use mostly te reo Māori) learn the skills and knowledge to be able to participate and contribute to Māori society and the wider world. The learning areas are te reo Māori, pāngarau (maths), pūtaiao (science), hangarau (technology), tikanga-ā ā iwi (social sciences), nga toi (arts), hauora (health and physical education), nga reo (languages) and te reo Pākehā (English).

Your child’s teacher will be able to answer questions that you may have about the curriculum.

“The high school you need to build relationships – with the principal, with your child’s teachers. I’m on a first name basis with them all. I ring them and email them all the time. Communication is the key.”

Parent

What is the Expanded Core Curriculum?

You may hear your child’s vision team talk about the Expanded Core Curriculum (ECC). The ECC is an internationally-recognised term that refers to the vision-related skills that students who are blind, deafblind or low vision use to access the school and classroom curriculum. It is not an alternative or additional curriculum. Instead, the ECC is used as guidance for the Resource Teachers: Vision to help adapt and differentiate teaching and learning within the national curriculum to best meet the needs of students who are blind, deafblind or have low vision.

The ECC is also sometimes called Stepping Stones it includes the following skills areas.

**Communication** – braille, tactile skills, handwriting, computer use, keyboard skills, sign language, communication, concept development and listening skills.

**Sensory efficiency skills** – development and use of vision skills and visual aids.

**Physical abilities** – postural control and balance, movement, physical strength and endurance, and physical education.

**Orientation and mobility** – muscle development and coordination, development of orientation, environmental considerations, mobility devices and formal strategies for travel.
Social skills – interaction, socially acceptable behaviour, self-esteem, self-confidence and self-advocacy, interpersonal skills, recreation and leisure.

Living skills – self-care, organisation, time management, decision-making, vocation and career, advocacy, awareness of and access to community resources, independence and interdependence, and money management.

Technology – use of technologies and research and referencing skills.

Career and future planning – awareness of opportunities beyond school, eg, tertiary study, work and community opportunities.

Funding and support at school

There is a range of funding and support available to students who are blind, deafblind or have low vision at school.

Ongoing Resourcing Scheme (ORS)

The ORS is Ministry of Education funding for individual children with a range of special education needs (not just for those who are blind, deafblind or have low vision) who require extra support at school to participate and learn.

The amount of funding differs according to whether your child is verified as high or very high. Not all children with low vision qualify for ORS funding.

The school where a child who receives ORS funding is enrolled receives:

- additional teacher time
- support from a teacher’s aide as agreed by the team
- funding for consumable items
- specialist services as agreed to support the curriculum.

Applying for ORS

Usually your Resource Teacher: Vision will process your child’s application to be verified for ORS funding by responding to questions relating to his learning needs. Talk to someone in your child’s vision team to find out more about the application process.

The Blind Foundation produces textbooks, handouts and exam materials in accessible formats for school students who are blind, deafblind or have low vision. Students can access resources in large-print, braille and a range of audio formats.

The Blind Foundation also has an extensive library of recreational reading material called BLINK (Blind and Low Vision Information Network for Kids and Young Adults).

See: blinklibrary@blindfoundation.org.nz Freephone 0800-243 333
Section 2: School Years

Special Education Grant

All schools receive an operations grant for all children enrolled. In addition, schools receive a Special Education Grant (SEG) to support children with special education needs. Schools have discretion over how they use their grant. It may be used to cover extra teacher’s aide hours, to adapt programmes or the learning environment, or provide extra equipment or curriculum material. The school principal sets the priorities for student needs and decides how this fund will be used within their school.

Special Education School Transport Assistance

The Ministry of Education also provides a subsidy or allowance for transport assistance so your child can travel between home and the nearest appropriate school.

To get this support, a child must:

• be aged between 5 and 21
• be enrolled at a state or state integrated school
• meet the Ministry’s requirements for mobility and safety
• attend the nearest appropriate school or educational setting that is able to meet their special education needs.

Talk to someone in your child’s vision team to find out more about how to apply.

Changing schools

If your child is changing schools, you and your child’s vision team will need to plan ahead to make sure the change goes as smoothly as possible. It’s important to tell the new school about your child’s needs well ahead of time so that the right support is in place when your child starts. It’s also important that you and your team know that resources might change from school to school.

If your child receives ORS funding, the funding, specialist and teacher time will go with them to the new school. But the level of teacher’s aide time may need to be reviewed.

Your child’s vision team will know how to help you and your child prepare for the change and adjust to the new school.

They may suggest discussing these points as you plan for the change together.

• A planning meeting for your child’s transition.
• Preparing your child for change – when shall we talk about it? What will we cover? How can we help them see the positives?
• Any changes to property required – this will need to be checked every time your child changes schools.
• The transfer of your child’s records to the new school – who will do it? Is written consent needed?
Heading off to intermediate school has been a big deal for 11-year-old Boston Beattie and his mum, Sharon. Boston, who was born 26 weeks prematurely with hydrocephalus (or water on the brain), is blind.

He started intermediate school this year, after several months of transition planning led by Boston’s Resource Teachers: Vision, Judy Fox and Cathy West.

Sharon is delighted, and a teeny bit relieved, to report that Boston is settling in well. “I felt a bit nervous about it, I think. He’d done so well at primary school thanks to wonderful teachers, his Resource Teacher: Vision at the time and a lovely teacher’s aide. His primary school had worked so hard on developing a really supportive culture.”

“I just worried that intermediate would be different. Kids can be a bit hard on one another as they get older. We’ve all experienced that,” says Sharon.

But, so far, so good, she says. “In fact, I’ve noticed a huge growth in Boston’s confidence. I’m putting it down to having an awesome teacher and the preparation work Judy and Cathy have done. He’s become more open in his talk. He’s up earlier and his independence has grown.”

“I’m actually thinking he might like to spend a bit more time up in Auckland in the Homai centre with BLENNZ to experience life away from home.”

Sharon, who is mum to six kids, says parenting Boston is more hands on and takes more planning compared with the others.
And that’s why Boston’s Resource Teachers: Vision over the years have been an invaluable support.

“We’ve both (Boston and I) built up some very good relationships with Boston’s Resource Teachers: Vision. They are relationships that will be with us forever. Each of them has offered us a lot. With Boston, they’ve made him persist with learning his braille – he’s doing well with it now. But he tires easily and needs a lot of encouragement.

“They’ve got him involved in Homai immersion courses to develop his daily living skills and helped him get to know the layout of his new school before he started.

“With Boston’s teachers, Judy and Cathy make sure they have the large-print and braille materials he needs and that his technology is working as it should.”

Sharon says Boston’s Resource Teachers: Vision give her confidence that Boston will do the best he can at school.

“My advice to parents is to spend time with your child’s Resource Teacher: Vision. Trust they will do their best for your child. Develop a good relationship with them. You’ll need it. I take my cues from Judy and Cathy all the time. I ask them heaps of questions and I tell them my honest opinions.

“They’ve been a huge source of strength for me, too. They help me stick with things and remind me to notice the positives.

“Sometimes it’s a smile on Boston’s face that’s my reward. Other times it’s the bigger stuff like maths achievement. Both are lovely to see.”
Preparing for secondary school

Preparing yourself and your child for secondary school can be another tricky time emotionally, as well as practically.

Your child is growing up and getting out in the world more and more. Aside from that, there is a lot to organise. It’s normal to feel worried and for some of the old feelings of sadness and apprehension to resurface.

Take some time to sit down and talk to your child about where you are both at. Talk about your feelings. Get your child’s vision team involved and discuss some of the changes your child can expect from secondary school. Your child will have an exciting choice of subjects, travel to a new location and maybe wear a uniform for the first time.

Think about how you will plan ahead for the move – discuss what has worked well in the past and what you might do differently this time. Give you and your child’s vision team 12 to 18 months to plan.

Together, think about:
- how to transfer funding and other support your child receives at primary or intermediate school
- any property modifications that might be needed (when you’ve decided on a school, these need to be planned for well before your child starts)
- checking the assistive technology your child uses is suited to the new school environment
- any additional curriculum input your child will need from a Resource Teacher: Vision
- exam support needed further down the track and how to plan for that, eg, your child’s vision team and school may want to apply to the New Zealand Qualifications Authority for exam papers to be provided in braille or enlarged print
- familiarising your child with the new environment and new routines of secondary school
- emotional and practical support needed to manage the change of environment
- preparing the new school.

“We started planning for secondary school in term two of the previous year. And I’m pleased we did. It gave us time to pick her subjects, order braille resources and visit the school numerous times. It meant she was ready to go from day one.”

Parent

Ask the Blind Foundation about STRIPES – an ideal programme for young people. It teaches daily living skills; pre-employment skills (such as time management, decision-making, connections and leadership); personal and social development skills (such as teamwork, confidence, and achievement) and teens get to take part in a range of recreation events.

BLENNZ runs immersion courses for secondary school students on study skills and planning for tertiary education. Contact your Resource Teacher: Vision for more information.
Starting secondary school

Your child will find secondary school very different from primary or intermediate school. There will be new routines, new teachers, new support people and a new school system.

Some of the things they might find different about secondary school include:

- a new and wider set of classmates
- having a form teacher and different teachers for each subject (instead of one main teacher for all lessons)
- different support people from the people who worked with them at primary school
- getting used to a timetable where lessons for different subjects are held in different classrooms
- finding their way to the next class and getting there on time
- a longer school day
- learning new subjects such as languages
- more homework.

“Don’t underestimate the importance of mobile phone technology. Our daughter has hers linked to her braille note, using blue tooth. She can research online much faster now and texting has given her a whole new way to join in the conversations of her peers.”

Parent
National Certificate of Educational Achievement (NCEA)

NCEA is the main secondary school qualification for students in years 11 to 13. NCEA stands for the National Certificate of Educational Achievement and can be gained at three levels – usually level 1 in year 11, level 2 in year 12, and level 3 in year 13.

The NCEA system gives a more accurate picture of a student’s achievement, because any student who demonstrates the required skills and knowledge to the level of a particular standard achieves NCEA credits. Each student receives a School Results Summary that presents all standards taken throughout their school years and the results for each.

Support for tests and exams

Most students who are blind, deafblind or have low vision will need extra support (called Special Assessment Conditions) to sit tests and exams at secondary school and to be assessed for qualifications such as NCEA.

Students can apply for the following support.

- Exam and test papers to be provided in braille, large print or an electronic format.
- Permission to use the assistive technology your child usually uses to learn in the classroom.
- Reader, writer or reader-writer support, where a student has content of the assessment read aloud to them and they speak the answers to a writer.
- Extra time (in some situations) for assessments over a certain length.
- Other support such as rest breaks, home supervision and special papers.

Talk to your child’s Resource Teacher: Vision and vision team to find out more about Special Assessment Conditions.

Check out the Halberg Allsports website to find out about the Halberg Disability Sport Foundation’s community programme. The programme includes disability sport advisors who help get young people with disabilities more involved in sport in their region. It features open days for young people to try out sports, mentoring, funding and more.

Go to: www.halbergallsports.co.nz.

Contact the Blind Foundation to access their wide range of talking books, braille books and audio magazines. The library is a great study resource – and the Foundation delivers free to anywhere in the country.
Enjoying life outside the school gates

For young people growing up, there’s more to life than school! Getting out and about in the community, making friends and generally enjoying life are just as important as good grades.

The Blind Foundation has a nationwide team of advisors who help children and young people take part in all kinds of activities. They organise camps and activities and can adapt sports, so that children who are blind, deafblind or have low vision can participate and enjoy life. For more information about their activities, contact the Blind Foundation on: children@blindfoundation.co.nz.

BLENNZ regularly runs two- or three-day immersion courses in Auckland for young people keen to meet, socialise and learn about topics such as music or performing arts. Travel and accommodation costs are covered. For more information on BLENNZ immersion courses, talk to your Resource Teacher: Vision.

The Ministry of Social Development also offers the Out of School Care and Recreation Subsidy to help cover the cost of an after school or school holiday programme (for school-aged children). Check out the Ministry’s website for more information at: www.familyservices.govt.nz

Finding life tough

It’s not uncommon for teens to find life a bit tough at times – sometimes exam stress can be too much or they may struggle to fit in with their peers. Feeling down in response to difficult situations is pretty normal and usually these feelings fade over time. But it could be depression when these feelings are intense and will not go away.

A range of mental health resources and services are available for teens. Talk to your family doctor if you have any concerns about the mental health of your child.

Youthline (0800-376 633)
The Depression Helpline (0800-111 757)
Lifeline (0800-543 354)
Alcohol Drug Helpline (0800-787 797)
See: www.thelowdown.co.nz

Other support services

You might also want to contact the following organisations for counselling and support.

Blind Foundation (0800-243 333)
Parents of Vision Impaired (0800-312 019)
Ngāti Kāpō O Aotearoa (0800-770 990)
Parent2Parent (0508-236 236)
Deafblind (NZ) Incorporated (www.deafblindnz.org.nz)

The Blind Foundation offers people who are blind, deafblind or have low vision a peer support service called Telefriend. All calls are confidential and protected by a code of practice.

Call Telefriend on 0800-100 051 on weekdays from 1pm to 4pm. Outside these hours, a message can be left and the call will be returned.

The Ministry of Health offers a range of initiatives aimed at young people through the Youth Mental Health Project.

Find out more by checking out the Ministry’s website, go to: www.health.govt.nz (search using the terms ‘youth mental health project’).
For Letitia Patete, all it took was one meeting to Wellington Girls’ College and she was convinced her 14-year-old daughter Renee would love it there.

“I’d heard lots of good things about the school, but I did need to check it out and see for myself. “I was afraid Renee wouldn’t be accepted; that it would be much harder for her at secondary school.

“But after that first meeting I felt reassured. The principal was incredibly welcoming. She was excited to have Renee enrol. I could see the teachers were passionate. I could see they cared about the kids in their classes.”

Renee is an exceptionally gifted student who’s been blind since birth.

She excels at a wide range of subjects, including maths, science, English, languages and music.

By three, she’d learnt braille. At six, she was one of the youngest people ever to master a braillenote (a braille word processor).

“She’s got this incredible memory and ability to retain information. She just loves to learn. But it’s hard work keeping up with her and making sure she has everything she needs to be successful,” says Letitia.

That’s why Letitia and Renee’s Resource Teacher: Vision started planning for Renee’s transition in term two of Renee’s last year at primary school.

They started by visiting the school and meeting the learning support team. By term three, they began to pick Renee’s subjects and order her braille textbooks. In term four there were regular visits to the school to get Renee used to the layout and comfortable with her teachers.

“The well-planned transition made all the difference,” says Letitia. “But, I have to say, the support didn’t stop there.”

Right now, Renee’s teachers are planning for NCEA to make sure Renee has the braille resources she needs and the assessment process is well organised.
The principal recently rejigged the timetable to foster a fledgling friendship that’s developed between Renee and another student in her German class.

This term the girls were encouraged to do a joint presentation to the school assembly on the importance of being polite and conscientious towards one another.

“Renee’s friend had noticed that Renee was finding it hard to get in and out of doorways after class with 1,300 girls rushing from place to place.

“So, their teachers encouraged them to talk to assembly about the importance of looking out for each other and being courteous. Renee wasn’t singled out for attention. It was a message for everyone. That’s the way they do things here.”

Letitia believes Wellington Girls’ College, with support from Renee’s Resource Teacher: Vision, are doing a great job of helping Renee to succeed academically, as well as setting her on the path to a happy, independent adult life.

“Adolescence doesn’t come without its challenges – and there tends to be even more for kids with disabilities. But I’ve noticed Renee becoming happier and happier at secondary school and I’m over the moon.

“Last weekend she and her new friend jumped on a bus and spent five hours in town like a couple of regular teenagers. It was lovely to see her off and venturing into the world.

“She was buzzed for days. And, to be honest, so was I.”
SECTION 3

YOUNG ADULT YEARS
Growing up

Many blind or deafblind adults and adults with low vision live fully independent lives, get married, have families, compete internationally in sport and work in all types of jobs and careers.

Technology is increasingly making it easier to communicate and get about safely and independently – thanks to advances in screen reading and computer software. Building law means cities and buildings are becoming more accessible for everybody. Employment law means employers have to be responsive to the needs of employees with disabilities, including people who are blind, deafblind or have low vision.

Planning to go to university or finding a job takes time.

Ask your teen’s vision team to talk to the Blind Foundation in your child’s last year of school to plan ahead and discuss the options.

Call the Blind Foundation on: 0800-243 333.

“Our daughter’s talking about teaching as a career – and she would be amazing. She’s also thinking about writing, composing music. I can see her on the world stage, actually.”

Parent

Leaving school

Leaving school is an important step for all young people. It can be both exciting and challenging and is usually more successful with some planning and forethought.

Talk to your teen’s vision team about how you want to do this.

You may want to develop a plan to help them make the transition from school to adult life as easy as possible.

You may also want to involve a broader range of people than you usually do. For example, you might want to plan with:

• your teen
• their friends and family friends
• you and your family or whānau
• the school
• BLENNZ
• Blind Foundation
• specialists from the Ministry of Education
• Ngāti Kāpō O Aotearoa national field coordinators
• representatives from community service providers or other government organisations.

Talk to your teen’s vision team about what to include in the transition plan.

Often they feature:

• a young person’s goals
• how they will achieve those goals
• what support they will need for employment, study, financial independence, taking part in community activities and groups, cultural support, leisure activities, living arrangements, mobility, transport, peer relationships, sexuality and self-esteem
• what happens with any equipment your child uses at school and what equipment they may need when they leave school and go on to work or further study.
Planning for change

By now, you and your child’s vision team will be experienced at planning for change. You will know a lot about what works well and what is not so good.

“Planning for life after secondary school is so important for all kids – yes, we may be blind or deafblind, but we deserve a life, we have goals and there’s plenty we can do. With an open-minded society, the options are endless.”

Deafblind adult

“Preparing for your child to leave home isn’t straight forward. Everyone transitions the child, but no one really transitions their parents.”

Parent

Here is a list of things you and your child’s vision team might want to consider, alongside the things you’ve already got sorted.

- Plan early to give you time to set up the right support and for your child to learn the new skills they might need when they leave school.
- Identify what training and skills they want to develop.
- Think about the emotional and practical support that they may need from others. Think about your needs too.
- Consider who will act as liaison, information and advocacy people for you and your child. This means that when they finish school, there are people they know (and you know) who are familiar to them and familiar with what they need.
- Update the plan (or make it more specific) as your child gets closer to the end of school.
- Talk to your child’s Resource Teacher: Vision to find out what will happen to their assistive technology when they leave school.
- Encourage your child to lead the process, wherever possible, with your support (they know their own dreams and aspirations and will be more likely to achieve them if they have a say in what happens).
- Encourage your child to identify their interests, strengths and challenges in achieving their goals – and build on those strengths and interests.
- Identify someone from the Blind Foundation to be available and in touch with your child as your child is leaving school – having a familiar support person for the first few months can make all the difference to their confidence and ability to cope with change (and possibly to yours as well).
Before daughter Katelyn came along, Oamaru parent Pat Fox reckons she was really, really shy.

“I was. I truly was. But then Katelyn was born with very complex needs and I had to come out of my shell. I was terrified to start with. But I had to stand up for her. I had to become her advocate,” she says.

Katelyn was born six weeks early. At 17 months old, she had brain surgery to stop continuous epilepsy, lost her vision and speech and developed cerebral palsy. After surgery, Katelyn was given a 50 percent chance of survival.

Looking back, Pat says those early days were devastating as a new parent and simply a matter of getting through each day.

“It was the stuff of nightmares. But my husband Steve and I got through it. And look at the result we have. Katelyn left high school last year and is now living in an IHC residential home. It’s been quite the journey.”

Pat says meeting other parents through an organisation called Parents of Vision Impaired (PVI) was the turning point for her – and the thing that drew her out of her shell.

“My husband and I promised each other, when Katelyn came home from hospital, we would give her the best life we could in the time we had her. PVI helped us achieve that.”

Pat heard about the national parent group by chance.

“I was so overwhelmed by information in those early days I can’t exactly remember how I came across them. But I did. And I remember really wanting to go to one of their conferences in Auckland.

“Being shy, I thought, I’ll go. But I’ll hide at meal times and keep out of people’s way.”

But that’s not how things panned out. Instead Pat immediately connected with people at the conference because they were parents just like her.
“It was amazing, I realised I wasn’t alone. I wasn’t judged either. I realised we were in this together. By the time I got home. I felt ten feet tall and bullet proof.”

Pat went on to become board member, then chairman of PVI, positions she held for several years.

“Through PVI’s training programmes, I gained a lot of skills and knowledge and felt empowered to help and support others to do the same.”

These days Pat is extremely knowledgeable about the workings of the health and education systems, the funding and services available to children who are blind and have complex needs and expert in the innovative teaching practices that work for children like Katelyn.

Along the way, she picked up some valuable tips for parents, which she still shares with new PVI members today.

“I tell parents you are your child’s best advocate. Your job is to ensure your child gets the best education and opportunities available. Never let go of that. You have the right to ask questions, to challenge decisions, to get answers and to be heard.”

“I let them know that I’ve personally experienced the good, the bad and the ugly. I tell them I’ve also experienced some truly innovative solutions from some talented people in education.

“And I’m honest when I say, this journey, well, I wouldn’t have missed it for the world. I never anticipated there would be times when it is fun and exhilarating and that I’d grow so much as a person. If someone told me that at the start, I’d have thought they were completely bonkers.”
Socialising and developing life skills

Hanging out with friends, having fun and taking part in recreation are important goals for all children and young people. Your child will be no exception. That is why it is important your child gets the chance to develop the self-confidence and life skills they need to socialise and participate.

“Sometimes asking for help can be the hardest thing in the world to learn. But you need to, particularly when you get older and want to leave home; that’s my experience. I’ve done it and I’ve found people want you to succeed and they like to be part of your journey.”

Blind adult

The Blind Foundation runs a programme aimed at teens called the TRACKS programme. It helps with:

- daily living – new skills and improved abilities
- pre-employment – time management, decision-making, connections and leadership
- personal and social development – teamwork, confidence, achievement, enjoyment and wider horizons
- participation in recreation events.

For more information, talk to your child’s vision team or contact the Blind Foundation on 0800-243 333 or children@blindfoundation.org.nz.

Talk to your child’s vision team about any other programmes and support available and what you can do to support your child to develop life skills at home.

Tips on developing life skills

- Set aside time to have regular conversations about what adult life is like and what it involves.
- Involve your teen wherever possible in your everyday activities such as budgeting, planning meals, preparing for work and keeping receipts of expenses. Talk to your child’s vision team for additional support if you need it.
- Give your child responsibility for daily tasks such as cooking and cleaning and opportunities to make real-life decisions.
- Look at the different options for living away from home such as flatting and group or community homes (if your child has other disabilities) and visit these types of places to see how things work.
- Talk about sexuality – contact the Blind Foundation for ideas and advice if you need it.

Roles for people close to your child

Here’s a list of the roles that people in your child’s life could play. Talk to your child’s vision team for more ideas and to set these opportunities up at home or at school.

- Lead the development of a transition or career plan for your child.
- Include life skills in the classroom programme.
- Monitor your child’s transition or career plan.
- Provide careers advice and support through a careers advisor.
- Help your child put a CV together.
- Provide work experience programmes and opportunities to try out tertiary courses.
Going to uni or polytech

Finding the right tertiary course can be challenging. A good place to start is by identifying your child’s academic aspirations and particular strengths. Then, sit down with your child’s vision team to narrow the list of potential courses in other ways.

- Location – does your child want to be close to home or do they want the challenge of travelling to study?
- Size – some courses have large classes and little interaction with tutors, others are smaller and more intimate. What would your child prefer?
- Atmosphere – some tertiary institutions and courses are known for their friendliness. Ask current students or graduates about the atmosphere and how well they feel they’re supported.

Your child’s school might have a transition programme that allows their students to try courses at tertiary institutions. By trying a course, your child might have a better idea about whether it’s a good choice for them.

“My advice is to encourage your child to try things out before they leave school. Get them involved in work experience. Let them meet employers and work alongside other people. Give them a real-world experience. These kids want to work, pay their taxes and make a living like everyone else.”

Deafblind adult

Contact and support

You and your child’s vision team might also want to talk to people in the tertiary education sector to find out more about what they offer to young people who are blind, deafblind or have low vision.

Here are some ideas of who to contact.

- All tertiary providers have a contact person or service for people with disabilities. Contact the provider and ask for this person’s details.
- Study Link can help with student loans and allowances.
- Work and Income can provide you with information about Training Incentive Allowances and other allowances.
- The Tertiary Education Commission funds a number of schemes to help young people who leave school with no or low qualifications. These include the Youth Guarantee Scheme, the Youth Training Scheme and Training Opportunities programmes.
- Workbridge provides funding for training support and supports people with disabilities to find employment (provided they meet certain eligibility criteria).
- Contact the Blind Foundation early in your planning. They can offer:
  - equipment assessment and training services, tailored for the tertiary education sector
  - help to apply for funding to meet disability-related costs and pay for equipment.
Getting a job

Your child may prefer to leave school and get a job. If so, you may want to talk to your vision team about contacting the following agencies for advice and support.

- The Blind Foundation offers:
  - information and advice related to applying for work, getting ready for work (e.g., by preparing a CV, writing cover letters, approaching employers and so on)
  - equipment assessment and training service, tailored for the workplace
  - help to apply for equipment that meets disability-related needs.

- Workbridge can help your child find work, write their CV, and access equipment and support related to their disability (provided they meet the Workbridge criteria).

- Careers New Zealand provides career information advice and services at school and outside of school.

- Work and Income provides a service in some areas called PATHS – Providing Access to Health Solutions. This provides extra health assistance to people who receive a sickness benefit and want to find work. Contact your local office to see if it is available in your area.

Agencies, called supported employment agencies, are another good option. They are located throughout New Zealand and are funded to help people with disabilities find meaningful paid employment. The Blind Foundation is a supported employment agency.

They provide:
- career planning, job matching and training, work experience and other support such as transport
- help with accessing equipment, property modifications, transport and other support related to your child’s disability
- employment advocacy
- support to access funding for post-school courses, training and study.

Local agencies are listed on the website of the Association for Supported Employment in New Zealand. For more information, you or your child’s vision team may want to check out their website. Go to: www.asenz.org.nz

“I’m excited about the future for my daughter. She’s amazing and I can see her doing anything she sets her mind to.”

Parent

The Blind Foundation provides advice on accessible signage and making workplaces accessible for employees who are blind or visually impaired.

Talk to one of the Blind Foundation’s environmental awareness advisors for more information.
Settling into a job

Not all employers will know exactly what your child needs to settle into a job, feel welcome and have access to all parts of the buildings and premises they work in. This is where the Blind Foundation can help.

The Blind Foundation offers a range of advice and consultancy services to New Zealand employers who employ people who are blind, deafblind or vision impaired.

- Environmental design – advice on the physical environment or space to make sure it is safe and accessible and set up to ensure an employee can complete their role. This service includes advice on lighting, glare management, signage and finding their way around buildings and surrounds.
- Website accessibility – advice on making sure a company website is accessible, useable and meets New Zealand’s standards for web accessibility.
- Document accessibility – same as above, except for documents and publications.
- Presentations and awareness training for teams and employers who work with and employ people who are blind, deafblind or have low vision.
- Corporate partnership advice – advice on partnering with a credible charity, volunteering and employing people who are blind, deafblind or have low vision.

Finding a place to live

As part of your planning, you and your teen’s vision team will also need to think about where your child wants to live.

Set some time aside to discuss living with other people. Is it important to be handy to local transport? What about local health and support services?

Some of your choices will include:

- living at home (household rules and responsibilities can still give your child some independence)
- living in a house (this has maintenance responsibilities but there is often more living space and freedom to make alterations)
- living in a rental property (there are fewer maintenance responsibilities but less freedom to make alterations)
- Housing New Zealand accommodation
- group or community homes (where small groups of people with disabilities live together in the community and the home is managed by a community organisation).

Talk to your Resource Teacher: Vision about Kickstart. The Kickstart programme is a BLENNZ programme that provides an opportunity for young adults who are blind or low vision to live in a supported flatting situation as they make the transition to tertiary, the workplace or independent living.

The programme takes a holistic view focusing on living and working as a member of a team. A senior teacher, teacher and two adaptive daily living instructors work closely with the students to support the development of individual goals and achievement.
Growing up with low vision – Mary's story

"I was very much an ordinary kid, growing up. I enjoyed school, did well academically and had some good friends – one I'm still close friends with."

Mary

At 21, Mary Fisher has clocked up a few impressive achievements.

She’s swum in the 2012 Paralympics, winning a gold medal in world record time. She’s become a Member of the New Zealand Order of Merit (for services to swimming). In 2013, she was named finalist in the Attitude Award for Sport Performer of the Year. Right now, she is studying part-time towards a Bachelor of Science at Massey University, while training for the Pan Pacific Swimming Championships.

Mary was born with low vision and gradually lost it in her teens due to congenital eye condition aniridia (no irises). In 2014, she started working for Parents of Vision Impaired as a family support worker.

Here she reflects on her experiences growing up with low vision.
What are some of your early memories of school?

I was very much an ordinary kid, growing up. I enjoyed school, did well academically and had some good friends – one I’m still close friends with. My earliest memory of what happened in class is my first teacher showing us what different letters looked like by using pencil on paper. I remember worrying because I couldn’t see the shapes. I asked where the letters were and she cottoned on and ended up writing the letters on paper with a vivid marker, which I could see. Things like that were important to me. They helped me keep up and not be singled out.

What would you say to your teachers now?

I’d say that the times they spoke in concrete terms about what was going on in the classroom and were able to verbalise everything worked really well. Teachers should do this more – and they probably do a lot more these days. Teachers need to have high, but realistic, expectations of kids who are blind or have low vision. Let them explore at their own pace. Don’t smother them. Give them opportunities to socialise and have experiences like playing sport and learning music. I’d also say it’s important to teach kids how to ask for help when they need it. Sometimes I think I was a bit afraid of asking for things growing up in case I inconvenienced people or was going to look like the ‘needy’ kid.
What advice would you have for blind or low vision kids wanting to make friends at school?

I’d say not to worry too much about fitting into a particular group. Choose subjects and try things that you enjoy and that interest you and let friendships develop naturally from those interests.

Do you use braille and, if so, why?

I do. I learnt braille from my Resource Teacher: Vision when I was 15 because my sight was deteriorating and I’d get so tired reading large print and was really slow.

I thought I’d pick it up quickly. But it takes time and patience and you’ve got to practise to become fluent. I’ve a few totally blind friends who read braille and they encouraged me. I’m still not as fast as them, but it is very useful for making lists or reading numbers in lifts etc. I think it comes down to doing a little bit each day.
You’ve left the family home in the suburbs for life among friends in the city. Tell us about that.

I moved out of our home in Silverstream to be closer to the Kilbirnie pool where I train every day. It was a huge step. I love it. At the moment there are eight of us living together. I only knew one of my flatmates before we moved in. But we all get on well. We each cook for the others once a week (the person who’s not cooking that week puts the rubbish out) and we go shopping together. They help me out and I do the same for them. We all contribute to the decisions of the house, which I like. I think the key is to find the environment that is going to work best for you.

How do you get on with using public transport in Wellington?

It’s good. I use the bus system lots and the train to visit my parents. With the help of an orientation and mobility instructor, I’ve memorised my main routes and become much better at asking for help when I need it. Sometimes I ask the driver if I’m on the right bus or when the stop is coming up. I’ve learnt that things like that, which originally can seem like losing some autonomy, actually mean you can get out there, enjoy life and enjoy your independence.
Support from government agencies

Other government agencies you may like to contact about the employment and accommodation funding available include Ministry of Social Development (including Work and Income) and the Ministry of Health’s Disability Support Services.

Work and Income

Work and Income can provide you and your child with advice about the following support.

- Disability Allowance – a payment that helps with the costs related to an ongoing disability.
- Jobseeker Support Payment – a temporary payment paid while someone is looking for work, in training or unable to work because of a health condition or disability.
- Supported Living Payment – payment for people who are permanently and severely restricted in the ability to work because of a health condition or disability.
- Accommodation Supplement – help with accommodation costs.
- Training Incentive Allowance – help with employment-related training costs.

Ministry of Social Development

The Vocational Services Transition Service is funded by the Ministry of Social Development. It assists all school leavers with high and very high needs who receive ORS funding to transition from school.

You should receive information about this service before your child leaves school (the service will begin the year before your son or daughter leaves school). Discuss the information with your child’s vision team.

The Youth Transition Scheme, contracted out to community providers by the Ministry of Social Development, is available to all young people who have left school and who need extra support and encouragement to enter into employment or further training or education.

Ministry of Health

The Ministry of Health’s Needs Assessment and Service Coordination (NASC) service is available to look at the needs of a young person and identify the disability support services best suited to meet their adult needs.

The Ministry’s household management and personal care services help young people with a range of daily tasks such as preparing meals, house cleaning, showering and getting dressed.

Talk to someone in your child’s vision team or visit the Ministry of Health’s website to find out more about NASC service.

Making a complaint

Things don’t always go smoothly in life and there may be a time when you or your child wants to complain about unfair treatment or discrimination.

The Human Rights Commission offers a free, confidential service for members of the public with human rights enquiries and complaints of unlawful discrimination.

The Commission’s dispute resolution process is limited to unlawful discrimination complaints. However, the Commission also addresses broader human rights issues related to disability, housing, education, detention, employment and race relations.

Freephone 0800-496 877
See: www.hrc.co.nz

Looking to the future

Having a child leave home, become independent and join the adult world is a big step in any parent’s life. You may feel excited about your child’s future. You may feel anxious about how they will cope without the vision team they’ve had in place for so long. You may even find yourself thinking, “What about me? What am I going to do now?”

This can be a good time to reconnect with other parents going through a similar life change for help and support. Talking to the Blind Foundation about their counselling services is another good option. You may simply want to reach out to your wider family and whānau. Whatever your choice, it’s worthwhile giving yourself time to reflect and think about what the future has in store for you.

Other support services

You might also want to contact the following organisations for advice and support.

Blind Foundation (0800-243 333)
Parents of Vision Impaired (0800-312 019)
Ngāti Kāpō O Aotearoa (0800-770 990)
Parent2Parent (0508-236 236)
Deafblind (NZ) Incorporated (www.deafblindnz.org.nz)

“The handing over your child to life can present lots of challenges – for me, I was left thinking who am I now, now that I’m not so-and-so’s mum? What skills have I got after all these years? That’s when parent groups can be an enormous help.”

Parent

The Ministry of Health provides a range of disability support services through the Needs Assessment and Service Coordination (NASC) service. One service is Supported Living, which supports disabled people to live as independently as possible in their own home.

It is available to anyone aged 17 or older who is assessed as meeting the Ministry’s Disability Support Services eligibility criteria.

For more information, go to: www.health.govt.nz (search using the terms ‘supported living’).
People, roles and responsibilities

Here is a list of the people referenced in this book, together with a definition of what they do.

**BLENNZ teacher (or Resource Teacher: Vision)**
Qualified teacher who supports children and their parents and caregivers, providing general advice, teaching and development support, as well as overall service coordination.

**Blind Foundation counsellors**
Qualified counsellors who provide a free, nationwide counselling service.

**Child’s vision team**
The range of people (usually from BLENNZ, the Blind Foundation and the Ministry of Education) who support a child who is blind, deafblind or has low vision from birth until they finish school. The team will refer your child to other relevant agencies for additional services and support.

**Clinical vision assessor**
People in the health sector who carry out clinical vision assessments.

**Early intervention teacher**
Ministry of Education staff who provide advice and support related to a child’s early learning and development.

**Family doctor (or GP)**
A health professional who looks at the general health of babies and children and refers them to specialists for assessments when required.

**Head of Learning Support**
Experienced teachers employed within secondary schools to coordinate school-wide programmes, services and support for students with special education needs.

**Living skills specialist**
Blind Foundation staff who teach living skills.

**Ministry of Education specialists**
A range of specialists who work in the special education sector with early childhood education services and schools to support children and young people and their families and whānau. Specialists include special education advisors, physiotherapists and occupational therapists.

**Ngāti Kāpō O Aotearoa national field coordinators**
Specialist support workers who use a kaupapa Māori approach to help children and their whānau to access education, health and disability services.

**Occupational therapist**
Health professionals who assess and advise on the physical needs of children and young people who are blind, deafblind or have low vision. Focus is on the physical movement associated with everyday life and activities.

**Orientation and mobility specialist**
BLENNZ and Blind Foundation staff who teach and advise on orientation and mobility. BLENNZ call their staff Developmental Orientation and Mobility (DOM) specialists.

**Ophthalmologist**
A specialist eye doctor.
Optometrist
Professionals trained and registered to examine the eyes for visual defects, diagnose problems or impairments and recommend glasses or other corrective lenses or provide other types of treatment.

Orthoptist
A health professional who works as part of the eye clinic team. Orthoptists diagnose and treat eye problems related to eye movement and coordination.

Paediatrician
Medical specialists (doctors) in child development and health.

Physiotherapist
Health professionals who assess and advise on the physical needs of children and young people who are blind, deafblind or have low vision (in both health and education). Focus is on physical movement and function.

Paraprofessional
Another name for a teacher’s aide.

Recreation advisors
Blind Foundation staff who help parents and children take part in all kinds of recreational activities together.

Resource Teacher: Vision (RTV)
See definition of BLENNZ teacher.

Special Education Needs Coordinator (SENCO)
Experienced teachers employed within primary schools to coordinate school-wide programmes, services and support for students with special education needs.

Teacher’s aide
A support person employed by schools to help classroom teachers teach students with special education needs.

Vision hearing technicians
Health sector specialists who test the hearing and vision of children and young people in preschool, school and in clinics (part of the Ministry of Health’s B4 School Check programme).

Visiting neuro-developmental therapists
A specialist in child development who works with very young children (usually children under five-years-old).
Organisations and their websites

Here are some useful organisations, followed by their websites.

The Accident Compensation Corporation (ACC)
www.acc.co.nz

Association for Supported Employment in New Zealand
www.asenz.org.nz

BLENNZ
www.blennz.school.nz

BLINK Library
blindfoundation.org.nz/members/library/homai-special-formats-library

Blind Foundation
www.blindfoundation.org.nz

Blind Sport New Zealand
www.blindsport.org.nz

Careers New Zealand
www.careers.govt.nz

Child Development Services

Deafblind services
blindfoundation.org.nz/about/member-services/deafblind-services

Deafblind (NZ) Incorporated
www.deafblind.org.nz

District Health Boards

Education Review Office
www.ero.govt.nz

Equipment and Modification Services

Halberg Allsports
www.halbergallsports.co.nz

Housing New Zealand
www.hnzc.co.nz

Human Rights Commission
www.hrc.co.nz

IHC
www.ihc.org.nz

Lowdown youth depression website
www.thelowdown.co.nz

Ministry of Health
www.moh.govt.nz

Ministry of Health, Child Development Services

Ministry of Education, Assistive Technology

Ministry of Education, Special Education
www.minedu.govt.nz/NZEducation/EducationPolicies/SpecialEducation.aspx

Ministry of Social Development
www.msd.govt.nz

Ministry of Social Development, Family Services
www.familyservices.govt.nz
Glossary of terms

Here is a list of useful terms used in this book, followed by an explanation of what each term means.

Assistive technology
Equipment and technology students who are blind, deafblind or have low vision use to learn, e.g., screen readers and large-print software. Refer to page 35.

B4 School Check
A nationwide programme offering free health and child development checks to four-year-olds. Refer to page 27.

Braille
Tactile writing system used by people who are blind, deafblind or have low vision. Refer to page 35.

Careers New Zealand
Government agency providing career information and advice. Refer to page 56.

Child Development Services
A range of child disability services provided by the Ministry of Health. Refer to pages 14, 23.

Child Disability Allowance
Funding from the Ministry of Social Development (Work and Income) for caring for children with disabilities at home. Refer to page 22.

Children’s Spectacle Subsidy (glasses subsidy)
A subsidy provided by the Ministry of Health to children 15 years and under (who meet criteria). Funding contributes to assessment, lenses and frames. Refer to page 23.

Clinical assessment
A type of assessment involving observation and clinical tests, resulting in a medical diagnosis. Refer to page 14.

Communication
A key learning area within The Expanded Core Curriculum. Refer to page 37.
Community Services Card
A Work and Income card for people 18 years old or over (or 16–17 years old in full-time tertiary study) who are on a low to middle income. Gives holders cheaper prescriptions, doctor’s fees, etc. Refer to page 23.

Contact Lens Subsidy
A subsidy provided by the Ministry of Health to children who for medical reasons cannot wear glasses (and who meet criteria). Refer to page 23.

Disability Allowance
Government funding for adults with disabilities from Work and Income. Refer to page 62.

Distance vision
The ability to see detail at a distance. Refer to page 15.

Early childhood education services
The range of services available within the early childhood education sector, eg, kindergarten, playcentre and kōhanga reo. Refer to page 24.

Education Review Office (ERO)
Government agency responsible for reviewing and assessing schools. Refer to page 26.

Equipment Modification Services (EMS)
Services and funding available to children and young people with a high level of needs (subject to an assessment from an EMS assessor and meeting other criteria). Refer to page 23.

Functional assessment
An assessment that looks at what a child can see and how the child uses their vision. Refer to page 14.

Halberg Allsports
A website with information about Halberg Disability Sport Foundation programmes. Refer to page 44.

High Health Use Card
A Work and Income card offering cardholders cheaper prescription fees. Refer to page 22.

High or Very High Needs
Terms used by the Ministry of Education to describe needs that meet particular criteria for funding. Refer to page 38.

Homai Campus School
The main campus school of BLENNZ, based in Auckland. Refer to page 32.

Housing New Zealand
Government agency responsible for housing policy, funding and services. Refer to page 57.

Immersion courses
BLENNZ programmes (usually lasting a day or more) on a range of topics for children and young people who are blind, deafblind or have low vision and their families and whānau. Refer to pages 32, 42, 45.

Individual Education Plan (IEP)
A written plan, showing how the school and classroom programme will be adapted to suit a child or young person who is blind or has low vision. Refer to page 36.

James Cook High School
A school in Auckland running a satellite class for students with special education needs. Refer to page 31.

Jobseeker Support Payment
Temporary payment from Work and Income for people with disabilities who are looking for work. Refer to page 62.

Kindergarten
A type of early childhood education service. Refer to page 24.

Kōhanga reo
A type of early childhood education service where the main language of instruction is te reo Māori and where children learn about te ao Māori (the Māori world) and tikanga Māori (Māori culture). Refer to page 24.
Large-print software
Assistive technology commonly used by students with low vision to learn. Refer to page 35.

Little room
A box-like structure that gives children who are blind, deafblind or who have low vision the opportunity to explore objects. Refer to page 19.

Long (white) cane
Assistive technology used for mobility. Used to identify surface changes, curbs and other obstacles. Refer to page 35.

Ministry of Education
Government agency responsible for education policy, funding and services. Refer to page 9.

Ministry of Health
Government agency responsible for health policy, funding and services. Refer to page 10.

Ministry of Social Development
Government agency responsible for a wide range of disability policy, services and funding. Refer to page 62.

Mobility and orientation support
Services to help the mobility and orientation of people who are blind, deafblind or have low vision provided by BLENNZ and the Blind Foundation. Refer to pages 26, 32, 35, 37.

National Certificate in Educational Achievement (NCEA)
New Zealand’s main secondary school qualification. Refer to page 44.

National Assessment Service
An assessment service provided by BLENNZ from the Homai Campus School in Auckland. Refer to pages 14, 32.

National Travel Assistance
Support from the Ministry of Health to travel to and from hospital, specialist appointments and early childhood services. Refer to page 23.

Near vision
The ability to see things close up. Refer to page 15.

Needs Assessment and Services Coordination (NASC)
A service provided by the Ministry of Health. Refer to page 10.

Ongoing Resourcing Scheme (ORS)
Ministry of Education funding and services for children and young people with high and very high special education needs. Refer to page 39.

Parent and Child Enrichment (PACE) programme
Blind Foundation programme offering children and young people a suite of age-specific programmes, eg, the Life Skills programme for young adults to prepare them for independent living. Refer to page 19.

Parents As First Teachers (PAFT) programme
Ministry of Social Development parenting education programme. Refer to page 19.

Providing Access to Health Solutions (PATHS)
Employment support for people on a sickness benefit from Work and Income. Refer to page 56.

Playcentre
A type of early childhood education service. Refer to page 24.

PlunketLine
A free information service for parents with information on the B4 School Check programme. Refer to page 27.

Satellite class
A special class in a school for children with a high level of special education needs. Refer to page 31.

Screen reader
Technology designed for blind students to help them learn. Refer to page 35.
**Section 9 Agreement**
Legal agreement parents and caregivers need to send their child to a special school. Refer to page 31.

**Sensory efficiency skills**
Skills referred to within a key learning area of The Expanded Core Curriculum. Refer to page 37.

**Special Assessment Conditions**
Special conditions granted to students with disabilities by the New Zealand Qualifications Authority. Refer to page 44.

**Special Education Grant**
Funding from the Ministry of Education that goes to all schools for the purpose of supporting students with special education needs. Refer to page 39.

**Special Education School Transport Assistance**
Funding available from the Ministry of Education for transport assistance while a child is at school. Refer to page 39.

**Special school**
A day school for children and young people with a high level or complex set of special education needs. Refer to page 31.

**STRIPES**
A Blind Foundation programme for young people aged 6 to 12 focused on daily living skills, pre-employment skills etc. Refer to page 42.

**Study Link**
Government agency that helps with student loans and allowances. Refer to page 55.

**Supported Living Payment**
Payment for disabled people who are permanently and severely restricted in their ability to work from Work and Income. Refer to pages 62, 63.

**Symbol (white) cane**
Assistive technology cane used for mobility. Refer to page 35.

**Support (white) cane**
Assistive technology cane used for extra support. Refer to page 35.

**Supported Employment Agencies**
Agencies funded to help people with disabilities find work. Refer to pages 86.

**Telefriend**
Peer support service from the Blind Foundation. Refer to page 45.

**Tertiary Education Commission**
Government department responsible for tertiary education. Refer to page 55.

**The Correspondence School**
The school for distance learning in New Zealand. Called Te Aho o Te Kura Pounamu – The Correspondence School in full. Refer to page 32.

**TRACKS**
A Blind Foundation programme for young people aged 13 and older focused on daily living skills, pre-employment skills etc. Refer to page 54.

**Training Incentive Allowance**
Funding from Work and Income for training. Refer to page 62.

**Training Opportunities programmes**
Programmes from the Tertiary Education Commission aimed at school leavers with no or low-level qualifications. Refer to page 55.

**Transition plan**
A written plan and set of strategies developed for times of change or transition. Refer to page 49.

**The Expanded Core Curriculum (ECC)**
The ECC is used as guidance for the Resource Teachers: Vision to help adapt and differentiate teaching and learning within the national curriculum for students who are blind, deafblind or have low vision. Refer to page 37.
Visual acuity
A measure used to describe the ability of the eye to perceive the size and shape of objects. Refer to page 16.

Visual Resource Centres
BLENNZ centres located throughout New Zealand. Refer to page 32.

Vocational Services Transition Service
Support for students with high and very high needs from the Ministry of Social Development to transition from school. Refer to page 62.

Work and Income
Government agency within the Ministry of Social Development responsible for a wide range of tertiary and social services and funding. Refer to page 62.

Workbridge
Government agency that funds training and employment support for people with disabilities. Refer to pages 55, 56.

Youth Guarantee Scheme
Programme from the Tertiary Education Commission aimed at school leavers with no or low-level qualifications. Refer to page 55.

Youth Training Scheme
A scheme from the Tertiary Education Commission aimed at school leavers with no or low-level qualifications. Refer to page 55.

Youth Transition Scheme
Support from the Ministry of Social Development to help students with disabilities leave school and enter employment or further training. Refer to page 62.