



RAISING YOUR CHILD WITH DISABILITIES

A Comprehensive Guide for
Australian Parents



"A Journey of Love, Strength, and Discovery"

BY CHARLENE MCIVER

RAISING YOUR CHILD WITH DISABILITIES:

A Comprehensive Guide for Australian Parents

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This book provides general information and guidance based on Australian laws and resources as of the date of publication.

It is not intended to be a substitute for professional legal, medical, educational, or financial advice.

Consult qualified professionals (such as a doctor, lawyer, accountant, or NDIS expert) before making specific decisions regarding your child's care or your family's finances.

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CHAPTER 1: INTRODUCTION – YOU ARE NOT ALONE

Welcome. If you're reading this, you may be at the beginning of an unexpected journey. Perhaps you've recently received a diagnosis for your child, or maybe you're still navigating the process of understanding your child's needs. Whatever brought you here, please know this fundamental truth: you are not alone, and you are already doing better than you think.

Approximately one in five Australians lives with a disability, and hundreds of thousands of families across Australia are raising children with various disabilities. While your journey will be unique to your child and family, countless parents have walked similar paths and built fulfilling, joyful lives alongside their children.

This book is designed to be your companion during this journey. It offers practical guidance, professional insights, and evidence-based strategies to help you navigate the complex landscape of raising a child with disabilities in Australia.

More importantly, it aims to empower you to become your child's best advocate while maintaining your own well-being and that of your entire family.

What This Book Covers:

Throughout these pages, you'll find information on the Australian medical system, educational rights, the NDIS, Centrelink benefits, and emotional support. You'll learn about early intervention services, assistive technologies, and community resources available across Australia. But beyond the practical information, this book also recognises the emotional complexity of your experience and offers guidance for maintaining hope, resilience, and joy.

A Note on Language:

You'll notice this book uses person-first language ("child with a disability" rather than "disabled child") and identity-first language ("autistic person"), depending on context. Different communities have different preferences, and both approaches have validity. What matters most is respecting your own child and the preferences of the disability communities they may identify with as they grow.



CHAPTER 2: THE EARLY DAYS- PROCESSING THE DIAGNOSIS

The Emotional Landscape

Receiving a diagnosis, or even the initial signs that your child may have a disability, can trigger a complex range of emotions. Parents commonly experience:

- Shock and disbelief: Even when you suspected something was different, hearing it confirmed can feel overwhelming.
- Grief: You may grieve the future you had imagined for your child, and this is both normal and valid.
- Fear and anxiety: Worry about your child's future, your ability to meet their needs, and the unknown road ahead.
- Relief: If you've been searching for answers, a diagnosis can provide clarity and direction.
- Guilt: Many parents wonder if they did something to cause the disability, though in most cases, they did not.
- Love and determination: Alongside difficult emotions, most parents feel fierce love and commitment to their child.

These emotions don't follow a linear path. You may cycle through them repeatedly, and that's completely normal. There's no "right" way to feel.

Allowing Yourself to Grieve

The concept of "chronic sorrow" was first described by researcher Simon Olshansky in 1962. It recognises that parents may experience waves of grief throughout their child's life, triggered by milestones, transitions, or comparisons.

This doesn't mean you don't love or accept your child; it means you're processing the ongoing challenges and differences in your parenting journey.

Permit yourself to:

- Feel your emotions without judgment
- Seek support from professionals, support groups, or trusted friends
- Take time to process information rather than making all decisions immediately
- Recognise that acceptance is a journey, not a destination



Practical First Steps

While processing your emotions, there are concrete actions you can take:

1. **Gather Information:** Learn about your child's specific condition from reputable sources (medical professionals, established organisations like Children with Disability Australia, peer-reviewed research).
2. **Document Everything:** Start a binder or digital folder with all medical records, evaluations, and correspondence. This will be invaluable moving forward.
3. **Connect with Other Parents:** Seek out parent support groups, either in-person or online. Other parents who've been through this can offer invaluable practical advice and emotional support.
4. **Identify a Medical Home:** Find a GP or paediatrician who has experience with your child's condition and can coordinate care through Medicare.
5. **Register with the NDIS:** If your child is under 7, contact Early Childhood Early Intervention (ECEI). For children 7+, begin the NDIS access request process.
6. **Ask Questions:** Write down your questions as they arise and bring them to medical appointments. No question is too small.

What NOT to Do

- Don't blame yourself: Most disabilities are not caused by anything parents did or didn't do during pregnancy or early childhood.
- Don't isolate: While you may need time to process, staying connected to support systems is crucial.
- Don't believe everything you read online: Stick to evidence-based information from reputable sources.
- Don't make major life decisions immediately: Take time to understand the situation before making dramatic changes to your career, residence, or relationships.



CHAPTER 3: UNDERSTANDING YOUR CHILD'S RIGHTS IN AUSTRALIA

Your child has legal protections and rights under Australian federal and state laws. Understanding these rights is fundamental to effective advocacy.

Key Australian Legislation

Disability Discrimination Act 1992 (Commonwealth)

The DDA makes it unlawful to discriminate against a person based on disability in many areas of public life, including:

- Education
- Employment
- Access to premises
- Provision of goods, services, and facilities
- Accommodation
- Clubs and sports

Key Provisions:

- Schools must make reasonable adjustments to support students with disabilities.
- Public spaces must be accessible
- Service providers cannot refuse service based on disability
- Protections extend to family members and carers

Disability Standards for Education 2005

These standards clarify the obligations of education and training providers under the DDA:

- Students with disabilities have the right to enrol in any school
- Schools must make reasonable adjustments to support participation
- Students have the right to participate in education on the same basis as students without disabilities
- Adjustments must address individual needs

Reasonable Adjustments might include:

- Modified curriculum or assessment
- Additional support staff
- Assistive technology
- Modified physical environment
- Flexible attendance or deadlines

National Disability Insurance Scheme Act 2013

The NDIS provides funding for reasonable and necessary supports for eligible Australians with permanent and significant disability. Key principles include:

- People with disability have the same rights as others
- Support for people to exercise choice and control
- Early intervention to improve outcomes
- Mainstream services remain responsible for their obligations

Healthcare Rights

Medicare: All Australian children have access to Medicare, which covers:

- GP and specialist appointments (bulk-billed or with gap payment)
- Essential medical services
- Hospital treatment in public hospitals
- Pharmaceuticals under the PBS

My Health Record: Your child has the right to a digital health record that can be shared between healthcare providers.

Informed Consent: Parents/guardians must provide informed consent for medical treatment. You have the right to:

- Full information about proposed treatments
- Second opinions
- Refuse treatment (with some exceptions for life-threatening situations)
- Access your child's medical records

The UN Convention on the Rights of Persons with Disabilities (CRPD)

Australia ratified the CRPD in 2008, committing to international standards, including:

- Respect for inherent dignity and individual autonomy
- Non-discrimination
- Full and effective participation and inclusion in society
- Respect for difference and acceptance of disability as part of human diversity
- Equality of opportunity
- Accessibility

Becoming an Effective Advocate

Understanding your child's rights is just the beginning.

Effective advocacy requires:

1. Documentation: Keep detailed records of all services, evaluations, and communications.
2. Knowledge: Learn the terminology and processes used in medical and educational systems.
3. Communication: Develop clear, assertive communication skills for meetings and negotiations.
4. Collaboration: Approach professionals as partners while maintaining clear boundaries about your child's needs.
5. Persistence: Don't accept "no" as a final answer if you believe your child needs a service or accommodation.

Where to Get Help

Advocacy Organisations:

- Children with Disability Australia: Help with advocacy, information, and support
- Australian Federation of Disability Organisations (AFDO)
- State-based advocacy services (Disability Advocacy Network Australia can help you find local services)

Complaints Processes:

- Discrimination: Australian Human Rights Commission
- NDIS: NDIS Quality and Safeguards Commission
- Education: State education departments have complaints processes
- Healthcare: Health Care Complaints Commission (varies by state/territory)

CHAPTER 4: BUILDING YOUR SUPPORT TEAM

Raising a child with disabilities truly takes a village. Your support team will likely include medical professionals, therapists, educators, and personal supports. Building and managing this team is one of your most essential tasks.

Medical Professionals

General Practitioner (GP): Your child's GP is central to coordinating care under Medicare. Choose a GP who:

- Has experience with children with disabilities
- Is willing to coordinate with specialists
- Bulk-bills or has reasonable gap fees
- Is accessible for regular appointments

Paediatrician: Specialises in children's health & development.

Can be a:

- **General Paediatrician:** Broad expertise in child health
- **Developmental Paediatrician:** Specialises in developmental and behavioural issues
- **Subspecialist Paediatrician:** Focuses on specific conditions (e.g., respiratory, cardiac)

Specialists: Depending on your child's condition, you may work with:

- Neurologists
- Geneticists
- Orthopaedic surgeons
- Cardiologists
- Ophthalmologists
- Audiologists

Allied Health Professionals: Medicare, NDIS, or private health insurance may cover these services:

- Speech pathologists
- Occupational therapists
- Physiotherapists
- Psychologists
- Dietitians

Therapeutic Supports:

Physiotherapists (Physios): Work on gross motor skills, strength, balance, and mobility.

Occupational Therapists (OTs): Address fine motor skills, sensory processing, and activities of daily living.

Speech Pathologists: Support communication, feeding, and swallowing.

Behaviour Support Practitioners: For children with complex behaviours (must be registered with NDIS Quality and Safeguards Commission if NDIS-funded).

Psychologists: Support emotional well-being, mental health, and behavioural strategies.

Educational Team

Classroom Teachers: General education teachers who work with all students.

Integration/Learning Support Teachers: Provide additional support for students with disabilities.

Educational Support Officers/Teacher Aides: Provide direct assistance in the classroom.

Student Support Services Officers: School psychologists, social workers, and other specialists.

Principal/Assistant Principal: Responsible for school-wide support and adjustments.

NDIS Supports

Support Coordinator: Helps you understand and implement your NDIS plan, connect with providers, and coordinate services.

Local Area Coordinator (LAC): For children 7+ with less complex needs, LACs help develop plans and connect with mainstream and community supports.

Early Childhood Partner: Provides support to children under 7 through the ECEI pathway.

Service Providers: Organisations and individuals who deliver NDIS-funded supports.

Personal Support Network:

Family Members: Immediate and extended family who can provide emotional support and practical help.

Friends: Don't underestimate the value of friendships that existed before the diagnosis.

Parent Support Groups: Connect with other parents facing similar challenges through organisations like Carers Australia or condition-specific groups.

Respite Care Providers: NDIS may fund respite care for temporary relief.

Community Groups: Playgroups, religious communities, sports clubs, and other social connections.

Managing Your Team Effectively

Create a Contact List: Maintain a centralised list of team members' names, roles, contact information, and notes about each team member.

Managing Your Team Effectively (continued)

Use MyGov and the NDIS Portal: Keep your MyGov account organised by consolidating information from Medicare, Centrelink, and the NDIS in one place.

Schedule Regular Team Meetings: For children with complex needs, periodic team meetings ensure everyone is working toward consistent goals.

Set Boundaries: You're the parent, not the secretary. It's reasonable to establish communication boundaries.

Express Gratitude: A simple thank-you goes a long way in maintaining positive relationships with people who support your family.

Know When to Make Changes: If a team member isn't a good fit, you have the right to seek alternatives. This is your child's team, and it needs to work for your family.



CHAPTER 5: NAVIGATING THE AUSTRALIAN HEALTHCARE SYSTEM

The Australian healthcare system can feel complex, especially when your child has ongoing medical needs. Here's how to navigate it more effectively.

Understanding Medicare

Medicare Coverage: Medicare provides access to:

- Free treatment in public hospitals
- Lower costs for GP and specialist appointments
- Subsidised pharmaceuticals through the Pharmaceutical Benefits Scheme (PBS)
- Some allied health services are provided through chronic disease management plans.

Medicare Safety Net: Once your family reaches a certain threshold in out-of-pocket costs (\$560.70 for 2024), you receive higher rebates for the rest of the calendar year.

Chronic Disease Management (CDM) Plans: Your GP can create a:

- GP Management Plan (GPMP): Coordinates care for chronic conditions
- Team Care Arrangement (TCA): Coordinates care with at least two other providers

These plans allow access to Medicare rebates for up to five allied health visits per calendar year (e.g., physiotherapy, occupational therapy, psychology).

Private Health Insurance

Hospital Cover: May provide:

- Private hospital admission
- Choice of doctor
- Shorter wait times for elective surgery

Extras Cover: May include:

- Optical services
- Dental care
- Allied health services (physio, OT, psychology)
- Hearing aids

Considerations:

- Loading periods before you can claim
- Gap payments, even with insurance
- Pre-existing condition waiting periods
- Compare policies carefully for coverage of your child's needs

Accessing Specialist Care

Referral Process:

1. See your GP for assessment
2. GP provides referral to specialist (valid for 12 months)
3. Book an appointment with a specialist (wait times vary)
4. Attend appointment (Medicare rebate available)

Out-of-Pocket Costs:

- Many specialists charge above the Medicare schedule fee
- Gap fees can be substantial (\$100-\$500AU+ per appointment)
- Ask about costs when booking

Public Hospital Outpatient Clinics:

- Free specialist care through public hospitals
- Often long wait times
- Limited choice of doctor
- May be appropriate for ongoing specialist care

Medical Appointments

Prepare for Appointments:

- Write down questions in advance
- Bring a list of current medications and supplements
- Keep a symptom log or progress notes
- Bring someone with you to take notes if possible
- Bring your child's health record or summary

During Appointments:

- Don't hesitate to ask for clarification if something isn't clear
- Request written summaries or instructions
- Ask about the purpose and expected outcomes of any tests or treatments
- Discuss how recommendations fit with your family's values and logistics
- Ask about Medicare, NDIS, or private health insurance coverage for recommended treatments

After Appointments:

- Follow up on any action items promptly
- Request copies of all reports and test results
- Update your records
- Add information to My Health Record if desired

Managing Medical Records

My Health Record:

- National digital health record
- Can be accessed by healthcare providers you authorise
- You can upload documents and information
- Can set access controls
- Optional but increasingly useful

Managing Medical Records (continued)

Personal Records: Create a medical summary including:

- Diagnosis/diagnoses
- Current medications and dosages
- Allergies
- Major medical history
- Current healthcare providers
- Emergency contacts
- Medicare and private health insurance details

Pharmaceutical Benefits Scheme (PBS)

Concessional Benefits: If your child has a Health Care Card or Pensioner Concession Card:

- Maximum \$7.70 per PBS prescription (2024)
- Safety Net threshold of \$277.20 (2024) - after which prescriptions are free

General Benefits:

- Maximum co-payment of \$31.60 per PBS prescription (2024)
- Safety Net threshold of \$1,647.90 (2024) - after which co-payment is \$7.70

Safety Net Card: Keep receipts and register with your pharmacy to track your progress toward the Safety Net threshold.

National Disability Insurance Scheme (NDIS) Health Supports

NDIS may fund health supports that are:

- Related to your child's disability
- Not the responsibility of the health system
- Reasonable and necessary

Examples include:

- Specialised disability-related equipment
- Some therapy services
- Continence products
- Assistive technology for communication

Medicare and the NDIS should work together; neither should cost-shift to the other.

State-Based Health Services

Each state/territory has additional services:

Victoria:

- Better Start program (early intervention for children with disability or developmental delay)
- Maternal and Child Health Services
- Royal Children's Hospital services

NSW:

- Early Childhood Intervention Services
- Child and Family Health Nurses
- Children's hospitals in major centres

Queensland:

- Child Development Services
- Maternal and Child Health
- Queensland Children's Hospital

Other States/Territories: Check your state health department for specific programs.

Emergency Care

In Emergencies:

- Call 000 for an ambulance
- Go to the nearest hospital emergency department
- Public hospital emergency care is free
- Ambulance services may charge (consider ambulance cover).

Hospital Admissions:

- As a public patient: Free, but fewer choices
- As a private patient: May have out-of-pocket costs but potentially faster access and choice of doctor



CHAPTER 6: EARLY INTERVENTION – THE CRITICAL FIRST YEARS

The first few years of a child's life are a period of remarkable brain development and learning. Early intervention services can make a significant difference in outcomes for children with disabilities or developmental delays.

What is Early Intervention in Australia?

Early intervention refers to services and supports provided to infants and young children (typically 0-6 years) with disability or developmental delay, and their families.

The goal is to:

- Support children's development and learning
- Build family capacity and confidence
- Facilitate inclusion in early childhood and community activities
- Connect families with services and supports

Accessing Early Intervention

For Children Under 7: NDIS Early Childhood Early Intervention (ECEI)

ECEI Approach: The ECEI pathway provides support for children under 7 with developmental delay or disability. You don't need an NDIS plan to access ECEI support.

How to Access:

1. Contact your local Early Childhood Partner
2. Initial conversation about your child's needs
3. Early Childhood Partner connects you with appropriate supports
4. May include short-term early intervention or referral for NDIS access

ECEI Partners Help With:

- Information about early intervention
- Connection to community and mainstream services
- Short-term early intervention (funded by NDIS)
- NDIS access requests if needed

When Full NDIS Plans Are Needed: Children with more significant or permanent disabilities will be referred for a complete NDIS access request and plan.

State-Based Early Intervention Programs

Many states also have early intervention programs:

Victoria:

- Better Start: Early intervention for children aged 0-6 with vision or hearing loss, cerebral palsy, or Down syndrome
- Provides funding for services like speech pathology, OT, physio, and psychology.

NSW:

- Early Childhood Intervention Services through health districts
- Integrated services for children with developmental concerns

Queensland:

- Child Development Services
- Therapy and support for children with developmental needs

Other States: Check your state health or disability services department.

Early Childhood Education: Types of Early Intervention Services

Therapeutic Services:

- Speech pathology: Communication, feeding, swallowing
- Occupational therapy: Fine motor skills, sensory processing, daily living
- Physiotherapy: Gross motor development, strength, mobility
- Psychology: Behavioural support, emotional wellbeing

Family Support:

- Parent education and training
- Sibling support
- Family counselling
- Inclusive preschool and kindergarten
- Specialist early childhood programs
- Supported playgroups

Assistive Technology:

- Communication devices
- Mobility aids
- Adaptive equipment for play and learning

Service Delivery Models

Centre-Based Services:

- Child attends a therapy centre or specialist program
- May include group programs with other children
- Access to specialist equipment and resources

Home-Based Services:

- Therapists visit your home
- Work with the child in a familiar environment
- Coach parents in strategies to use throughout daily routines

Community-Based Services:

- Support in childcare, kindergarten, or community settings
- Promotes inclusion and generalisation of skills

Telehealth:

- Increasingly common, especially in regional areas
- Video appointments with therapists
- Parent coaching model

Making the Most of Early Intervention

Active Participation: The most effective early intervention involves parents actively implementing strategies throughout the day, not just during therapy sessions.

Natural Learning Opportunities: Practice skills during everyday activities; dressing, bathing, mealtimes, and play. This helps skills generalise.

Communication with Providers: Share observations, concerns, and what works at home. You're the expert on your child.

Consistency: Regular participation in recommended services leads to better outcomes.

Documentation: Keep records of progress, reports, and any concerns. This will be helpful for NDIS reviews and school transitions.

Inclusive Early Childhood Education

Childcare and Kindergarten:

- Your child has the right to attend any service
- Services must make reasonable adjustments
- The Inclusion Support Programme provides additional assistance for eligible children
- Early Childhood Teacher Scholarships are available in some areas

Inclusion Support Programme (ISP):

- Additional funding for early childhood services to support inclusion
- Provides additional educator support, resources, and professional development
- Accessed through your early childhood service

Transition Planning

Starting School: As your child approaches school age:

- Begin transition planning at least 12 months before starting school
- Visit potential schools and discuss support needs
- Enrol early (some schools have specific enrolment timelines for students with additional needs)
- Request transition meetings with school staff
- Ensure NDIS plan includes school-aged supports if needed

Choosing a School: Consider:

- School's experience with and attitude towards inclusion
- Available specialist staff and resources
- Physical accessibility
- Size and environment
- Distance from home
- Philosophical approach



CHAPTER 7: EDUCATIONAL PLANNING AND ADVOCACY IN AUSTRALIA

Every Australian child has the right to education.

Understanding how to access appropriate support within the education system is essential for ensuring your child thrives at school.

The Disability Standards for Education

The Disability Standards for Education 2005 require all education providers to:

- Make reasonable adjustments for students with disability
- Ensure students with disability can participate in education on the same basis as other students
- Consult with students and families about adjustments

Types of Schools

Government Schools:

- Free to attend (except voluntary contributions)
- Must enrol all students in their designated area
- Support services vary by state and school
- Specialist schools are available in most states

Catholic Schools:

- Generally lower fees than independent schools
- The system of support varies by diocese
- Must comply with Disability Standards

Independent Schools:

- Fee-paying (range from low to very high)
- Vary widely in approach and support
- Must comply with Disability Standards
- Can include specialist schools for specific disabilities

Specialist Schools:

- Schools specifically for students with disability
- Smaller class sizes, specialist staff
- Available in most states (government and independent)
- May focus on specific disabilities or be more general

School Enrolment

Your Rights:

- Your child cannot be refused enrolment solely due to disability
- Schools must consider reasonable adjustments before refusing enrolment
- Refusal must be based on unjustifiable hardship (high bar to meet)

Enrolment Process:

1. Research and visit potential schools
2. Discuss your child's needs with the principal
3. Provide relevant reports and assessments
4. Complete enrolment application
5. Attend the enrolment interview
6. Participate in transition planning

What to Bring:

- Birth certificate
- Immunisation history
- Medicare details
- Relevant medical and therapy reports
- NDIS plan (if applicable)
- Assessment reports

Support Planning at School

Unlike the US IEP system, Australia doesn't have a single federal model. Each state has its own approach:

Victoria: Student Support Group (SSG)

Process:

- Meetings are held at least twice per year
- Parents, teachers, and specialists attend
- Develops Individual Education Plan (IEP) or Individual Learning Plan
- Reviews progress and adjusts support

Program Support Group (PSG):

- For students with high needs
- More frequent meetings
- More detailed planning

NSW: Personalised Learning and Support Plans (PLaSP)

Process:

- Created for students needing adjustments
- Outlines learning goals and adjustments required
- Reviewed regularly with parents

Learning and Support Team:

- School-based team that coordinates support
- Includes learning and support teachers, counsellors, and other specialists

Queensland: Individual Curriculum Plan (ICP)

Process:

- Developed for students accessing a modified curriculum
- Annual review with parents
- Outlines educational goals and adjustments

Education Adjustment Program (EAP):

- Provides additional funding for students with disability who need significant adjustments
- The application process involves a comprehensive assessment

Other States/Territories:

- South Australia: Negotiated Education Plans (NEP)
- Western Australia: Individual Education Plans (IEP)
- Tasmania: Individual Learning Plans (ILP)
- ACT: Individual Learning Plans (ILP)
- NT: Individual Education Plans (IEP)

Types of Adjustments

Curriculum Adjustments:

- Modified assessment tasks
- Altered learning materials
- Different teaching methods
- Additional time or simplified instructions

Environmental Adjustments:

- Preferential seating
- Quiet space for breaks
- Modified physical environment
- Noise-reducing headphones

Personnel Support:

- Teacher aide/integration aide support
- Small group instruction
- Additional teacher check-ins
- Peer buddy systems

Assistive Technology:

- Communication devices
- Adapted computers or tablets
- Text-to-speech software
- Mobility aids

Funding for School Support

Program for Students with Disabilities (PSD) - Victoria:

- Additional funding for students with significant disabilities
- Requires a comprehensive assessment and application
- Provides funding for teacher aide support and resources

Integration Funding Support (IFS) - NSW:

- Funding for students needing adjustments
- School applies based on student need

State-Specific Programs: Each state has similar funding programs with different names and criteria. Ask your school about available funding.

NDIS and School

What NDIS Covers at School:

- Specialist disability supports are needed because of disability (not education)
- Examples: therapy for disability-related goals, specialised equipment, behaviour support
- Transport to/from school if related to disability

What NDIS Doesn't Cover:

- Standard curriculum delivery
- Teacher aide support (school's responsibility)
- Excursions, camps, textbooks (unless specifically disability-related adjustment)
- General learning support

School and NDIS Collaboration:

- NDIS therapists can attend school meetings
- Therapists can provide consultation to school staff
- School and NDIS should complement each other, not duplicate

Advocacy Tips for Parents

Build Relationships:

- Maintain positive communication with teachers and the principal
- Attend school meetings and events
- Volunteer if possible
- Express appreciation for the support provided

Document Everything:

- Keep copies of all plans, reports, and assessments
- Follow up verbal conversations with emails
- Note dates, times, and content of conversations
- Take notes at meetings

Know Your Rights:

- Reference the Disability Standards for Education
- Understand what "reasonable adjustments" means
- Know the complaints process if needed

Be Solution-Focused:

- Come to meetings with specific suggestions
- Frame requests around your child's needs
- Acknowledge the school's constraints while advocating for rights
- Work collaboratively when possible

When to Escalate:

If informal resolution isn't working:

1. Request a meeting with the principal
2. Contact the regional/district education office
3. Contact the state advocacy service
4. Lodge a complaint with the state education department
5. Australian Human Rights Commission (discrimination complaints)

Resources for Educational Advocacy

National:

- Children with Disability Australia: cda.org.au
- Australian Coalition for Inclusive Education: acie.org.au

State-Based:

- Each state has advocacy organisations and parent support services
- Check your state education department website for parent resources

Transitions Throughout School

Primary to Secondary:

- Begin planning 12 months before transition
- Visit potential secondary schools
- Ensure support documentation transfers
- Update NDIS plan if needed

Senior Years:

- Consider VCE/HSC or alternative pathways (VET, VCAL, etc.)
- Discuss post-school goals and pathways
- Connect with disability employment services if appropriate
- Consider tertiary education options



CHAPTER 8: THE NDIS – UNDERSTANDING AND ACCESSING SUPPORT

The National Disability Insurance Scheme (NDIS) is Australia's primary funding system for people with permanent and significant disability. Understanding how to access and navigate the NDIS is crucial for many families.

What is the NDIS?

The NDIS provides funding for reasonable and necessary supports for eligible Australians under 65 with permanent and significant disability. It aims to:

- Support people to pursue their goals and participate in the community
- Provide choice and control over supports
- Fund early intervention to improve long-term outcomes
- Ensure mainstream services meet their responsibilities

Who is Eligible?

Age Requirements:

- Under 65 when you first access the NDIS
- Must be an Australian citizen, permanent resident, or hold a Protected Special Category Visa

Disability Requirements: Your child must have a disability that:

- Is permanent (likely to be lifelong)
 - Significantly affects their ability to participate in everyday activities
 - Requires support from the NDIS
- OR...

Early Intervention Requirements: Your child may be eligible for early intervention supports if:

- They have a developmental delay or disability
- Early intervention will reduce their future support needs
- Early intervention is likely to be beneficial

Accessing the NDIS

For Children Under 7: ECEI Pathway

1. Contact an Early Childhood Partner:

- o Find yours at [ndis.gov.au](https://www.ndis.gov.au)
- o Initial conversation about your child and needs

2. Support Without a Plan:

- o Partner may provide short-term early intervention
- o Connection to mainstream and community services
- o Information and capacity building

3. Referral for Access:

- o If your child needs ongoing NDIS support, Partner will help with the access request

For Children 7+: Access Request

Step 1: Gather Evidence: You'll need to provide evidence of your child's disability, which may include:

- Medical reports from specialists
- Diagnostic assessments
- Therapy reports (OT, speech, physio, psychology)
- Functional assessments
- School reports

Step 2: Submit Access Request:

- Online via the 'myplace portal'
- Phone: 1800 800 110
- Face-to-face at the NDIS office or through a partner

Step 3: NDIS Decision:

- NDIS has 21 days to decide
- You'll be notified in writing
- If approved, planning begins
- If refused, you can request an internal review

The Planning Process

Step 1: Pre-Planning:

- Prepare for your planning meeting
- Think about goals and daily life
- Gather reports and information
- Consider what supports you need

Step 2: Planning Meeting:

- Meet with NDIS planner or LAC (Local Area Coordinator)
- Discuss your child's goals, strengths, and needs
- Talk about current supports and gaps
- Be specific about what you need

Step 3: Plan Approved:

- Usually, within 28-56 days of meeting
- Plan sent to you in writing
- Includes funding amounts and categories

Understanding Your NDIS Plan

Plan Duration:

- Usually 12 months (can be longer for children)
- Review before it ends

Funding Categories:

Core Supports (flexible):

- Daily activities (personal care, domestic help)
- Consumables (continence, low-cost assistive technology)

Core Supports are the most flexible category and can often be used across different needs, depending on the situation.

Within this category, funds may cover:

Core Supports (continued)

- Assistance with daily life: Support workers to help with personal care, dressing, feeding, or household tasks directly related to your child's disability.
- Consumables: Items such as continence products, low-cost assistive technology (e.g., sensory tools, visual aids), feeding equipment, or communication boards.
- Social and community participation: Support workers who help your child access community activities, sports, programs, or social groups.

Capacity Building Supports

Capacity Building funding is not flexible across categories; it must be used for the specific purpose described. These supports help your child develop skills, increase independence, or improve participation.

Key Capacity Building categories include:

Improved Daily Living

Covers therapy services such as:

- Occupational therapy
- Speech pathology
- Physiotherapy
- Psychology
- Behaviour support

These therapies help build functional skills for everyday life, including communication, mobility, self-care, and emotional regulation.

Improved Health and Well-being

May include:

- Dietitian services
- Exercise physiology

Improved Learning

Supports for school-related learning, such as:

- Assessments supporting educational planning
- Skill development for transitioning to school or managing routines

Improved Relationships

Supports aimed at helping children with behavioural or social challenges, including:

- Behaviour support practitioners
- Development of behaviour support plans

Improved Life Choices

Covers plan management fees if you choose to use a **plan manager**.

Support Coordination

If included, a support coordinator can help you:

- Understand your plan
- Source providers
- Manage service bookings
- Prepare for plan reviews

Capital Supports

Capital supports are for large, one-off purchases.

Assistive Technology (AT)

Includes items such as:

- Communication devices (AAC)
- Specialised seating or mobility equipment
- Wheelchairs, standing frames, walkers
- Modifications to assist with positioning or feeding

Assistive Technology is divided into levels based on risk and complexity. Higher-risk items require professional assessments.

Home Modifications

Includes structural changes such as:

- Ramps
- Handrails
- Bathroom modifications
- Widened doorways

How to Use Your Plan

Once your plan is approved, you can begin accessing supports.

Types of Plan Management

1. Self-managed: You pay providers directly and claim reimbursement.
2. Plan-managed: A plan manager pays invoices on your behalf. Most families choose this option.
3. NDIA-managed: Only registered providers can be used.

Most families benefit from plan management, as it offers flexibility and administrative support.

Working with Providers - Choose providers who:

- Listen to your goals
- Communicate clearly
- Involve you in decision-making
- Provide evidence-based support
- Respect your family's values

You can change providers at any time.

Preparing for NDIS Plan Reviews

Plan reviews occur annually (sometimes every 2–3 years for stable situations). Preparation is key.

What to Bring to Your Review

- Updated therapy reports: Progress toward goals
- Recommendations for future support
- Examples of challenges or gaps in your current plan
- Notes about what worked well or didn't

Tips for Successful Reviews

- Think about long-term goals as well as immediate needs.
- Describe your child's day-to-day life, including what they cannot do without support.
- Use clear examples: "My child needs support to dress safely," rather than "My child struggles with dressing."

When Things Don't Go as Expected

If your plan doesn't meet your child's needs:

- Request a review of a reviewable decision within 90 days
- Provide additional evidence
- Seek advocacy support if needed

If the internal review still results in an unsatisfactory outcome, you may appeal to the **Administrative Appeals Tribunal (AAT)**.

Common NDIS Myths (and the Truth)

- **Myth:** You must use all your funds, or they will be reduced next year.
 - **Truth:** Plans are based on current needs and evidence, not past spending.
- **Myth:** You can't change providers until your next plan.
 - **Truth:** You can change at any time.
- **Myth:** Only medical diagnoses matter.
 - **Truth:** The NDIS focuses on functional impact, not labels.

Becoming a Confident NDIS Advocate

You will become more confident the longer you engage with the NDIS. Keep learning, stay organised, and remember that you know your child best.

CHAPTER 9: FINANCIAL PLANNING AND AUSTRALIAN RESOURCES

Raising a child with a disability can involve additional costs. Understanding the financial support available in Australia can ease some of the pressure.

Centrelink Payments and Support

Many families are eligible for government financial support through Centrelink.

Carer Allowance

- A supplementary payment for parents who provide daily care for a child with disability.
- Not income tested.
- Requires medical forms completed by a doctor.

Carer Payment

- Income-tested payment for parents who cannot work due to caring responsibilities.
- Requires significant care needs.

Child Disability Assistance Payment

- Annual lump sum paid to families receiving Carer Allowance.

Health Care Card

Provides:

- Cheaper medicines under the PBS
- Lower medical costs
- Concessions on utilities, transport, and more.

Children receiving Carer Allowance automatically qualify.

State-Based Supports

Each state offers additional support.

Examples:

- **Companion Card:** Allows a free ticket for support workers at venues.
- **Public Transport Concessions**
- **Carer Card Programs:** Discounts and benefits for carers.

Check your state government website for details.

Additional Financial Considerations

Budgeting for Therapies

If therapy needs exceed the NDIS budget:

- Ask providers about group sessions (often cheaper)
- Use telehealth options when appropriate
- Prioritise goals for the plan period

Private Health Insurance

Consider whether extras cover may reduce therapy costs.

Keeping Receipts For:

- Out-of-pocket medical expenses
- Therapy costs
- Assistive technology purchases

These may be helpful for plan reviews.

Grants and Non-Profit Assistance

Many charities and organisations offer grants for:

- Assistive technology
- Respite camps
- Therapy programs

Examples include:

- Variety – the Children’s Charity
- Starlight Children’s Foundation
- Cerebral Palsy Alliance grants

CHAPTER 10: SELF-CARE AND FAMILY WELLBEING

Caring for a child with a disability is deeply rewarding—but it is also emotionally, mentally, and physically demanding. Prioritising your own wellbeing is essential.

The Importance of Self-Care

Self-care isn't indulgent; it's survival. When you are rested and supported, you can better support your child.

Strategies for Self-Care

- **Schedule regular respite** (NDIS may fund respite support)
- **Connect with other parents** who understand your journey
- **Seek counselling** when needed
- **Maintain your own health appointments**
- **Say yes to help** when offered

Supporting Siblings

Siblings can experience a mix of emotions: pride, worry, love, and frustration.

Ways to support them:

- Provide one-on-one time
- Involve them appropriately in their sibling's journey
- Seek sibling support groups
- Encourage open conversations

Supporting Your Partnership or Family Unit

Communication is key; schedule time to connect without discussing care tasks.

CHAPTER 11: BUILDING COMMUNITY AND CONNECTION

Connection reduces isolation and builds resilience. Finding community is vital for your emotional and mental well-being. You are not alone on this journey.

Ways to Build Community

1. **Join Parent Support Groups:** Seek out both diagnosis-specific groups (for deep knowledge) and general support groups (for emotional validation and resilience).
2. **Attend Therapy Playgroups:** Use these professional settings to naturally connect with other parents navigating similar NDIS goals and intervention routines.
3. **Participate in Inclusive Programs:** Find all-abilities programs in local sports or arts. This promotes your child's sense of belonging and helps the wider community normalise differences.
4. **Connect with Local Disability Organisations:** Use these local hubs for region-specific workshops, social gatherings, and advocacy training sessions.

Finding community reminds you that you are not alone.



CHAPTER 12: CELEBRATING PROGRESS AND MILESTONES

Every child develops in their own way, and children with disabilities often follow unique developmental paths. Celebrating progress, no matter how small, builds confidence, strengthens resilience, and reinforces your child's sense of achievement.

Redefining Milestones

Traditional milestones don't always apply. Instead, focus on:

- Functional milestones: using a new communication method, feeding independently, and navigating a new environment.
- Emotional milestones: confidence in social settings, reduced anxiety, and trying a new activity.
- Therapy milestones: mastering a goal set by a therapist.

Celebrate the Moments That Matter. Some families use:

- Achievement journals
- Photo albums documenting progress
- "Wins of the week" conversations
- Celebratory rituals for significant breakthroughs

Avoiding Comparison

Every child's path is their own. Avoid comparing your child to peers or siblings. Celebrate *your child's* strengths, curiosity, and growth.

Encouraging Self-Advocacy As your child grows, teach them to:

- Express their needs
- Ask for help when needed
- Celebrate their own achievements

These skills build confidence and independence.

CHAPTER 13: PLANNING FOR THE FUTURE

Planning can feel overwhelming, but preparing early brings peace of mind and ensures your child is supported throughout their life.

Future Educational Transitions

Consider planning early for:

- Preschool to primary school transitions
- Primary to secondary school
- Senior school pathways (VET, tertiary education, alternative learning)

Ask schools to support transitions through:

- Orientation visits
- Tailored transition plans
- Additional meetings with staff

Post-School Pathways

For older children and teens:

- Explore tertiary education and disability support services
- Research disability employment services
- Consider vocational training or supported employment
- Investigate community participation programs

Housing Options (for Adulthood)

As your child approaches adulthood, thinking ahead about housing can help them live as independently, safely, and happily as possible. The right option depends on their abilities, preferences, and level of support required.

Supported Independent Living (SIL)

SIL is designed for people with higher support needs who require help with daily tasks such as cooking, cleaning, personal care, or community access.

Supported Independent Living (SIL) Continued

Support workers provide assistance either 24/7 or as needed, depending on the individual's plan. SIL can be delivered in a shared home with other residents or in a private residence.

Specialist Disability Accommodation (SDA)

SDA refers to specially built or modified homes for individuals with extreme functional impairment or very high support needs. These properties may include accessible bathrooms, reinforced walls, assistive technology, ceiling hoists, wide hallways, or on-site overnight assistance. SDA funding is only provided to eligible participants through the NDIS.

Independent Living Options (ILO)

ILO offers more tailored, flexible arrangements for people who don't require the intensity of SIL. It can include living alone with visiting supports, living with roommates, or using a network of paid and unpaid support. ILO is person-centred and often includes family and community networks.

Living with Family

Many adults with disability choose to remain at home. Families may use NDIS supports, such as home modifications, personal care, or community access, to ensure the environment remains safe and sustainable.

Private Rental or Home Ownership

Some individuals with disability can live independently in private rentals or their own home with appropriate supports. This may involve home modifications, visiting support workers, or assistive technology to enable daily living.

Community Housing

Community housing providers offer affordable, long-term rental options. Some specialise in disability-inclusive models and work closely with the NDIS or local support services.

FINAL ENCOURAGING MESSAGE

As you reach the end of this guide, take a moment to acknowledge your strength, your persistence, and the love that has carried you through each chapter, both in this book and in your life.

Raising a child with a disability is a journey filled with challenges, triumphs, learning, and profound joy. You have already shown extraordinary dedication by seeking knowledge, advocating for your child, and building a future that honours who they are.

No parent has all the answers, and no path is walked perfectly. What matters most is your commitment to showing up each day with courage, compassion, and hope. Your child is fortunate to have you, someone who believes in their potential, celebrates their individuality, and stands beside them through every milestone.

As you continue forward, remember this:

You are not alone, and you are more capable than you realise.

Your child's story is still unfolding, full of possibilities, growth, and joy. And you are guiding them toward a life filled with dignity, purpose, and belonging. You are doing an incredible job. Keep going, one step, one season, one moment at a time.

Charlene

Australian Resources: Websites

- National Disability Insurance Scheme (NDIS):[ndis.gov.au](https://www.ndis.gov.au)
- Children with Disability Australia (CDA):[cda.org.au](https://www.cda.org.au)
- Australian Human Rights Commission (AHRC):[humanrights.gov.au](https://www.humanrights.gov.au)
- Centrelink / Medicare (Services Australia):[servicesaustralia.gov.au](https://www.servicesaustralia.gov.au)
- NDIS Quality and Safeguards Commission:[ndiscommission.gov.au](https://www.ndiscommission.gov.au)
- Administrative Review Tribunal (ART):[art.gov.au](https://www.art.gov.au)
(This body replaced the AAT for NDIS reviews)
- Australian Federation of Disability Organisations (AFDO):[afdo.org.au](https://www.afdo.org.au)
- Disability Advocacy Network Australia (DANA):[dana.org.au](https://www.dana.org.au)
- Carers Australia:[carersaustralia.com.au](https://www.carersaustralia.com.au)
- Variety – the Children's Charity:[variety.org.au](https://www.variety.org.au)
- Starlight Children's Foundation:[starlight.org.au](https://www.starlight.org.au)
- Cerebral Palsy Alliance:[cerebralpalsy.org.au](https://www.cerebralpalsy.org.au)
- Spina Bifida Foundation Victoria (SBFV):[sbfv.org.au](https://www.sbfv.org.au)

ABOUT THE AUTHOR



Charlene McIver is a dedicated author and advocate who empowers Australian families raising children with disabilities.

Her compassionate wisdom is forged from her most profound role: mother to her late son, Leigh, who bravely navigated a lifetime of complex medical challenges in Melbourne until his passing in 2016 at age 33.

Charlene channelled the vital lessons learned, including the importance of self-advocacy and holistic wellness, into her writing.

She is the author of a series of award-winning, inclusive children's books and created this comprehensive guide to give Australian parents the practical, structured support she wished she had during her own journey.



