

A handbook by Down Syndrome South Africa



Guiding Every Step:

Health and
Development
from Birth to
Adulthood



Adapted from the American Academy of Pediatrics [AAP] and the South African Down Syndrome Health
Passport





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What is Down syndrome?

Down syndrome is a genetic condition caused by the presence of an extra full or partial copy of chromosome 21. This additional genetic material alters the course of development and causes the characteristics associated with the syndrome. While individuals with Down syndrome share some common features, each person is unique and may have different abilities and health needs.

Some of the typical features include:

- eyes that slant upwards
- tiny folds covering the inner corners of the eyes (epicanthic folds)
- small white flecks on the iris (Brushfield spots)
- a small nose with a broad, flat bridge
- a small mouth which makes the tongue appear large

- small low set ears
- a single crease on the palm of the hand
- short hands and fingers
- inclining pinkie
- wider gap between the big toe and second toe
- A slightly flattened appearance of the back of the head

Types of Down Syndrome

- 1. **Trisomy 21:** The most common type (about 95% of cases), where every cell in the body has three copies of chromosome 21 instead of two.
- 2. **Translocation:** About 3-4% of cases. A part of chromosome 21 becomes attached (translocated) to another chromosome before or at conception.
- 3. **Mosaicism:** About 1-2% of cases. Some cells have three copies of chromosome 21, while others have the typical two copies.

Common Health Challenges

- Congenital heart defects
- Hearing and vision problems
- Thyroid dysfunction
- Sleep apnoea
- Gastrointestinal issues (e.g. constipation, reflux, celiac disease)
- Low muscle tone (hypotonia) and delayed motor development
- Increased risk of infections
- Orthopaedic problems such as atlantoaxial instability



The Importance of Early Intervention



Early intervention refers to services and supports available to babies and young children with developmental delays and disabilities. **These can include:**

- Physical therapy
- Speech and language therapy
- Occupational therapy

Why it matters: Early intervention has been shown to significantly improve outcomes in language development, social skills, learning, and independence.









Everyday Activities That Teach



- **Talking through routines:** Describe what you're doing as you get dressed, cook, or clean "Let's put on your red shirt" or "We're washing the green plate." This builds vocabulary and understanding.
- **Sorting laundry:** Grouping clothes by colour, size, or type teaches categorisation and early maths concepts like matching and patterns.
- **Bath time songs and games:** Singing while bathing builds language and makes learning fun. Splashing and pouring water supports sensory play and fine motor development.
- **Kitchen play:** Giving your child safe kitchen tools like spoons, plastic bowls, or measuring cups helps build coordination, imagination, and problem-solving skills.
- Nature walks: Going outside even just around the block provides a chance to talk about colours, animals, weather, sounds, and textures. "Feel the rough bark," or "Look at the yellow flower!"



Learning in the Community

Outings into the community are filled with learning potential:

- Include your child in shopping: Let them help pick items from the shelf, talk about prices, colours, shapes, or what the item is used for. "Can you find the red apples?" or "This milk costs R25 look at the number 2 and 5."
- **Talk about money:** Explain how you pay for items, the concept of value, or how change is given. This introduces basic financial literacy.
- **Use signs and labels:** Read signs at the shop, clinic, or park aloud. "This sign says 'STOP' what colour is it?"
- **Encourage polite interactions:** Greeting shop assistants or saying "thank you" teaches social skills and confidence.
- **Use public transport:** If safe, taking a bus or taxi can be an adventure! Talk about the route, the driver, and the surroundings.
- **Visit the clinic or library:** These spaces help children become comfortable in public settings and expose them to different experiences, people, and environments.



The Power of Connection



- Language and communication
- Early maths and science
- Social and emotional skills
- Motor coordination and independence

Every moment spent talking, listening, and playing helps your child's brain grow.

• A love of learning

Parents and caregivers are a child's first and most important teachers. By including your child in everyday tasks — whether at home or out and about — you're helping them build the skills they need for life. No formal classroom needed — just your time, voice, and presence.

The Power of High Expectations **

Believing in a child's potential makes a real difference.

Research shows that expectations influence outcomes. When families, educators, and health professionals believe in a child's potential, children tend to achieve more. It is important to remember that children and adults with Down syndrome often have stronger receptive language than expressive language, meaning they usually understand more than they can say—so always assume they do understand. Believing in their ability to learn, participate, and contribute meaningfully helps create inclusive, empowering environments where they can thrive.

This is especially important for children with Down syndrome or other developmental delays. Too often, outdated stereotypes or low expectations limit opportunities before a child even has the chance to try. But when we start with the mindset that every child is capable, we open the door to real growth and success.



Why High Expectations Matter:

- **They build confidence:** When a child feels that others believe in them, they start to believe in themselves. Confidence leads to greater motivation, persistence, and resilience.
- They drive effort and achievement: Children are more likely to take on challenges and engage in learning when they are encouraged and supported by adults who expect them to succeed.
- They shape opportunities: If we assume a child won't understand or isn't ready, we may hold back experiences that could support their development. High expectations ensure that children are included, challenged, and supported in meaningful ways.
- They influence how others treat the child: When families and professionals model high expectations, others (including peers, teachers, and extended family) are more likely to view and treat the child with respect and dignity.





What High Expectations Look Like:



- **Assuming competence:** Always presume that a child can learn even if they need support or learn differently.
- **Providing opportunities:** Include children in daily routines, play, conversation, and decision-making. Offer chances to try, even if mistakes happen that's how learning works!
- **Setting goals:** Help children set and work toward achievable goals, celebrating progress along the way.
- **Encouraging independence:** Support children to do things for themselves, with guidance when needed, rather than doing it for them automatically.
- Inclusion in education, play, and community: Advocate for inclusive education and community participation so the child is seen as a full and valued member of society.

We should make reasonable accommodations for a child's cognitive abilities, but not lower our expectations for their social skills or behaviour. Appropriate behaviour should be expected, encouraged, and supported—just as with any other child. Believing in their ability to learn, participate, and contribute meaningfully helps create inclusive, empowering environments where they can thrive.

High expectations don't mean ignoring a child's challenges — they mean recognising their abilities, supporting their growth, and never putting a ceiling on what they might achieve. When children are surrounded by people who believe in them, they're far more likely to believe in themselves.

Let's raise our expectations — and watch our children rise to meet them.

Enclusion: Evidence and Benefits

Inclusion is not just a right — it's a proven approach that benefits everyone. Inclusive education means that children with and without disabilities learn together in the same classrooms, participate in the same activities, and are equally valued as members of their school and community. It goes beyond simply placing children in the same space — it's about meaningful participation, support, and belonging. The evidence is clear: inclusion works. When children with Down syndrome are educated in inclusive settings, they thrive — academically, socially, and emotionally — and so do their peers.







Inclusive education supports both academic and social development. Research shows that students with disabilities who learn in inclusive environments often achieve better academic outcomes compared to those in segregated or special education settings.

Being in a classroom with diverse learners exposes children to ageappropriate language, curriculum, and social norms. This encourages growth in literacy, numeracy, communication, and problem-solving. Socially, inclusive settings provide natural opportunities to build friendships, learn social skills, and participate in group activities, just like any other child.

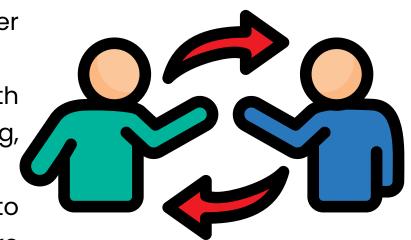


Improved Communication and Adaptive Skills

Students with Down syndrome in inclusive settings often show stronger communication and adaptive behaviour outcomes.

Daily interactions with typically developing peers help children with Down syndrome practise language, develop conversational turn-taking, and expand vocabulary in real-world contexts.

Being part of a shared routine supports independence — learning to follow class instructions, manage personal belongings, and take initiative — skills that also support long-term success beyond school.



Benefits for All Students



Inclusion benefits all children, not just those with disabilities!

Classrooms that are inclusive tend to foster empathy, cooperation, and understanding. Children learn to appreciate diversity and recognise that everyone has different strengths and challenges.

Studies show that peers without disabilities develop stronger social-emotional skills, improved communication, and more accepting attitudes when they learn in inclusive environments.

Inclusion Fosters a More Equitable Society

Inclusive education promotes respect for human rights and the dignity of all people.

It challenges societal barriers and reduces stigma by showing that everyone has value and can contribute meaningfully.

Schools that practice inclusion become more welcoming, flexible, and responsive to the needs of all learners — setting a foundation for inclusive communities and workplaces in the future.

The Bottom Line: Inclusion Works

Inclusion is not just about placing children together — it's about belonging, participation, and high expectations for every learner. With the right support, all children can learn, and all children benefit from learning together.

Let's ensure that inclusion isn't the exception — it's the norm.

Supported Decision-Making in Healthcare

Everyone – including persons with disabilities – has the right to make choices about their own health.

Supported decision-making is a rights-based approach that recognises the capacity of persons with intellectual disabilities to be involved in decisions that affect them. Instead of making decisions for them, healthcare providers, families, and supporters should aim to make decisions with them — providing the guidance, tools, and time needed to support understanding and participation.

Why It Matters

Historically, people with intellectual disabilities were often excluded from healthcare decisions, with choices made entirely by family members or professionals. This can lead to feelings of powerlessness and can sometimes result in treatments being misunderstood, resisted, or even refused.

Supported decision-making helps people with Down syndrome:

- Understand their health conditions and options
- Express their preferences
- Develop independence and confidence
- Make informed choices with dignity and respect

How to Support Decision-Making

Here are some ways healthcare professionals, parents, and caregivers can help:





Involve the person in discussions about treatment plans:

- Ask questions like "How are you feeling today?" or "Would you like to know more about your medicine?" Encourage them to be part of the conversation from the beginning.
- Use simple, concrete language:
- Avoid jargon. Instead of "You need to take this medication to reduce inflammation," say "This medicine helps when your joints feel sore."

Include visual aids and demonstrations:

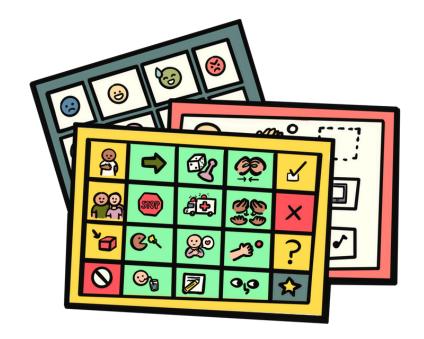
Use pictures, diagrams, or real objects to explain procedures or treatments. A visual chart showing when to take medicine or what will happen during a clinic visit can be very helpful.

Respect their preferences and consent:

Always ask before doing something and explain why. For example, "Is it okay if I check your blood pressure now?" If the person says no, take time to understand their concerns rather than pushing ahead.

Offer choices where possible:

Even small decisions matter — like choosing between two plasters or picking the arm for an injection. These options help build confidence and a sense of control.





V Inclusion in Healthcare: Practical Tips

Healthcare encounters can be overwhelming for anyone — especially for individuals with Down syndrome.



These practical strategies can help ensure visits are more comfortable, respectful, and inclusive:

Always speak directly to the person, not just the caregiver:

Greet them warmly, make eye contact, and use their name. Even if a supporter is present, remember that the person with Down syndrome is the patient.

Give extra time for responses:

People with Down syndrome may need more time to process information and respond. Avoid interrupting or rushing them — patience builds trust and understanding.

Use visuals, gestures, and a reassuring tone:

Combine spoken words with gestures or images to help reinforce meaning. Pointing, miming, and showing pictures can make concepts easier to grasp.

Encourage participation, especially for adolescents and adults:

As children with Down syndrome grow older, it's important to include them more actively in managing their own health. This may include asking them to describe their symptoms, helping manage their appointments, or understanding their own medication.

Be flexible and kind:

People may be nervous or unsure. A calm, welcoming approach goes a long way — so does explaining what you're doing, step by step.



Remember: The goal is not to simplify information too much, but to make it accessible. Everyone can be involved in their own health — with the right support.

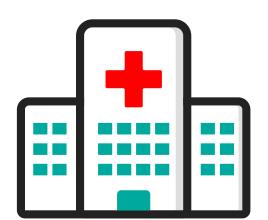
Below you will find the following:

Health Passport - for when you son / daughter ends up in hospital - to provide guidance to Drs and nurses about:

- his / her needs
- likes / dislikes
- challenges
- communication
- Necessary history

Guidelines for health check-ups from birth to adulthood





My hospital passport



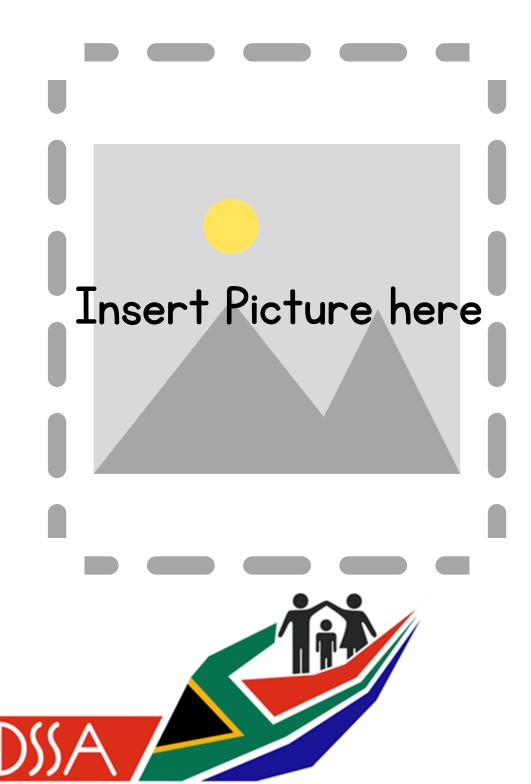
My information is in this book



If found please return to me.

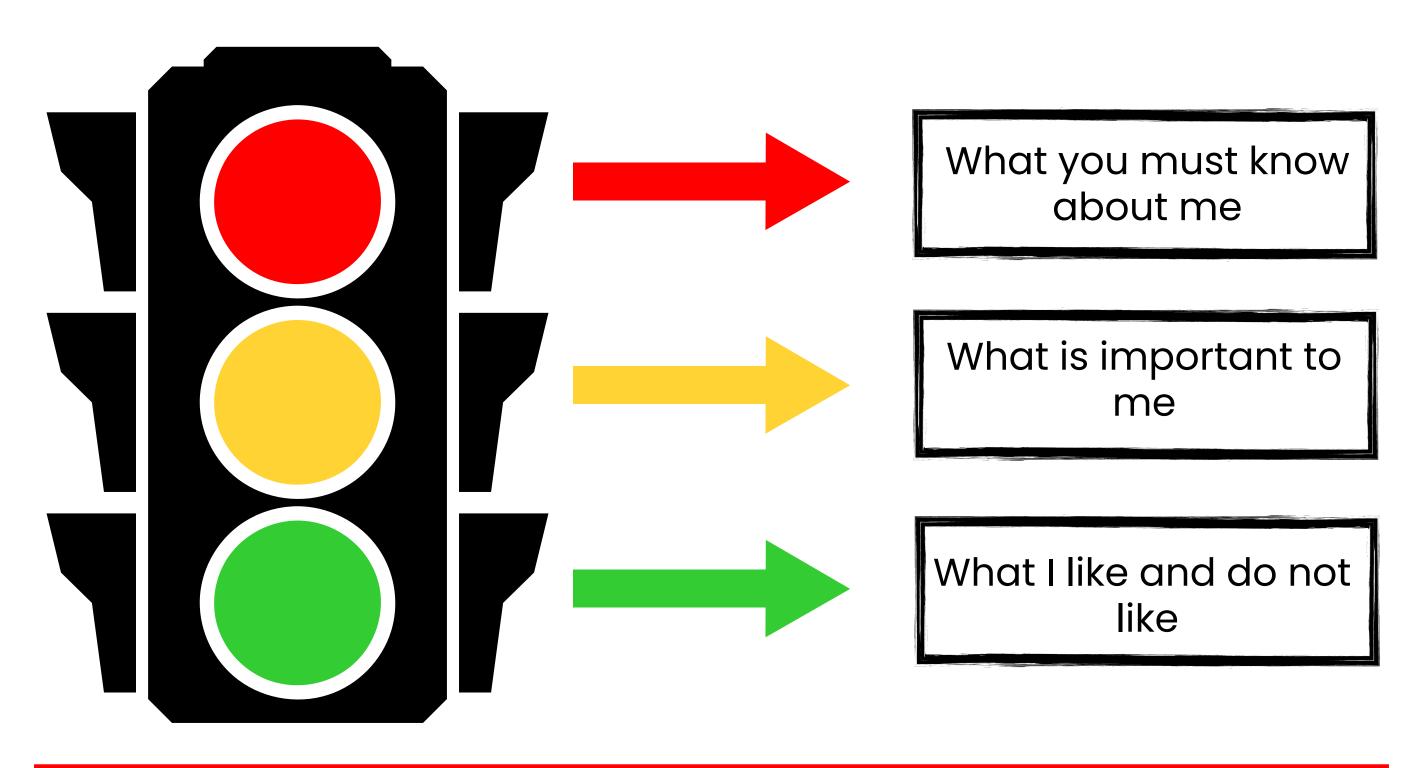
Name:

Contact Number: _____



Down Syndrome South Africa

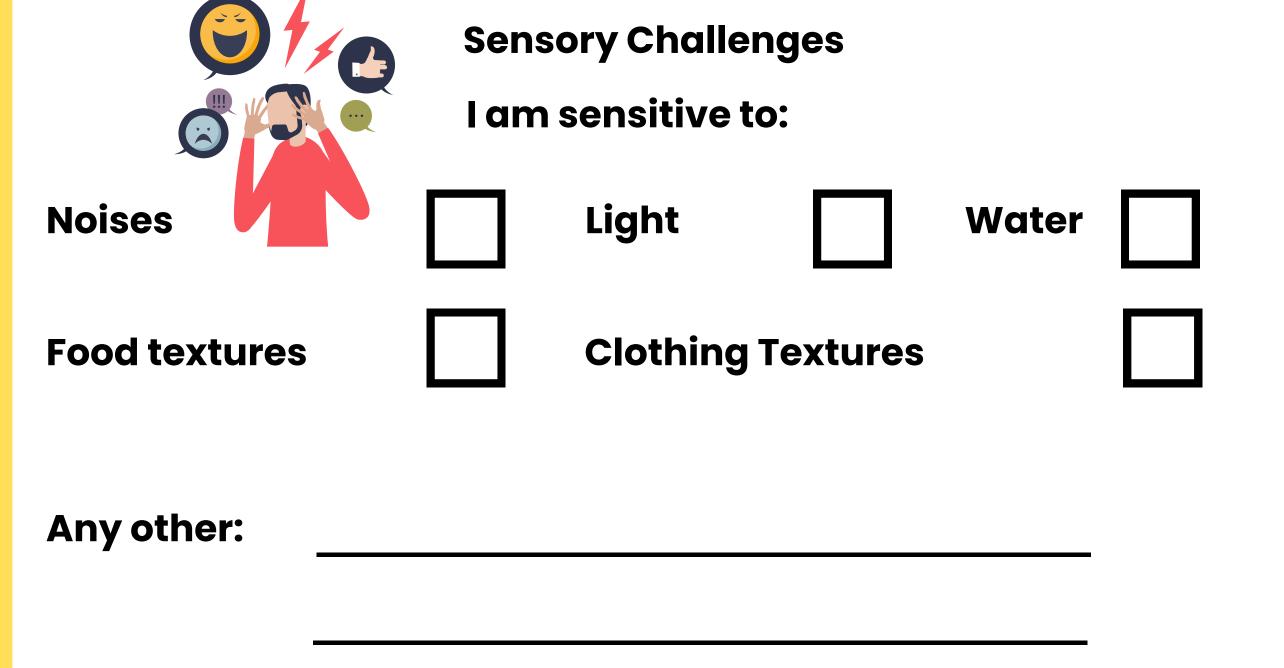
All information in this book is colour coded



<u>IMY PERSOI</u>	NAL INFORMATION
Name and Surname:	
What I like to be called:	
Date of Birth:	Gender:
Parents / Caregiver Contact Details:	
Main Caregiver:	
Home Language:	
Hospital / clinic number:	
Health Conditions:	



Verbal	YES NO	Non-Verbal	YES NO
Uses Sign Language	YES NO	Toilet Trained	YES NO
Needs assistance:			
Walking	YES NO	Bathing	YES NO
Brushing Teeth	YES	Dressing	YES NO
Washing hands/fac	e YES NO		
Other _			
	Sensory Cha	llenges	







Behaviour

Behaviour Challenges:	





My Likes



What I don't like





ny other information I want you to know:	
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Notes		





Birth to 3 Months

- Confirmatory karyotype and genetic counselling
- Echocardiogram or cardiac clinic referral
- OAE hearing screen
- Red reflex eye test
- Monitor feeding, constipation, and growth
- TSH test (if no newborn screen)
- FBC if pale or unwell
- Refer to support groups

😲 1 Year

- Growth and feeding review
- Upper airway obstruction symptoms
- FBC if pale/petechiae/bleeding
- TSH if not already tested
- Audiology review

3-4 Years

- Annual health review (sleep apnoea, BMI, gait, neck posture, gluten sensitivity)
- FBC if symptoms
- TSH test
- Hearing and vision checks
- Flu vaccination

6 Months

- Hearing screen (if not done previously)
- TSH test
- Monitor growth and feeding
- Check for signs of upper airway obstruction (snoring, restless sleep, etc.)

2 Years

- Eye referral for strabismus or acuity concerns
- TSH test
- Physiotherapy review
- FBC if needed
- Monitor growth and feeding



Milestone	age range for children with Down syndrome	Typical age range		
	Gross Motor Skills			
Sits unassisted Crawls Stands Walks unassisted	6 – 30 months 8 – 22 months 1 – 3.25 Years 1 – 4 years	5 – 9 months 6 – 12 months 8 – 17 months 9 – 18 months		
	Language			
First Word Two-word phrases	1 – 4 years 2 – 7.5 years	1 – 3 years 15 -32 months		
Social/self-help				
Smile Finger feeds Drinks from cup unassisted Uses spoon Bowel control Dresses self unassisted	1.5 – 5 months 10 – 24 months 13 – 39 months 12 – 32 months 2 -7 years 3.5 – 8.5 years	1 – 3 months 7 – 14 months 9 – 17 months 12 – 20 months 16 – 42 months 3.25 – 5 years		



5−6 Years

- Continued health review (see 3-4 years)
- Vision and hearing screening
- TSH and FBC
- Monitor for behavioural concerns

• Adolescents (11–18 Years)

- Monitor mental health (anxiety, ADHD, mood)
- Sleep disturbances (snoring, daytime fatigue)
- Puberty and sexuality education (body changes, safe touch, contraception)
- TSH and FBC
- Check for celiac disease if symptoms
- Daily living skills and independence
- Transition planning

2 7-10 Years

- Continued health review (upper airway, BMI, behaviour, school support)
- TSH if symptomatic
- Vision annually
- Hearing every 6 months until independent ear tests
- Social safety discussions

Young Adults (18+ Years)

- Cardiac monitoring if symptomatic
- Watch for early signs of Alzheimer's
- Annual TSH and FBC
- Celiac screening if needed
- Transition to adult care and support for independent living
- Employment and community participation planning

Supported Employment: Summary of Key Guidelines

Supported employment is an inclusive approach that helps individuals with intellectual disabilities, including Down syndrome, access meaningful work in the open labour market. It is based on the belief that everyone can work, provided the right support is in place.

Key Principles:

Begin Early

Introduce the idea of work and develop job readiness skills from a young age. Exposure to structured routines, responsibilities at home, and community engagement lays the foundation.

Job Sampling

Provide short-term, real-world work experiences (e.g., in retail, admin, gardening) to build confidence and help individuals discover their preferences.

Reasonable Accommodations

Adapt the work environment to support success. Examples include visual schedules, task prompts, simplified instructions, extra time for learning, or pairing with a workplace buddy.

Person-Centred Career Planning

Focus on the individual's strengths, interests, and support needs. Involve the person, their family, and professionals in identifying suitable roles or career paths.

Job Coaching

Offer intensive support during the training and onboarding phase. A job coach helps break down tasks, provide repetition, and model appropriate workplace behaviour.

Ongoing Support

Monitor progress with regular check-ins, problemsolving support, and encouragement for both employee and employer. Support can taper off as the individual becomes more independent.

Employer Engagement

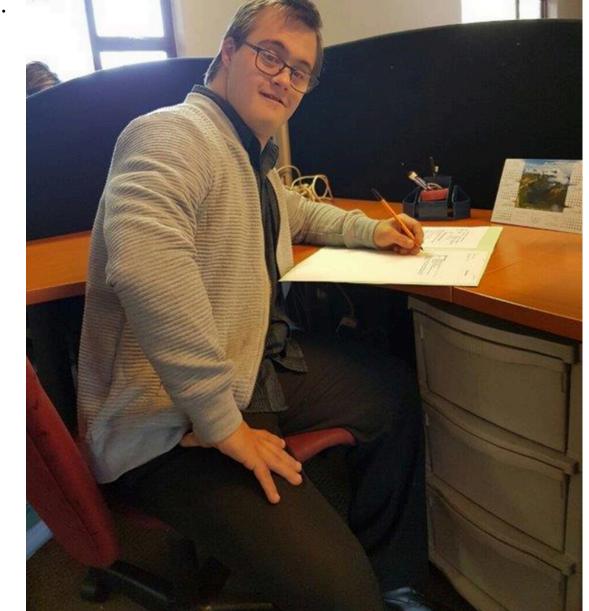
Build relationships with inclusive employers. Provide training on disability awareness, clarify the role of support

organisations, and offer guidance on workplace adaptations.

Outcomes:

Supported employment leads to greater independence, improved self-esteem, and social inclusion for people with Down syndrome. It also promotes diversity and acceptance in the workplace, benefiting everyone involved.









MTWTFS

Notes



Examples of chores



Toddlers (Ages 2-4)

With close supervision and modelling

- Put toys in a box or basket
- Throw rubbish in the bin
- Help wipe up spills with a cloth
- Help feed pets (e.g. pour dry food)
- Put laundry in the washing basket
- Match socks during folding

Early Childhood (Ages 5-7)

With visual steps or verbal prompts

- Set the table (with support)
- Clear own plate after meals
- Help water plants
- Wipe down tables with a cloth
- Put folded clothes in drawers
- Sort laundry into colours
- Help pack their own school bag

Middle Childhood (Ages 8-11)

With gradually reduced supervision

- Make the bed
- Dust furniture
- Help sweep or vacuum small areas
- Help prepare simple meals (e.g. sandwiches)
- Unpack groceries (e.g. fruit into a bowl)
- Feed and brush pets
- Pack lunchbox with help

Teens (Ages 12+)

With increasing independence and accountability

- Load and unload the dishwasher
- Fold and put away laundry
- Help cook simple meals (e.g. boil pasta, cut soft veggies)
- Sweep, mop, or vacuum rooms
- Take out the rubbish
- Wash the car (with a peer or adult)
- Create a weekly chore checklist for themselves





- Keep instructions clear and simple
- Offer praise, not perfection—focus on participation and effort
- Break complex chores into smaller steps
- Make it routine: assign the same chores on the same days











Sort laundry

Wipe surface

Pack away toys

Take rubbish out

Do laundry











Fold laundry

Set the table

Wash dishes

Water plants

Make bed

Contact your local Association















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Contact your local Outreach / Support Group









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