Flashcards

Down Syndrome



- **These flashcards contain information about working with people with Down Syndrome (DS) in low resource areas.**
- **These flashcards are made to be used by fieldworkers, or anyone interested.**
- **These flashcards are based on the information about Down Syndrome from the RehApp.**

rehapp

Download on the App Store

GET IT ON Google Play

The goals of the flashcards are:

- To meet the needs of people with disabilities and their families.
- To improve knowledge and skills of fieldworkers in providing basic (functional) rehabilitation services for people with disabilities and their families.
- To enhance participation in daily, family and community life.
- To improve the quality of life of people with disabilities and their families.
- To support you (as fieldworker) in the process of guiding a family by providing you with a resource you can keep with you on your phone (offline) or in your bag.

What can you do with these flashcards:

- To help guide your visits to families that have a family member with Down Syndrome.
- Make an inventory of the needs of the person with Down Syndrome and their family.
- Learn about the implications of a disability for the person and their family.
- Use them to do an assessment.
- Use them to set goals for a person with Down Syndrome.
- Use them to help you discuss interventions with the family.
- Use them to help you keep client records.
- Use them to help you monitor process.

Index:

The content is organised according to the International Classification of Functioning, Disability and Health (ICF) of the World Health Organization (WHO). These cards don't replace the knowledge and skills of doctors and therapists. We advise you to seek their advice first.

The ICF framework contains the following domains. They are interlinked which means that one part can create barriers and opportunities for other parts and that information can overlap.

Information about Down Syndrome	
	Introduction
	Body functions & structures
	Activities & participation
	Personal factors
	Environmental factors

Index

Down Syndrome

Index

Down Syndrome: content

Introduction:

- ❑ What is Down Syndrome 1
- ❑ Causes of Down Syndrome 1
- ❑ Common physical characteristics 1
- ❑ Misconceptions and Reality 2

Body functions & structures:

- ❑ Types of Down Syndrome 3
- ❑ How can DS affect the body 3
- ❑ Some of the medical conditions 3
- ❑ Possible characteristics and associated health conditions 4
- ❑ Risk factors in Down Syndrome 5
- ❑ Prevention and early detection 5
- ❑ General health 6-7

Activities & participation:

- ❑ 'Favourite' words 8
- ❑ (Self)care 9-10
- ❑ Eating & Drinking 11
- ❑ Brushing of teeth 12
- ❑ Handwashing 12
- ❑ Dress independently 13
- ❑ Learning skills 14
- ❑ Livelihood 15
- ❑ Communication 16-17
- ❑ Social activities 18
- ❑ Community activities 19
- ❑ Addressing behaviour issues 20
- ❑ Get help from where? 21
- ❑ Things to try at home 22

Personal factors:

- ❑ Wishes and needs 23
- ❑ Safety situations 24
- ❑ Sexual education 25
- ❑ Personal boundaries 25

Environmental factors:

- ❑ Safeguarding 26
- ❑ Healthcare 27
- ❑ Education 27
- ❑ Livelihood caregivers 28
- ❑ Family counselling and mental support 29
- ❑ Assistive devices 30
- ❑ Stakeholder network of services 31

Card 1

Introduction

What is Down Syndrome (DS)?

DS is the most common genetic chromosomal disorder and a cause of intellectual disability. Chromosomes are structures found inside the body's cells.

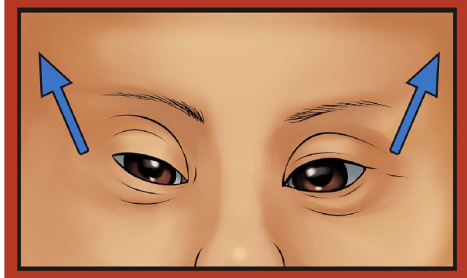
Causes of DS

- The unusual activity in a specific chromosome (number 21) during the development of the fetus leads to having an extra copy of this chromosome and DS. People have 46 chromosomes, but those with DS have 47 chromosomes. This can be tested in a laboratory at a medical facility.
- Physical characteristics, medical and health conditions that often appear upon birth as well as intellectual disability and developmental delays are the results of this extra genetic material.
- The extent of the disability and delays vary per person.
- DS is not caused by sin, bad spirits or bad parenting.

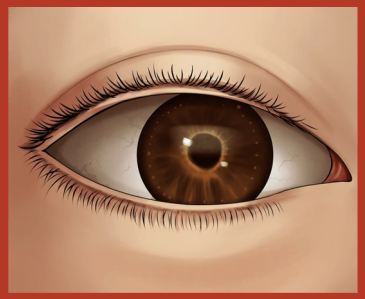
Common physical characteristics

1. Smaller skull than the average
2. The skull's back part is less round than the usual
3. Slanted eyes with folds of skins at the inner corners (see picture)
4. Small low-set ears
5. Small white or grayish/brown found in a circular pattern around the iris of the eye (see picture)
6. Flat nasal bridge (see picture)
7. High-arched palate
8. Tongue protrusion (= moving outside the mouth) with an open mouth (see picture)
9. Short, broad hands
10. Short webbed neck
11. Folded fingers at the part of the finger closest to the hand
12. Crease located horizontally over the entire length of the hand palm (see picture)
13. Gap between the 1st and 2nd toes (see picture)
14. Slow physical growth and short height

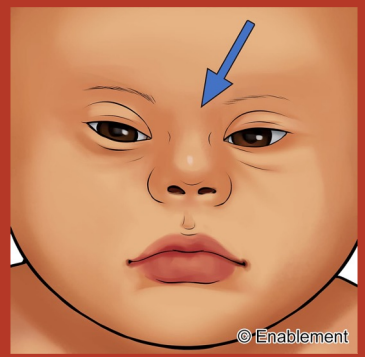
Note: You may refer to some illustrations below



3

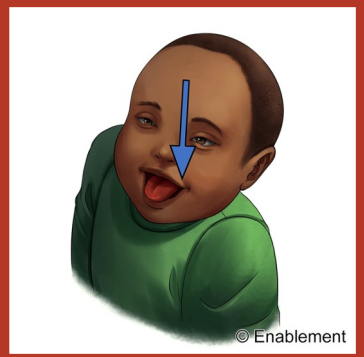


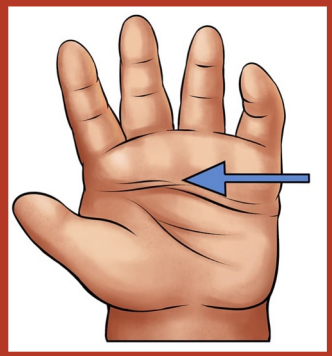
5



6

8





12



13

Introduction

Card 2

Misconceptions and reality

There are a lot of misconceptions, myths, and beliefs about disability in general and Down Syndrome specifically. See here some of the misconceptions that are not true and the reality.

Misconceptions

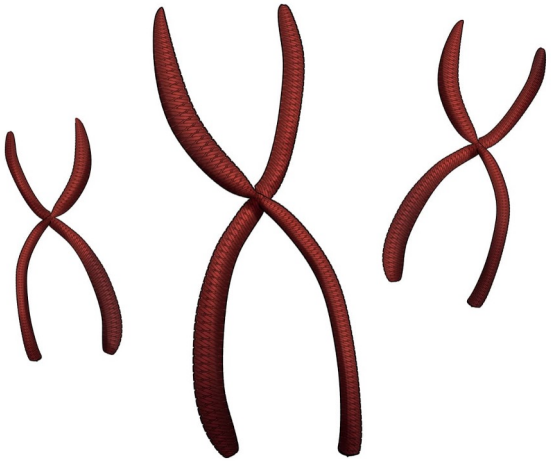
- People who have DS are always happy.
- A child with DS negatively impacts her siblings.
- Adults with DS are unable to form close interpersonal relationships.
- People with DS cannot have children.

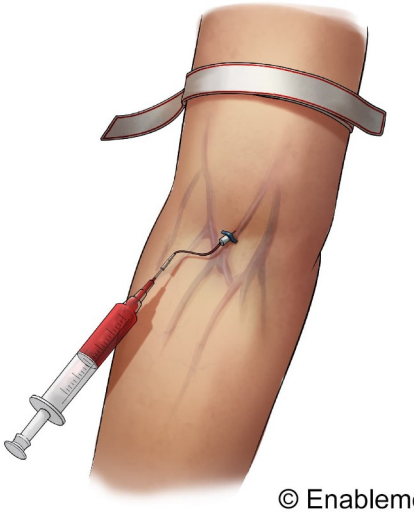


Reality

- People with Down Syndrome are more similar to typical people than they are different. Everyone has feelings and moods. One study found that people with Down Syndrome are at a higher risk for depression. And there is evidence that it is under-treated. Just as in the typical population, it is important that adults with Down Syndrome have educational, work, and social opportunities, as well as adaptive life-skills.
- Studies do not support that a child with Down Syndrome has a negative impact on siblings. For example, a recent study published in the 'Journal of Intellectual Disability Research' found no long-term detrimental effects on siblings. In fact, some mental health professionals point to the psychological advantages of such a child cared for within the family circle. They have documented siblings who have increased tolerance, compassion, and awareness, unlike all typical siblings.
- People with Down Syndrome can have meaningful friendships, go on dates, socialise, form ongoing relationships, and even get married.
- It may partly be true; however, there is limited research. Older research shows that men with Down Syndrome had challenges in bearing children, but in rare cases, they fathered a child. Women with disabilities are fertile and give birth to both children with and without Down Syndrome.









Body functions and structures:

Information and actions to take





Card 3

Body functions and structures

Types of Down Syndrome

There are three types of Down Syndrome:

1. **Trisomy 21** – DS is also often called this type since 95% of people with DS have this chromosomal defect.
2. **Mosaicism** – In this type, the characteristics of DS are lesser than those of the other two types. Only 1% of the persons with DS are affected by this type.
3. **Translocation** – 4% of people with DS have this type. For babies with the translocation type of DS, the cause is often suspected to be more hereditary than trisomy 21 and mosaicism. If one of the parents is a carrier of the translocation type, then there is a greater risk of having a child with this condition.

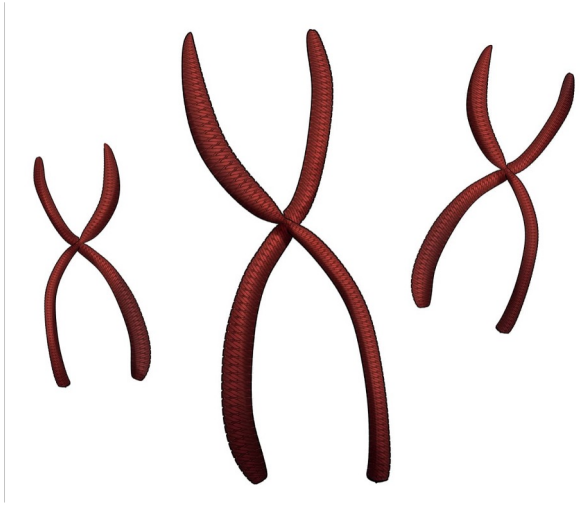
How can Down Syndrome affect the body?

Medical and health concerns are often associated with DS. The variety and severity differ per person. Some complications become more evident as people get older.

These concerns require early diagnosis and immediate medical interventions, e.g., medication and surgery. Most of these are life-threatening. If these are not addressed soon, the development and acquisition of skills can be hampered and delayed, affecting the person throughout life. Worse, these can lead to early death.

Some of these medical conditions are:

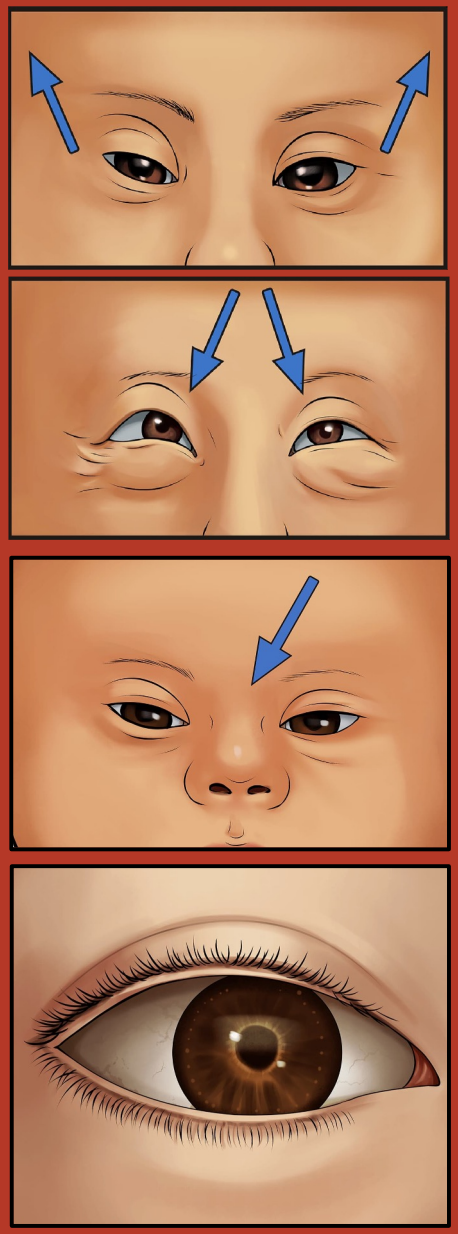
- Heart diseases (i.e., congenital heart diseases)
- Blood problems (i.e., leukemia)
- Thyroid problems (i.e., hypothyroidism, obesity, diabetes)
- Vision problems (i.e., cataracts, farsightedness or nearsightedness, crossed eyed, astigmatism)
- Ear and Hearing problems (i.e., ear infections)
- Spinal problems (misaligned bones in the upper part of the spine)
- Hypotonia (low muscle tone and strength)
- Epilepsy
- Respiratory problems (i.e., pneumonia, asthma, bronchitis)
- Gum diseases and dental problems
- Nose and throat problems (i.e., sleep apnea)
- Digestive and gastrointestinal problems (i.e., imperforated anus)
- Skin problems (i.e., premature skin wrinkling)
- Mental and emotional problems (i.e., dementia)

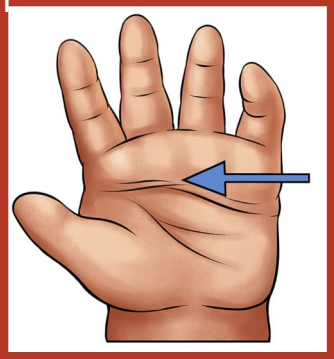


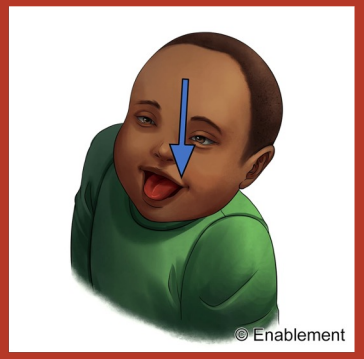
Possible characteristics and associated health conditions

- Growth failure
- Flat back of the head
- Abnormal ears
- Many ‘loops’ on fingertips
- Palm crease
- Special skin ridge patterns
- Absence of a rib on one side or both
- Intestinal blockage
- Some intestines coming out through an opening near the bellybutton
- Abnormal pelvis
- Diminished muscle tone
- Broad flat face
- Slanting eyes
- Skinfold of the upper eyelid
- Short nose
- Short and broad hands
- Small and arched palate of mouth
- Big, wrinkled tongue
- Dental anomalies
- Heart problems from birth
- Enlarged colon
- Big toes widely spread











Card 4

Body functions and structures

Card 5

Body functions and structures

Risk factors in Down Syndrome

- It is often associated with the mother's age, especially when 35 years old and older.
- Most babies with DS are still born to younger women since they have more chances of bearing more children.

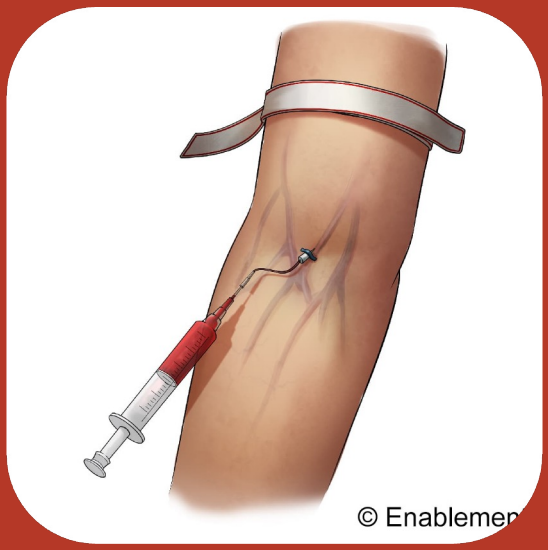
Prevention and Early Detection

- It is difficult to prevent DS as this is a genetic condition.
- Genetic counseling is an option for parents at risk of having another child with DS.
- A genetic counselor can help parents understand the chances of having another child with DS and discuss available pre-natal tests and their advantages and disadvantages to make an informed decision.
- For babies who are suspected of having DS, a chromosomal analysis test called karyotyping is highly recommended to confirm the condition.
- Karyotyping testing is done at the hospital by taking blood to be analysed in a laboratory or by taking a sample from the amniotic fluid in the womb by a doctor.
- Karyotyping testing is needed:
  - when one or both parents have a family history of a certain genetic disease;
  - with mothers in the age of 35 and up and first-time mothers;
  - when infants or young children show signs of DS.

Actions to take

- When you suspect the child might have DS, refer to a specialist for further assessment and consultation.
- Assist in referring the child to a doctor for a formal diagnosis if the child is suspected to have DS.
- Assist the child and family in looking for and facilitating a karyotyping test once a doctor recommends it.
- Assist with genetic counseling for parents if the mother of the child with DS is conceiving again.





General health

It is important to check the general health of the person with DS during the first family visit to early identify any medical and health concerns associated with DS. Not all people with DS have these issues. The severity differs but requires immediate attention to prevent life-time effects on the person's overall growth and development or even death. See the following checklist for early identification and referral:

Card 6

Body functions and structures

Actions to take

1. Check the general health of the person with DS.
2. Refer to a doctor when you observe the following:

- ❑ Fast, irregular breathing
- ❑ Shortness of breath
- ❑ Bluish skin particularly around the mouth, fingers, and toes
- ❑ Heart problems (i.e., murmur)
- ❑ Delayed growth and development
- ❑ Poor eating or feeding, such as difficulty sucking milk
- ❑ Weight loss or poor weight gain for young children
- ❑ Overweight, especially for adolescents and adults
- ❑ Little or no control of neck muscles, so the head tends to flop
- ❑ The body is too soft when held, as if it can slip through the hands
- ❑ Unusual flexibility in the hips, elbows, and knees
- ❑ Presence of blurriness/cloudiness in the eyes and sensitivity to light (eye cataract)
- ❑ Frequent discharge and tearing of the eyes
- ❑ Eye misalignment
- ❑ Hearing loss
- ❑ Absent or blocked anal opening
- ❑ Getting infections easily
- ❑ Constant fever, sweating, and fever chills
- ❑ Constant fatigue
- ❑ Disrupted sleep patterns
- ❑ Loud snoring
- ❑ Excessive daytime sleepiness
- ❑ Observed episodes of stopped breathing during sleep
- ❑ Gum diseases
- ❑ Small, missing or misaligned teeth
- ❑ Episodes of seizures
- ❑ Often constipated
- ❑ Frequent observations of behavioral problems such as disruptive, impulsive, inattentive, hyperactive, and oppositional behaviors
- ❑ Anxiety
- ❑ Depression, social withdrawal, decline in interests or caring for oneself
- ❑ Memory loss



Card 7

Body functions and structures

Despite the medical and health challenges, continuous research and advancements in medical technology have increased the life expectancy of people with DS. They can be expected to live more than 60 years, depending on the severity of their health condition.

General actions to take

- ❑ Assist the family in finding doctors to address the person's various medical and health issues as well as the other concerns associated with these.





- ❑ Monitor the person and the family for implementation and/or follow-ups of medical interventions recommended by the doctors.



- ❑ Monitor and assist people with DS in getting routine health check-ups and medical treatments when needed to maintain a healthy lifestyle.





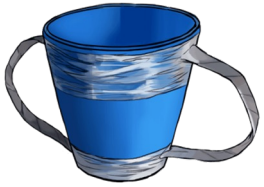




Activities and participation:
Information and actions to take













Card 8

Activities and participation



FAMILY



FUNCTIONING (ACTIVITIES)



FRIENDS





FITNESS



FUN



FUTURE

CanChilds' Six 'Favorite' words in the lives of children with disabilities (2018). These are areas in the life of a person that need to be addressed. Keep this in mind when discussing priorities and setting goals. Source: https://www.canchild.ca/en/research-in-practice/f-words-in-childhood-disability

Family: represents the essential 'environment' of all people

Functioning: refers to what people do (for children, 'play' is their 'work')

Friends: refers to the friendships established with peers; social development is an essential aspect of personhood

Fitness: refers to how a person stays physically active, including exercise and other recreational opportunities

Fun: includes particular activities a person is involved in or enjoys participating in

Future: is what child development is all about; it refers to parents' and children's expectations and dreams for their future

Card 9

Activities and participation



(Self)care

Caring for a person with Down Syndrome requires patience, empathy, and more. Behavior problems, along with some physical problems, make life challenging for the parents and caregivers. Help the child become an adult who can live with his/her disability and be as independent as possible. Teach caregivers and other family members not to do everything for the person. This applies, for example, to self-care activities such as brushing teeth and dressing.

Actions to take

Explore strategies and coach the family on how to support them:

- Instruction
- Show how and let the person copy
- Put your hands over the hands of the person and guide their movement
- Help with the first step of the activity and let the person do the rest or
- Help the person and let them do the last step, gradually learning to do more themselves
- Using pictures that show the steps of an activity. Let the person perform the step on each picture, step by step.
- See the next page for a description of some techniques for how to do this.

Card 10

Activities and participation

Hand over hand

Put your hand over the hand of the person to guide the movement of washing the body.



Mirror

Brush teeth in front of a mirror for the person to see their movements while supporting the body.



Drawings to show sequence

Make drawings that show the steps of washing the body. Let the person follow the steps, gradually becoming more independent.



Clothing ready in a row

Put the clothes in front of the person while sitting in the corner of the room or on the bed or chair. Help with words and, if needed, physically if the person gets stuck.



Helping aids

If handling the clothes is difficult, talk with a therapist to see if you can make small, low cost helping aids as a key chain on the zipper to pull down and up easier, adapted cup or bottle.











Card 11

Activities and Participation

Eating & drinking

A person with DS can have difficulty controlling their tongue, chewing, and closing the mouth. Feeding a person lying on his back is dangerous, and there is a risk of choking. Practice with the person eating by himself. This will not happen in one day. It takes time. Coach the person and caregivers on how to practice themselves over the course of a few weeks or months, depending on their learning and physical skills.







Actions to take

- Teach the person good hygiene practices for food preparation and eating/drinking.
- Ensure the diet is balanced and extra high in nutrients (for health) and calories (for strength).
- Ensure that you are eating in an upright position. When feeding smaller children, ensure the child is not lying down but slightly sitting up.
- If the person has difficulty chewing or swallowing, consult a specialist.
- If a person cannot feed him/herself, feed sensitively: small mouthfuls, slowly, watching, and pausing. NO FORCE.
- Give the person at least 1 liter (5 cups) of water per day.
- Practice eating if needed by guiding the hand or spoon to the mouth. If possible, practice in front of a mirror so that the person sees the movement he/she makes.
- Make the spoon handle bigger if the person has difficulty managing the spoon. You can thicken the handles for easier grip with old clothes (braided for a firmer hold) or attach a piece of wood or object to the handle.





Card 12

Activities and participation





Brushing of teeth

Helping persons with DS develop healthy habits to care for teeth, especially when young, is important. Explain to caregivers the good things about brushing the teeth, how to guide them, and the risks of not brushing the teeth (e.g., decay of teeth, cavities, pain).

To practice brushing teeth: break down each step into one simple sentence that the person can then do step-by-step:

- Wash your hands
- Take the brush
- Put toothpaste on the toothbrush
- Brush your teeth up, down, and inside for 30 counts
- Clean the inside of your mouth by rinsing it with water
- Clean your toothbrush

Handwashing

People come into contact with germs every day. Proper handwashing can stop the spread of many illnesses, from a common cold to more serious illnesses. Explain when people should wash their hands, why it is good, and what can happen if they do not. Try the strategies from the previous card together with the person and family.

Suggested steps for handwashing instruction:

- Get your hands wet
- Apply soap
- Rub the palms well with soap
- Clean all the parts of your fingers
- Clean the back side of your hand
- Wash your hands well with water
- Make your hands dry

Card 13

Activities and participation

Dress independently

Persons with Down Syndrome who do not have severe physical disabilities can learn to dress themselves. Help the family teach the person how to dress himself or herself through explanation and practice.

Actions to take

Explore strategies and coach the family on how to support learning to dress:

- Explain what you are doing. Give it extra time.
- Let the person choose their outfits.
- If they appear confused about what to wear, give them two or three choices.
- Choose clothes that are easy to put on and take off, fasten, and comfortable, such as slip-on shoes with Velcro closures.
- When shopping for garments, look for clothes with snaps, zippers, Velcro, or elastic.
- If the person needs help getting dressed, hand them one item at a time – but it's a good idea to let them do as much as possible.
- When helping someone get dressed, if they have a weakness on one side of their body, start by dressing that side first. With undressing, use the same rule – undress the weaker side first.





Card 14

Activities and participation

Learning skills

DS can affect learning abilities differently, but it usually causes mild to moderate intellectual impairment. Persons with DS usually learn and progress more slowly than most other people. Persons with DS often:

- Have a slower rate of motor development;
- Seem to struggle with basic number skills;
- Struggle with verbal short-term memory;
- Have delayed development of speech and language.

Learning occurs in daily life, at home, and in the community. Learning will not occur spontaneously if no opportunities are provided to learn. A lot of 'spontaneous' learning takes place when moving around, playing, singing, and chatting, such as at home or in school. Repetition, stimulation, and appraisal are important to developing to one's full potential.

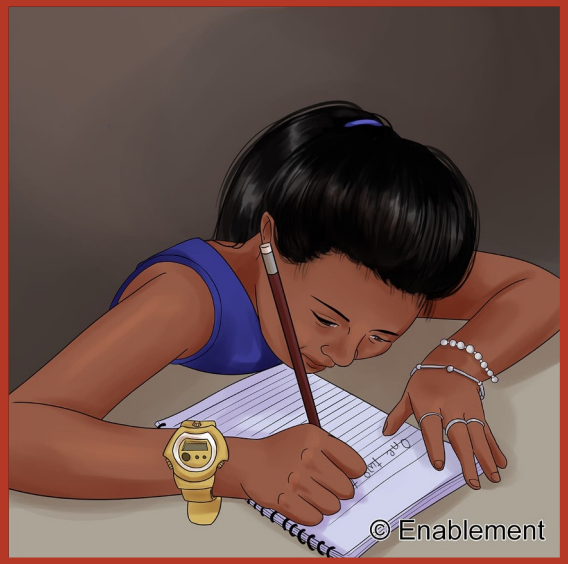
Most children and adults with DS continue to develop good social skills. However, a significant minority may develop difficult behaviours, particularly those with the greatest delays in speech and language development. Keep in mind that persons with DS might understand more than they can express.

Actions to take

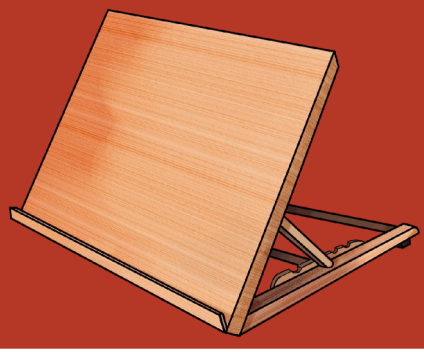
- Find out if the person is in school or went to school. If not, find out why and address those issues.
- Help create opportunities for the person to learn in school, at home, and in the community.
- Adapt school materials where needed: thicken pen, enlarge worksheets, or add helplines for writing.











Card 15

Activities and participation

Livelihood

People with Down Syndrome can have meaningful work, sustain themselves and their families, and become productive members of society.

However, they might need to be sensitised and supported to access vocational training or livelihood programmes such as loans and employment opportunities, as well as relevant social protection schemes.







Actions to take

- Find out what type of work the person does or can do as per their ability.
- In general, there are three types of employment options: competitive, supported, and sheltered.
- Volunteer work is a great option for gaining additional job training.
- Refer the person to vocational training programmes.
- Support them and the family in accessing these programmes.
- Advise the programme providers to ensure the person's active involvement.
- Identify job placement opportunities for the person that matches their interests and abilities.
- Raise awareness amongst local employers on the value of hiring people with Down Syndrome.
- Explore suitable ways to access employment opportunities.
- Facilitate the development of local support and self-advocates for persons with DS and their families.
- These groups can promote inclusion and participation in livelihood and employment opportunities and inclusion in the community as a whole.





Card 16

Activities and participation

Communication

People with Down Syndrome often have difficulties expressing themselves in words (expressive language) due to several distinct oral structures, such as the tongue, speech motor difficulties, hearing loss and ear infections that prohibit them from hearing sounds clearly, and intellectual delay, among others.

- Communication is important to express wishes, needs, pain, and interact with familiar and unfamiliar people.
- There are various ways to communicate: by words or body language, such as facial expressions and pointing.
- It is possible that someone can understand what is said but cannot respond in words.
- Also, processing in the brain can be delayed which results in needing more time to respond.

Alternative ways (these do not replace the use of words; it supports communication and learning):

- Choosing between two options (1)
- Using daily objects to make clear which activity is coming (2)
- Using gestures to support communication (3)
- Using a picture card to communicate choices or feelings (4)
- Using a booklet with pictures to communicate (5)



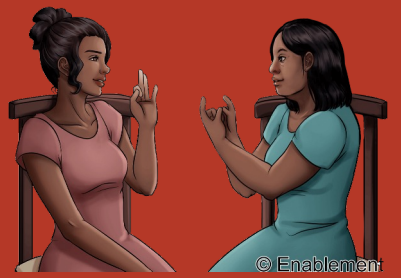
1



2

Actions to take

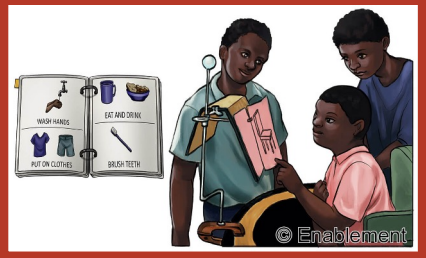
- Encourage other people to interact with the person.
- Teach family and close community members why and how to use various ways of communication with the person.
- To improve understanding of words, tell the person throughout the day about what you see around you.
- Before asking the person a question or explaining something specific:
  - get their attention by saying their name;
  - make eye contact.
- Keep in mind it takes time to learn different ways and to instruct the people around the person as well.
- Do not force the person to speak, but praise and encourage communication efforts.



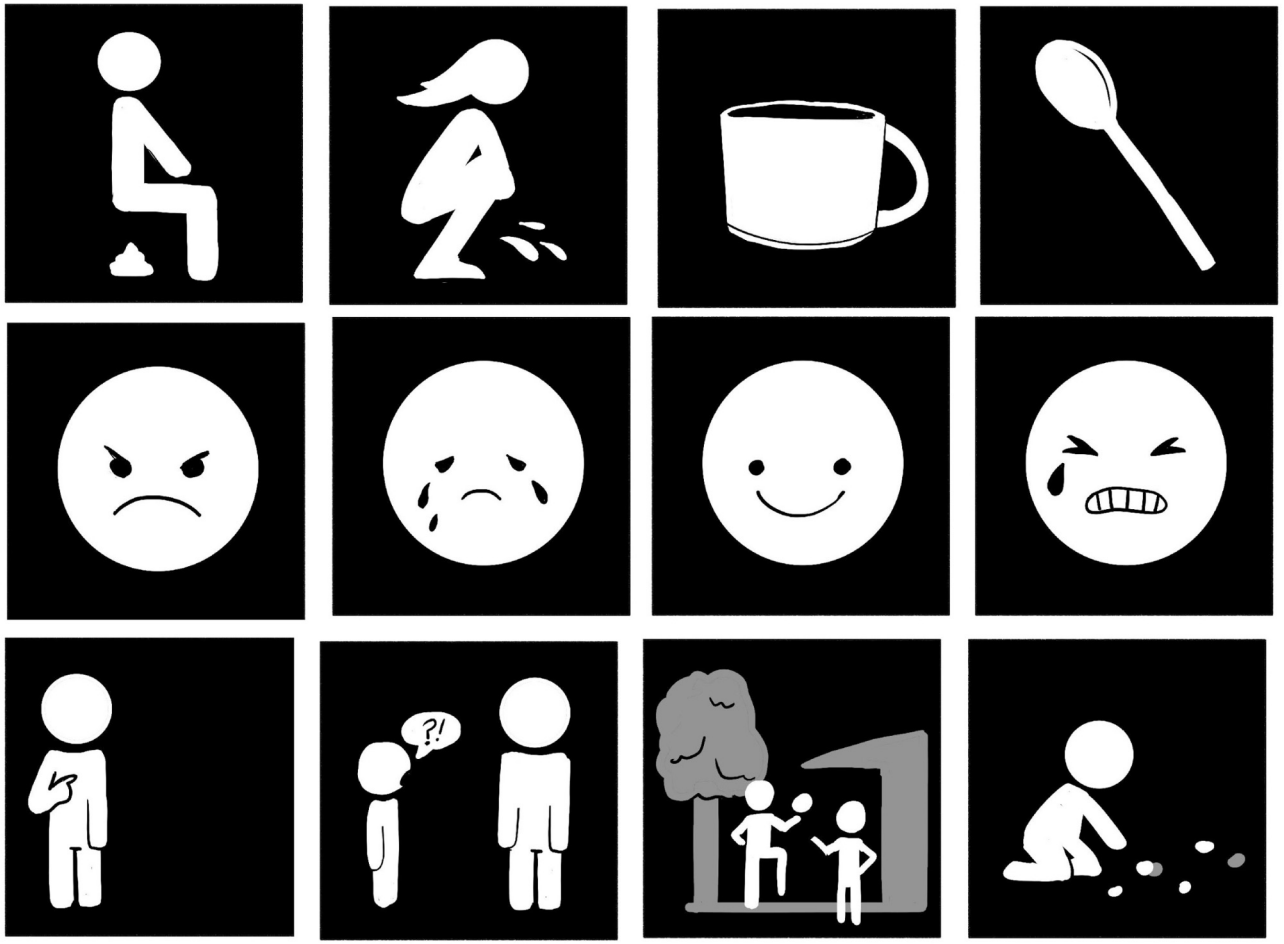
3



4

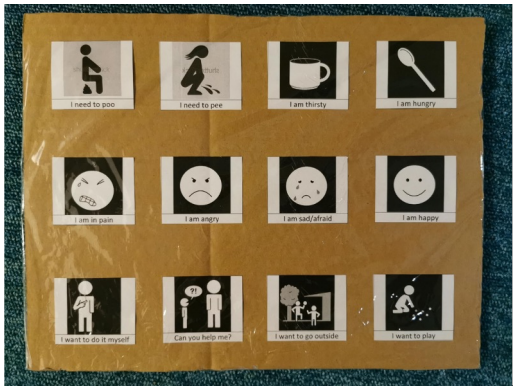


5



Example picture card to support communication.

You can find pictures on the internet (www.sclera.be). Print and paste or draw them. Glue the pictures on a cardboard and protect with see-through tape (see picture on the right).



Card 17

Activities and participation

Card 18

Activities and participation

Social activities

Persons with Down Syndrome may experience nervous feelings when meeting new people or strangers. This may develop into social anxiety. A person might suffer from social anxiety when (s)he:

- has trouble communicating,
- cannot express him-/herself,
- has difficulty understanding what others say or do,
- becomes frustrated and has trouble managing that,
- has trouble relating to peers.



Actions to take

Behaviour problems or anxiety are very common for all persons with DS. Try to figure out what prevents people from participating in community life and what they find difficult, and help them overcome these burdens. Together with the person and family, try the following interventions:

- Improve the persons' play and leisure skills through practice and support;
- Help improve social skills and language/speech (refer to a special teacher or therapist if needed);
- Create play and leisure and learning situations that are more suited to the person's abilities and preferences;
- Invite friends or classmates to play and/or enjoy time at the person's home;
- If needed, improve opportunities for easy social interaction in the class or community. Use a buddy system by pairing a classmate with the person for support in various activities and situations;
- Create a 'circle of friends';
- Reinforce appropriate social behaviour;
- Give peers clear directions for their behaviour towards the person with DS.

Card 19

Activities and participation

Community activities

Every person needs to be included in family and community activities. Participation in daily life is important for the development of motor and social skills, learning, and future work skills. Active participation is also needed for developing social networks and a feeling of belonging and well-being.

Actions to take

- Raise awareness in the community about inclusion when you feel the person is excluded.
- Ensure inclusion in home and community activities. Practice skills needed for these activities if they are challenging for the person.
- Involve family, community members, and peers in these activities to understand how to include the person in activities, both physically and socially. Explore and enjoy together.





Card 20

Activities and participation

Addressing behaviour issues

Persons with DS can experience behaviour challenges that must be addressed to prevent worse. The most common mental health concerns are:

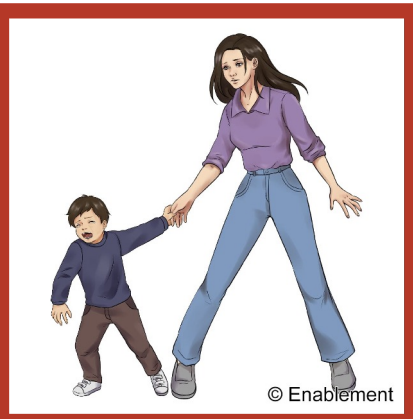
- General anxiety
- Repetitive and obsessive-compulsive behaviour
- Oppositional behaviour
- Impulsive behaviour
- Inattentive behaviour
- Sleep-related difficulties
- Depression
- Autism spectrum disorder (see the respective chapter)

Such behaviour may negatively impact regular in terms of:

- Safety
- Learning
- Social acceptance and inclusion
- Family relationships
- Placements in classroom or work settings
- The overall quality of life

Reasons for this behaviour can be:

- Trouble controlling impulses
- Trouble communicating
- Trouble relating to other children and adults
- Trouble managing frustration







Actions to take

- Teach the family to do a simple behaviour analysis chart commonly called the "ABC" of behaviours.
- A/Antecedent means noting down the situation prior to the behaviour.
- B/Behaviour means noting down the specific observable behavior.
- C/Consequence means noting down the approaches/ strategies done to address the behaviour and the reaction/ response of the person with DS.
- This chart can help identify patterns of behaviour and, with the guidance of the fieldworker, assist the family in choosing the most appropriate approach/strategy.
- Refer to a specialist when needed or if behaviour becomes harmful to the person or the family.

Card 21

Activities and participation

Get help from where?

The family has the primary role in teaching and supporting their member with Down Syndrome. The role of the fieldworker is to capacitate and support the family in areas where services are inaccessible. Specialists' roles are still of utmost importance. The fieldworker might consult the specialist for advice or refer for specialised services. Not every country has all these specialists mentioned here. If a team, composed of available professionals mentioned below, has been identified, it is ideal for the specialists and the family to work together in ensuring the attainment of goals.

Occupational Therapist
Occupational therapists work with individuals who have conditions that are mentally, physically, developmentally, or emotionally disabling. They help people to develop, regain, or maintain daily living and work skills. Not every country has an occupational therapist. If there is none, go to a physiotherapist.



Pediatrician
A pediatrician checks and monitors a person's overall health and development. They recommend appropriate interventions such as prescribing medicines, administering medical tests and referring to other medical specialists when needed. A developmental pediatrician is a medical doctor highly trained and experienced in identifying different developmental and behavioural conditions from childhood to adolescence.



Speech Therapist
A speech and language pathologist, commonly referred to as a speech therapist, assesses, treats, and monitors communicative skills related to speech and language problems. They also address issues and concerns related to swallowing and feeding. Not every country has a speech therapist. Ask the pediatrician where to go or ask the specialist teacher for assistance.



Specialist teacher
A specialist teacher has additional qualifications, training, and experiences in teaching and managing children and youth with disabilities primarily in school and extends to the home and community settings.



Physiotherapist
A physical therapist focuses on restoring motor function, strengthening muscles, and improving coordination, balance, endurance, and joint movement. They also determine a person's ability to be independent and reintegrate into the community or workplace after injury or illness.



Community worker/ Social worker
The type of worker available in the community varies according to country, region, and community. This worker identifies persons in need and can assess the situation to refer them to the appropriate specialist or provide basic support in consultation with a specialist.



Card 22

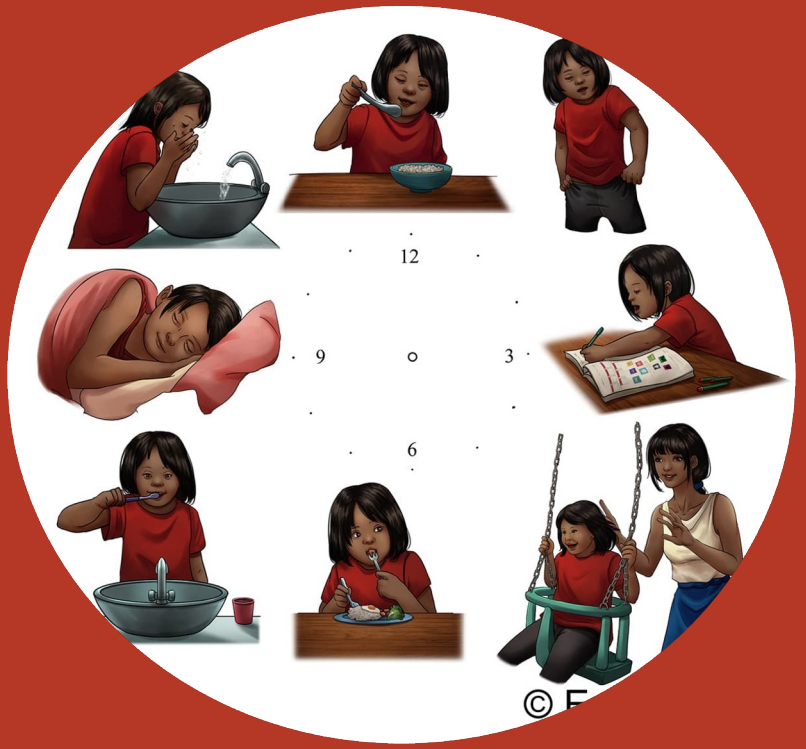
Activities and participation

Interventions (things to try at home)

As a fieldworker, you can support the family by using small strategies to help them perform and manage daily activities. This can have a huge impact.

Explore together with the person and family:

- Give simple, clear directions
- Establish a daily routine and stick to it
- Use visual schedules
- Prepare the person of any changes in activities in advance
- Make time for fun
- Reward attempts and good behaviour
- Offer choices and empower the person
- Make hard tasks more fun
- Help them calm down and distract them when needed
- Keep activities interesting, e.g., finding food items in the market with a list of pictures.
- Correcting: model a better way, e.g., teaching a person who hits his peers for getting attention to give high fives
- The power of ignoring: if a behaviour is not appropriate, try to ignore it and give no feedback
- Take away privileges, e.g., no TV time after misbehaving.



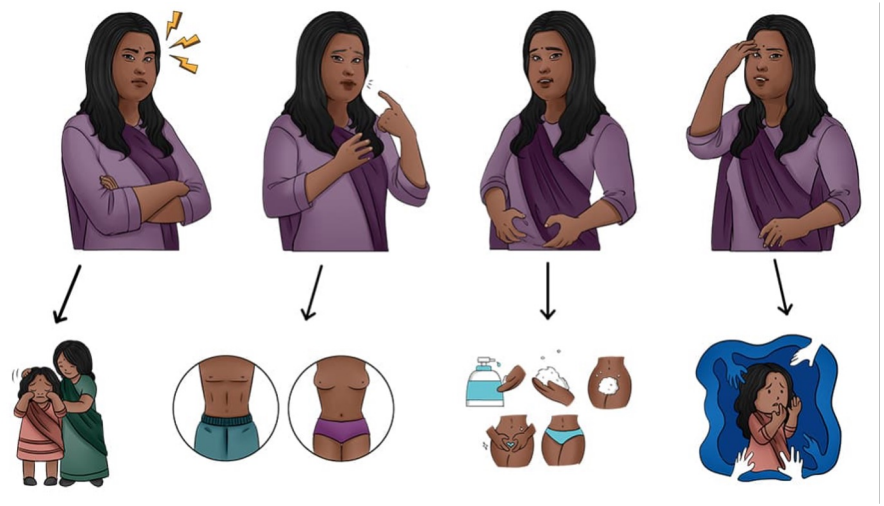










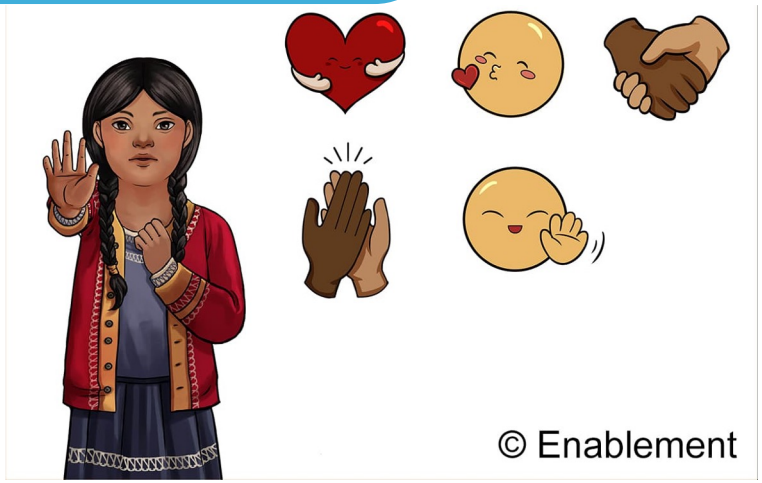






Personal factors:
Information and
actions to take





Card 23

Personal factors

Wishes and needs

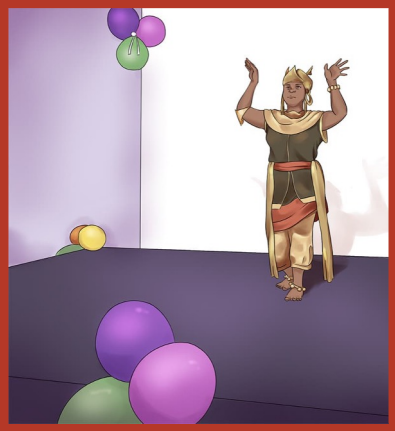
Every person, with or without a disability, has wishes and needs. Even when a person cannot speak or doesn't seem to be aware of certain things, that person still has needs. Everyone has the right to well-being. These wishes and needs must be considered when discussing priorities for intervention, setting goals, and taking action.

Actions to take

When talking to the person with DS and family and when making your action plan, consider the following:

- ❑ **Belief** ⛪🕌⛩: does the person have religious beliefs or a certain response to religion?
- ❑ **Education** 📚: what are the person's wishes and preferences?
- ❑ **Social background:** what does the person prefer regarding friends, family, and community?
- ❑ **Age: ...**
- ❑ **Gender:** 👩 👨
- ❑ **Lifestyle:** how does the person spend his/her days?
- ❑ **Habits:** which routines and habits does the person like or has the person developed?
- ❑ **Personality:** How does the person usually express himself/herself?
- ❑ **Character:** is the person content, motivated, and interested in the world?
- ❑ **Strength and challenges:** how does the person cope with this?
- ❑ **Interests and fascinations:** what does the person enjoy?
- ❑ **Preferences and dislikes:** what does/doesn't the person like?









Safety situations

Persons with DS are at an increased risk of entering dangerous situations. They often struggle to sense danger and, therefore, may be prone to literally walking into dangerous situations. However, there is still minimal professional information or guidance provided for parents and caregivers regarding safety issues and danger prevention.

Safety Checklist

Does the person understand:

- ❑ Concept of danger
- ❑ Strangers
- ❑ Height
- ❑ Heat/Fire safety
- ❑ Traffic/Street safety
- ❑ Electricity
- ❑ Sharp objects
- ❑ Water safety (capability to swim)
- ❑ Wandering alone (knowing their name and address)
- ❑ Internet safety
- ❑ Abuse prevention (also related to sexual education and psychosocial support)

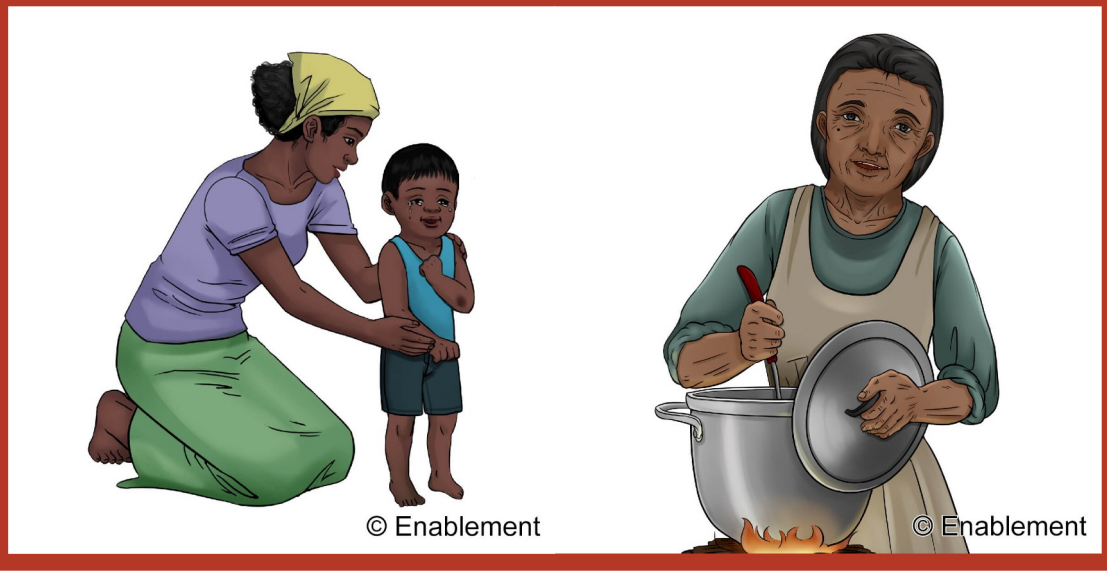
Actions to take

Teach the family to:

- Identify the person's ability and limitations in understanding safety situations;
- Point out the dangerous elements in the situation to the person and explain how those current dangers could cause him/her to get hurt;
- Work on safety at home and school. Work together to have a better chance at retaining information that is repeated and reinforced;
- If the person is prone to wandering, make sure to address major hazards in the neighbourhood that the person may be attracted to, such as lakes, ponds, wells, rivers, swimming pools or train tracks;
- Talk with community members to help safeguard the person when needed.

Card 24

Personal factors



Card 25

Personal factors

Sexual education

Persons with Down Syndrome have the same sexual development as other people. However, there is often a delay in developing social maturity, emotional self-control, and social communication.

Physical changes are among others:

- Female: growing breasts, menstruation, larger hips, pubic hair
- Male: wet dream, cracking/deeper voice, pubic hair

All youth should be prepared and educated as puberty can be frightening, and youth with DS may be more worried about these changes. Talk to them about the development and hygiene.

Action to take

Try to find out the following:

- How is the person's sexual development? (physical and emotional)
- What sexual education did or does the person receive? Who teaches them? What tools are used? Do they understand?

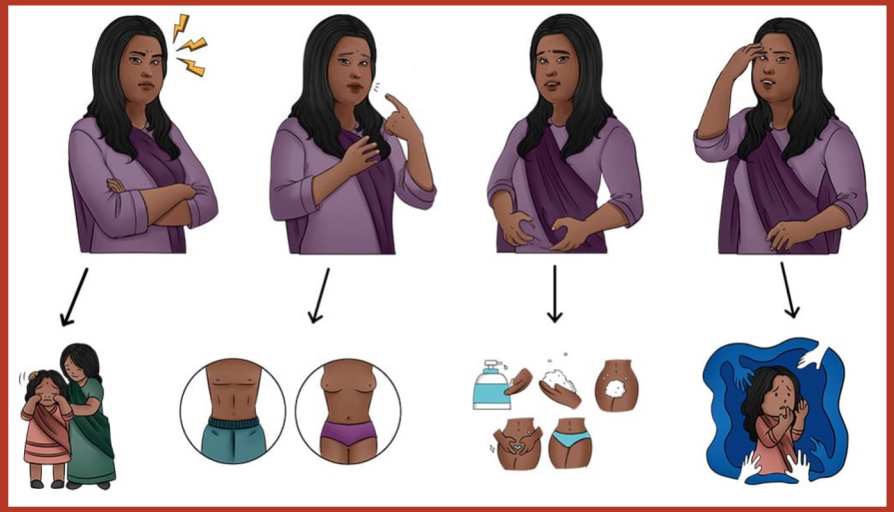
Personal boundaries

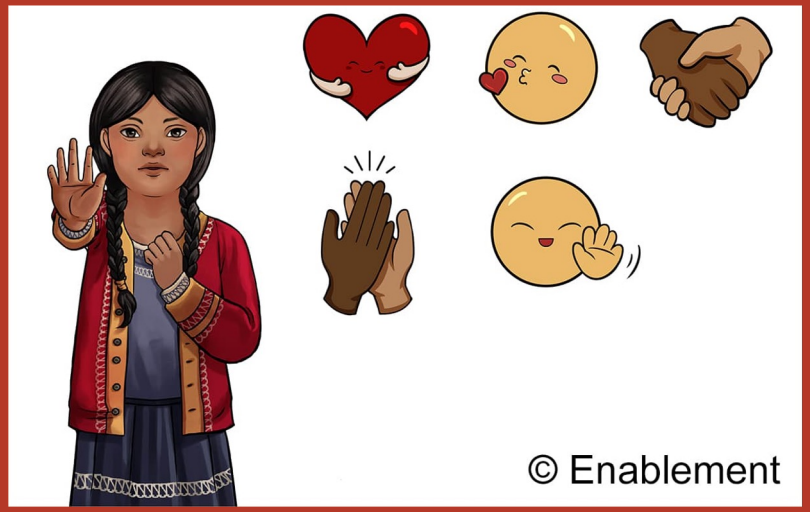
All people, including people with Down Syndrome, should be taught about a good touch and a bad touch. A good touch is OK when it's done for good and positive purposes, e.g., an appraisal from parents, a doctor's examination, and physiotherapy treatment. Everyone should know which people are okay with receiving a hug, kiss, handshake, high five, or hello. They should also know what private areas are and learn to say “No”.

Action to take

Try to find out the following. Does the person:

- ❑ Understand good touch
- ❑ Understand bad touch
- ❑ Understand what behavior and actions fit which people (hug, kiss, handshake, high five, hello).
  - 🤗 *Hug*
  - 💋 *Kiss*
  - 🤝 *Handshake*
  - 🖐 *High five*
  - 👋 *Hello*
- ❑ Understand what behaviour and actions fit which situations and/or locations (e.g., peeing on the toilet, undressing in a private area)





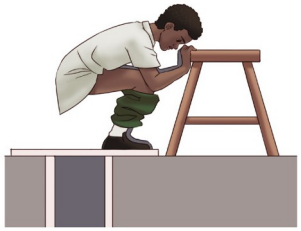




[Insert photos/illustrations representative of the impairment for activities and participation; e.g.:]



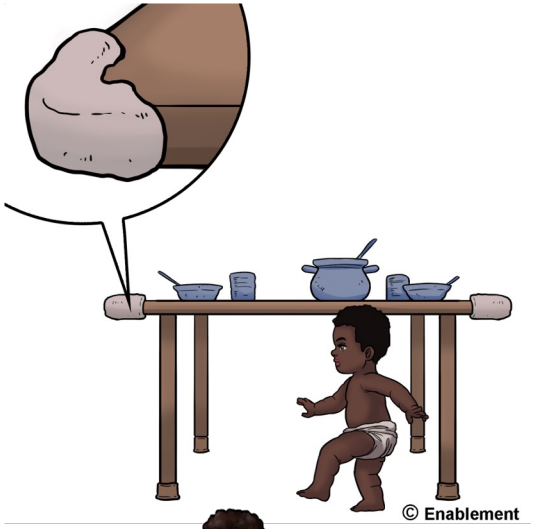






Environmental factors:

Information and actions to take









Card 26

Environmental factors

Safeguarding

Persons with DS might be at risk for abuse, and safeguarding needs to have important attention. Girls are especially at risk due to not always being able to protect themselves. Abuse can have many shapes: neglect (caregivers not being able to provide for the persons' needs or protection from dangerous situations), physical abuse, psychological or emotional abuse, and sexual abuse.

Address this issue in the community alongside creating awareness for the convention on the rights of people with disabilities.

Actions to take

Create awareness in the community on the rights of persons with DS and the need for protection against abuse, including bullying. Types of bullying:

- Physical: hitting, pushing and shoving, fighting, tripping, yelling at someone, making rude gestures, taking or breaking another person's things
- Emotional: name calling, making fun of someone, laughing at someone, leaving someone out on purpose, starting rumors or telling lies about someone, sending mean messages on a computer or cell phone, trying to make someone feel bad about who they are

- Be aware of the signs and symptoms of abuse. Teach the family these signs and symptoms.
- Teach persons with DS about self-protection and justice and how to speak up, if possible, for their rights.
- Being able to protect oneself is important, for example by learning to express yes and no and understanding boundaries.







Card 27

Environmental factors

Healthcare

Persons with DS and their families may find it difficult to access both routine and preventive healthcare services. Access to social security and the lack of knowledge about recognizing common medical conditions related to DS create challenges. The transition from child centers to the adult-oriented healthcare system makes it more complex, which may result in avoiding routine and preventive healthcare.

Actions to take

- Assess which difficulties children, adults, and their families face in their access to healthcare.
- Promote routine and preventive healthcare to prevent health issues (including prenatal testing)!
- Support access to health-related information.
- Inform health professionals about the person's needs. Be willing and able to take the time to communicate appropriately with and manage the (complex) healthcare needs.
- Provide follow-ups related to DS to prevent side effects.
- Help foresee the basic needs, development, own decision-making and inclusion in the daily life of the person with DS and their family.
- Help the person with DS and their family transition from a pediatric clinic to an adult clinic when the time is there.



Education

Individuals with DS may find it difficult to access education services especially to a regular school.
A child with Down Syndrome has delays in processing information, and working to complete tasks may lead to rejection.
A good understanding of how schools (can) support individuals with DS is important.



Actions to take

- Lobby with schools to prevent education issues (institutional and homeschooling).
- Provide information about DS to educational stakeholders (policymakers and teachers).
- Be willing and able to take the time to appropriately communicate with and manage the (complex) education needs.
- Help foresee the basic needs, development, own decision-making, and inclusion in the daily life of the person with DS and their family.
- Help the person with DS and their family transition from home to school when the time is there.
- Help to identify assistive technology for Down Syndrome, by making the information accessible to a special needs student. This may require using fewer words, enlarging the graphics and lettering or even highlighting key words so the information is not overwhelming in addition to verbal instructions.

Card 28

Environmental factors

Livelihood caregivers

Having to visit health clinics, hospitals, and rehabilitation centers regularly prevents persons with DS, their parents, and/or spouses from being able to work and hence can result in a loss of income, especially for single parents. Some organisations or parent support groups have soft loan systems that make it possible for individuals with a disability and their family to create a business near the house where they can also easily receive care.





Actions to take



- Check whether the person with DS or their family has a job and/or sufficient financial support to afford basic household needs and treatments.
- Help find suitable work, talk to employers, or help set up a business if needed.
- When there is no sufficient income, encourage and help to explore possibilities for financial support in the local community, such as churches, NGOs, income-generating activity programmes, micro-credit programmes or soft loan systems.
- Make a plan to address vocational, occupational, and life skill domains together with the person and their family.
- See flashcards and manuals for inclusive marketplaces: https://enablement.eu/wp-content/uploads/2020/06/Inclusive-Marketplaces-Flashcards.pdf
- See website of iSave for information and manuals of this economic approach: https://isave-inclusion.com/about-isave/what-is-isave/isave-model/

Card 29

Environmental factors

Family counseling and mental support

Having a child or sibling with DS changes the lives of family members. They may experience difficulties dealing with certain activities and situations or being accepted by family and the community. This can result in feeling hopeless or depressed. Parental stress levels in families with a child or spouse with DS are often high.

Overprotecting a child with DS may result in lower independent abilities. The home and community need to be safe places for the person with DS. Being supported by parents, siblings, or spouses will improve mental health, for example, through support and practice activities or involvement in adaptive household tasks.

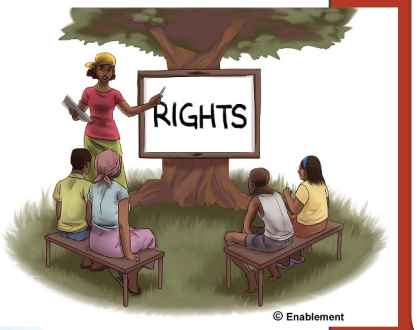


Actions to take

- Give the person with DS and their family practical and mental support to use their strengths and address difficulties.
- Teach the people with DS and their parents or spouses to advocate for themselves according to human rights when encountering medical, governmental, and educational staff.
- Help organise a support group for peers or family members.
- Talk about expectations on independent living, self-sustainability, managing medical care, and self-care.
- Identify any discrimination problems in the community and create awareness about DS in the community.
- Get community members involved i the life and rehabilitation of the person with DS and their family.









Card 30

Environmental factors

Assistive devices

Assistive devices and accessible terrain and buildings greatly affect activities and participation in daily life. When you observe a person with activity limitations or an environment that is not accessible, consider adapting daily materials to support movement skills, thinking skills, social skills, or school or job skills.

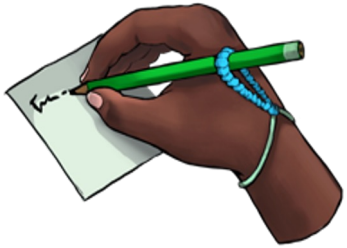
There are several types of devices and adaptations. These devices can help persons with a disability to:

- Eat by themselves or make feeding easier
- Communicate
- Study easier
- Play with their friends
- Become more independent



Examples of assistive devices for Down Syndrome:

- Slanted desks or a three-ring binder turned sideways
- Triangular-shaped pencils
- Smartboards
- Hearing and visual devices
- Writing aids
- Aid to transport the person on a bicycle or motorbike



Actions to take

Refer to an occupational therapist or physiotherapist when:

- the person does not have but needs an assistive device;
- the assistive device is too small or too large;
- the assistive device is broken;
- the family has but does not use the assistive device, but first find out why.



Card 31

Environmental factors

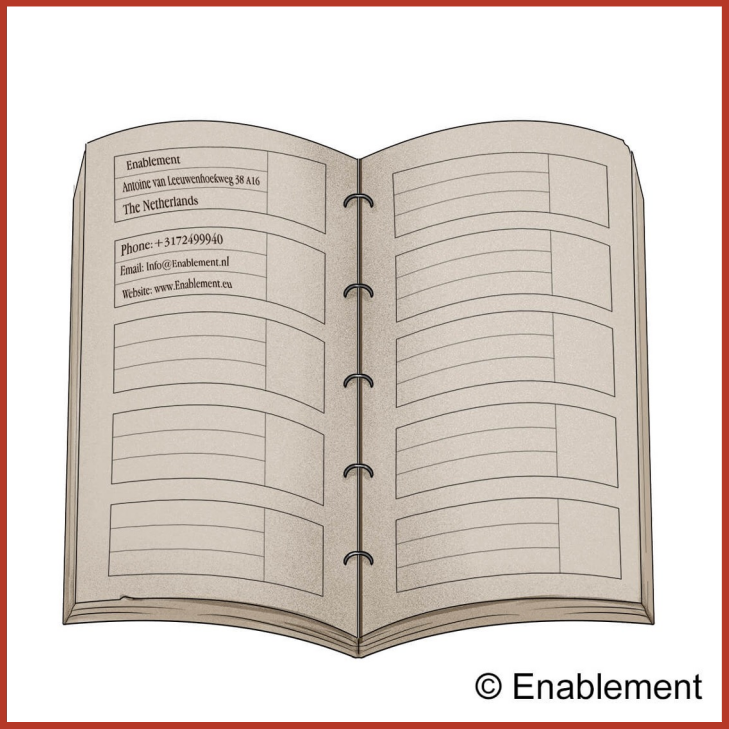
Stakeholder network of services

The availability of services and specialists in low-resource areas is often limited. It is important that you identify and map available services at the community, district, provincial, and national levels. Identify relevant stakeholders in the areas of health, education, livelihood, social services and stakeholders that empower persons with disabilities and their families. This will lead to a network that can help with timely identification, intervention, and referral.

Actions to take

- Make a map showing where relevant buildings, stakeholders, services, and specialists are located at the community, district, provincial, and national levels, together with their contact information, so you can contact them or refer them in a timely manner.
- Make an address book of the outcomes of your mapping and add any additional useful locations, services, e.g., social services for disability cards and/or allowances, and other persons such as the village, religious, and/or traditional leaders.





Colophon

For the development of the Down Syndrome chapter of the RehApp, we particularly want to express our gratitude for the valuable contributions of:

- Maricar Centeno, Program Officer Norfil Philippines
- Rosalyn Marie Sorongon, Technical Advisor Norfil Philippines
- Dyah Kusumodewi, Project Officer Down Syndrome NLR Indonesia
- Tamjidul Islam, Project Manager DRRA Bangladesh

CONTACT INFORMATION

The Netherlands
E-mail: info@enablement.nl
Website: www.enablement.eu

Published: February 2022

This was made possible with the support of: