Flashcards **Autism Spectrum Disorder**



Autism Spectrum Disorder

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

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The goals of the flashcards are:

- To meet the needs of people with ASD and their families.
- To improve knowledge and skills of fieldworkers in providing basic (functional) rehabilitation services for people with ASD and their families.
- To enhance participation in daily, family and community life.
- To improve the quality of life of people with ASD 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, child, adolescent or adult with ASD.
- Make an inventory of the needs of the person with ASD 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 ASD.
- 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:

Note: These flashcards contain information about ASD. The content is organised according to the International Classification on Functioning, Disability and Health domains of the World Health Organization (2012). These cards don't replace the knowledge and skills of doctors and therapists. We advise you to seek their advice first.

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Autism Spectrum Disorder

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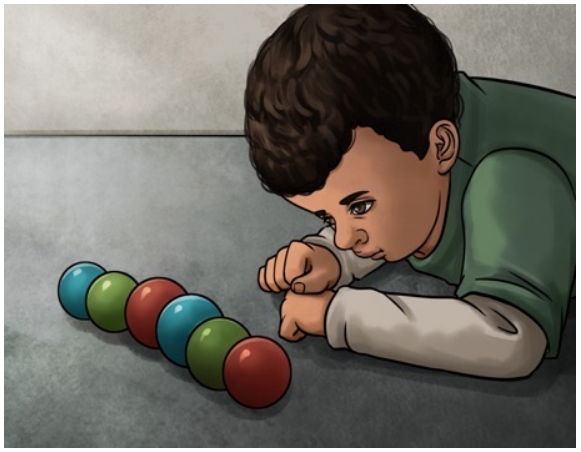
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Introduction











Card 1

Introduction

What is autism?

Autism is a developmental condition, not a disease. It is referred to as Autism Spectrum Disorder (ASD), meaning there is a wide range of symptoms. Each person is unique, requiring interventions tailored to the person.

It is a lifelong condition with:

- social and communication challenges
- restricted repertoire of behaviour
- sometimes, learning, thinking, and problem-solving challenges

- 10 to 20% of persons with ASD have near-normal intellectual development and can go to school like others.
- 1 in 100 has higher level of intellectual functioning
- 70% of the children have mild to moderate levels of intellectual disability and need the help of a special educator



What causes autism?

The cause is unknown, but genes can play a key role.

The following are risk factors for autism:

- Medication (e.g., Valproate) during pregnancy
- Preterm birth
- Advanced paternal age
- Family history of autism
- Males are at higher risk

ASD is seen in all countries, nationalities, ethnicities and socio-economic groups, rich and poor.









How to identify autism?

ASD can be identified around 2-3 years of age, but characteristics as early as 6 months can indicate autism (red flags).

ASD is diagnosed through interviews with the person or family (checklists) and observation by a psychologist, psychiatrist, pediatrician, an experienced general physician or teacher.

Actions to take

- Early identification and home-based intervention.
- Some persons with ASD need referral help from specialists.

Which interventions are available?

- There is no cure.
- Behavioural, educational, and family interventions focused on visual schedules help reduce and manage challenges.
- Parent-child-interaction intervention.
- Social and communication skills training.
- Every person is unique. It is important to take into account the person's abilities and customise education, livelihood and social intervention.
- School or daycare-based interventions support the development of a person with ASD.

In low-resource areas, ASD often remains undiagnosed until a later age, whereas early intervention can create better opportunities for the development and participation in life.

Actions to take

- Active listening to and observing all the abilities and challenges of the person with ASD and their family.
- Psychoeducation on what autism is for the persons with ASD and their families.
- Reference to school and other specialised services if available in the neighbourhood. Share your information.
- Raising awareness where needed.

Card 2

Introduction

Card 3

Introduction

Home/community-based screening for ASD

Communication and social interaction



Limited or no eye contact

Yes ☐ No ☐



Joins in only when an adult insists and assists

Yes ☐ No ☐



One-sided interaction i.e., speaks without expecting response

Yes ☐ No ☐



Delayed speech, does not speak or loss of previously acquired speech

Yes ☐ No ☐



Echolalic-copies words like parrot

Yes ☐ No ☐



Indicates needs by using an adult's hand

Yes ☐ No ☐



Does not play/spend time with peers

Yes ☐ No ☐



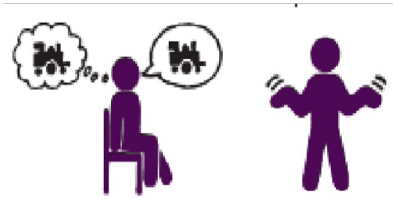
Displays indifference (uninterest) or seeming not to respond e.g., to name

Yes ☐ No ☐

Card 4 Introduction

Home/community-based screening for ASD

Restricted- or repetitive behaviours and interests



Talks constantly about only one topic

Yes ☐ No ☐



Handles or spins objects

Yes ☐ No ☐



Repetitive behaviour e.g., flicking fingers, flapping hands, rocking body

Yes ☐ No ☐



Lack of creative, pretend play or hobby i.e., prefers unusual play such as stacking or lining up objects

Yes ☐ No ☐

Card 5

Introduction

Home/community-based screening for ASD

Other characteristics



But some persons can do some things very well and very quickly except for tasks involving social understanding

Yes ☐ No ☐



Inappropriate laughing or giggling

Yes ☐ No ☐



Doesn't like change in routines

Yes ☐ No ☐

Signs of ASD

Some common symptoms include: a need for activities being the same and predictable, repetition of activities or movements, anxiety and atypical responses to sensory input, like unusual sensitivity to light, sound, smell or taste.

The signs mentioned here are not all present in every person with ASD. It differs per person. Hence it is important for you to talk with each family and listen to their story first. This is an example of an existing home/community-based screening.

Card 6

Introduction

Three levels of support

There are different levels of ASD. Abilities and difficulties vary per person and can range from needing little support to a lot of support.

Level 1: some support	Level 2: substantial support	Level 3: a lot of support
The person needs some support and can do most activities without help.	The person needs substantial support throughout the day to do activities or engaging in social situations.	The person needs a lot of support throughout the day to do activities or engaging in social situations.
• The person likely has difficulty to initiate social interactions. • The person might have problems organising and doing daily activities affecting independence. • The person might be very good in certain skills such as arts or science.	• Persons often have special interests that are limited, which are sought throughout the day, affecting social interactions. • The person often shows repetitive behaviours like flapping hands or spinning objects.	• The person might have severe difficulty speaking and non-verbal communication. • The person is likely to have difficulty dealing with changes in routines and situations. This can cause anxiety and difficulty focussing. • The person might also have other conditions.
		

Supporting persons with ASD and their family

Connect your action plan to the actual needs of the person and their family.

















Card 7

Introduction













Body functions and structures:

Information and
Actions to take







Card 8

Body Functions and Structures

Nutrition

Persons with ASD might have strong preferences and dislikes for types of food and liquids, causing difficulty eating. Not eating enough nutritious food can cause their minds and bodies to develop slow. It can also cause the person being low in energy, leading to moving less which is not good for the person's health and can cause difficulty with paying attention.

Actions to take

- In the first years of life when the brains develop most, make sure the child receives enough nutritious foods like breastmilk and others (see picture below). From 4-6 months, children usually can start being fed pureed vegetables, rice and such.
- When a person is picky in eating, make sure the person still eats various nutrients throughout the day, if possible, perhaps in smaller portions or when the person is hungry. Examples of nutrients are fruit, vegetable, fish, chicken, grains, milk, eggs and/or nuts. This depends on what is available locally.
- Be aware that food is cooked thoroughly to kill any bacteria and prevent intestinal worms.









Sleep

Sleep is important for the body and brain to recover from all activities and impressions during the day and to regain energy. Being active e.g., moving, playing, learning, and being awake throughout the day is important to feel tired enough to sleep. General health issues, such as malnutrition or intestinal worms (causing stomach pain) can cause problems getting to sleep and disturbing sleep.

Actions to take

- Try to find out if and why sleeping is difficult. Have the family write down how long the person sleeps per night and when they wake up.
- When the person is in pain or if general health is a problem, refer to a doctor. Inform the doctor that the person has Autism.
- When not active enough: incorporate activities in their day schedule e.g., helping with household activities and play or leisure by themselves or with friends.
- When hyperactive before bedtime: incorporate calming activities before bedtime e.g., listening to music.
- If after all actions taken the person still has difficulty sleeping at night and/or wakes up very early or frequently, seek the advice of a doctor.
- When there is difficulty going to bed (not wanting to go to bed or not understanding what is expected) try to:
    - build a bedtime routine: same bedtime daily, same routine before bedtime e.g., brush teeth, sing a song, undress, tell a story, turn off the lights;
    - prepare the person a few minutes in advance to stop the previous activity before going to bed (use a timer if possible or needed);
    - Use a visual schedule i.e., pictures that indicate the daily routine (activities from morning to evening) to guide them.







Card 9

Body Functions and Structures

Card 10

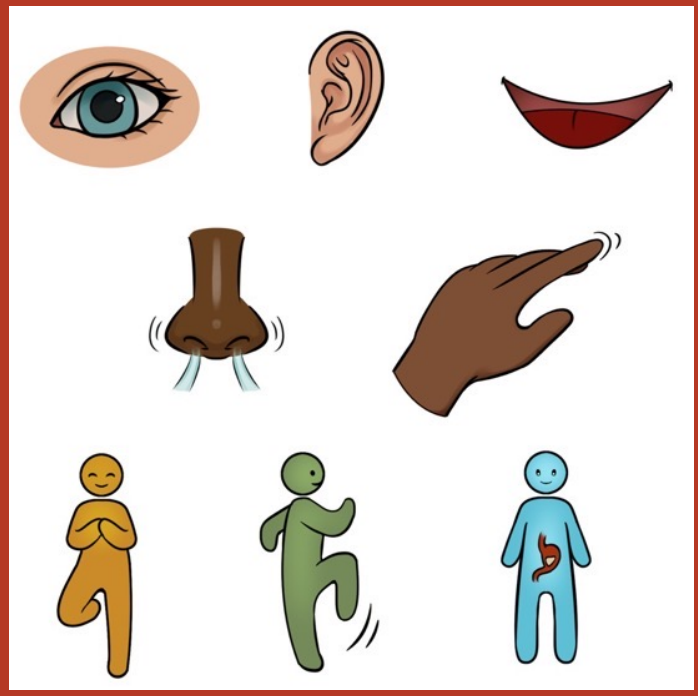
Body Functions and Structures

Understanding sensory challenges

Seeing, hearing, touching, tasting, smelling, feeling body positions, and body movements are senses that we all have and use. With persons with ASD, their brains might find processing sensory information challenging.

- We respond to what is important to us and ignore what is familiar, e.g., a car honking, or not important, e.g., lights in the house.
- Our senses process information constantly, e.g., water under the shower, a child crying, cars in the street, the smell of food, and moving in a crowd.
- For persons with ASD, e.g., sounds or touches may distract them or seem overwhelming, which can result in trying to get away from the source or responding anxiously. Textures or smells may cause gagging. LED or fluorescent lights can be overwhelming.
- This can cause being constantly 'hyper alert' and anxious, scared, or angry. It can cause tantrums.
- But a person may also seem unresponsive, bored, or tired, not noticing dirty fingers or craving to seek certain sensory experiences, e.g., not being able to sit still, touching people or objects, rocking back and forth, making loud sounds.
- These challenges can affect attention, self-confidence, participating in group activities and managing emotions, which can cause challenging behaviour.





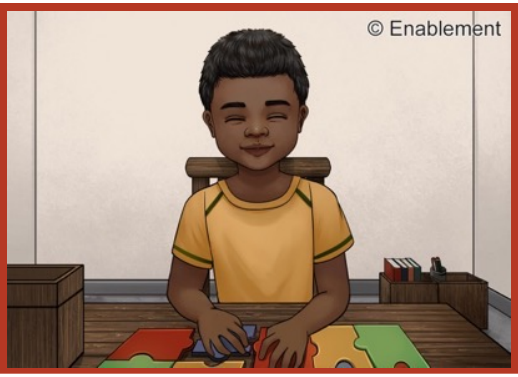


Actions to take

Here are some strategies to help a person with ASD and their family to process sensory information they might not notice or make them feel overwhelmed. Seek help from a specialised therapist if needed.

- When the person can speak, teach them to name each step of a challenging activity they're doing out loud or do so for them.
- When easily overwhelmed, make situations more predictable by preparing them, e.g., telling them when a certain sound is coming or how long the sound will be there and counting out loud.
- When easily overwhelmed in busy or loud areas, make sure they have a safe place to go and calm down, such as a bathroom. Sometimes, short usage of earplugs or ear covers can be helpful.
- When easily overwhelmed by community locations, e.g., a busy marketplace, go at a quieter time of day.
- When a person seems hyperactive, provide them with movement breaks throughout the day.
- When a person doesn't seem to respond, make sure you are near the person within sight, call their name, and touch their shoulder first before saying what you want to say.
- When having difficulty managing daily routines, make an image schedule showing the sequence to be prepared for what is coming. It gives a calming sense of control. See the example on the right.
- Deep pressure, like a firm hug, can work soothing.













Card 11

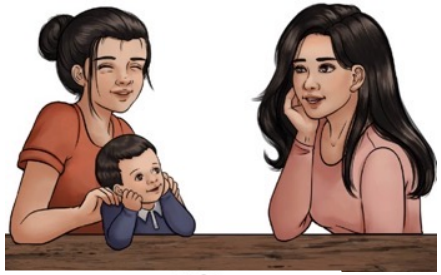
Body Functions and structures











Activities and Participation:

Information and Actions to take













Strengths of people with ASD

It is important to look at ability and not only at inability. There are famous athletes, scientists, and musicians known to have ASD. Persons that have ASD can be very good at certain skills, such as:

- Being honest about what they see, like, and dislike
- Responding quickly with words or behaviour
- Having a very good memory
- Being good at seeing details of objects and environment
- Being very good at organising objects or activities
- Being good at art
- Being good at technical activities like math, technical devices, and construction
- Not being bothered by what other people think
- Staying loyal to people they trust
- Sticking to routines and rules
- Having lots of knowledge on a specific topic they like
- Focusing extremely well on favourite activities





Helping a person with ASD

A person with ASD could communicate in a way you might not be used to or enjoy or dislike different things. It's important to know a person's strengths, challenges, and preferences. This provides information on how to help:

- learn or expand skills,
- participate in family and community life,
- communicate,
- socialise,
- manage emotions.

Actions to take

- Stimulate development.
- Provide opportunities for learning and working.
- Give the parents information on strengths.
- Give the parents information on how they can stimulate development in daily life activities.
- Make a pocket card briefly describing a person's likes, dislikes, and communication skills. This information can inform others on how to help the person when needed.
- The person with ASD or caregivers can show this card whenever needed, e.g., to neighbours, friends, teachers, or employers (see next page: copy, fill in, print, and wrap with cello tape).

Card 12

Activities and Participation

Card 13

Activities and Participation

Pocket card 'I HAVE AUTISM'
This pocket card can be used by persons with ASD if they recognise and agree with the content.

Actions to take
- Explain the person and/or their family member the use of this pocket card.
- Adapt the card if needed.
- Evaluate the use of the card and adjust if needed.

I HAVE AUTISM. Please read this card

- **I can be very anxious in situations that are new for me. Give me time and space to get used to the situation.**
- **When I am under stress, I might have difficulty communicating and need time to calm down.**
- **My behaviour might seem inappropriate or unpredictable. This is what makes me calm and happy.**
- **Do not touch me without asking me or do not use a loud voice as this might cause me pain or distress.**

My name is:

This is my emergency contact, but ask me first:

I HAVE AUTISM. This is how I like to communicate

- **I might have trouble understanding what you say. Please give me some time or try different ways to talk to me, such as:**
  - **shorter sentences**
  - **using gestures**
  - **using pictures to explain**
  - **using objects to explain what you mean**
- **Making eye contact may be difficult for me.**
- **I might have trouble speaking.**

Communication

- Communication is needed to participate in daily live.
- Communication helps to learn and interact with family, friends, teachers, community members and other people.
- Communication is important to express wishes and needs, pain, interact with familiar and unfamiliar people around you and being understood.
- Communication is more than just words. There are different ways how people communicate e.g., by words or body language such as expressions in the face and pointing, making gestures, drawing pictures and writing words.



Speech and language develop in the following order of skills from top to bottom:

1. contact of child – parent via feeding and caregiving
2. attention for sounds
3. playing with body and objects
4. understanding words and situations
5. using sounds
6. talking
7. communication with other people



Other ways to support communication

- Using daily objects to make clear which activity is coming
- Using gestures to support (but not replace) communication
- Using a picture card to communicate choices or feelings
- See next page for more information



Actions to take

- Encourage other people to interact with the person.
- Teach family and close community members why and how to use other ways of communication if the person cannot talk. Use an 'I HAVE AUTISM' card if necessary.
- Talk to the person throughout the day—tell them about what is happening. Use lots of facial expressions, gestures, and pictures to support communication.
- Talk in simple words or short rather than long sentences.
- Do not force the person to speak, but encourage and respond to any attempt of communication.
- Before asking or explaining something to the person:
  - get their attention: say their name and use eye contact;
  - make sure you are facing one another at eye level.
- Praise communication efforts with a positive reaction, such as a high five or compliment.

Card 14

Activities and Participation

Card 15

Activities and Participation

Other ways to support communication

Using daily objects (for level 3 in the levels of support)

For example: collect objects at a central point in the house where activities are done. Use them to indicate prior to the activity what is coming or what to choose from. This is for people having difficulty understanding communication.



Using gestures to support (but not replace) communication (for level 2 or 3 in the levels of support)

For example: many gestures are ones you already know. You can use pointing or e.g., use your hand 'as if' you are brushing your teeth to indicate it's time to brush their teeth. This will help to understand better what is expected of them.



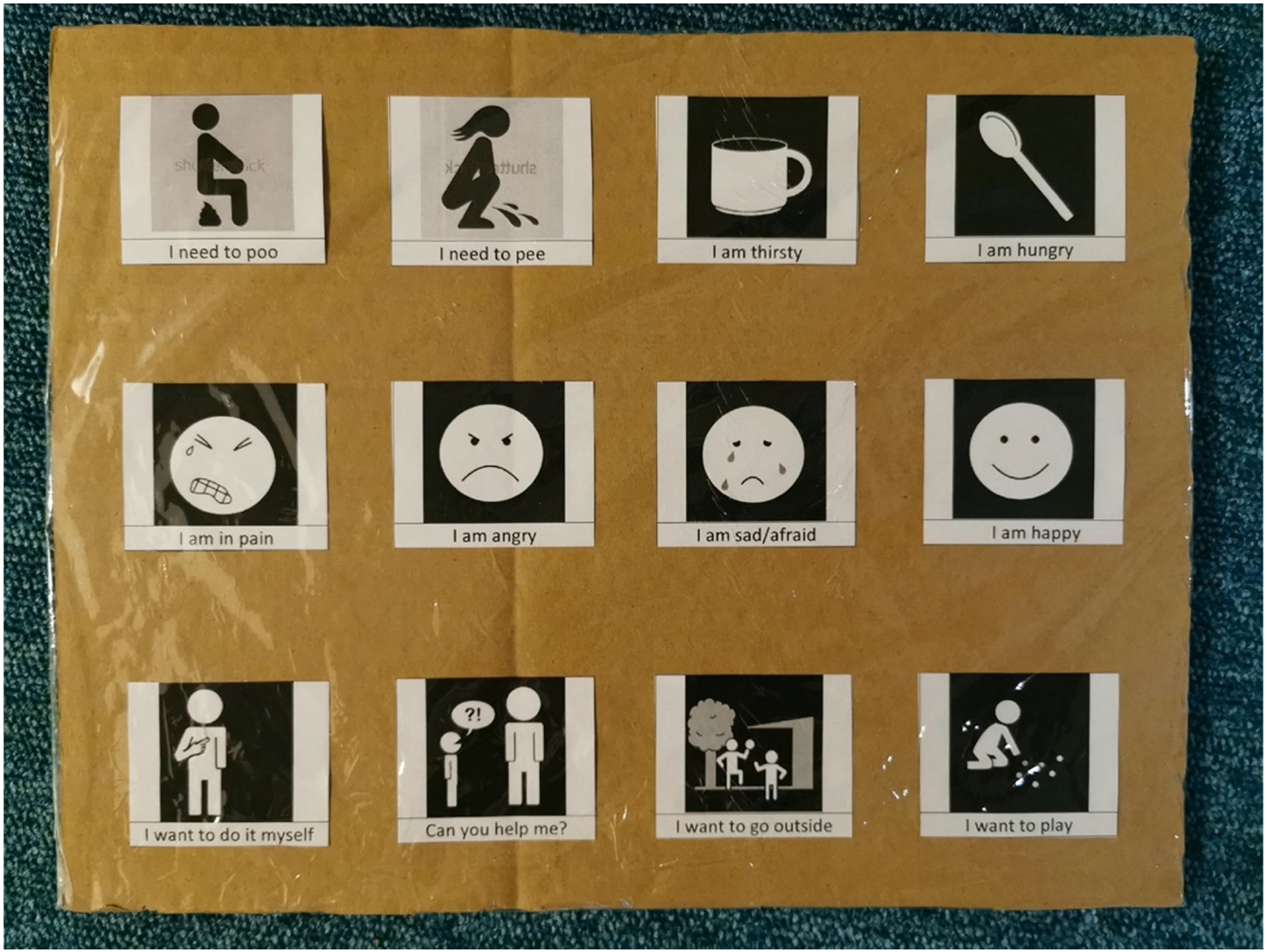
Using a picture card to communicate choices or feelings (for level 2 or 3 in the levels of support)

- Make a picture card with drawings or photos that are suitable for the person's situation (see example on the next page).
- Decide together with the person and/or their family which pictures are needed.
- Begin with a few pictures and gradually build the amount if the person understands and uses the card.
- Point to the picture that is accurate e.g., eating. If needed, guide the person's hand in pointing to the picture themselves.
- Keep the card within reach of the person.



Card 16

Activities and Participation



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.

Use as a board for the person to point out, with as many pictures as the person can handle, or as a set of separate pictures for the person to select from and present to express themself.

Card 17

Activities and Participation

Social interaction

Social skills include:

- being self-aware, achieving self-management and being socially aware of the people around you
- being able to make decisions in an appropriate manner, solve problems and use adequate skills in relationships

A person with ASD:

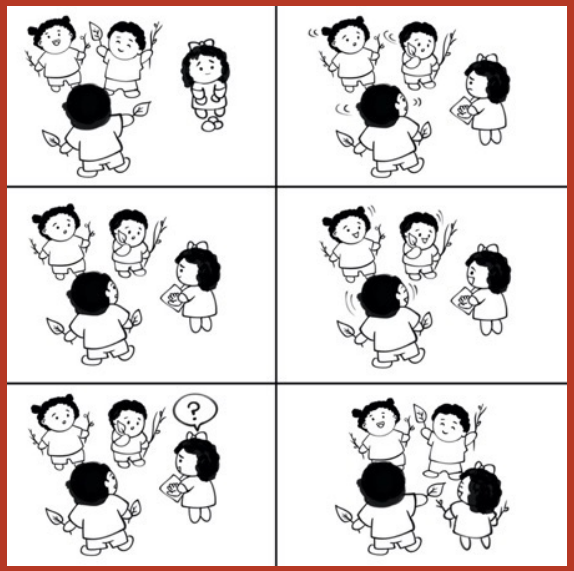
- may need help in interaction with peers, family and unfamiliar people
- may need extra time to understand what is said
- often understands more than you think
- may not be able to put into words what they want to say

On the other hand, a person with ASD:

- may be able to quote long complicated phrases or passages without understanding the meaning
- takes language literally e.g., by saying “pick up the pace” they might think you mean to pick up an object instead of moving faster
- might find jokes and cryptic language difficult to understand
- can get stuck on one specific topic e.g., talking in length about a TV character and cannot be distracted or topic diverted
- might not be interested in or have difficulty interacting with peers and requires guidance

Action to take

- Explain to people why a person with ASD responds in a certain way and what they need.
- Prepare a person with ASD for social situations in advance by explaining what they can expect with words, showing pictures or social picture stories.





How do social relationships affect a person with ASD ?

Persons with ASD deserve equal opportunities, where they can **make friends** and **engage in community activities**. Social situations can create boundaries for them. They are prone to being bullied or discriminated for communicating or behaving differently.

Persons with ASD often have **little peer contact**, because they have difficulty understanding social situations. It makes them harder to make friends and join group activities, because of their lack of social experiences. Teach them to understand and expand these experiences.

Actions to take

1. Follow the person's lead by:
   - listening to and watching what they are saying and doing
   - narrating their play
   - offering to help with what they are engaged in
   - imitating their actions
2. Practice interactive games with a predictable structure e.g., peekaboo, chase, I spy (depending on the age), to interact and learn new things.
3. Create opportunities for the person to request items or activities by placing them in sight but out of reach.

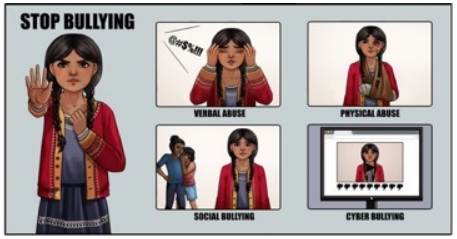
Card 18

Activities and Participation

Actions to Take



Help and teach a person with ASD how to **make friends** by **using social picture stories** (you can find examples on the internet).



Identify any **bullying** e.g., in class or community. Help **raise awareness and more acceptance** together with the teacher and other community members.



Explain to a person with ASD and their family, community members and peers that **their uniqueness makes them special.**



Discuss a buddy-system with the teacher, family and/or community member: **linking the person to a peer without a disability to support them in school and/or the community to enhance their participation.**

Card 19

Activities and Participation

Learning skills

Some persons with ASD may have difficulty learning new skills depending on the severity of the ASD. The person may find it difficult to concentrate, follow instructions or understand what is asked of them. Many persons with ASD achieve basic self-management, depending on the severity of their condition, but might meet developmental milestones later. If available, a therapist or special teacher can support in practicing skills that are challenging.

Many children and youngsters with ASD in low-resource settings do not go to school or get vocational skills training because the parents believe that this is not possible or that their child will not be accepted. In addition, schools are often concerned they cannot manage the persons' needs and may be hesitant in enrolling or supporting the child. Education is important for every person's development, and it is one of the most important interventions for persons with ASD. Every person has the right to go to school, learn, and prepare for a job or role in working life.



Actions to take

- Guide the person and family in finding the right school.
- Explain the importance of education to the family.
- Encourage directors and teachers to enroll the person.
- Provide information about ASD to the school staff.
- Help make an individual education plan together with the teacher e.g.:
  - arrange more time for doing school activities
  - provide individual instructions
  - help break down large tasks into smaller tasks
  - make tasks not too difficult, easy, exciting or boring
  - allow peers to assist the person e.g., through a buddy-system
- Arrange extra teacher support at home or practice challenging school activities with the person and family.
- Use or advice practical learning materials, such as a black or white board, leaves, shells or stones, which can be used to teach how to count or to identify shapes.
- Help to build in routines and transition warnings in the day.
- Positive reinforcement will be helpful, punishments won't.
- Coach teachers and peers: take time to get to know each other better.
- Use or advice calm down corners in areas e.g., the classroom, for persons that are easily overwhelmed or anxious.



Card 20

Activities and Participation

Self-care

A child with ASD will become an adult with ASD. Help the child to manage their challenges, build self-care skills and be as independent as possible.

- No matter what level, a person can often learn important basic skills.
- Sometimes a person cannot do the entire activity, e.g., dressing themselves, but they can take on certain steps e.g., pulling a shirt over their head or pulling up their pants.

Actions to take

- Go over the activities in a normal day and see where the person can do parts of activities or entire activities themselves.
- Instruct family members where to support the person and when to let the person try or do it themself.
- Support comes in various ways. Try this out together, coach the person and family and use what works best (see examples next page).
- Try out some of the techniques on the next card on how to embed this in their daily routine and coach the person and their family in how to use them. These techniques apply to different types of activities.
- From easy to difficult, you can gradually build skills such as dressing themselves. Easy: cooperate in dressing by stretching the arm or leg, taking off loose clothes. Moderate: putting on loose stretchy clothes. Advanced: managing buttons, tying shoes or sandals.





Eating & Drinking

Sensitivity to touch, sound, smell and/or taste might have an impact on how well a person eats and drinks.

A person can refuse food to be put in their mouth or only eat a few types of food. The person might find it difficult to eat food that is new to them or presented in a different shape.

Actions to take

- Use a picture schedule to show the sequence of activities in a day, including meals.
- Where possible, let the person choose between types of food and agree on how many bites to eat. Giving the option to choose gives a sense of control and might decrease anxiety.
- Follow the person's cues of what they like and don't force.
- Gradually introduce new types of food and use small bites at first to reduce fear and anxiety about eating and to build up tolerance of different food textures and tastes.
- Incorporate stimulation of the mouth into daily activities like toothbrushing and face washing.
- Use the same spot to sit for each mealtime. This helps to recognise the activity and works calming.

Card 21

Activities and Participation

Hand over hand

Put you hand over the person's hand, if they allow you to, to guide the movement. If this is too overwhelming, gradually build this strategy or use a different one.



Mirror

Do the activity e.g., brushing their teeth in front of a mirror for the person to see their movements and learn by seeing and feeling.



Modeling

Talk the person through the activity while showing the steps of the activity yourself and having the person copy you.



Drawings to show sequence activity steps

Make drawings that show the sequence of steps of an activity e.g., brushing their teeth or toileting. Let the person follow the steps by pointing to each, step-by-step. After a step is finished, remove the picture. Once the person is familiar with the routine and masters the skill, the drawings might no longer be needed.



Put materials ready in line from start to finish

Put the materials needed e.g., clothes, toothbrush, toothpaste, cup in front of the person. Instruct to start with the first and move on to the next and the next.



Helping aids

If, for instance, handling clothes is difficult, talk with a therapist or explore yourself to see if you can make small low cost helping aids, such as a key chain on a zipper to pull up and down easier or make a spoon handle thicker for a better grasp. Or perhaps a picture schedule as used above made from drawings, photos or pictures.







Play (children)

Children with ASD might be disinterested in interacting with peers. Help them to learn social skills and to play. In addition, children with ASD have difficulty understanding pretend play and might need guidance. Play is important to increase development and social skills.

Actions to take

Persuade parents to do fun activities together that encourage the development of interaction, communication, physical skills and self-care skills through play.

Help the parents identify what activities the child enjoys and see how they can teach skills through doing these e.g., if they like pebbles use these to count, stack and sort.

Playing with another person is the most valuable activity for babies and young children. Encourage playing with peers.

With level 3 in the levels of support, the person might enjoy sensory materials to feel, look or listen to e.g., a bottle with some pebbles or finding small objects hidden in a box of sand.

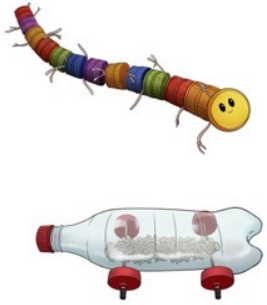
Make sure that all toys, home-made or bought, are safe.

Incorporate pictures of playtime in a picture day schedule.

When playing together with the child, encourage face-to-face interaction and use simple words or short sentences to name what you are doing or the objects you are using.

Reduce distractions in the environment such as a TV, phone, too many toys in front of the child and other noise.





Leisure (adults)

People with ASD are often excluded from social activities in the community, such as community festivities, going to the market or making friends due to misconception of the impairment or other reasons.

Actions to take

- People may need help learning to get to a friend's house or need support to interact with other people. Practice with the person and their family.
- Help by explaining ASD to other people: both strengths as challenges.
- Help the person and their family to explain to peers how to interact or enjoy leisure activities in alternative ways and how to support their friend.
- Help youngsters and adults to explain to peers what they like and don't like to help them make friends more easily and spend time together.
- Provide the person, when necessary, with a communication board or communication picture cards to use in leisure activities with others.



Card 22

Activities and Participation

Card 23

Activities and Participation

Vocational training and having a job

- It is important to guide young people and adults with ASD in finding a job they like and matches their skills.
- Persons with ASD may experience difficulties in finding or maintaining a job.
- Employers might need support in understanding the value of the person's strengths and creating a supportive workplace.
- Domestic tasks, such as gardening and cleaning, help to build vocational skills.
- Having a job or helping in domestic tasks is important for livelihood and autonomy.
- Having a job provides opportunities for making friends.

Actions to take

- Find and support access to vocational training or job coaching for youngsters and adults when needed.
- Coach the person with ASD to find work when ready.
- Discuss together what the person likes and is good at, for example making and selling soap, agriculture, tailoring or administration work.
- Give employers information on ASD. Explore together as employee, employer and fieldworker which activities and tasks are feasible.
- Discuss a tailor-made work schedule if needed.
- Help set up a business, if needed with the participation and support of a family member.



Participation community activities

People with ASD often experience social barriers. It is necessary to break these barriers. It is a human right to be included and participate in society. To prevent isolation at home, it is important to explore which barriers the family is experiencing and to set goals to address these barriers, raise awareness and create opportunities to participate in community activities.

Actions to take

- Fieldworkers play an important role in addressing stigma and social barriers. When needed, raise awareness in the community to include and accept all people, for example in going to the market and attending religious meetings or events like weddings.
- Some events can be overwhelming, being crowded and having too many sounds, for persons with ASD. Find out together how these events can be more pleasant, such as talking about what the person can expect e.g., what the place looks like, who will come, if there will be music, will there be a calming corner or space to retreat.





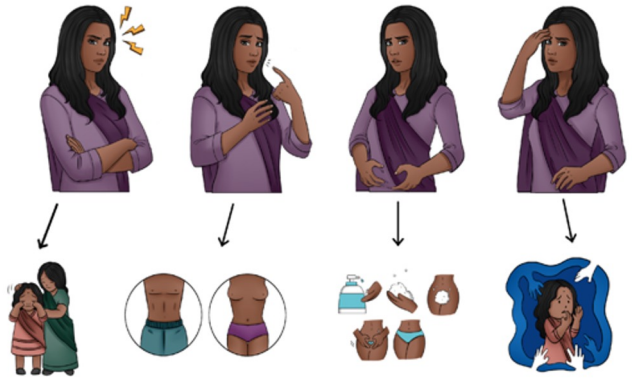




Personal factors:
Information and
Actions to take









Card 24

Personal Factors

Preferences and dislikes

Every person, with or without a disability, has wishes and needs. Also, when a person cannot speak or doesn't seem aware of it, that person has needs. Everyone has the right to enjoy life. Persons with ASD can't always explain why they prefer certain activities or movements but need to express themselves and remain calm. Often, they enjoy repetitive behaviours, e.g., flicking fingers, flapping hands, rocking, jumping, squealing, running in circles, or turning objects. People without ASD also self-stimulate to some degree, e.g., biting their nails, tapping a pen, or rocking a chair. It helps to release anxiety or excitement and seems to work soothing.

Actions to take

- Find out if the behaviour is due to being overwhelmed or bored. If so, help to incorporate more calming (or the opposite) activities in a normal day.
- Introduce and explore more ways to calm down or energise together, e.g., taking a deep breath, talking oneself through the steps of a task, or squeezing their hands together.
- The intelligence of children with severe disabilities is often underestimated. They need support and opportunities to learn and participate in daily life from an early age. Find out what they like, want, and don't like by listening to and looking at their sounds and movements and by asking their family members.
- Use these findings to provide support and to increase their participation.







Sexuality

- Persons with ASD develop sexually just as other people. They might need help to understand sexual feelings, sexual cues and sexual relationships.
- A clear understanding of consent, good and bad touch and masturbation (such as this is not suitable in a public place) helps to keep a person with ASD safe.

Actions to take

- Find out, when the person is in school, if education on sexuality is provided.
- Education about sexual function should be provided in the pre- and early teen years to both sexes in order to increase their sexual satisfaction, quality of life, understanding boundaries and learning to say “no”, similarly as you do so with all children.
- Doing so can prepare them for menstruation, stimulate the use of contraceptives, preventing sexually transmitted diseases, transmission of HIV, unintended pregnancy and helps to achieve a satisfying sexual life.
- Encourage children, adults and their families to share information in support groups or from peer to peer.
- Visual support and social stories are good tools for explaining sexuality to the person.



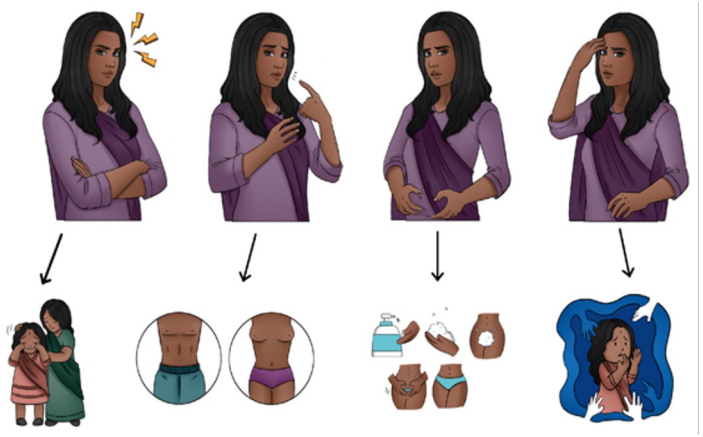


Personal boundaries

- Social skills are needed in different areas of life, such as at home, with friends, in school, at work, when meeting people and having a love life when grown older.
- A person with ASD (especially level 2 and 3 in the levels of support) might need support to understand what is appropriate or not, such as who you do or don’t hug, kiss, give a handshake, high five or say hello to.
- Or to understand which situations are acceptable or not e.g., not peeing outside the toilet and undressing with strangers around.
- It is important to help develop these social skills and understand social boundaries for safeguarding.

Actions to take

- Talk to the person and their family to identify any difficulties. Does the person understand personal boundaries?
- Teach the person and their family these social skills e.g., through social stories which you can draw or find on the internet.
- If there are any signs of abuse or neglect, take appropriate measures for social justice and protection.



Card 25

Personal Factors

Card 26

Personal factors

Safety

- All people, when growing up, learn about safety situations and what to look out for or be aware of, such as not to go with strangers, to pay attention around sharp, hot and electric objects, to be aware of high objects like when climbing trees and pay attention of traffic.
- People with ASD might need help in understanding and being aware of safe and unsafe situations.
- This learning process might take more time and guidance when growing up or when having level 2 or 3 ASD.
- Persons with ASD might interpret situations differently or are so focused on details that they do not identify dangerous or harmful situations.



Actions to take

With typically developing children, parents usually teach their children about what to watch out for by giving a strong verbal warning or by pulling them away from the situation after which they explain why. People with ASD don't always like to be touched or could feel distress and become anxious from this correction.

- With acute danger, provide a strong verbal warning and pull away if needed.
- Don't only say "no" to a person, but explain why you pulled them away and what could have happened.
- When the person has difficulty understanding language or they require additional learning strategies, you can also use social stories (picture) of dangerous situations to explain.



Card 27

Personal factors

Mental support

A person with ASD may feel insecure or anxious. They can feel rejected or bullied. It can lead to a variety of emotional and physical problems, such as loss of energy, a change in appetite, problems sleeping, feeling agitated or having self-harming thoughts. These are signs of depression.

Actions to take

- If you sense that there are signs of depression, refer to a mental health specialist immediately.
- Be sensitive to the stages of emotional distress e.g., exhaustion, worry, depression and anger, and provide mental support. Refer if needed to a professional counsellor.
- Provide mental support to the person and family. Highlight their strengths and support overcoming challenges.
- Listen to their stories and encourage to seek social support from family, friends, peers and community members to help provide a positive sense of the future.
- Do the same if you sense there are signs of depression on one of the parents. Taking care of a person with ASD can be exhausting.





Peer to peer support

Peer counselling consists of emotional and practical support provided by people in similar situations. Peer counselling can be an asset to a caregiver that recently learned the child has ASD or for persons with ASD. Peers can answer questions about parenting or share experiences, knowledge, and skills. Peer support can be given individually or in a group.

Learning your family member has ASD is a life-changing event for both the person with ASD and their family. Families may ask themselves why this misfortune happened to them. For spiritual support, they may benefit from consultation with a religious leader. It is good to be aware that ASD is not harmful, and a person with ASD also develops in their own way, having the same rights as other people.

Actions to take

- Find support groups and peers in the nearby area.
- Connect the person and/or their family with peers, groups, or a mental health coach to support them.
- These groups might also provide livelihood support by organising soft loan systems.



Card 28

Personal Factors

Managing emotions

People with autism have feelings and emotions like everyone. A person with ASD may need help developing a sense of understanding emotions of other people, because they may not be able to interpret what other people are feeling based on their body language. Downcast eyes or a turned-back, for example, don't necessarily signal ‘sadness’ or ‘anger’ to a person with ASD. However, if someone explains that another person is feeling sad or hurt, a person with ASD can respond with true empathy.

A person with ASD might also have difficulty regulating emotions and responding adequately to situations, resulting in challenging behaviour. This can have various causes: having difficulty expressing emotions or communicating wishes, having difficulty managing sensory experiences, not knowing what is expected of the person or not knowing what is coming next.

Actions to take

- Help the person with ASD, their family, teacher, and/or employer find out and understand the causes of this behaviour and provide appropriate support, e.g., using different ways of communication, using a picture schedule, providing space to calm down, explaining what is coming in advance, adapting the activity to the person’s preferences, and appraising successes and attempts.
- If needed, guide the family and/or community members how to ensure a day is structured and predictable by keeping the same routine and preparing the person for any changes well in advance.
- Together, explore strategies to help regulate emotions: take a deep breath, talk to others, listen to music, or retreat to a quiet area.
- Help the family focus on what goes well and praise achievements and efforts made. Children especially need positive learning experiences to be motivated to repeat what they’ve learned, e.g., give a high five or applause or do a little dance or song.
- Teach the person about the emotions of people by describing other persons’ emotions or using social stories (see card 17).













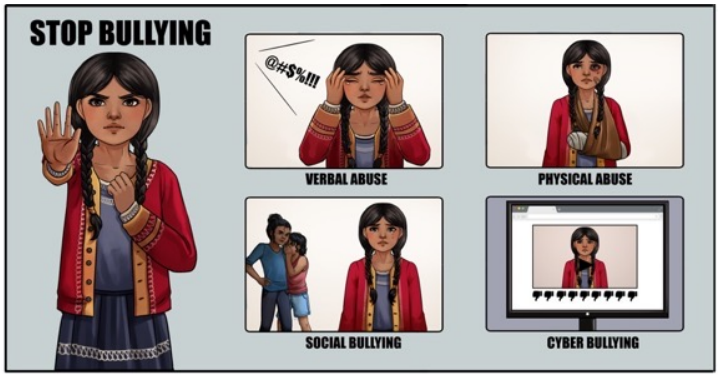


Environmental factors:

Information and

Actions to take







Card 29

Environmental Factors

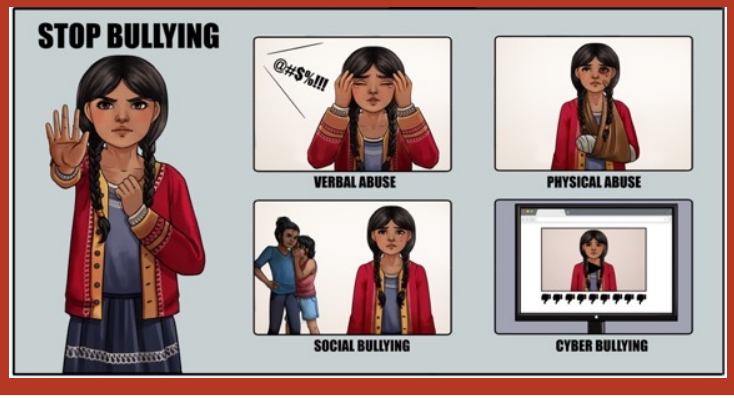
Social protection and justice

Abuse happens a lot, also with persons with ASD. Especially girls are at risk because they are not always able to protect themselves. Abuse can occur in different ways: ignoring a person's existence, bullying, physical abuse, psychological abuse, emotional abuse, and sexual abuse. Especially people with severe ASD might have difficulty understanding which personal boundaries are normal and which are at risk of abuse. **SAFEGUARDING REQUIRES SPECIAL ATTENTION.**

Actions to take

- Guide persons with ASD, their families, and community members about self-protection, justice and how to stand up for their rights.
- Create awareness for signs and symptoms of abuse.
- Report any signs of abuse to your organisation.





Livelihood of family

Having to visit a variety of support services and/or taking care of a family member with ASD, regularly prevents the caregivers from being able to work, resulting in a loss of income, especially without support of other family members.

Actions to take

- Check whether caregivers have sufficient financial means to afford basic needs and services.
- Help to enroll the person in school so caregivers can go to work.
- Find out livelihood schemes of governments and help the family connect with these services.
- When no sufficient income, help to explore financial support at: the local community such as churches, NGOs, income-generating programs, micro-credit programs or soft loan systems.
- See this information on the iSave economic approach: https://isave-inclusion.com/about-isave/what-is-isave/isave-model/



Attitudes from the community

People with developmental disabilities such as ASD:

- often live in poverty
- are more vulnerable to abuse
- are often overlooked in emergency situations
- experience greatest hindrance in stigma, prejudice, ignorance
- girls face double discrimination: being a girl having a disability

Actions to take

- Create awareness in the community for the rights of people with ASD. Here is an easy read version of the UN convention: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html.
- Create awareness on respecting and supporting the needs of a persons with a disability, including ASD.
- Create awareness on the strengths and capabilities of people with ASD.



Family's mental health support

- Having a child or spouse with ASD changes the lives of family members. It can be overwhelming.
- They may experience difficulties in daily life and being accepted and supported by relatives and the community.
- This can result in feeling hopeless or depressed.
- Parental stress levels in families with a child or spouse with ASD is often high.
- It can be hard for parents to ask others for support, especially if the cause of autism is misunderstood.
- They need all the non-judgmental support possible from friends, family, community members, and service providers.

Actions to take

- One of the most important things to assure the family of is acknowledge of their feelings and challenges.
- Help the family explain ASD to other people.
- Provide counselling to the family, listen to their story, address immediate needs, and refer to an appropriate service provider if needed.
- Get community members involved in support.
- If none are available, help organise a support group.
- Help arrange some free time for the parents away from their child to regain their energy.



Card 30

Environmental Factors

Card 31

Environmental Factors

Myths and beliefs

Due to a lack of access to ASD information and a lack of specialised services in low-resource settings, the cause of ASD is often misunderstood. Identification and intervention often come late, and myths and beliefs occur among family and community members, such as ASD being a religious test, a result of sin, bad parenting, or being possessed.

Actions to take

Provide accurate information about ASD, the causes, and the diversity of that can occur in strengths and difficulties.



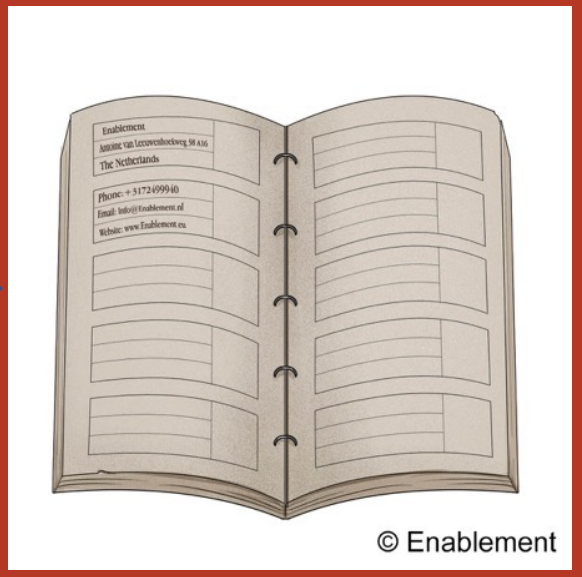
Stakeholder network of services

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

Actions to take

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





Colophon

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Card 41

References

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