Flashcards spina bifida



Photo by Chelsea Bulteel

- **These flashcards contain information about working with children with spina bifida (SB) in low resource areas.**
- **These Flashcards are made for the use of fieldworkers.**
- **These flashcards are based on the information about spina bifida available in the RehApp.**



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 and community-based services for people with disabilities and their families.
- To enhance participation in daily, family and communal life.
- To improve the quality of life of people with disabilities and their families.
- To support you (as a fieldworker) in your services for a family by providing you with an asset 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 Spina Bifida.
- Make an inventory of the needs of the person with SB and his/her 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 SB.
- Use them to help you discuss interventions with the family.
- Use them to help you keep client records.
- Use them to help you monitor progress.

Index:

These flashcards contain information about SB. The content is organised according to the International Classification of Functioning domains (ICF) made by the WHO. Each domain contains what you (as a fieldworker) can do, in collaboration with the family throughout the Rehabilitation Cycle: interview, assessment, writing plan, action, evaluation.

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	Body functions & structures
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Spina bifida

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Spina bifida

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Important note:

It may occur that you are not sure what type of intervention is needed for the person, family, or environment. *These cards don't replace the knowledge and skills of doctors and therapists.*
We advise you to seek their advice about topics and questions you need help with. If you cannot visit a doctor or therapist quickly, contact them and consider sending a photo or video you made, for consultation. For example: take a photo or video of a wound, malfunctioning assistive devices, or the exercises you have been advising. This may save time and costs for you and the person with SB.

Ask a professional for help and their advice. A video or photo can help you explain the issue and is helpful for the professional to understand.



About spina bifida and hydrocephalus (but hydrocephalus caused by spina bifida only)

These Flashcards are designed for people with spina bifida (SB), who may at some stage also develop Hydrocephalus.

So, the hydrocephalus we speak about in these flashcards is caused by spina bifida 'only'.

Hydrocephalus that has NOT been caused by spina bifida but for example by and infection or trauma, is not represented here.

Everyone is unique!
Not every intervention is suitable for everyone with spina bifida. Listen to the person, listen to their family, ask for their needs, and wishes. Use your knowledge and skills to help them or seek support of specialists. Make sure you have a network for advice and/or referral.



Network: "it takes a village"
Make a list of stakeholders' names, professions and phone numbers. The Flashcards can support you (a soft copy is freely available on www.enablement.eu/publication).

Good collaboration is necessary between the person with spina bifida, their family, fieldworkers, the healthcare centre, rehabilitation doctors, therapists, nurses and other stakeholders within the Community Based Rehabilitation (CBR) network. This also includes community members and local leaders. Local leaders can help in rights issues as well as a link up to support organisations for the person with SB and their family.

It helps to use a **'SHIP passport'** (spina bifida and hydrocephalus interdisciplinary program) or another type of follow-up card available in your area for a person with a disability. The person keeps the passport on him/her. During every visit, each professional can (shortly) write down their observations and interventions and read the notes of other professionals. This will help to reach goals and meet needs together. **Get it from info@child-help.international or directly on** https://www.child-help.international/downloadlinks

Card 1

Introduction
Spina bifida

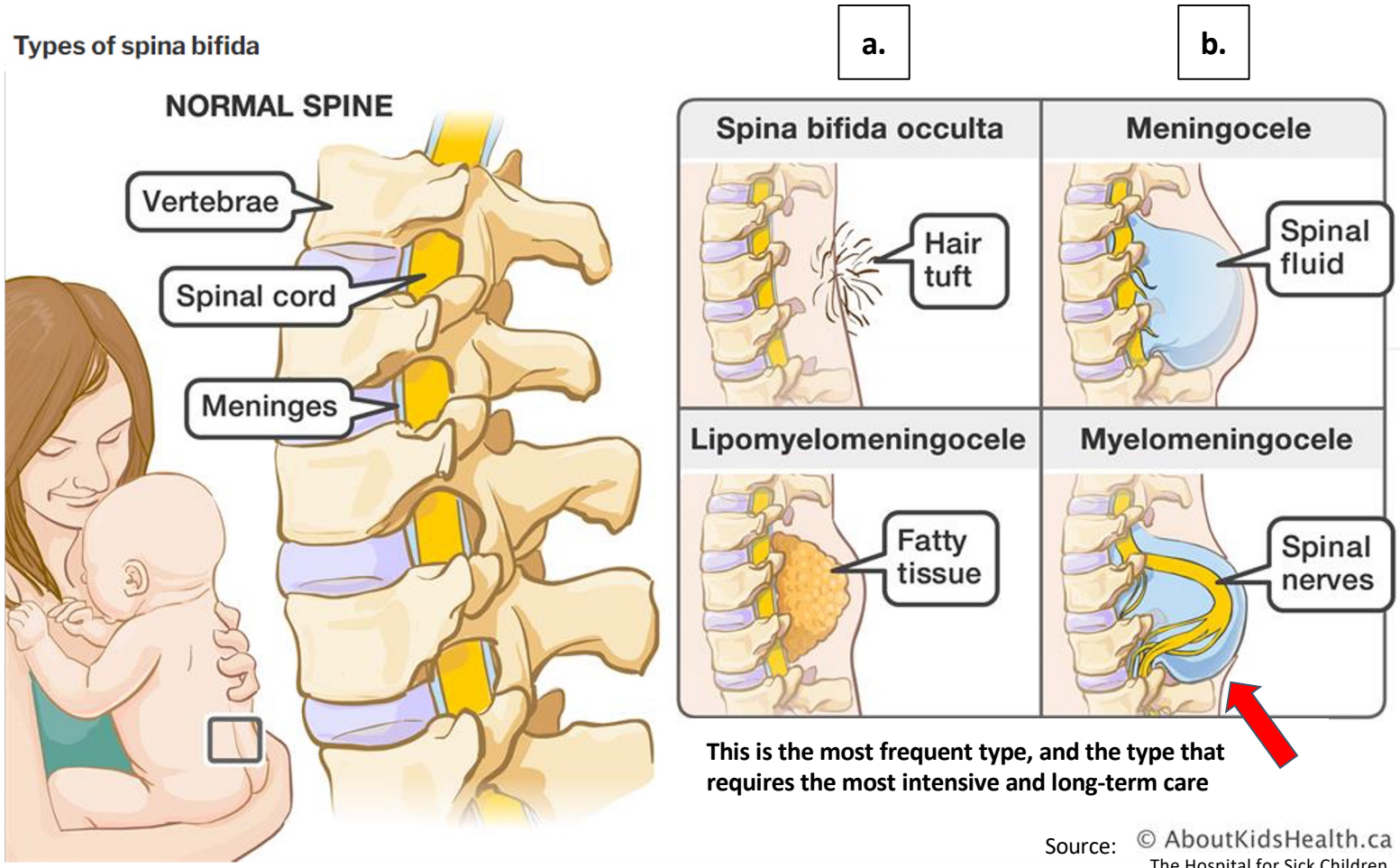
What is Spina Bifida (SB)?

It is a birth defect that is caused during the first 25 days of pregnancy. It happens when some of the back bones (vertebrae) do not close over the center tube of nerves (spinal cord). As a result, a soft unprotected spinal cord area is left, which may bulge through the skin as a dark bag. This 'bag of nerves' is covered by a very thin layer (membrane) which may leak liquid from the spinal cord and brain. About 3 of every 1,000 babies are born with spina bifida.

There are mainly two types of SB:

a. The closed ('hidden') SB (only 5%) that is sometimes recognized only later in life (first drawing with 'hair tuft')

b. The open SB (95%) with an (open) wound on the back or with a closed bulging bag, in 3 different types (other 3 drawings)



This is the most frequent type, and the type that requires the most intensive and long-term care

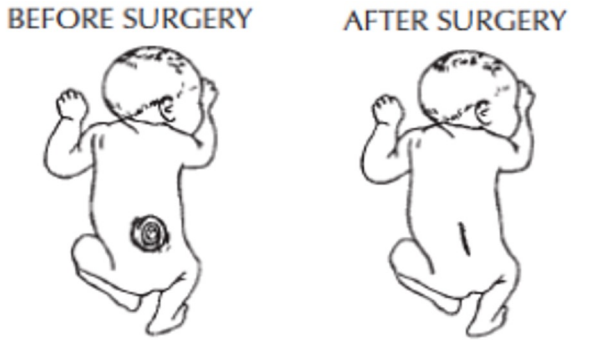
Source: © AboutKidsHealth.ca
The Hospital for Sick Children

A **person with SB with spina bifida can have a good life and live until old age.**
But he/she will need support by family and service providers, and this for a long time.

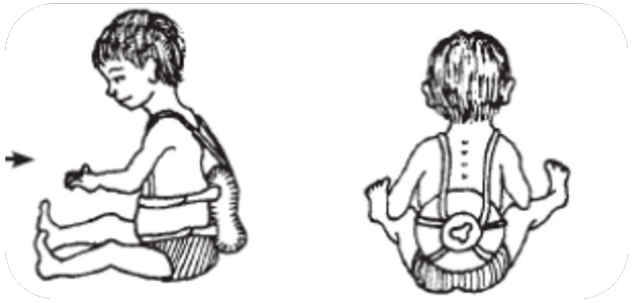
Caring for the child with Spina Bifida

High risk. Without early surgery to cover the bag of nerves, it almost always gets infected, and the child dies.

Care of the defect: surgery. When there is a 'bag of nerves' on the spine of a newborn baby, the child's chances of living are much better if he has an operation within a few weeks. The surgery covers the defect with muscle and skin. Without this operation, there is a high risk of injury and brain infection (meningitis); the child will probably not live very long.



ct the bag of nerves so that its thin covering is not injured or broken. If it breaks, meningitis can occur. One way to protect the bag is to make a ring or 'donut' of soft cloth or foam rubber and tie it to surround it. Do not let the ring or clothing touch the bag.

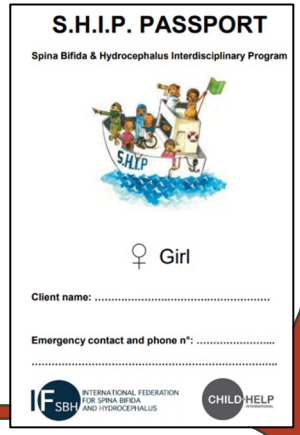


Illustrations: *Disabled Village Children*, p.169 (Werner, 2003)

Urgent action soon after birth

- If you recognize signs of SB, **immediately** send the child to a medical doctor (surgeon or pediatrician) for diagnostics and intervention: **don't wait!**
- **During transport to the hospital**, whether the back wound (cele) is OPEN or CLOSED, it is important to **protect the wound so that the thin covering is not injured or broken.** The wound in the back should be completely covered with non-adhesive sterile dressing and kept moist with sterile saline to minimize infection and injury during traveling to the hospital. (**Saline**: 1 liter water with 9-gram salt, boiled and cooled).
- Change dressing each time when there is urine or stool
- An extra covering will protect the child till the wound is healed.
- Use or ask for a **SHIP Passport** here:

https://www.child-help.international/downloadlinks



Causes of SB - and how to prevent spina bifida (in your next child)?

Causes of spina bifida
Most likely, spina bifida is mainly caused by a lack of folic acid (Vitamin B). There may also be genetic and environment factors.

Action to take
Women who have Spina Bifida, a child with SB, or had a pregnancy affected by SB should take 4.0 mg of folic acid per day, for one to three months before pregnancy and up to at least 2 months after pregnancy.

Folic acid is cheap, especially if it can be bought in big supplies.

Card 2

Introduction
Spina bifida

Card 3

Body functions and structures

Overview of most important challenges and action required

People with SB may experience a number of challenges in life. This doesn't mean all people with SB have all these difficulties. It can be either a few or several. These most common complications and the associated actions will be discussed in the following cards.

Control Hydrocephalus



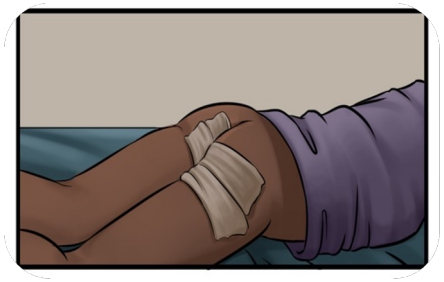
Will my child be able to walk?



Good bladder- and bowel care from birth onwards



Treat skin problems (especially where no feeling of pain)



Stimulate mental skills, self-care and independence



Stimulate social integration, schooling and relationships



Control hydrocephalus.

Card 4

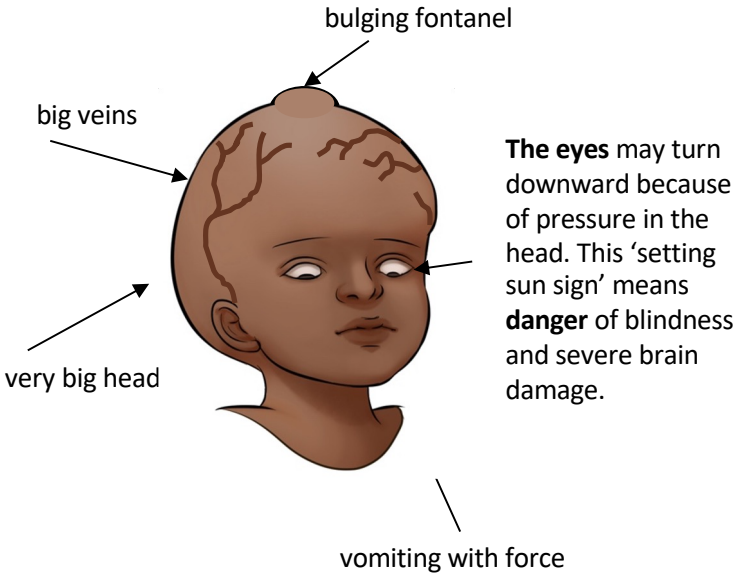
Body functions and structures

What is hydrocephalus

Hydrocephalus (H) is sometimes called locally: water in the brain. This occurs a lot with people with SB (80%). H is caused by an obstruction in the passages of the brain fluid. This leads to too much fluid in the brain, which may damage the brains. H can be treated but not healed with surgery.

Actions to take

- It is important to decrease the pressure in the brain immediately to prevent permanent damage to the brain which can affect health and functioning.
- **Go to a medical doctor immediately for treatment when the child is vomiting a lot, or you see some of the following signs:**



The eyes may turn downward because of pressure in the head. This 'setting sun sign' means **danger** of blindness and severe brain damage.

Follow the evolution: measure the head

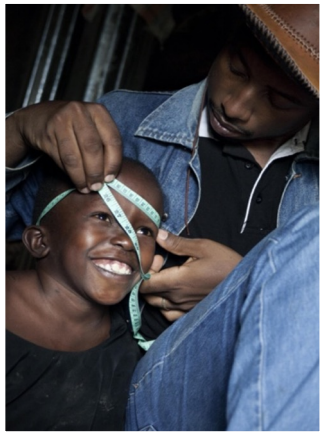
During the first 12 months of life, it is important to detect hydrocephalus early on by measuring the head of the child once per week with a measuring tape and record the size on a special chart. In case of a too high raise out of the normal growth: contact the doctor immediately!

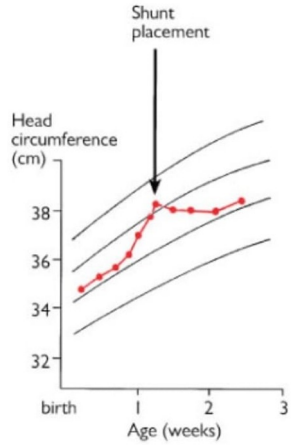


How to measure the head circumference

1. The baby will feel most comfortable in the mother's arms. Place the measuring tape (or piece of rope) just above the eyebrow ridges and around the prominent back of the head.
2. Next, read the tape measure from the side of the baby's head, to the nearest full millimeter.
3. If the head circumference increases faster than normal, the child probably is developing hydrocephalus. It is important to refer the child to a pediatrician for further treatment immediately.

- **The chart below is part of the SHIP passport.** Use or ask for a **SHIP Passport** here: https://www.child-help.international/downloadlinks





Source: Sandler, S. (1997)

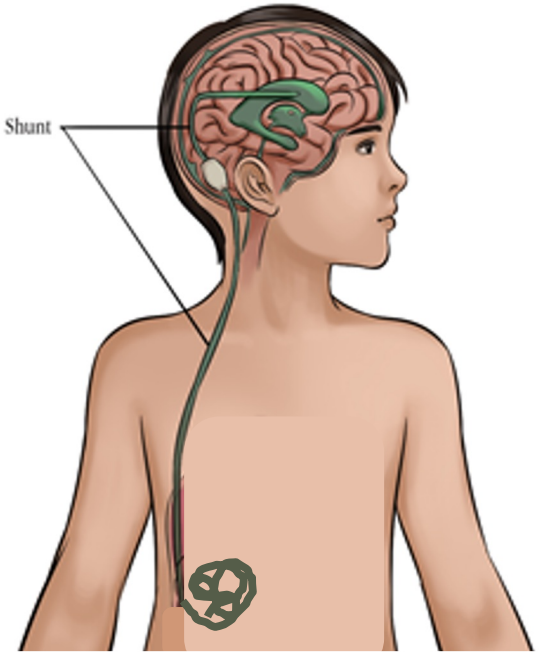
Card 5

Body functions and structures

Treat hydrocephalus

Not all children who have early signs of hydrocephalus need an operation. If the head measuring (see card 4) shows that the head stops increasing rapidly in size, then it may get better by itself a surgery may not be needed.

However, if the size of the head continues to increase rapidly, a surgical operation inserting a 'shunt' (='tube') may need to be done before the pressure of the liquid in the brain causes much damage. A tube is run from a liquid-filled hollow in the brain into the belly (abdominal cavity). This way the extra liquid is drained from the brain to the belly.



Problems with shunts and how to know

A child with a good working shunt can live a normal life. Unfortunately, the shunts cannot always prevent problems in development. More than half of persons with a late shunt or a malfunctioning shunt might develop an intellectual disability.

Once the shunt is placed, keep this in mind:

- **Problems with the shunts** may occur suddenly or gradually. Shunts can become infected, blocked, can twist, break, or can become too short when the child grows. A problem with the shunt will lead to blockage of the brain fluid and consequently increases pressure in the head.
- **How to know? Signs of shunt malfunction** are vomiting, headaches, sleepiness, seemingly confusion of the person, difficulty concentrating, seizures, irritability, swelling of the skin around the shunt or redness or sunset eyes (see card 4). **This is a severe complication that will result in brain damage.**
- I**f you notice or suspect a problem with the shunt, immediately go to a specialist doctor for medical help.**

Today there are more modern treatments, such as (in brief) '**ETV**', but only by a trained and equipped neurosurgeon. The advantage is that ETV does not require a shunt, meaning it is impossible to have a malfunctioning shunt with all the consequences. This treatment is only available in very specialized neurosurgical centers.

Card 6

Body functions and structures

Prevention and correction of contractures. Some children with spina bifida tend to develop **contractures** either because of muscle imbalance or, less often, because of **spasticity** (abnormal muscle tightness). Contractures most often develop in the feet, hips, and knees. **Range-of-motion** and stretching exercises can help prevent and correct early contractures. **Avoid clubfoot by plastering the feet early on (Ponseti method)**.

Treatment of clubfoot: Ponseti method

Ponseti treatment is a simple, cost-effective treatment method that has become widely used around the world. Many research studies have shown that more than 90% of children born with idiopathic clubfoot can be treated effectively with the Ponseti technique.

The goals of Ponseti treatment are:
to have functional, normal looking and pain-free feet;
to wear normal shoes, and;
to avoid permanent disability.

The Ponseti method consists of two equally important phases:
1. The corrective phase
2. The maintenance phase

The Corrective phase

During the corrective phase, the position of the foot is gradually corrected by using a series of manipulations and plaster of Paris casts which are changed every week. After about 5 - 6 weeks, a small procedure under local sedation is performed to cut the Achilles tendon (tenotomy). After the tenotomy, the cast usually stays on for another 3 weeks.





The images show the improvement in the positions of the foot from left to right. Manipulations and casting must be done every week. Some babies only need 5 or 6 casts while others need a few more casts. The corrective phase of treatment should be carried out in a specialist clubfoot clinic by at least two health workers who are trained in the Ponseti technique.

Avoid hip and knee contractures

Sometimes a child stands with hips and knees bent, partly because his feet bend up too much. This can lead to hip and knee contractures.

Lightweight below-knee braces that hold the feet in a firmer position may be all the child needs to stand straighter, walk better—and prevent contractures.



Illustration: *Disabled Village Children*, p.171 (Werner, 2003)

Card 7

Body functions and structures

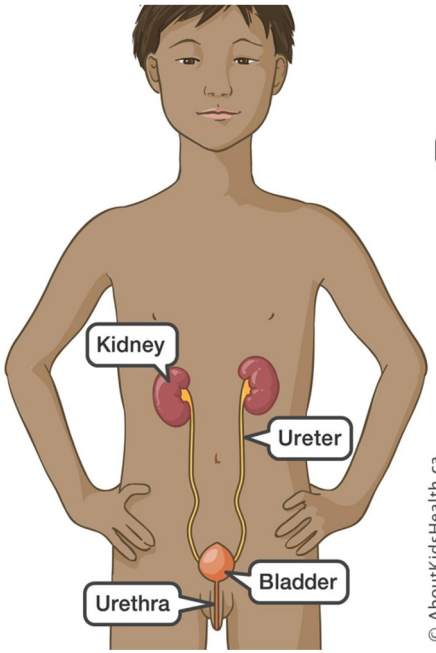
Bladder (urine) management actions to take:

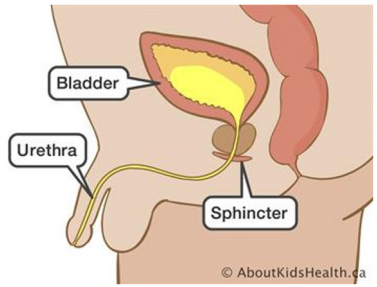
Danger from birth: most children (age 0-2) with or without SB don't have control yet over urine. So, urine incontinence may not yet be perceived as a problem. HOWEVER, for children with SB, as the bladder doesn't function normally, high pressure and infection in the bladder are dangerous problems for the kidneys.

Why? From birth, the child does not feel when the bladder is full. If the child wants to empty the bladder, the sphincter (=exit) does not open. The pressure in the bladder becomes dangerous. The urine that remains in the bladder will be infected and the pressure will send the infected urine towards the kidneys.

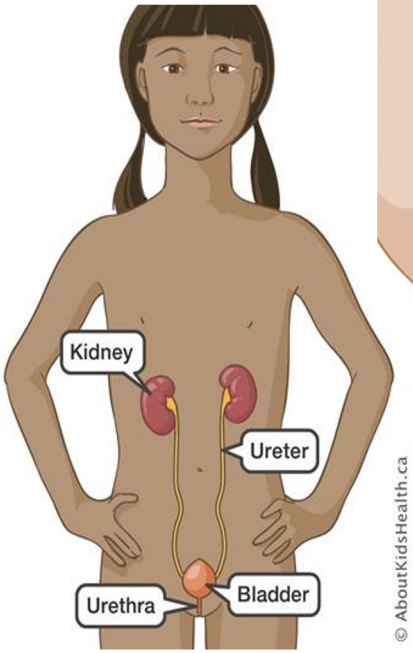
Make sure an ultrasound examination is done as soon as possible, on 0-3 months of age or as soon as possible
An ultrasound will tell us if the child has a dangerous bladder. Also, the clinical sign of a bladder infection with cloudy urine demands attention and a treatment (CIC will be needed).

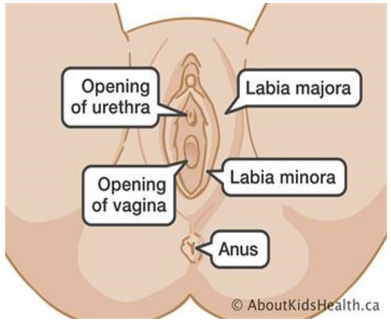
Catheterization (CIC). The only way to empty the bladder in a good and safe way is by CIC (clear intermittent catheterisation). This means emptying the bladder by inserting a tube through the entrance of the bladder (girl: urethra or boy: penis). Most people with Spina Bifida do this lifelong.





Source: The Hospital for Sick Children





Source: The Hospital for Sick Children

How to put a catheter

Health workers and parents can easily be taught to put in a catheter under supervision of a trained nurse. With a little practice, children with SB can learn to do it by themselves.

Note: Catheters come in different sizes. Catheter size #6 does not function well, because urine that is not clear can't pass through well. The best catheter size is usually #8, #10 or #12 for a small child and #14 or #16 for an adolescent. Children as young as age 5 can learn to catheterize themselves. The catheters for boys are a bit longer as those for girls. A mirror can help girls to find the urine hole.

Once a child has cloudy urine, time has come to train the mother and to start the catheterisation program.

A kidney infection can be recognized by (high) fever in combination with being very sick and cloudy or bloody urine.

Treatment of a kidney infection: send the child to the doctor to be treated with antibiotics.

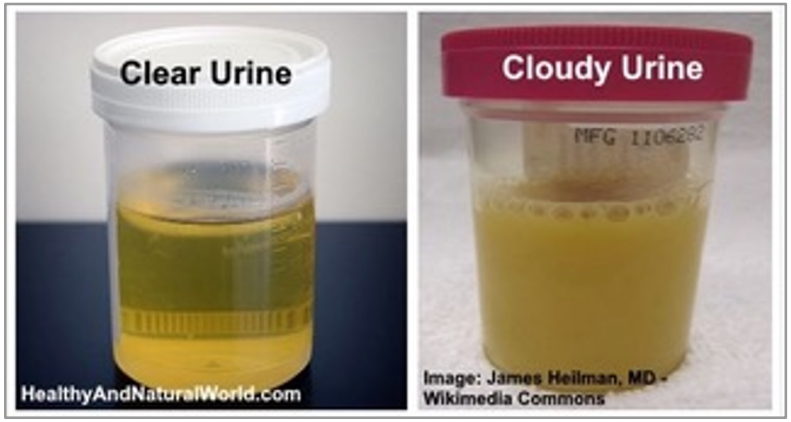
In case of a high-pressure bladder, for most of the children willing to be continent, **Oxybutynin** treatment will be needed as part of the CIC treatment.

For all children, becoming continent is crucial in order to go to school, to have friends, to stay at the homes of other caretakers etc. Being continent is also the best prevention against sores and wounds.

Catheterization (CIC)

must be done 4-5 times per day.

- When cleaned and stored safely, a catheter can be used usually up to a month before replacing with a new one.
- The catheter is only to be used by one (and the same) person.
- Cleaning the catheter: wash your hands, rinse catheter in- and outside with clean water, shake out remaining water, dry over a clean towel, store in clean piece of cloth or clean plastic bag.
- **A bladder infection** can be recognized by:
  - odd-smelling, cloudy urine (picture on the right)
  - collecting the urine in a glass and look at it. When the urine is not clear (=cloudy, like milk) there is an infection.
- **Treatment of a bladder infection:**
  - drink lots of water
  - empty the bladder completely (up to the last drop) and more often per day (at least 6 times)
  - urine should be clear after 2-3 days; if not see the doctor to prevent further kidney infection and damage



Card 8

Body functions and structures

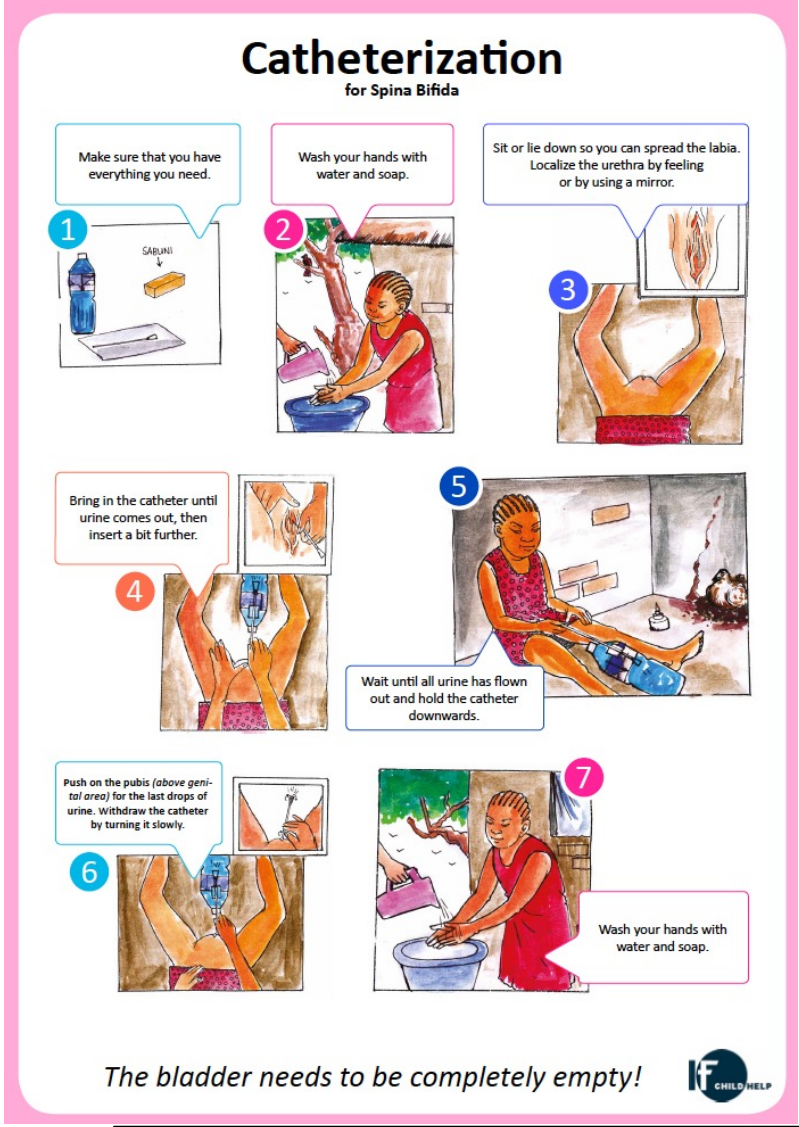
Card 9

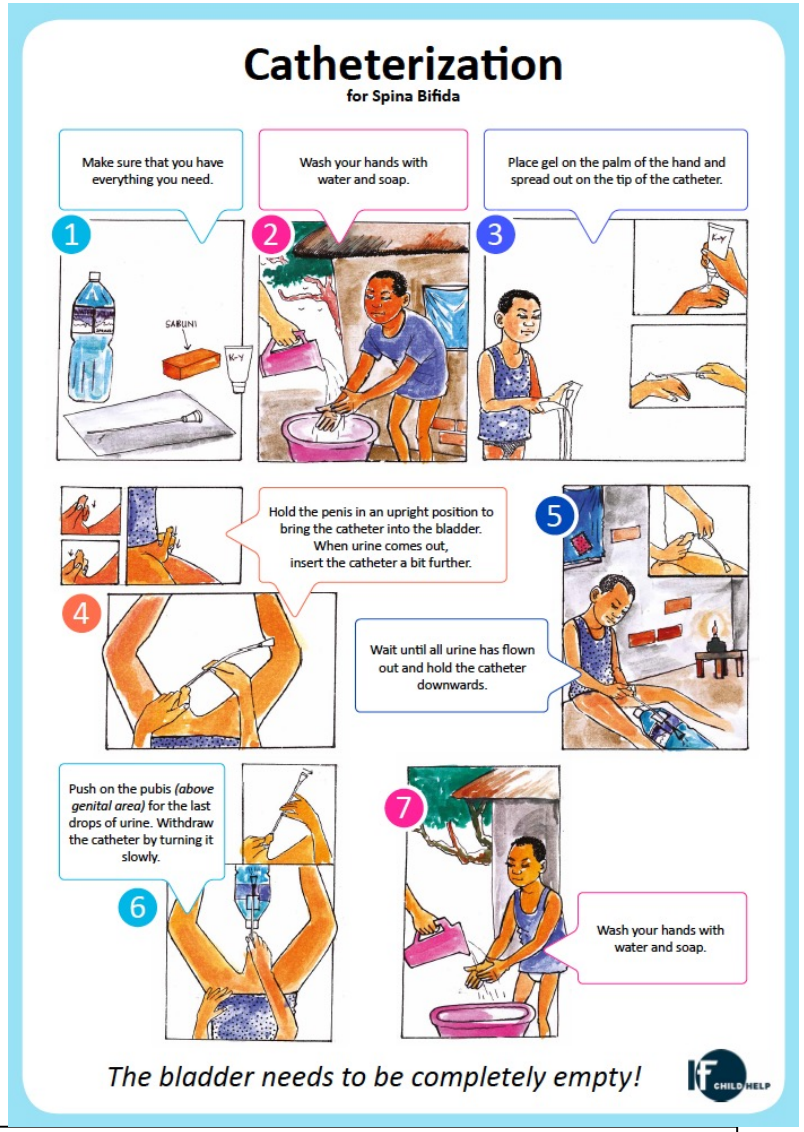
Body functions and structures

Training CIC for girls and boys:

Train the fieldworker to train the parent...

Get the files below from: https://www.child-help-vzw.be/images/pdf/Continentietraining/CatheterLowRes.pdf





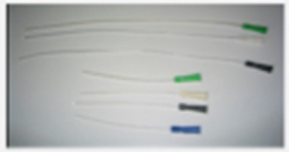
For all children, becoming continence is crucial in order to go to school, to have friends, to stay at the homes of other caregivers etc. Being continent is also the best prevention against sores and wounds.

Card 10

Body functions and structures

Parents tell us how important bladder and bowel management is:







“Name the most helpful thing in the care for Amina?”

“Nothing helps me more than the catheter”

“What do you want more?”

“Something like the catheter to help Amina for the stool”

Card 11

Body functions and structures

Bowel (stool) management actions to take:

Babies with SB, just as other babies, are not able to control their stool. So, parents having a baby with SB may not worry about that. However, a baby with SB may not be able to push sufficiently to empty the stool, which may lead to constipation. This means parents will need to help removing the stool.

Once the child gets a bit older, e.g., from the age of 2:

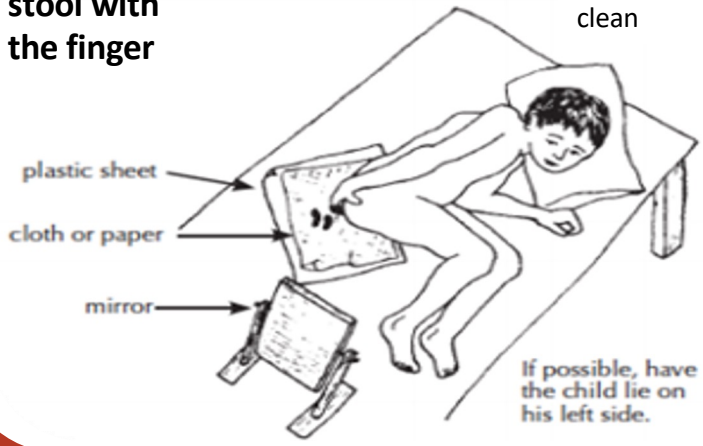
- Make a bowel schedule: make bowel breaks a daily routine by using the same method, set times each day.
- A healthy diet improves a person's stool: lots of fibers e.g., vegetables, bran, fruit, potatoes, bread, nuts.
- Drink enough (clear) liquids during the day such as water and tea.
- If needed, the bowel can be stimulated by putting pressure around the anus. Get instruction from a specialist first! Put a finger 1 inch into the anus and push against the wall of the bowel. Wait for the stool to come out. If not, repeat several times. If nothing happens, remove the stool gently by finger.

Fieldworkers should be trained on how to train the parents

Removing stool with the finger



A thin glove or 'fingercot' helps keep the finger clean



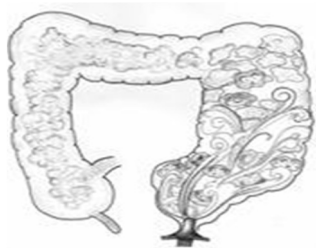
Bowel washout

If stooling remains a problem, the doctor might advise the '**bowel wash out**' method which is effective in children with SB. Also see card 12 or here: https://www.child-help-vzw.be/images/pdf/Continentietraining/Bowel_small.png

A cone with tube and bag for water



Introduce a cone and flush the bowel with water to make the stool soft and stimulate the bowel



Most of the hard stool can get out of the bowel



Regular washout leads to a clean bowel



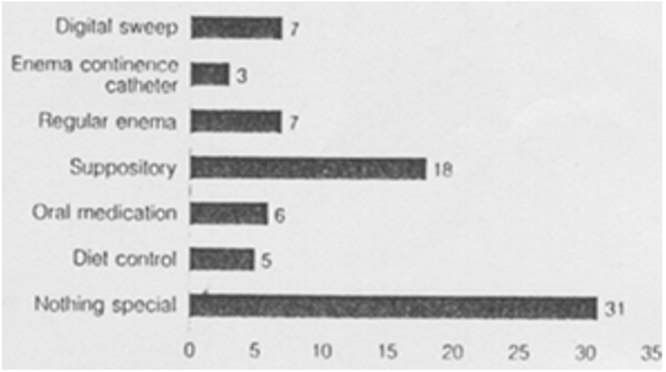
Latex allergy: don't use gloves with latex (rubber)!

Children with SB have an increased risk of developing an allergy to latex (rubber). This should be replaced by plastic e.g., plastic gloves and plastic catheters. In general, catheters used for intermittent catheterization do not contain latex (rubber) and at home they should not use gloves. Foley catheters used as indwelling catheter often contain latex (rubber).

Illustrations: *Disabled Village Children*, p.214 (Werner, 2003)

Bowel management is trial and error…

Don't be discouraged! This study with 71 children shows the many methods that were tried by the parents:



A mother showing how she cleans the bowel of her child



Bowel washout

INTERNATIONAL FEDERATION FOR SPINA BIFIDA AND HYDROCEPHALUS

CHILD-HELP

Make a toilet chair and make sure that the edges are smooth.

1

Give **clear explanation** to children and parents, use **drawings.**

2

3

Fill the bag with lukewarm water, use 20–30 ml/kg bodyweight.

4

Put the **cone into the anus** and press it **firmly against the buttocks** so that the water stays in the belly.

Hold the cone in the anus **for 5 minutes** so the water can soften the stool.

5

Make sure that the **legs have support** on the ground or on a bench.

6

Let the child **sit for 15 to 20 minutes** on the toilet chair for a good result.

- *Child still loses fluid after 2 hours: use less water.*
- *Child is still soiling between 2 rinses: use more water.*
- *Child is sweating, nauseous, dizzy: use less water.*
- *Difficult evacuation: add 10 ml of glycerin to 100 ml of water.*

If this causes cramps, reduce the amount of glycerin.

Card 12

Body functions and structures

Card 13

Body functions and structures

Treat skin problems (esp. where no feeling of pain)

Skin breakdown can occur due to loss of sensation, limited movement, weak muscles, poor blood circulation and external pressure. It is important to check the skin daily for sores!

Actions to protect the skin

- Encourage physical activity and movement
- Turn good skin care into a daily routine
- Instruct parents and caregivers to observe buttock areas; in case of redness, the child needs to lie on the belly, with the back upwards until the redness disappears or darkened parts disappear (for those with black skin colour)
- Avoid chafing. Keep the child away from rough surfaces whenever moving, even moving hands and feet while lying.

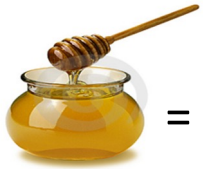
- Keep skin dry by catheterizing daily and good continence management



- On a **chair or wheelchair**: teach the person and family to regularly change position every 15-20 minutes to avoid pressure sores.
- Use special pillows to get pressure off the skin areas at risk (see picture left)



+



=



Actions to take

Prevention of open sores:

- Monitor risky spots: places where bones are right under the skin, where clothes may press against, or where the skin gets wet, for example the buttocks.
- Look for changes in the skin. Skin turns darker or redder under constant pressure.
- Avoid wearing too tight clothing such as trousers or shorts
- **If the skin color does not get back to normal within 20 minutes, address the cause immediately!**

If a sore has already formed:



- Get help from a doctor or nurse.
- Don't put pressure on the sore area!
- Keep the area clean. Wash it gently 2-3 times per day with clean (boiled and cooled down) water.
- Eat healthy food for quicker healing: food rich in protein such as beans, eggs, fish and milk.

Actions if the sore has dead tissue:

- Dead skin tissue needs to be removed to prevent burden of bacteria infecting the wound and to help the wound heal. Ask a specialist nurse for help and instructions.
- If you are qualified to treat wounds, try to clean the wound with a saltwater (saline) rinse carefully. This helps to remove the dead flesh until you reach healthy red flesh or bone.
- Once the sore is free of dead flesh, fill it 2 times a day with organic, pure, clean **fresh honey** readily available in rural areas, to prevent or reduce infection and help healing. This can be pressed deep into the sore.
- Cover with special clean and non-sticking dressing to keep the skin moist and to heal.
- **If the sore does not heal within 10-14 days or if it returns: visit a clinic!**



Card 14

Body functions and structures

Aging with SB

Due to timely treatment and lifelong care, some people with SBH can even reach the age of 90 and older. In a welcoming society and with some extra help they can study, be employed, get married and have children.

Most persons with SB have no intellectual deficit. Towards an independent life some adults need assistance in planning and allowing 'help'. This should be done in full participation and consultation with the person with SB. 'Nothing about us, without us!' 'Assistance' may not mean losing control of your life.

Medically, aging persons with SB have the same problems as other elderly persons. Due to the incontinence and mobility problems, there are some extra risks.

Energy

Adults learn to deal with their body through trial and error, which often slows them down. This remains a point of attention, especially when some bodily functions deteriorate with age.

Obesity

Adults with SB have a higher risk for obesity. Therefore, it is important to stick to a healthy diet and exercise regularly. This has many positive effects on for example the bowel functions, weight balance, immune system, healing of skin breakdown and mental wellbeing.

Changing Body

At all ages body functions may change by growing up. Often walking children need, towards adulthood, more and more technical aids and wheelchairs to ensure mobility. Scoliosis and spinal cord complications may increase.

Sexuality

Sexuality starts with a positive body experience in which intimacy is treated with caution. Relationship is central and full consent at every step is central. Juveniles and adults with SB are fertile. For men with SB, medical counseling is sometimes required to have children. During sex, adults will have to make extra preparations for their incontinence, such as catheterization and performing a bowel wash-out. Adults must be creative to combine pleasure and sexuality with the limitations of their bodies. Fair communication between the partners is crucial in this respect. Further also read Cards 26 and 27 on sexuality issues.

Sexual abuse

Children and adults with SB are known to be at higher risk of sexual abuse. Therefore, it is important that from childhood the incontinence program does not harm the intimacy of the body. The knowledge of the own body, even if you don't feel it, is important. The person must also be strengthened against possible abuses.

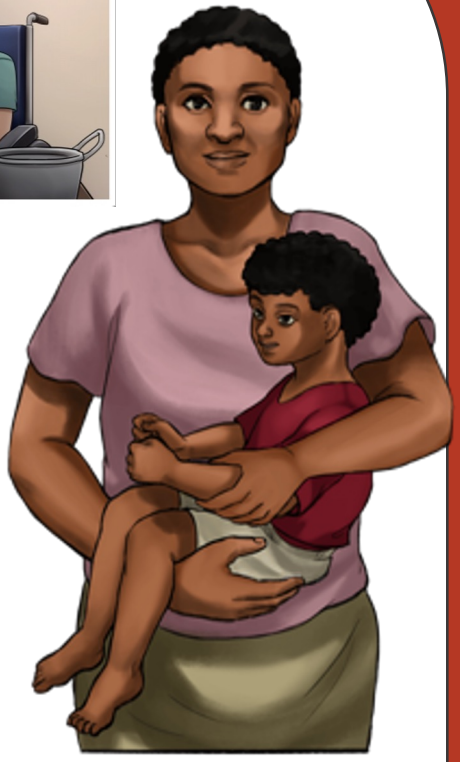












Activities and Participation:

Information and Actions to take



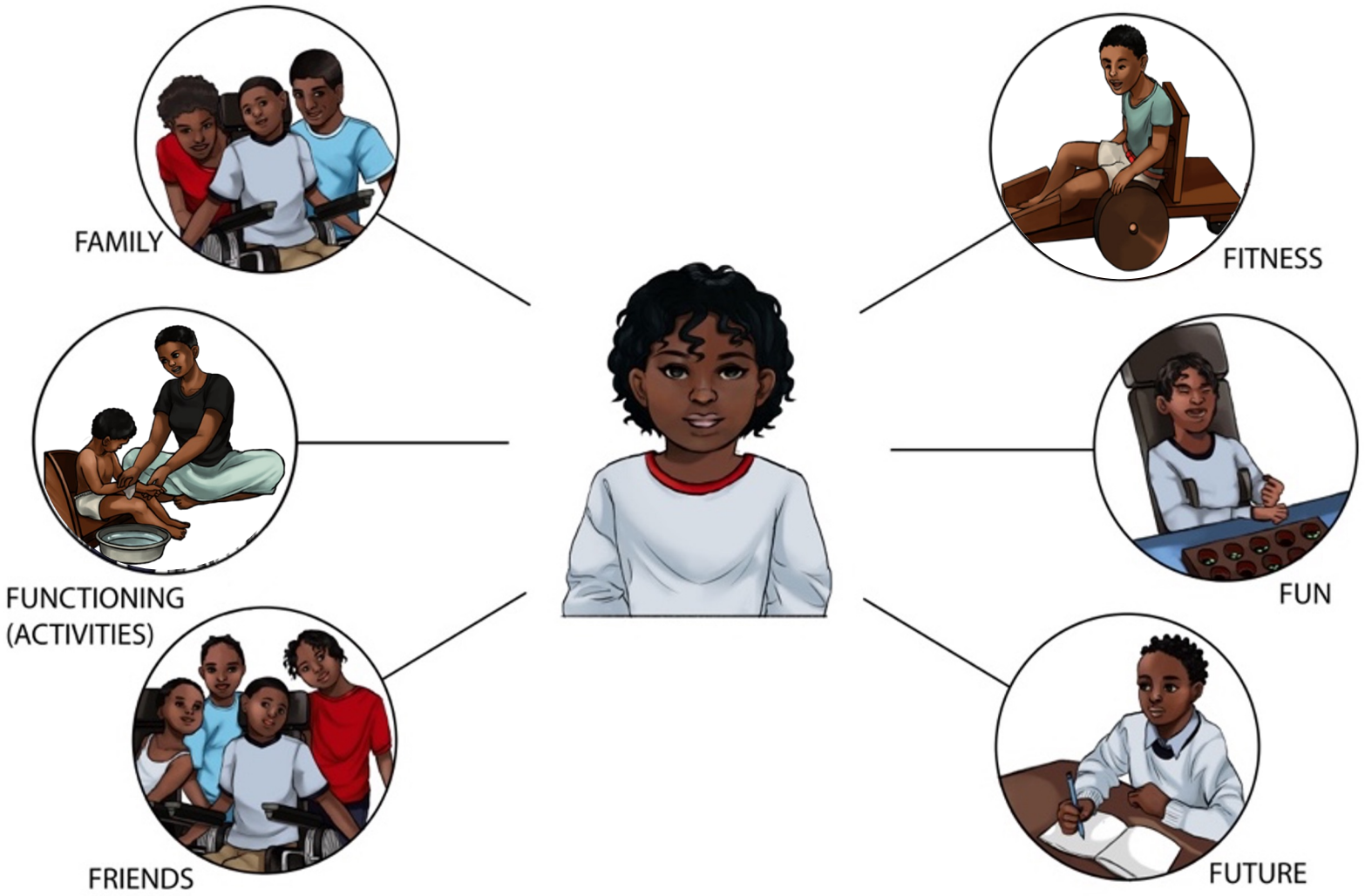






Card 15

Activities and participation



CanChilds' Six 'Favorite' words in the lives of children with disabilities (2018). These are areas in the life of a person that needs 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 children

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 children stay physically active, including exercise and other recreational opportunities

Fun: includes particular activities children are involved in or enjoy participating in

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

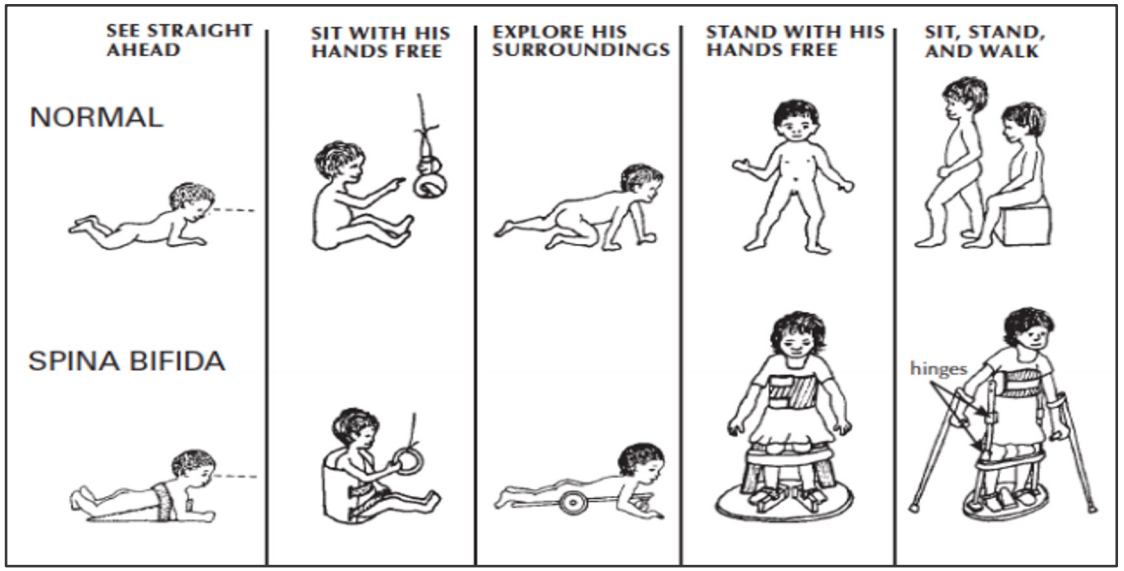
Card 16

Activities and participation

Stimulate development. Give information to the parents on what the child will be able to do and how they can stimulate the development with appropriate means

Many children with spina bifida are paralyzed from the waist down. Despite their disability, it is important for them to develop their bodies, their minds, and their social abilities as much as possible. Certain 'adaptive aids' can be used to help paralyzed children go through the same stages of development as able-bodied children, at close to the same age.

For the child to progress through the early stages of development, **it is important that to assist so that he can:**



Source: *Disabled Village Children*, p.172 (Werner, 2003)

See straight ahead: If she cannot get herself into a position where she can see what is happening in front of her, lie her on a 'wedge' or fix a carton or box so she can sit leaning back in it.

Sit with his hands free: You can make a seat from an old bucket or some other object, so that she can sit and play.

Explore his surroundings: You can make a little cart that helps her to move. The cart can have a handle so that another person can push it.

Stand with his hands free: Make a standing frame that holds her in a standing position. Holding up the weight of her body on her legs will strengthen her bones, so they will not break as easily.

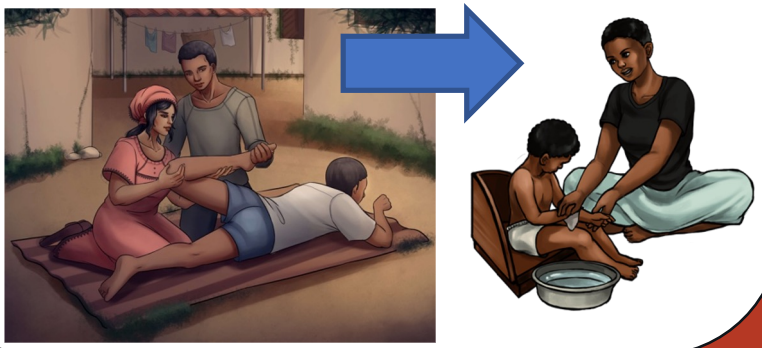
Sit, stand and walk: She can use a brace that holds her up, so that she can walk with crutches. It helps if the brace has hip and knee hinges so that she can sit down.

Stimulate mental skills, self-care and independence

All persons can develop to their own potential. This is influenced by the difficulties discussed earlier as well as being offered opportunities to develop, stimulated to develop and supported emotionally in a way that is motivating and encouraging. A supportive environment is very important. What a child is doing during a day depends on the cultural and personal environment. Connect to that when setting goals and actions There are differences between countries, city or rural area, ethnic groups or one family to the other.



Many therapists and fieldworkers tend to give 'homework/ exercises' for the caregivers to do at home. Usually, they do not consider how these exercises fit within the daily routine, neither do they analyse the daily routine and how to use this. Passive exercises only do not improve functioning in activities of daily life. For that, the person needs to actively be involved in daily life activities such as moving, helping with eating, play or other. Coach the family in practicing skills that are integrated in activities that are close to daily life.



Actions to take

- ❑ Learn what a person likes and use that to connect to a person and get to know each other. They may like to hear stories, watching peers play or just have someone to hold their hand. Ask the family and take your time to build trust.
- ❑ Caregivers are experts of their children. Listen to their story and make an action plan together; team up with the family.
- ❑ Follow the steps of the Rehab cycle: https://enablement.eu/publication/rehapp-flashcards.
- ❑ Keep the 'Six favorite words' in mind when setting goals and making an action plan to support a person and their family. See the Favorite words on card 15.
- ❑ Include the person in (routine) activities of daily life and make it fun. This is like a therapy moment that is good for health and development. For example, you can clean the house or work in the garden and leave the person on a mattress inside if they are not able to move themselves. The person will see and hear and experience almost nothing. Or you can take the person with you, sitting in a (special) chair. The person can watch, hear and communicate with you and learn from that.
- ❑ Focus on the abilities of a person and the families' wishes and priorities.
- ❑ Remember that when a person cannot speak or think well, it can be difficult to know what they are feeling. They may be lonely and unhappy and need friends. Find friends who will visit, talk and play with them. Guide them if needed.
- ❑ The intelligence of children with severe disabilities is often underestimated. They need support and given opportunities to learn and participate in daily life from an early age. Find out what they like, want and don't like by listening, looking at the sounds and movements which is communication.
- ❑ Look at the sequence of steps in child development for goals and actions for children: https://www.dinf.ne.jp/doc/english//global/david/dwe002/dwe00236.html#292

Card 17

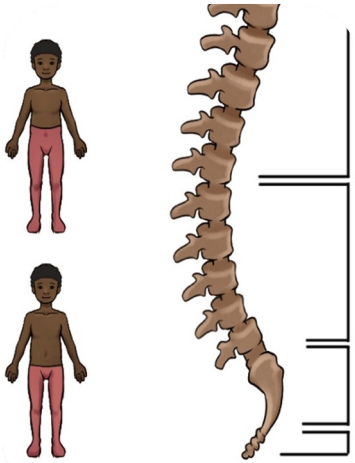
Activities and participation

Card 18

Activities and participation

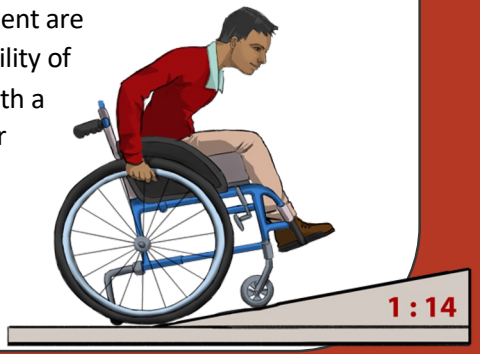
Different levels of mobility

Being able to move around (mobility), or be moved around, is important and provides a way for all people to function and participate in daily life activities, while also stimulating a healthy lifestyle. Some people are more affected by SB than others. The neural damage can vary from part to complete loss of muscle strength. It depends on the level of spinal defect, and on complications in the brain. The higher the lesion in the spine, the more loss of muscle strength, and the less able a person is to walk. The risk of increased damage is higher with open SB than with hidden SB.



Actions to take

- Consult a doctor to learn about prognosis of mobility.
- A mobility prognosis can be made, based on the level of the early mobility that the baby shows. This assessment can be done by a rehabilitation therapist or a multidisciplinary spina bifida team.
- Consult a rehabilitation therapist to help explore different ways of moving around, such as with an assistive device like crutches, walker, a scooter board or a wheelchair.
- Adjustments in the environment are important to ensure accessibility of the house and community with a wheelchair, walking device or crutches, see card 36.



The prognosis of walking abilities varies from independent walking to walking with devices at home to complete dependency on a wheelchair, see below. It reflects the child's capability for participation in society. Functional mobility includes all the methods a person uses to move and interact within the environment, including the need for any assistive or mobility devices (Source: Functional Mobility Scale FMS).



1. Uses wheelchair. May stand for transfers, may do some stepping supported by another person or using a walker/ frame.



2. Uses a walker or frame. Without help from another person.



3. Uses crutches. Without help from another person.



4. Uses sticks (one or two). Without help from another person.



5. Independent on level surfaces. Does not use walking aids or need help from another person (if uses furniture, walls, fences: it's level 4). Requires rail for stairs.



6. Independent on all surfaces. Does not use any walking aids or need any help from another person when walking over all surfaces including uneven ground, curbs etc. and in a crowded environment.

Card 19

Activities and participation

Will my child be able to walk?

Because of SB which is basically a blockage in the neural tube that takes away the feeling and the control of the muscles, for mobility there are three things to take care off:

1. Give answers to the parents' questions about walking
2. Prevent the feet to turn into fixed clubfoot by very early on plastering the feet (Ponseti method). See the chapter on 'Clubfoot' in the app – RehApp – on Google and Apple Store, or here: https://enablement.eu/publication/rehapp-flashcards.
3. Avoid contractures
4. Avoid pressure wounds

Answers for the parents

Depending on where the backbone is open, there will be problems with the body structure and related functions:

Lower back, located high (a):

- the child will likely not walk and need a wheelchair
- cannot control bladder and bowel

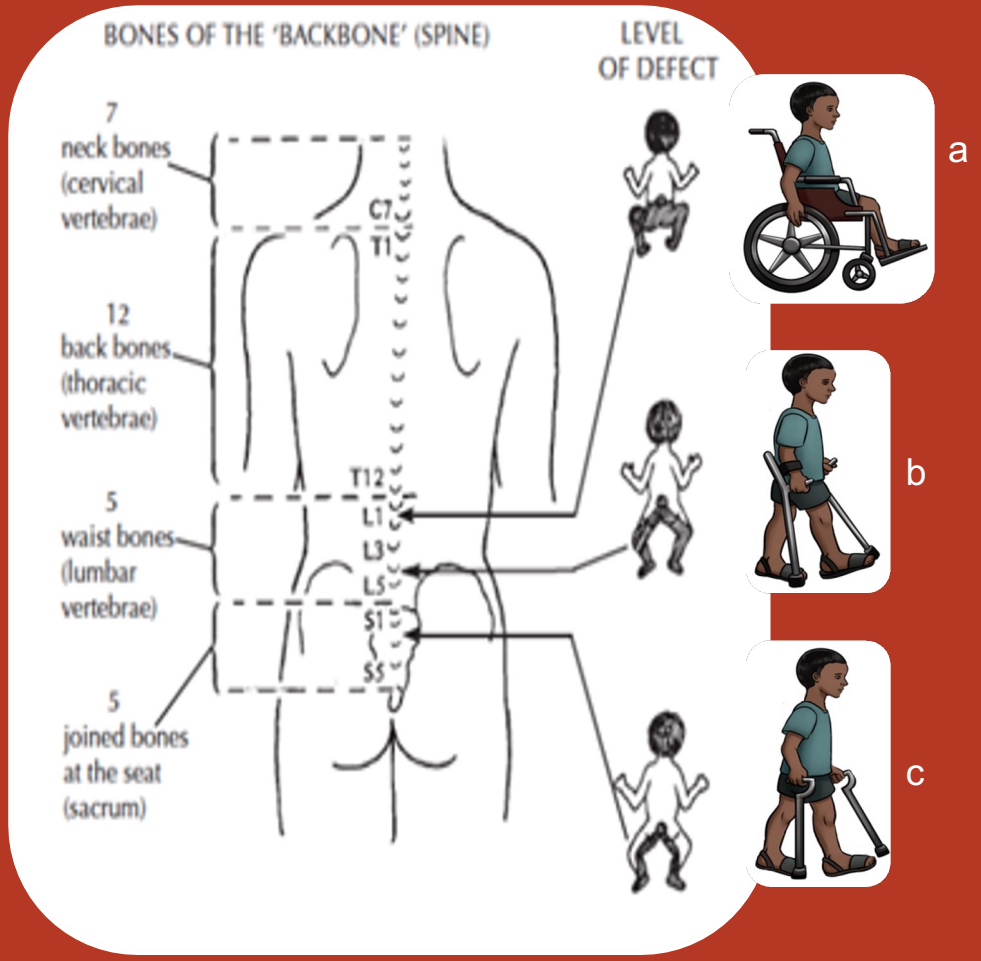
Lower back, located low (b):

- when small, might be able to walk with assistive devices
- when older, may need a wheelchair
- cannot control bladder and bowel

Sacral located (c):

- might walk with little help or none
- might be able to control bladder and bowel
- can have a high-pressure bladder that is dangerous for the kidneys: follow-up is necessary

The most common complications and the associated actions will be discussed in the following cards.



Source: Disabled Village Children (Werner, 2003)

Card 20

Activities and participation

Transfers



When a person is in a wheelchair, it requires specific techniques for moving from one place to the other (= transfer), for example from the bed to the wheelchair. Some people with SB will be able to learn and do this themselves, others might need help. Avoid the use of overhead lifting points, such as handles above the bed or roof handles in a vehicle, as these are likely to cause shoulder problems. Also, try to minimise the number of transfers carried out each day to prevent shoulder injuries but do change positions throughout the day to prevent pressure sores.

Horizontal transfer A wooden transfer board can be used to bridge the gap between the two seats like the picture above. It is better though to lift the buttocks than slide the over the surface, to prevent sores.



1. Remove the detachable armrest if possible.
2. Move the buttocks to the front edge of the seat.



3. Position the feet on the footrest (some people prefer to first place their feet on the bed or in the car, depending on the target seat).



4. Position the hand (closest to the bed) close to the body, and the other hand forward and away.
5. Lift and shift the body onto the target seat with the head rotating towards the pushing hand.



Vertical transfer

When moving from the floor to the wheelchair, you can use a vertical transfer requiring 6 steps. For the helper: let the person do as much as possible by him/herself to prevent problems such as back injuries due to heavy lifting.



1. Place the wheelchair next to you at a 90-degree angle. Put the wheelchair on the brakes.



2. Position the legs with the feet as close to the buttocks as possible.



3. Position the hands with the dominant hand forward and away from trunk onto the edge of the wheelchair and the other hand close to the hip.
4. Lift and rotate the hips to the wheelchair.



5. Position the buttocks on the wheelchair.



6. Move into an upright position.

Gross motor activities



Crawling, walking, balancing, climbing, and jumping are all examples of gross motor activities. Gross motor development in children with SB is frequently delayed or even limited due to the lesion of the spine causing less muscle strength.
Children with a low lesion who can walk, usually start to walk independently between age 2 and 3 years. Children with lesions around the mid back are the ones that later can walk, say at 5 years, while those with higher lesion may never walk but depend on use of wheelchair.

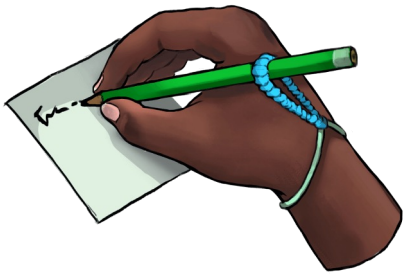
Actions to take

- Avoid high expectations from some families, it is important to have this information embedded too.
- Moving too little, within the person's abilities, can cause development to stop or go backwards.

Fine motor activities

Using cutlery, cleaning teeth, drawing, handling small objects are examples of fine motor activities. Children with SB can have poor motor skills, such as less strength, perception of pain and temperature and positioning of the hands. See here at the right and on the next cards which actions to take. Look at an overview of steps in child development here: https://www.dinf.ne.jp/doc/english//global/david/dwe002/dwe00236.html#292





How can SB affect daily life and development

The development of reaching, grasping, and fine motor skills can be delayed. Decreased strength of the hand muscles, reduced feeling or eye function disorders also have an influence. The intellectual development of the child plays a role in learning and managing activities. This can make play-, learning- and self-care activities challenging.

The movement possibilities of the child depend on the strength of the muscles, on being overweight or malnourished, on contractures in hips and/or knees, and on the overall health. Walking for example, if the lesion is not too high, is extremely exhausting. Therefore, keeping the child motivated to walk is a big challenge for parents.

Actions to take

- Being active daily, moving and being stimulated to move the body and parts of the body, is needed to make the muscles strong and to keep the activity level maintained! Children should engage in 60 minutes or more of physical activity each day, adults should reach 150 minutes each week!
- Being active can be integrated in daily activities, for example in play or leisure activities, helping in household chores (handing objects or helping with parts of activities), helping with self-care activities (even if it can only be pointing to where the clothes are). Coach the person and family to integrate this in daily life.





Card 21

Activities and participation

Card 22

Activities and participation

Self-care

A child with SB will become an adult with SB if the health of the child allows this. Help the child become an adult who can live with their disability and be as independent as possible. Most important is that the caregivers and other family members learn not to do everything for the person. Families can do a lot to help their children or family members carry out activities and participate happily in daily life. Even children with severe disability can often learn important basic skills. Maybe not the entire activity, but they might be able to help with parts which is good for the muscles to become and stay strong and active.

See the to the right and on the next page for some techniques to stimulate self-care. You can explore these techniques and combine different ones if needed. Use assistive devices for sitting and self-care where needed.



Actions to take

- Go through the activities in a normal day and see where the person can do parts of tasks or entire tasks themselves.
- When the child is able and indicating wanting to help with toileting or other ways of bladder- and bowel management, explore with a health professional how the child can help in these activities and do (parts of) them.
- When you dress the child: ask him/her to help (lifting the leg, changing position, reaching out the arm).
- Help the child just enough so that they can learn to do more for themselves. For example, if the child is beginning to hold up their head, and to take things to their mouth, instead of always feeding them yourself, look for ways to help your child begin to feed themselves.
- Try out some of the techniques on this card together with the caregiver and coach the person and caregiver how to do this themselves on a daily basis, embedded in their daily routine. These techniques apply to different types of activities. You can replace the activities below with others you are working on.
- From easy to difficult, you can gradually build skills such as in dressing: cooperating in dressing, removing loose clothes, putting on loose clothes, managing fasteners, little help, tying shoes or sandals.

Verbal instruction

Explain to the child by words step-by-step what he/she has to do, guiding them through the activity.



Card 23

Activities and participation

Hand over hand

Put you hand over the hand of the child to guide the movement of washing the body.



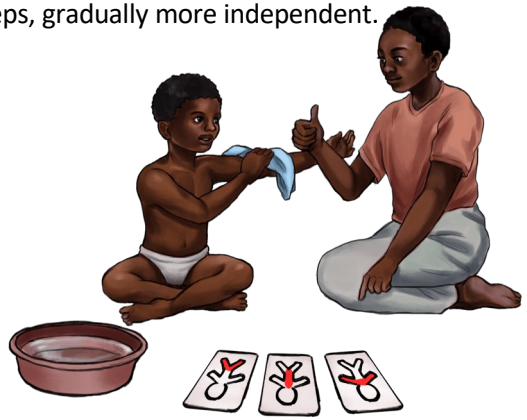
Mirror

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



Drawings to show sequence

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



Clothing ready in a row

Put the clothes in front of the child while sitting in the corner of the room. Help with words and if needed physically if child gets stuck.



Helping aids

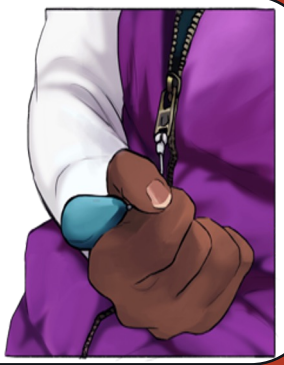
If handling the clothes is difficult, talk with a therapist to see if you can make small, low cost helping aids such as a key chain on the zipper to pull down and up easier, adapted cup or bottle.











Card 24

Activities and participation

Participation in the community

People with SB and their family often experience social barriers. It is necessary for social barriers to be taken down, it is a human right to be included and participate in society.

Most adolescents and young adults with severe SB are wheelchair dependent, and they catheterize themselves or need help catheterizing several times per day. To prevent isolation in the home, they need to have access to facilities to do this in a private area as there is often a lot of stigma about this. These facilities are necessary for an to be as independent as possible and participate in family- and community life.

Actions to take

- Fieldworkers play an important role in addressing stigma and social barriers. Make sure that the person with SB, like any other person, is included in all social activities within the family and community such as events, joining the parents for example to the market. If needed, educate the community about human rights for all.
- Provide support in making home and public areas accessible for people using assistive devices.





Social activities

People with SB are often excluded from social activities in the community or with friends due to misconception of the impairment or other reasons. Problems with bladder and bowel management may lead to staying at home as the person might soil themselves when outside then may smell bad, which leads to feeling ashamed and being stigmatised.

Actions to take

- People may need help getting to a friend's house or need physical support to play with other children.
- Peers might need explanation how to play in alternative or adapted ways and how to support their friend.



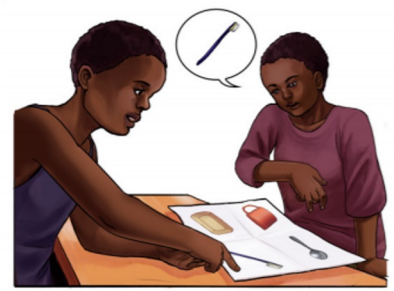




Learning capacity

Some persons with SB have cognitive difficulties depending on the severity of the SB and shunt complications. In the first years of childhood, children and parents are often preoccupied with the accompanying medical disorders, hospital visits and treatment that developmental delay often go unrecognized and are misunderstood by parents, family, teachers and community members.

The child may find it difficult to focus on a task, to follow instructions or with reading comprehension. Speech and language are intact but processing visual information might be difficult. Memorizing information can be difficult, as well as planning, organising and initiating tasks. Many children with SB achieve basic self-management, depending on the severity of their condition, yet often lag 2-5 years behind their typically-developing peers. If available, an occupational therapist or special teacher can support in practicing skills that are challenging.

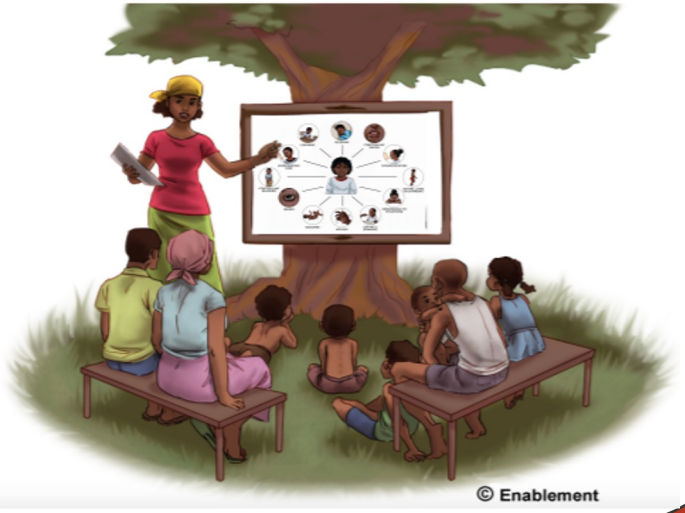






Actions to take:

- Use healthcare appointments and follow-up meetings to develop functional and for the person meaningful goals and monitor progress.
- Find support of an occupational therapist or special teachers, if available, to help practice daily skills and learning skills that are delayed or challenging.
- Support parents to develop an action plan with strategies to support their child's independency and participation in activities in their community and school.
- Encourage participation in activities such as family- or parent group activities that provide safe places to develop peer relationships with children or adults who may have the same condition and challenges.
- Work with people with SB and their families together to address personal barriers such as bowel/bladder care, medical events, assistive devices, as well as environmental factors that may affect meaningful activities and participation.
- Organise support groups to exchange experiences and peer-to-peer support. .



Card 25

Activities and participation

Card 26

Activities and participation

School

Many children and youngsters with SB in low-resource settings do not go to school 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 child's needs and may be hesitant of enrolling or supporting the child. There are 4 areas in which a child with SB may require extra support in school:

1) Bladder and/or bowel management;
2) Mobility;
3) Learning activities and;
4) Possible other problems (epilepsy, vision impairment).

Guide parents in finding the right school. With support to learn, by using assistive devices if needed, such as a wheelchair, pen adaptation or accessible toilets, going to school may be possible. Encourage directors and teachers.

Children with SB may be absent from school more regularly due to medical needs and appointments. It's important the school accepts this.

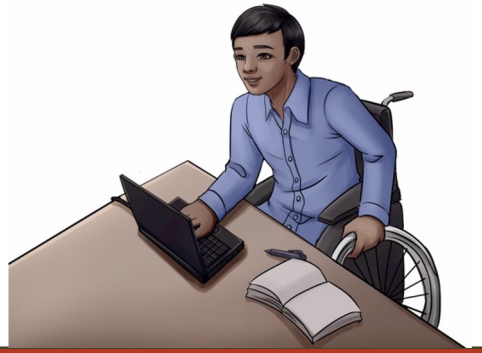
Actions to take at school:



- Provide health education about SB.
- Explain rights of every child to go to school and learn.
- Arrange more time for school- and self-care activities when needed.
- Break down large tasks into smaller tasks.
- Allow peers to assist the child with SB.
- Provide practical learning materials to use in class such as black or white board, leaves, shells, stones, which can be used to teach counting or to learn about shapes.
- Teach the child how to answer questions in relation to SB to decrease any bullying that can lead to drop out of school.
- Use locally available materials to adapt the school environment for example movable wooden ramps, private and accessible toilets, wheelchair accessible desk, supportive seating. See cards of environmental factors for examples.

Work

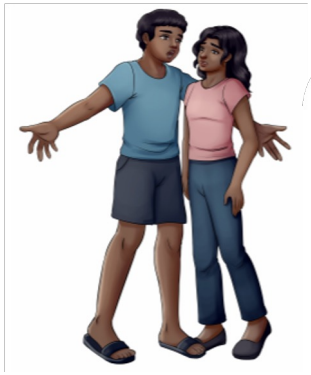
It is important to guide young people and adults with SB in finding a job they like and can do and where they can receive more support. They may experience difficulties in finding or maintaining a job. Integration into work and community life is important for quality of life and life satisfaction as well as self-sustaining. In addition, work provides opportunities for making friends.



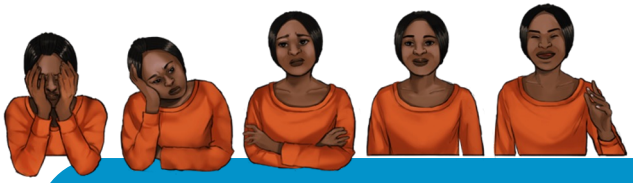
Actions to take at work:

- Coach the person with SB to find work. Discuss together what the person is good at and explore different options for work, for example making and selling soap, tailoring or administration work.
- Provide information on SB to employers. Explore together, employee, employer and fieldworker, which activities and tasks are feasible and discuss a tailor-made work schedule if needed.
- Discuss with the employer if any structural modifications are needed, such as to ramps, working on ground floor, accessible toilets and parking.
- Encourage the employer to modify where needed the direct workplace such as room for the wheelchair to move around, arranging a seat and/or desk at the appropriate height, and toilets seats, modified workspace. See card 37 for home modifications.

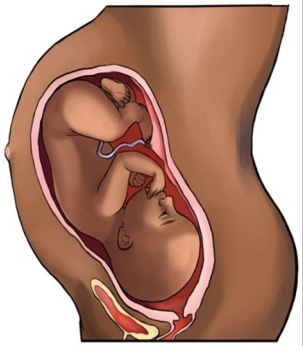








Personal factors:
Information and
Actions to take





Card 27

Personal factors

Personal wishes and needs

Every person, with or without disability, has wishes and needs. Also, when a person cannot speak or doesn't seem aware, that person has needs. Everyone has the right to well-being. These wishes and needs must be taken into account when discussing priorities for intervention and setting goals and actions.

Actions to take

- When talking with families, always include the person you are talking about.
- When a person cannot speak, use alternative ways (see 'communication' in the previous cards) and observe body language and facial expression when talking with the person and the caregivers.



Social skills and boundaries

Social skills include being able to manage yourself, being self-aware, being aware socially of the people around you, being able to make decision in an appropriate manner, solve problems and skills in relationships. Social skills are needed in different areas of life such as at home, friends, school, work, when meeting people and having a love life when grown older. One of the things that is needed is personal space and understanding when just talking or touching is appropriate. Knowing when you can trust a person. When a person has a disability intellectually or is not used to connecting with people, it might be difficult to develop social skills and understand social boundaries. This is important to prevent unwanted contact.

Actions to take

- Talk to the person and caregivers to identify any difficulties. Is there a difficulty in understanding physical and social boundaries or is it difficult for a person to protect oneself, for example when a person is home alone and doesn't have the social or physical capacity for self-protection.
- Discuss with the person, the caregivers and family how to teach about social skills if this is a challenge. This does not mean it is a challenge for all people with SB.
- If there are any signs of abuse or neglect, take appropriate measures for social justice and protection.



Card 28

Personal factors

Mental support

Children and adults with SB may feel insecure and have low self-confidence. They can feel less valuable or rejected. They might feel ashamed because of their incontinence or their wheelchair. Youngsters may feel anxious, insecure, or unloved because of their condition. Children with SB have shown a more negative outlook on their quality of life than their peers. Children with a positive attitude towards SB, future expectations, and coping skills are more positive about their quality of life.

If you sense that there is depression that grows worse, refer to a specialist immediately. It can lead to a variety of emotional and physical problems, such as loss of energy, a change in appetite, sleeping more or less, feelings of worthlessness, and thoughts of self-harm or harm to the person with SB.

Actions to take

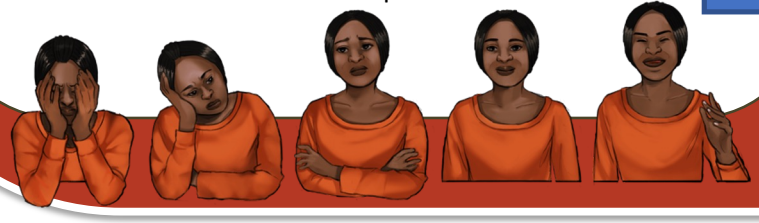
- Be sensitive to the stages of emotional distress (e.g. exhaustion, worry, depression, anger)and provide mental support and courage to hold on. Refer if needed!
- Provide the child and family practical and mental support for developing resilience and learning to live with their strengths and weaknesses. Help find alternative ways where needed.
- Listen to their stories, encourage to seek social support from family, friends, peers and community members to help provide a positive sense of the future.



Caregiver's role

The caregiver assisting the person with SB is crucial in improving and maintaining quality of life. SB can vary in severity. When a child has a severe disability, more support is needed from caregivers. At all times, it is important to include the wishes and needs of the person with SB, but It is also important for the caregiver to be conscious of the following:

- The responsibility this entails in life, and where to find support.
- The impact of caregiving on the caregiver and preventing physical and mental overburden.
- The goals the caregiver, or the person with SB themself, wants to achieve or maintain for the person with SB.



Actions to take

- Coach caregivers to understand what they can do in their daily life routines and in their skills as caregivers.
- Help to manage caregiver stress and/or fatigue.
- Avoid over protecting the person with SB by not allowing him/her to use his/her full functional potential in daily life.
- Help the caregiver to find up-to-date information about SB and upgrade his/her knowledge and skills on how to take care of their child and stimulate development.
- Answer or seek answers with health professionals to questions of persons with SB and caregivers.
- Provide realistic information on (re)habilitation outcomes together with a health professional.
- Include them in your interventions by making decisions together. This will improve your collaboration together.

Card 29

Personal factors

Peer counseling

Peer counselling consists of emotional and practical support provided by people in similar situations, such as other caregivers of persons with a disability. Peer counselling can be an asset to a caregiver that recently learned the child has SB or for youngsters with SB. Still, the peer counsellor should be aware that everybody has his unique coping style; experiences and practices can't just be replicated without adaptation to the person and the context. Peers can answer questions on how to take care of the child in daily life, share experiences, knowledge and skills. Peer support can be directed at the individual caregiver or person with SB as a "buddy", but also at caregivers in the form of family counselling, or as group counselling.



Learning your child has SB is a life-changing event for both the person with SB and their family. They may ask themselves why this misfortune overtook them. For spiritual support, they may benefit from consultation with a religious leader – a priest, an imam, a rabbi- or from partaking in religious rituals. It is good to be aware that not only practical support is needed but also spiritual support, if it is not harmful or causes financial problems.

Actions to take

- Be aware of what support is asked from and provided by traditional healers and that this does not do harm to the persons' body such as making burns or cuts to the back.
- Connect the caregivers to other caregivers or parent support groups. These groups can provide mental support but also livelihood support by organizing soft loan systems.



Card 30

Personal factors

Relationships

Individuals with SB have the same needs and desires for affection as everyone else. With the right information and help they can have a satisfying relationship at an appropriate age. However, there is a possibility that partners may find it difficult to establish or maintain a relationship with someone with SB. Therefore, also pay attention to the questions and needs of the partner.



Sexual functions

Young adults with SB generally feel not well informed about sexual health. The construction of genital organs is normal in boys and girls with SB, but the functions can be disturbed. Because of the spinal cord damage, they can experience sensory loss and paralysis. Many factors may affect a person's ability to position herself during sexual activity, including level of mobility, history of weak bones, and fracture risk.



Actions to take:

In collaboration with medical experts, provide information, and guidance about:

- ❑ **Support groups:** Encourage children, adults, and their families to share information in support groups or peer to peer conversations.



- ❑ **Sex education:** Education about sexual function should be provided in the pre- and early teen years to both sexes in order to increase their sexual satisfaction and quality of life, similarly as you do with all children. Preferably, the education should be given by a fieldworker of the same sex. 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.

- ❑ Children and young persons with disabilities are more prone to sexual abuse than typically developing people. Provide information on child protection, keeping physical care private and reporting assault and abuse to both the child and parents. See "**Safeguarding**" at card 32 for more information.

- ❑ **Sexually transmitted diseases:** Protection against sexually transmitted diseases (using latex-free condoms as they are likely to be allergic to latex), as well as birth control.

Card 31

Personal factors

Fertility

The fertility of many men with spina bifida is minor. In women, fertility is usually not disturbed, however, extra checks are required during pregnancy. Due to inadequate sex education, people with spina bifida are less likely to use birth control when sexually active. Erectile and ejaculatory function will vary in a male with SB, depending on the level of the lesion. Men with sacral lesions are usually able to ejaculate, but this is uncommon for higher lesions.

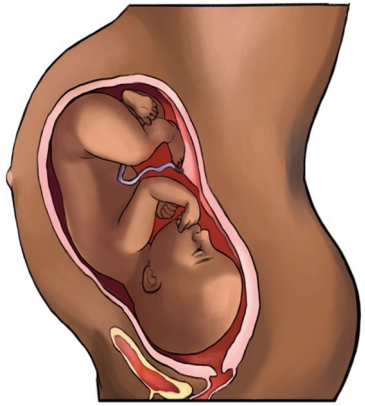


Pregnancy

During pregnancy, complications can occur such as pain, prolapse of organs, and pelvic instability. Women may worry about their child having a disability. Women with SB have an increased risk of obstetric complications. The inability to ambulate is highly correlated with the need for cesarean delivery.

Actions to take

Make sure that the person receives medical assistance in case of pregnancy. This is very important!



Actions to take:

In collaboration with medical experts, provide education, and guidance about:

- **Pregnancy:** Educate men about the risk of giving SB to their children because of heritability. Women with SB who would like to conceive are advised to see a gynecologist for assessment. They need to be advised about taking folic acid (*see introduction*). Make sure women go to extra check-ups and assess if the pregnant has fears or insecurities. Assess if the (future) parents need any help.
- **Hygiene measures:** Both sexes should understand that practicing good hygiene and maintaining good bowel and bladder schedules play important roles in developing healthy, happy relationships.











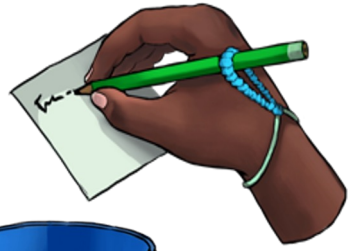
Environmental factors:

Information and
Actions to take















Card 32

Environmental factors

Rights

People with disabilities have the same human rights as other people. Unfortunately, lack of mobility, adaptive equipment, education and support, accessibility, discrimination, and lack of social acceptance create serious barriers to freely exercise these rights. Older people with disabilities may have lost their belief in having human rights already. They should be empowered and protected, receive support by informing the community and to participate in the community. The community needs to be taught about inclusion of all people in all areas and activities of the communities. All these subjects apply for home, school, university, communal areas, professional institutions, clubs and (adaptive) sports.

Safeguarding

Abuse because of disability happens a lot. Especially girls are at risk because they are not always able to protect themselves. Abuse can occur in different ways: neglect, physical abuse, psychological abuse, emotional abuse, and sexual abuse. Teaching the community, a person with SB and family to understand social and physical boundaries may help inclusion in the community and respecting boundaries in social contacts and physical relationships.

SAFEGUARDING REQUIRES SPECIAL ATTENTION.



Actions to take:

- Download and read this document online for more information on rights for persons with a disability: https://www.un.org/esa/socdev/documents/disability/Toolkit/Intro-UN-CRPD.pdf. This is an easy read version: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/345108/easy-read-un-convention.pdf.
- Use this document to explain rights to children: https://www.unicef.org/publications/files/Its_About_Ability_final_.pdf
- Download and read this document online for more information on sexual and reproductive health and rights: https://www.dcdd.nl/everybody-matters-stories-and-practical-tips-to-put-an-often-neglected-topic-on-the-map/
- Create awareness in the community for the rights of people with a disability, which are the same for all community members.
- Create awareness of the network of the person with SB for signs and symptoms of abuse.
- Inform persons with SB, their families, and community members about self-protection, justice, and how to stand up for their rights.
- Encourage planning and use of support services (e.g., legal, in college) for safeguarding, self-management and independence.



Card 33

Environmental factors

Livelihood

Having to visit health clinics, hospitals, and rehabilitation centers regularly prevent persons with SB, parents or spouse from being able to work and hence results in a loss of income, especially for single persons. Some organizations 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 receive care easily.





Actions to take:



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

Healthcare

Individuals with SB may find it difficult to access both routine and preventive health care services. The accessibility to wheelchairs or people with limited balance, and lack of knowledge about recognition of common medical conditions related to SB form challenges. The transition of child centers to the adult orientated healthcare system makes it more complex. This may result in avoiding routine and preventive healthcare.



Actions to take:

- Assess which difficulties children, adults and the family face in their access to healthcare. Use the Flashcards “Rehabilitation Cycle”, see https://enablement.eu/publication/rehapp-flashcards.
- Promote routine + preventive healthcare to prevent health issues!
- Provide education to health professionals about SB. Be willing and able to take the time to appropriately communicate with and manage the (complex) health care needs.
- Provide follow-ups related to SB, to prevent side-effects.
- Help to foresee in the basic needs, development, own decision-making and inclusion in daily life for the person with SB and his or her family.
- Help the person with SB and their family transition from a pediatric clinic to an adult clinic when the time is there.

Card 34

Environmental factors

Family counseling & mental support

Having a child or spouse with SB 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 SB is often high.

Overprotecting the child with SB may result in lower independent abilities of the child. The home needs to be a safe place for the person with SB. Being supported by parents, siblings or spouse will improve mental health for example with supporting and practicing activities or involving in adaptive household tasks.





More actions to take:



- Listen, ask, identify priorities, observe, identify strengths & difficulties, make a plan, support actions, monitor it, and evaluate with the family and the person with SB.



- Advise a team of practitioners with knowledge of SB issues to support the family with a child, adult, or spouse with SB.



- Give the person with SB and his/her family practical and mental support to use their strengths and address difficulties.
- Teach the person with SB and parents/ spouse 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 about independent living, self-sustainability, managing medical care, and self-care.



- Identify any discrimination problems in the community. Create awareness in the community about SB.
- Get community members involved in the life and rehabilitation of the person with SB and his/her family.

Card 35

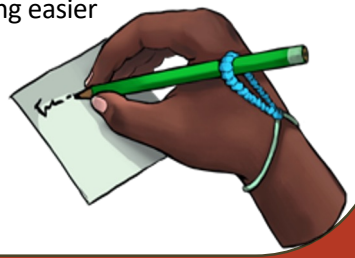
Environmental factors

Assistive devices

Assistive devices have a huge effect on being able to do activities and participate in daily life. When you observe the person has activity limitations, consider if adapting daily materials can support the activity. If this is not sufficient, an assistive device such as a wheelchair, supportive seat, walker. Home and/or community adaptations might be needed.

There are several types of devices and adaptations. These devices can help children to:

- move around
- eat by themselves or make feeding easier
- communicate
- go to school
- play by themselves
- play with their friends
- or become more independent



Actions to take

Refer to an orthopaedic technician, an occupational therapist or physiotherapist when:

- the person does not have but needs an assistive device;
- the person has pain or cries when placed in the device;
- the person cannot sit or stand up straight in the 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: find out first why.





People with SB that have difficulty walking could benefit from a wheelchair, crutches or walker to move around. People who need support sitting upright can benefit from special seats. It is important the person changes positions regularly during a day to avoid stiffness and pressure sores. The seat of the (wheel)chair should prevent skin problems, maintain posture and enhance independent mobility and functioning.

Besides mobility devices, there are also assistive devices to support and improve self-care, learning, work, social activities or play. Connect to an occupational therapist, physiotherapist or technician for advice and attaining suitable devices.



How to make a flat toilet higher for easy sitting



Strong, wooden transfer board to slide from (wheel)chair to bed or back.

Card 36

Environmental factors

Mobility devices

Standing on 'your own feet' and/or moving around in an alternative way, e.g., by wheelchair, gives a person the ability to go where they need and want to go. It enables people to self-support, perform activities, and participate in daily life.

With a scooter board, the young child can move around while arm strength and sitting balance are trained. With a wheelchair or walker, the child or adult is less dependent on family, schoolteachers, and others. Make sure the mobility devices are adapted to the individual, with the correct size, according to the physiotherapist or occupational thera







Actions to take

- Observe activity limitations and consider if mobility devices are needed. If so, refer to an organization that provides assistive devices and support the family throughout this process.

Standing devices

By putting weight on the legs and stretching the legs while standing, contractures of muscles are less likely to occur in the ankle, knees and hips. A standing frame (see picture below) can be made and fitted to help strengthen the muscles. Usually, this frame is used for about half an hour, two times per day. Make sure it is safe and provide opportunities for the person to play with and enjoy while standing.

Sometimes splints are needed for the feet to support standing and/or prevent contractures in de ankle.

Actions to take

- Identify if these devices are needed and help with acquiring this through a medical centre and specialist.
- Be aware of skin breakdown from wearing or standing. If skin breakdown occurs, go back to the specialist. See card 13.



plastic splint



simple splint made from a sandal



shoe adapted to be a splint



Standing frame

Card 37

Environmental factors

Actions for home or community modifications

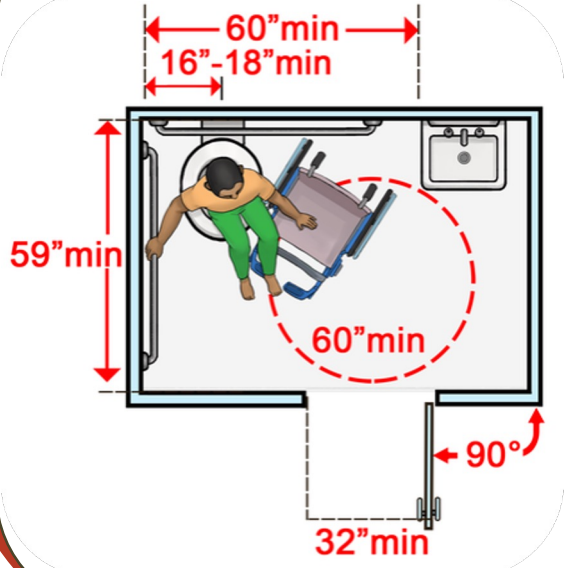
- Discuss with young adults with SB and family their expectations for independent living, accessible housing, finances and local organisations to approach for support in these areas.
- When the house has different level heights, install ramps in or around the house for wheelchair users.
- Remove obstacles one can easily trip over or bump into.
- Install handles at doorways to support moving and keeping balance.
- Ensure sufficient turning space (minimum of 60 inches) to rotate the wheelchair on the spot.
- Doorways should have a minimum width of 32 inches.
- Tables and kitchen sink should be wheelchair accessible
- Keep inventory and cupboards within reach.
- The toilet commode should be at the same level as the wheelchair.
- Install grab rails alongside and behind the toilet.
- Use a plastic chair with a hole and splat screen over flat toilets.

Sitting at a table

If trunk balance is challenging, using the arms and hands, such as for eating, fine motor skills, play and (school) work will be easier to do at a table. A table in which space has been cut out for the trunk to position the arms better. The size of the table must be adapted to the height of the person while sitting down.



Living room modifications



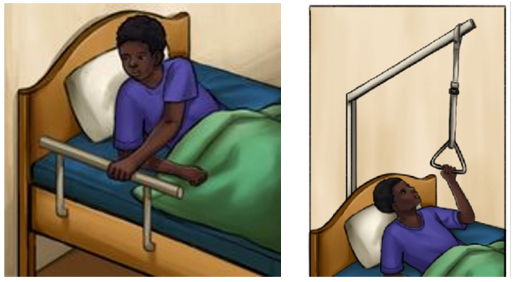
Kitchen modifications

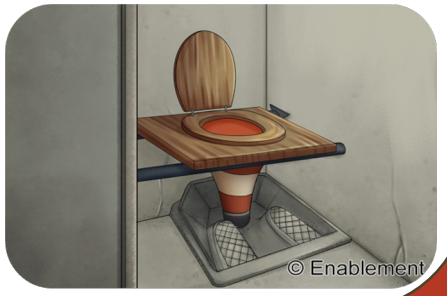


Bathroom modifications



Bedroom modifications





Card 38

Environmental factors

Moving outdoors

Inaccessible environments can make use of wheelchairs, walkers and crutches difficult. A bumpy road is not wheelchair-friendly, especially if the tires are thin, or the destination is simply too far. This may disrupt participation in the community for the person with SB. It may also be that parents have no means to take their child outdoors or experience stigma when using public transport. A wheelchair with large wheels or tri-bike can help move around in the community.



Being independent outdoors

Going to school or work will be easier if the child or adult is as independent as possible. Modifications at home will not always be available at other locations such as communal buildings. Things like being able to go independently to the toilet may be encouraging in feeling comfortable doing activities outdoors. Occupational therapists or physiotherapists can help find ways to perform these kind of activities outdoors. As a fieldworker, you can help with practicing these actions in similar situations.



Actions to take

- Check if there are difficulties when the person with SB goes outdoors. Ask for specific problems and observe these.
- If you identify stigma in the community, raise awareness among community members. Explain that SB is not contagious, and every person has the same rights.
- Practice appropriate community activities with the person at home and in the community.
- Check if transport is a problem for the child or adult with SB and its family to go to school, work, or medical treatments. If so, refer to a technician, physiotherapist or occupational therapist.
- Explore to what extent the community can help the person with SB within community activities or moving around?
- See these flashcards and manuals for making marketplaces inclusive: https://enablement.eu/publication.



The content of these Flashcards is made with the support of:
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Stichting INTERPLAST HOLLAND

LIGHT FOR THE WORLD

Norges Handikapforbund

NLR

IFSBH

PLAN INTERNATIONAL

Sightsavers

VRHL

Card 39

Contact & colophon

Card 40

Colophon

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When drafting the content of the Flashcards, several resources were particularly helpful:

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