



Deafblindness

Basic principles

A parent's manual

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Introduction

The idea behind this booklet was conceived in a car on a bumpy road in Malawi, where Ms Lilian Mariga, first showed me a copy of a teachers manual for supporting children with disabilities. The manual was comprehensive and detailed, and well used. An idea started to grow; Ms Marigas manual should be adapted to provide information on deafblindness. And – it should be accessible for not only teachers, but for parents and for all persons who interact with persons with deafblindness. Knowing that many of the persons we wanted to reach with information on deafblindness were illiterate, a more radical approach was needed. A whole new manual had to be developed, where the information should be communicated through illustrations primarily.

Deafblindness is a distinct, low incidence disability. Within this small group of persons with deafblindness, there are great variations between each individual. Some persons with deafblindness have some usable vision and/or hearing. Some persons with deafblindness have additional physical, medical and/or cognitive challenges. Some persons have deafblindness from when they are born and before language acquisition; congenital deafblindness. Some persons develop deafblindness after language acquisition; acquired deafblindness. All this results in huge individual differences between persons with deafblindness.

This booklet takes use of the Nordic definition of deafblindness: Deafblindness is a combined vision and hearing disability. It limits activities of a person and restricts full participation in society to such a degree that society is required to facilitate specific services, environmental alterations and/or technology.

The idea of trying to simplify the complicated field of deafblindness into illustrations, was considered to be almost impossible, and feared to result in a manual that will not fit all,

only a few, and possibly even be harmful to some. To make the challenge even worse: We are quite certain that this booklet will be copied and distributed outside our control. Hence, the illustrations had to be developed to be copy-friendly, and to be able to stand alone, without any further information other than the short texts that follow some of the illustrations.

The booklet you are holding in your hands is the result of a desire of making very easy and accessible, something that is very complicated. It is meant to provide an overview of the basic principles on how to interact with persons with deafblindness. The primary target groups for the booklet are parents, families and other persons who are close to persons with deafblindness.

However, we hope that the booklet can be an inspiration for teachers and other professionals, and be used as a starting point to provide information about deafblindness, and to discuss how to best interact with persons with deafblindness. If the booklet is successful, it will be developed further in the years to come, with more information and more details.

Oslo – October 2015 – Kenneth Verngaard, the Signo Foundation

1. How to interact with a child with deafblindness

Figure 1



The most important for a child with deafblindness is to not be left alone over time.

Figure 2



Communication is all about sharing something with another person.

Communication can be between two persons...

Figure 3



... or between several persons.

Figure 4



Communication never happens when someone is alone.

Figure 5



Figure 6



When you are together with persons with deafblindness you need to be physically close to the person for her/him to know that you are there.

Figure 7



When you are together with persons with deafblindness you need to be physically close to the person for her/him to know that you are there.

Figure 8

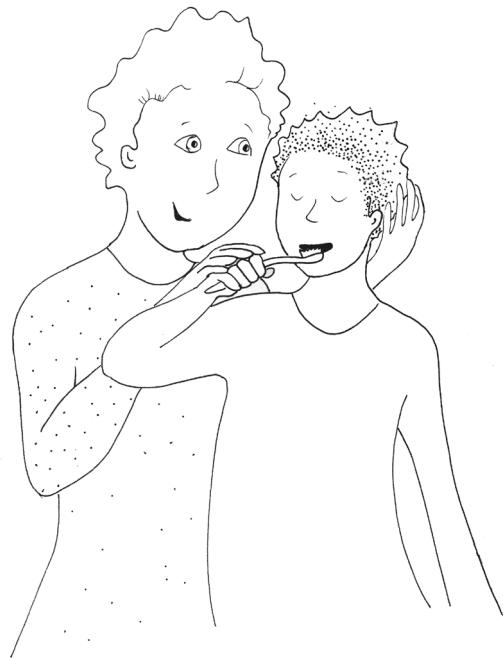


The hands are one of the most important means of communication.

Figure 9



Figure 10



A child with deafblindness learns to communicate in all situations where she/he is together with someone who understands the child's individual expressions.

When the child is doing the Activities for Daily Living (ADL).

Figure 11



When the child is playing.

Figure 12



A child with deafblindness learns to communicate in all situations where she/he is together with someone who understands the child's individual expressions.

When the child explores the surroundings.

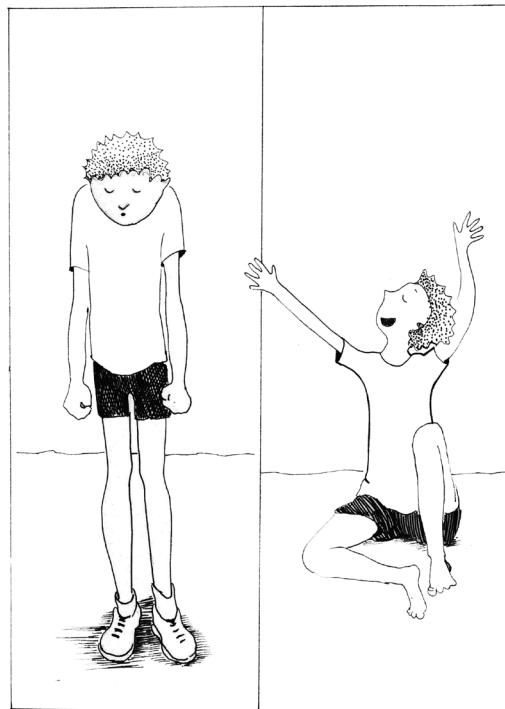
Figure 13



When the child is doing chores.

2. Communication - Bodily expressions

Figure 14



Your child is always communicating with the whole body. Movement, facial expressions, sounds, pointing: everything is communication!



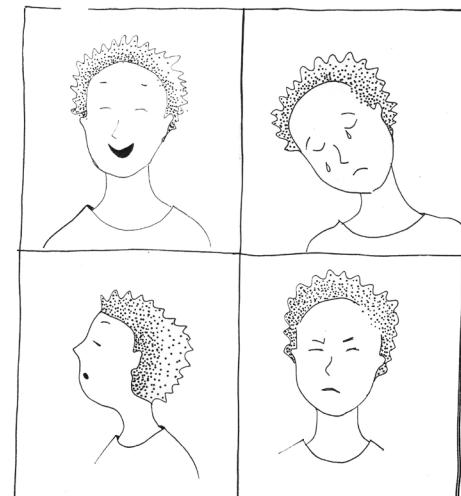
Your child will communicate what is important to her/him at all times.

Figure 15



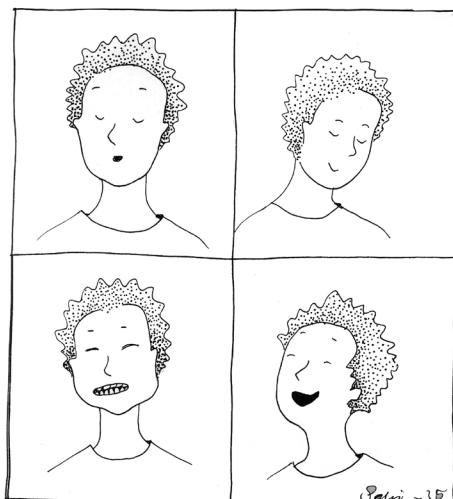
Pointing

Figure 16



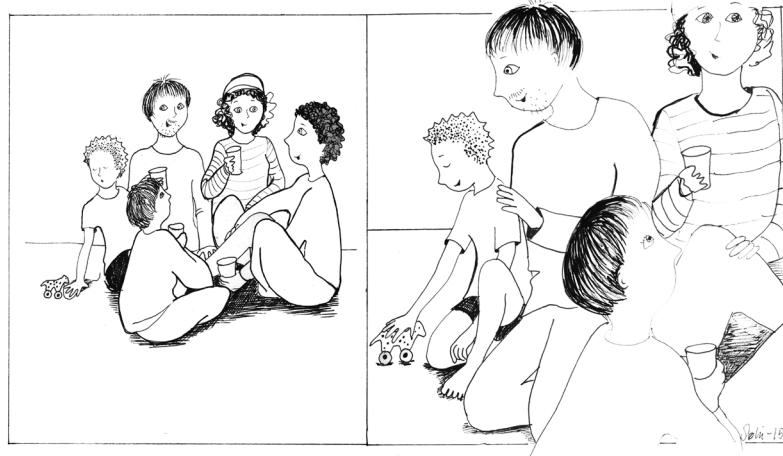
Your child is always communicating with the whole body. Movement, facial expressions, sounds, pointing: everything is communication!

Your child will communicate what is important to her/him at all times.



Emotional expressions

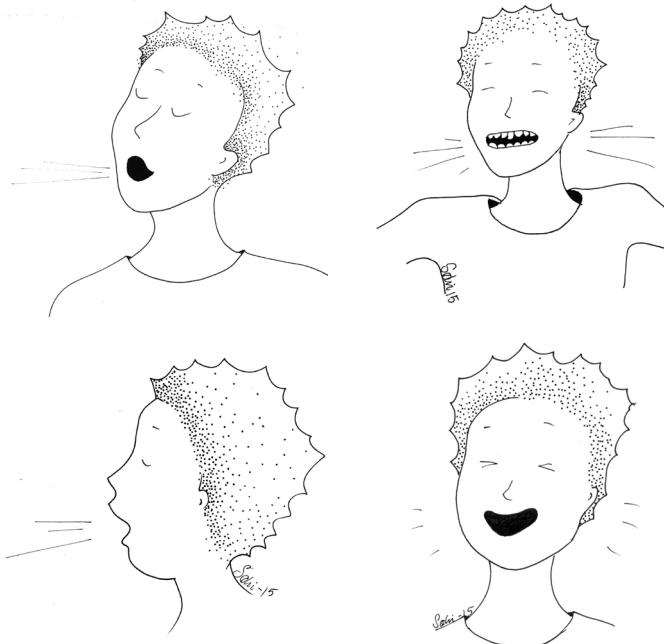
Figure 17



Movement and attention

Your child is always communicating with the whole body. Movement, facial expressions, sounds, pointing: everything is communication!

Figure 18



Your child will communicate what is important to her/him at all times.

Voice and sound

Figure 19



Your child is always communicating with the whole body. Movement, facial expressions, sounds, pointing: everything is communication!

Your child will communicate what is important to her/him at all times.

3. How to establish and maintain contact

Figure 20



You observe the child sitting on the floor with her/his toy.

Figure 21



Contact the child by gently touching the child's shoulder...

Figure 22



... or the child's arm.

Figure 23

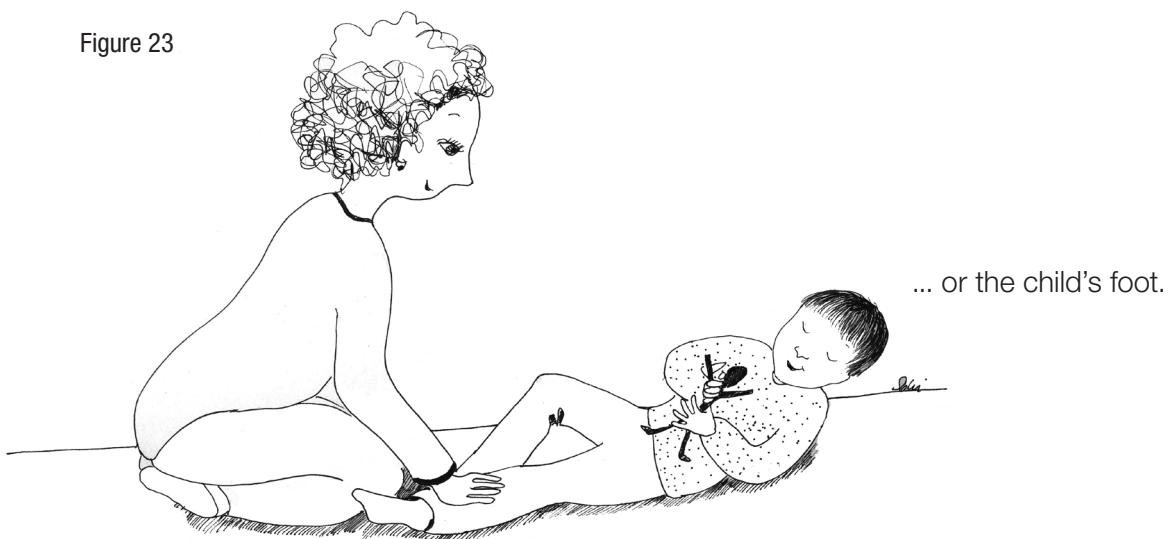


Figure 24

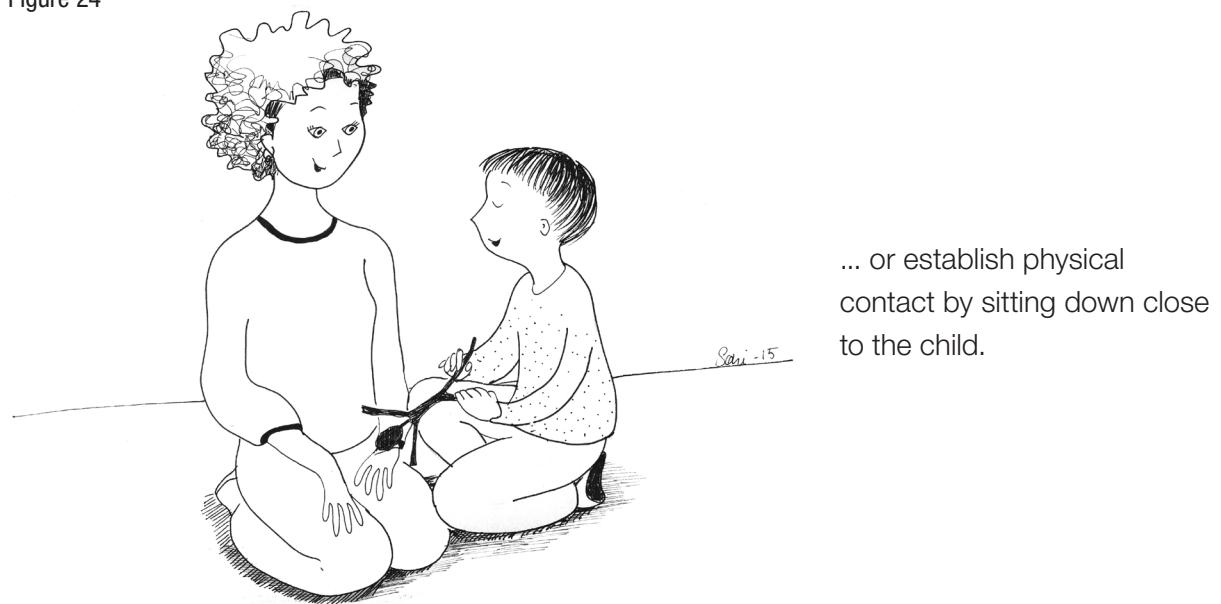


Figure 25



Let the child know who you are. The child can feel with her/his hands when you are signing your name.

Figure 26

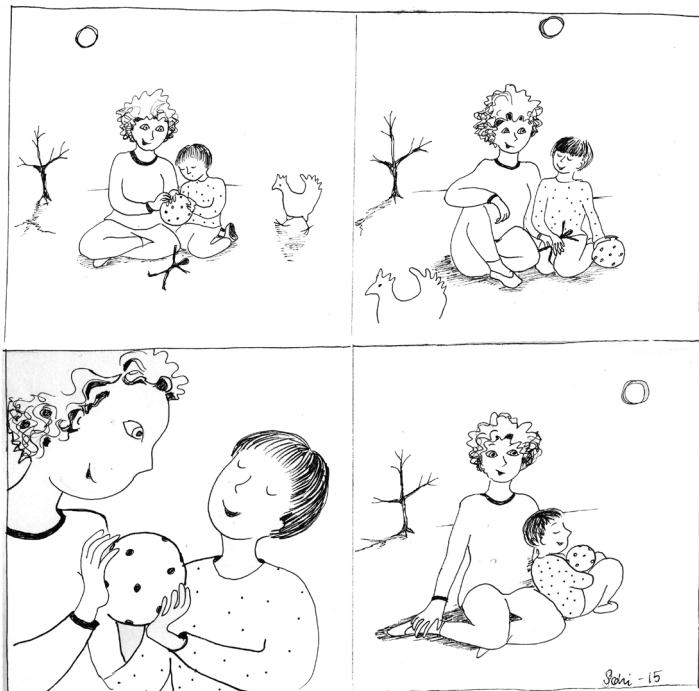


Let the child know who you are by letting her/him touching your hair, your face or your hand.

Gently place your hands on the child's hands to confirm that you can see the same as the child.

Maintain contact over time

Figure 28



Be together with your child over an extended period of time. Stay close and allow the child to know that you are there by being in physical contact with the child.

Stay close to the child when the child is interested in something.

Figure 29



Let the child be together with you in the activities you are doing. One example could be when you are preparing a meal.

Figure 30



Keep the child close to you at all times, also when socializing with others. The child can sit on your lap if she/he wants to.

Figure 31



Always place your hand on top of the child's hand to confirm that you can see the same as the child is.

Show interest in what the child is doing. Place your hand gently on top of the child's hand to confirm that you can see what the child is doing.

Place your other hand next to, or under the child's other hand.

Explore the object together.

Figure 32



Show the child that you also can feel elements on an object when you explore together.

Touch different parts of the object, and allow the child to touch it too, if the child wants to.

This can take long time, and you should not force the child to touch the objects. If you touch it, the child will know it is safe, and may also want to touch it.

4. Activities of Daily Living

A child will learn and develop by being together with other persons (parents, family, caregivers etc) in all the different activities during the day.

A child with deafblindness, who has no vision and no hearing, will have to learn about all in the daily life by touch, smell and tactile senses.

Bring the child with you in all activities. The child will then have access to you, to conversations, to experiences and to the surroundings.



Mother and child eating together.

Figure 33



Figure 34



Figure 35



Bring the child with you in all activities. The child will then have access to you, to conversations, to experiences and to the surroundings.

Figure 36



Figure 37



Bring the child with you in all activities. The child will then have access to you, to conversations, to experiences and to the surroundings.

Figure 38



Figure 39 A



Bring the child with you in all activities. The child will then have access to you, to conversations, to experiences and to the surroundings.

Figure 39 B



Figure 40



Bring the child with you in all activities. The child will then have access to you, to conversations, to experiences and to the surroundings.

5. Listening hands – Talking hands

Figure 41



When the child is pointing at something. Place your hand on top of the child's hand.

You are then showing that you are “listening” to what the child is telling.

The child can experience that he or she is the one who is leading the conversation.

Figure 42



Show directions by placing your hand gently under the child's hand. The child's hand shall rest on your hand. Then the child is listening to you, and you are the one leading the conversation.

Figure 43



Show interest in what your child is doing by placing your hands gently on top of the child's hands when the child is playing.

Then the child will know that you can "see" what the child is doing.

6. Understanding the physical environment

How you can walk together

Figure 44



When walking, stay close together to allow the child to feel the motion in your body.

The child will then know, when you are moving, which direction you are moving in and when you stop.

This will make the child feel safe.

Figure 45



The child can hold your hand, or...

Figure 46



Figure 47



Figure 48

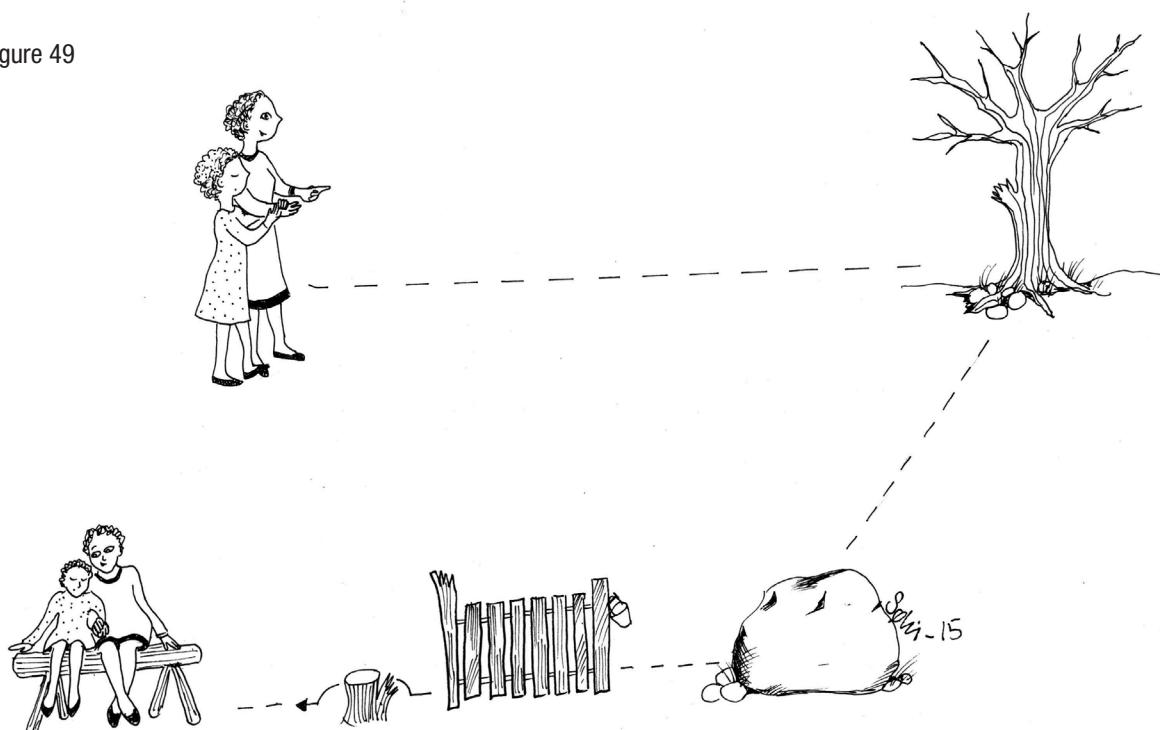


... arm in arm.

Let the child choose
how she/he feels most
comfortable and safe.

How the child can learn to find the way in environments of interest and importance for them.

Figure 49



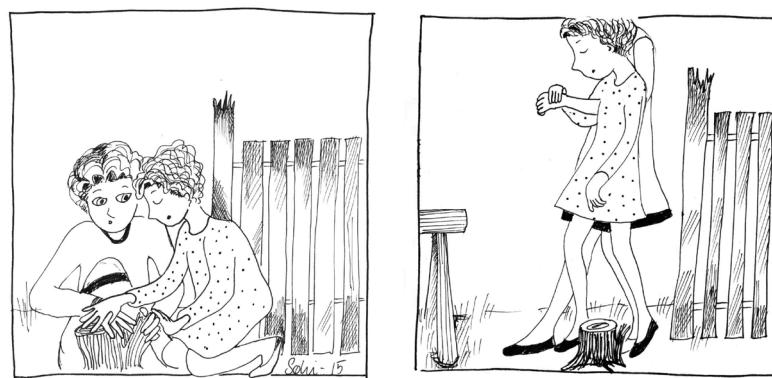
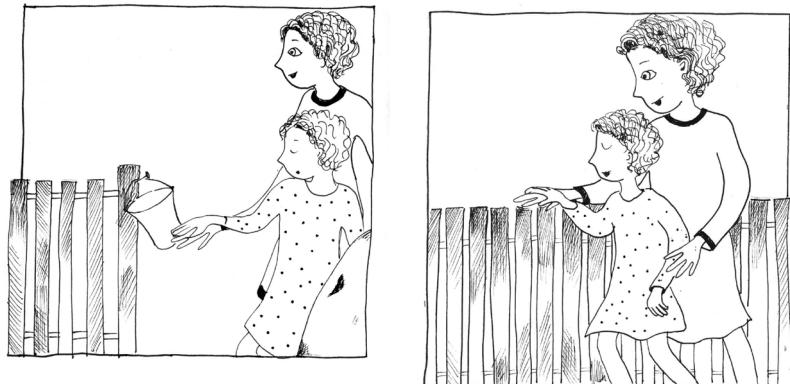
Let the child get familiar with a set route in her/his surroundings. Walk the same route several times to familiarize the child with the environment. Walk in straight lines.

Figure 50 A



Show the child landmarks along the route. The landmarks can be a tree, a stone on the ground, a fence or whatever is suitable in your surroundings.

Figure 50 B



Place your hand under the child's hand and allow the child to follow your hand to the objects you would like to show.

Explore together. Use time.

Do not hold the child's hand or wrist and place the child's hand on objects. Always allow the child to chose to follow your hand.

