



Deafblindness

Basic principles

A parent's manual

Innhold

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Acknowledgements

This booklet is the second edition of a booklet that was first developed in 2015. The first edition of the booklet would not have been possible without the valuable experience and knowledge in the field of deafblindness found at Signo School and Resource Center, and Signo Vivo in Norway. Anette Bolkesjoe Brandt, Marit Brubakken, Reidun Franzen Bjartvik and Haakon Lie took on the huge challenge of developing the technical content in the first edition of the booklet in close collaboration with Sr. Emma Kulombe at Chisombezi Deafblind Centre and Kenneth Verngaard in the international department of the Signo Foundation.

The booklet was introduced in Malawi in October 2015, and has been used extensively by the competent teachers at Chisombezi Deafblind Centre since then. Based on the teacher's experiences, the booklet is now revised, and we would like to express our gratitude for the dedication and great effort the teachers have made to provide feedback and input to the development of this booklet.

Solvi Aspen Solvang has produced the illustrations in the booklet, and we would like to express our gratitude for the hard work she has put in to develop the illustrations included in the booklet, and several illustrations and drafts that have not been used.

We would also like to express our gratitude to the Norwegian Government through Norad and the Atlas Alliance who have funded the booklet.

Introduction

The idea behind this booklet was conceived in a car on a bumpy road in Malawi, where Ms. Lilian Mariga first showed 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. Mariga's 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 impairment of such severity that it is hard for the impaired senses to compensate for each other. Thus, deafblindness is a distinct disability.

The idea of trying to simplify the complicated field of deafblindness into illustrations was considered to be almost impossible, and was feared to result in a manual that would not fit all, only a few, or 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 than the short texts that follow some of the illustrations.

The booklet you are holding in your hands is the result of a desire to make something that is very complicated easy and accessible for everyone. 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.

Since the first edition of the booklet was introduced in Malawi in 2015, we have observed that the booklet has proved to be a powerful resource for the families and for the teachers. The illustrations are good starting points for discussions between the teachers and the families. They provide illiterate parents tools to convey what they have learnt about deafblindness to other family members. Parents have used the booklet to discuss issues related to deafblindness with neighbors and community members, such as gender issues, cultural issues and how the local community can support families with children with deafblindness.

The experience with the first edition of the booklet has also shown a need for a revision of the booklet to make it an even better resource for the families, and has shown a great need for a new booklet to be developed. This resulted in the development of a new booklet for teachers. The booklet contains written information about the background for each of the illustrations in the booklet for the parents, with suggestions for how they can discuss the illustrations with the parents as well as tips for practical exercises.

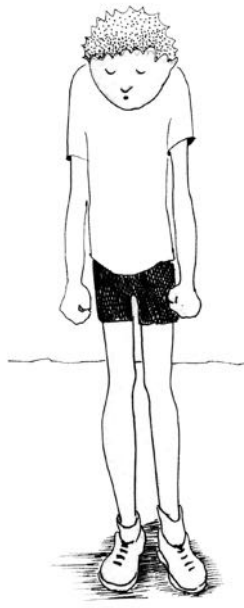
We hope that the booklet can be an inspiration for teachers and other professionals, and be used as a starting point to provide information about deafblindness, and to discuss how to best interact with persons with deafblindness.

Oslo – October 2016 – Haakon Lie and Kenneth Verngaard, the Signo Foundation

1.Communication

1.1 Bodily expressions

1.1.a

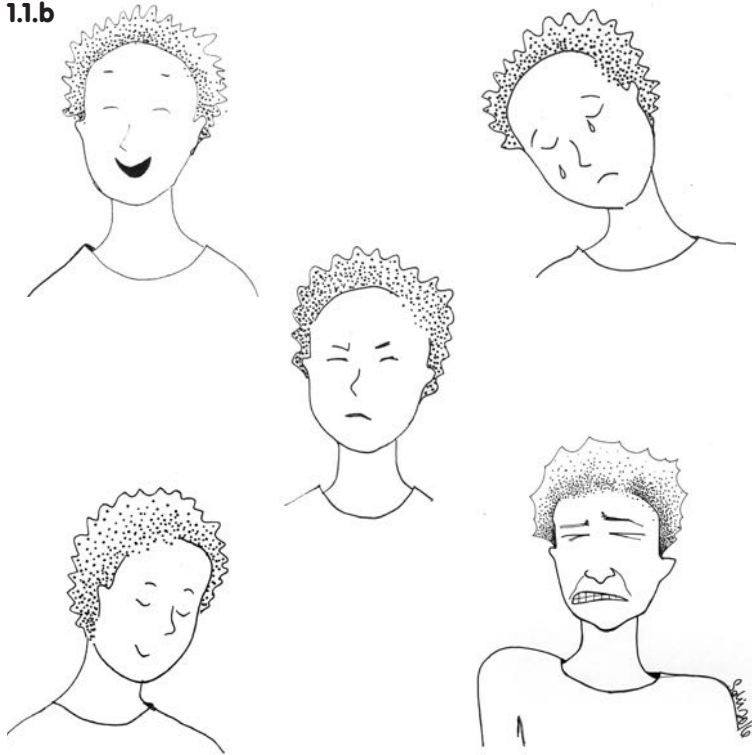


Your child is always communicating with the whole body. Movement, facial expressions, sounds, pointing: everything is communication!

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



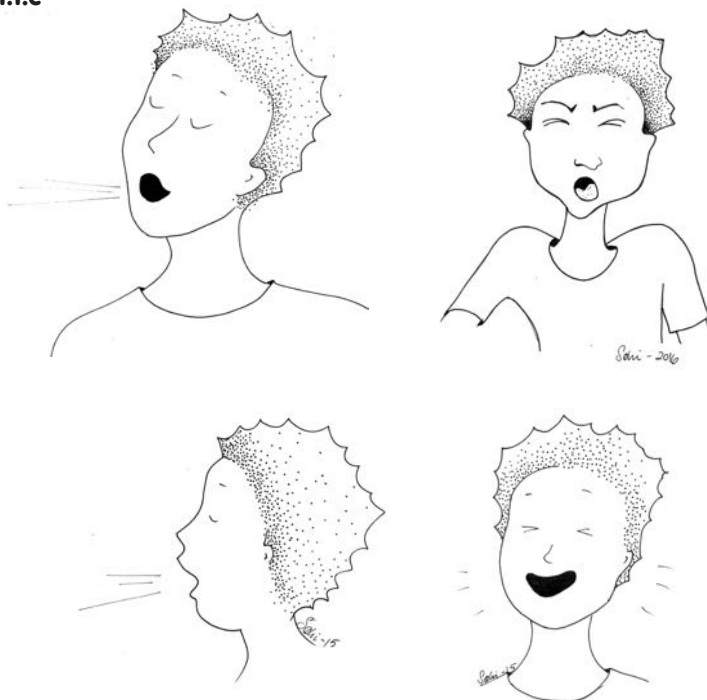
1.1.b



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

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

1.1.c



1.1.d



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

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

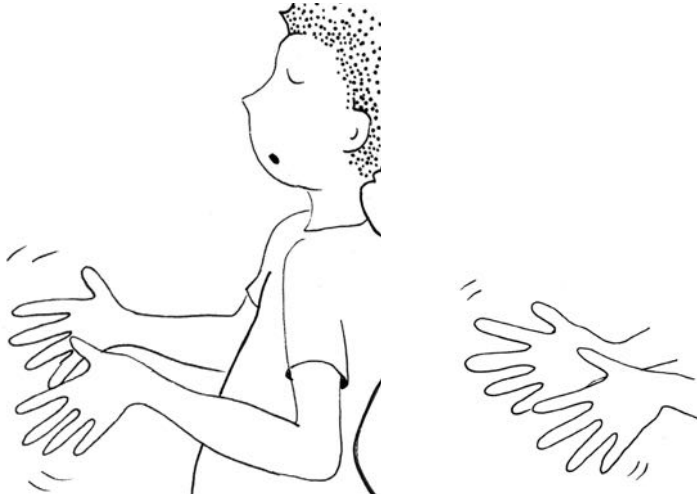
1.1.e



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

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

1.1.f



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

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

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



1.2 Listening hands - Talking hands

1.2.a



Placing your hand gently on top of the child's hand shows that you are listening, and that you see what the child sees.

1.2.b



Place your hand under the child's hand to show that you are talking or directing the child's attention to something.

1.2.c



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 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.

1.2.d



2.How to establish and maintain contact

2.1 Establish contact

2.1.a



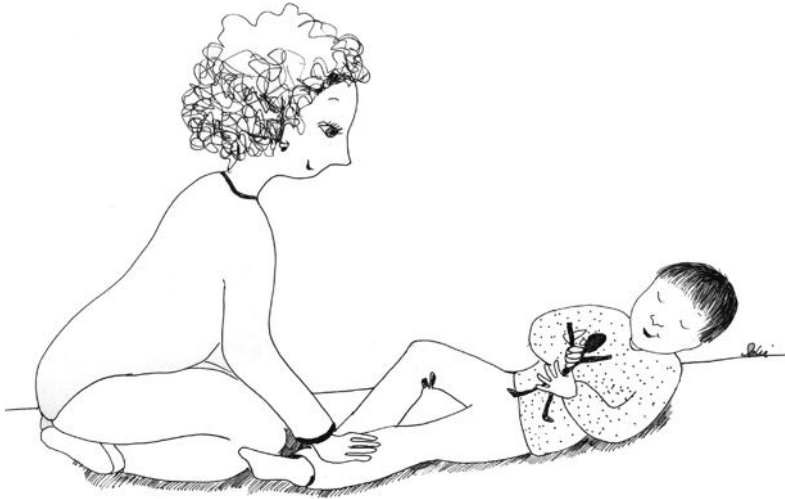
Contact the child by gently touching the child's shoulder...

2.1.b



... or the child's arm.

2.1.c



The child's foot...

2.1.d



... or sit down next to the child
in a way that your bodies are
in contact with each other.

2.1.e



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

2.1.f



Let the child know who you are by letting her/him touching your hear, 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.

2.2 Maintain contact

2.2.a



Be together with your child over an extended period of time.

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.

2.2.b



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.

3. Being together - being included

3.a



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

3.b



Interaction and communication is all about being together and sharing something with another person.

Interaction can be between two persons, or

3.c



..among several persons..

3.d



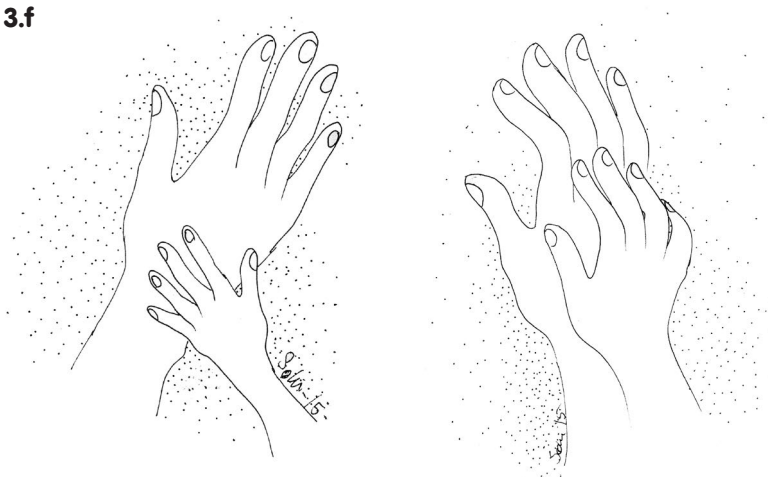
Interaction and
communication never
happens when someone is
alone.

3.e



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.

3.f



The hands are one of the most important means for interaction and communication.

4. Orientation and mobility

4.1 Mobility

4.1.a



Sitting between the legs will often be the best way to start, and it is the best way to sit to open for communication. If the child sits in a corner, it is very important that the parent is with her/him the whole time to support the child and to open for communication.

Do not let the child sit alone!
Be together with the child the whole time.

4.1.b



4.1.c



You should be in tactile contact with the child and help her/him to learn the necessary movements by repeating them together. The child must decide the pace of the activity and you must follow. Do not force the child if she/he does not want to.

4.1.d



Assist the child to stand on her/his own feet. You might have to give the child a lot of assistance to begin with, by supporting the legs and the body.

4.1.e



Assist the child to stand on her/his own feet. You might have to give the child a lot of assistance to begin with, by supporting the legs and the body.

4.1.f



4.1.g



Let the child step on your feet and walk together while facing each other. The child will feel the movement in the feet and the whole body, and will learn how the legs are moving because of the physical and close contact with you.

4.1.h



4.1.i

Be close to the child to let her/
him feel how you move.



4.1.j



When walking, stay close together to allow the child to feel the motion in your body. Then the child will know when you stop, when you are moving, and which direction you are moving in.

This will make the child feel safe.

4.1.k



The child can hold you in your hand...

4.1.l



..around the wrist, or...

4.1.m



.. your finger, or...



4.1.n

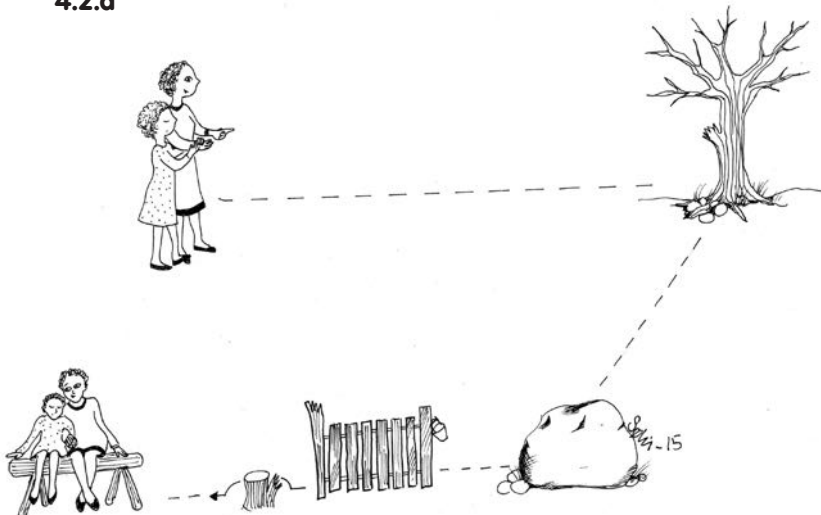


..arm in arm.

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

4.2 Landmarks - Navigating the surroundings

4.2.a



Let the child get familiar with a set of route around in the surroundings. Walk together the same route many times to familiarize the child with the environment. Walk in straight lines.

4.2.b



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

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 choose to follow your hand.

4.2.c



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

5. Activities of Daily Living

5.a



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

5.b



5.c



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

5.d



5.e



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

5.f



5.g



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

5.h



5.i



5.j



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

5.k



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

5.l



5.m



5.n



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

5.o



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

5.p



6. Play Activities

6.a



Children with deafblindness need social contact with siblings and friends like any other child. Be together with the child in all activities. The child will then have access to the friends, to conversations, to experiences and to the surroundings.

6.b



6.c



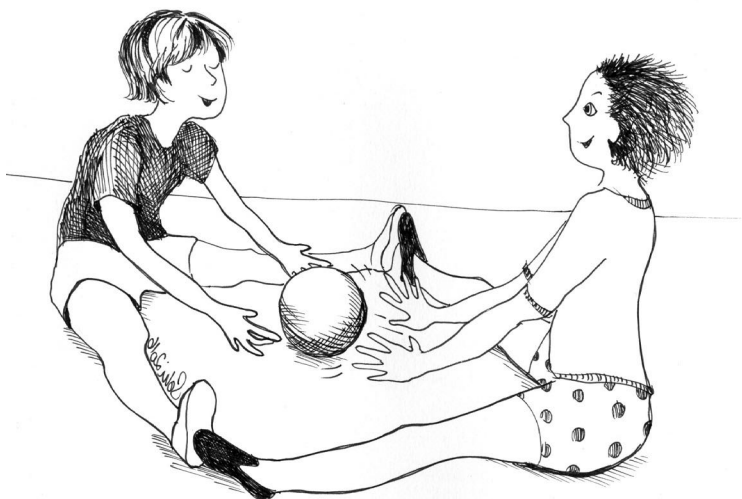
Children with deafblindness need social contact with siblings and friends like any other child. Be together with the child in all activities. The child will then have access to the friends, to conversations, to experiences and to the surroundings.

6.d



Fig 35 - Spille brommer

6.e



6.f



Children with deafblindness need social contact with siblings and friends like any other child. Be together with the child in all activities. The child will then have access to the friends, to conversations, to experiences and to the surroundings.

6.g



Children with deafblindness need social contact with siblings and friends like any other child. Be together with the child in all activities. The child will then have access to the friends, to conversations, to experiences and to the surroundings.

6.h

