



Professionals for Visually Impaired Persons Training XL and Knowledge Sharing

KnowProViP

HANDBOOK

Subject:

Acquired deafblindness



Official handbook for the KnowProViP course

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I General information for the trainer

The content is aimed at those professionals working with people aged 16+, i.e. youth through to older deaf blind people.

The content of this course does not cater for those working and or teaching children i.e. those aged under 16.

1.1 Aim of this handbook

- The professionals will understand what is essential in the contact with clients with dual sensory loss and can choose the right attitude and circumstances.
- In this course the professionals get a short introduction about hearing impairment and the practical problems in daily life. They will be informed where to find materials for self study about hearing impairments. They must already have knowledge about issues relating to vision impairment.
- The professionals will acquire knowledge about the different forms of deafblindness and its influence on daily life. They will acquire specific knowledge about elderly deafblindness and Ushers 2 and 3.
- They are known with the alternative ways of communication, the possibilities and difficulties. They know how to speak with a client with a hearing aid and by spelling in the hand. They will know where the client can get, when needed, special training in alternative ways of communication.
- Where appropriate they can teach the client in daily life skills and mobility, considering the dual sensory loss.
- The professionals know where to find support and services for persons with ADB¹

¹ ADB = Acquired Deafblindness

1.2 Points of attention

Acquiring knowledge & experience about deafblindness is intense. There is time needed for feedback on the topics of the program.

- There must be good alternation of practice and theory
- In a program of two days all topics can only be dealt with briefly. It is not necessary to be complete. The professionals will be encouraged to conduct more personal research to obtain further information (literature, websites, deafblind organisations).

Information can be placed online so professionals can prepare themselves prior to the course or use materials afterwards.

1.3 Methodology

The program is started with a welcome, introduction of the trainers and housekeeping issues.

After that an overview of the course is given:

- overview of course contents
- delivery structure
- expected outcomes

Note: It can be interesting to invite (a) client(s) with acquired deafblindness to support the days.

After the introduction the program will follow the subjects in these manual. The total program is attached as 'enclosure 1' to this document.

2 Simulation of Deafblindness

Trainers: professional in deafblindness
Person with ADB

2.1 Aim of this chapter

In this part of the course the professionals will experience the complexity of deafblindness and will understand what is essential in the contact with clients with dual sensory loss. They can choose the right attitude and circumstances.

2.2 Required media and material

For the experience:

- Totally dark glasses for half of the group
- Earplugs for all members of the group
- Headphones for half of the group (to exclude more sound)
- Sheets with orders

For the mindmap:

- big paper for each small group of 3 persons
- pens

2.3 Methodology

In this part one of two professionals experience different situations with dark glasses, earplugs and headphones. The other of the two accompanies his colleague in this situations. After 15 minutes roles will be changed.

2.4 Organisational information and advise

- (1) Each companion gets orders on small sheets.
Tell the companion not to speak but try other ways to communicate with the 'client'.
Give the companion a new order after finishing the previous.
Change roles halfway time.
- (2) Make small groups after the experience.
Let the members make a mindmap to sample their reactions of this exercise.
Central questions: what subjects you think are related to communication with deafblind people and what is important in attending them?
- (3) After that there is a central meeting where the outcome of the mindmap will be presented and discussed. What are points of attention? What can go wrong in communication and support of Deafblind people?

2.5 Useful additional literature, sources, links

Orders at (1) (proposals):

- Ask (without speaking) the deafblind client whether he/she would like a cup of tea or coffee? Ask whether he/she takes milk or sugar. Ask if he/she would like a biscuit.
- Make clear to your deafblind client (without speaking) that you are going to do groceries and that you need to make a shopping list for that now. Make the shopping list.
- Make clear to your deafblind client (without speaking) that the alarm is going off and you need to go outside. Because of the time limit, you will not effectively go outside.
- I would like to introduce myself to you (without speaking). Explain what your position is and let your client introduce himself as well.
- Make clear to your client (without speaking) that you will leave him alone for a moment to go to the toilet.
- Make clear to your deafblind client (without speaking) that the phone is ringing. They are calling for your deafblind client.
- Make clear to your deafblind client (without speaking) that you need to go and post a letter. Ask whether he or she would like to join you walking to the letterbox. Because of the time limit, you will not effectively go outside.
- Make clear to your deafblind client (without speaking) that we will continue together in a minute and that you want to go to the toilet before that. Ask whether your client needs to go as well.
- Make clear to your deafblind client (without speaking) that you think it is very 'stuffy' inside. Ask if he / she minds that you are opening a window.
- Make clear to your deafblind client (without speaking) that you are speaking to the dentist on the phone. Tomorrow's appointment is cancelled. Ask if your client is able to go on Friday next week at 11.30 am.
- Make clear to your deafblind client (without speaking) that it is lovely weather outside and that you would like to go and have a cup of coffee outside. Ask whether the client wants to join.
- Make clear to your deafblind client (without speaking) that you would like to go for a walk outside. Ask whether the client feels like joining you for a walk? Go and get your jackets. Because of the time limit, you will not effectively go outside.

Support for the central discussion (3): see 'enclosure 2' for tips for contact

3 Hearing impairment

Trainer: Audiologist
Professional in deafblindness
Person with ADB

3.1 Aim of this chapter

In this part of the course the professionals get a short introduction about hearing impairment and the practical problems in daily life. They will be informed where to find materials for self study about hearing impairments. They must already have knowledge about issues relating to vision impairment.

3.2 Required media and material

To make this theoretical part gripping it is important to use Powerpoint, CD's with examples of a hearing impairment.

3.3 Methodology

The following subjects will be shortly explained:

- hearing, how does it work
- bad hearing and deafness, congenital and acquired, on young and old age
- the ways of testing
- the influence on growing up and daily life
- using a hearing aid, different forms of hearing aids

3.4 Organisational information and advise

See 2.2

3.5 Useful additional literature, sources, links

The audiologist can use literature of his specialisation.

Study-material for professionals:

http://www.ecovip.eu/downloadarea/eco4vipcoursemedia/ecovip_tutorial_s2_visual_auditorial_impairment_v3.doc

Course and testing:

<http://www.fue-bfw-dueren.de/ATutor/users/index.php>

User ID: *ecoguest*

PW: *braille*

With this user ID and password the site is free accessible.

For the subject deafblindness the trainer can use the books mentioned in the references in chapter 9.

4 Personal aids for Deafblind

Trainer: professional in deafblindness

4.1 Aim of this chapter

In this part of the course the trainee gets an introduction on other a view basic aids for using in daily life.

4.2 Required media and material

- Warning systems
- Telephone systems
- Waking up systems
- Communication aid
- And others

4.3 Methodology

After a presentation the professionals can test the aids in practical. The trainer is walking around to give explanation and support.

4.4 Organisational information and advise

See 3.3.

4.5 Useful additional literature, sources, links

Use information of national providers of tools for Deafblind people.
Point out the websites of the providers

5 Introduction in Deafblindness

Trainer: Professional in deafblindness
Person with ADB

5.1 Aim of this chapter

In this part of the course the professionals get a short introduction about acquired deafblindness and the practical problems in daily life. The professionals will be informed where to find materials for self study.

5.2 Required media and material

The person with Acquired Deafblindness can give examples of his own experiences, problems and solutions. To show more examples of deafblindness the trainer can also use DVD about deafblindness a.s.o.

5.3 Methodology

The following subjects will be shortly explained:

- what is acquired deafblindness? Different forms and grades
- What is the difference with congenital deafblindness?
- Two examples: Usher and elderly
- Practical and psychosocial problems
- What is the influence on the identity of the ADB-person (loss, independency, fear, isolation, relationship a.s.o.)
- What support is needed?

5.4 Organisational information and advise

See Required media and material and 5.3

5.5 Useful additional literature, sources, links

See chapter 8 for literature and websites
Use DVD from institutes for deafblindness or Sense

End of the first day

Review of the day, questions and answers
Overview of the next day of the course

Start of day 2

Day 2 starts with an overview of today's course and questions about the previous day.

6 Communication

Trainer: professional in deafblindness; communication
Person with ADB

6.1 Aim of this chapter

The professionals know the alternative ways of communication, the possibilities and difficulties. They know how to speak with a client with a hearing aid and by spelling in the hand. They will know where the client can get, when needed, special training in alternative ways of communication.

6.2 Required media and material

Materials to show the different forms of communication: DVD, photographs, books, communication aids

6.3 Methodology

- Meeting and greeting a deafblind person. The trainer reminds at the tips for contact mentioned at the first day.
- What does it mean to grow up deaf? Introduction of the trainer
- Introduction on the different forms of communicating:
- writing in the hand (practice will follow later)
- using materials to explain the situation: do you want coffee ---→ showing a cup
- sign language (different forms)
- manual sign language
- Lorm
- Communication by an interpreter

6.3.1 Practice:

In this module the professionals are not taught in the different forms of communication. Training in alternative communication is done by experts.

- Writing capitals in the hand
Exception is an exercise with 'writing capitals in the hand'. This is a way of communication every person can easily use and can be understood by every Deafblind person when communication by speaking fails. See 'enclosure 3'
- Communication with communication aids
There are different kind of aids for communication: to increase the spoken words, to Braille text, at the computer a.s.o. The professionals get an impression of the possibilities and can try out several tools.

6.4 Organisational information and advise

This part of the course can be made even more interesting by practical examples in PP, on DVD and others.

It is inspiring to learn a view subjects from sign language as 'hello, do you want tea/coffee a.o.'

6.5 Useful additional literature, sources, links

See 'enclosure 3': capitals in the hand and chapter 9 for more literature.



7 Activities in Daily life and Mobility

Trainer: professional in deafblindness; communication
Person with ADB

7.1 Aim of this chapter

The trainee is conscious of the effect of the double sensory loss on daily life skills and mobility. Where appropriate the professionals can teach the client in daily life skills and mobility, considering the dual sensory loss.

7.2 Required media and material

- Different hearing aids (and cleaning material)
- Dark glasses, earplugs, headphones
- Red-white canes
- Practical materials: water, glass, water boils etc.

7.3 Methodology

Different methods can be used to let the professionals experience what the impact is on ADL and mobility. We choose the method of self-experience and discussion to know what attitude and instruction is needed.

Attention to other senses, such as touch and intuition, is very important.

7.3.1 ADL

Let people have different experiences wearing hearing aids or glasses, earplugs and ear protectors.

In couples of 2 persons:

- 1 Reading a story to a client with hearing aids or a deafblind client. What is possible to follow for the client? What can he reproduce?
Do the same exercise with background noise
- 2 Using a telephone with a hearing aid
- 3 Kitchen activities:
 - o fill a glass with water, using a level detector
 - o simple activity in cooking: when is water boiling? What safety is needed? What aids?

7.3.1.1 Examples of Practical Exercises for Acquired Deafblindness - ADL

Exercise 1:

Your client is deafblind

Your task is to train him/her to make a banana sandwich. To do this you will first need to tell the client what the task is, then train them in the process.

Take a few quiet minutes to consider how best to approach this task.

Good luck and enjoy!

Exercise 2:

Your client is deafblind.

Your task is to train him/her to pour liquids by pouring from a bottle into a glass. To do this you will first need to tell the client what the task is, then train them in the process.

Take a few quiet minutes to consider how best to approach this task.
Good luck and enjoy!

Central discussion

- What is important in guiding the client? Which instruction has to be given?
- What points of attention?
- What experiences have people in their own working place? How do they solve problems with Deafblind clients.

7.3.2 Orientation and Mobility

Couples of 2 persons

- Go outside, one person wears dark glasses, earplugs a.s.o. and uses the white cane.
- The other person is the escort, takes care and tells in which direction they are going to walk.
- Walk on an easy road, first guided by arm, afterwards free.
- Search for different situations: busy and quiet. Cross streets.
- Notice which sentences you use and which marking points for orientation.
- The escort notices which way of escort he has to give and which instructions.
- Change halfway.
- Do the same actions using a hearing aid(quiet, busy).

7.3.2.1 Examples of Practical Exercises for Acquired Deafblindness - *Mobility*

Exercise 1:

Your task is to guide your deafblind friend to the supermarket and purchase a small item. Talk to your friend about the route and environment as you travel.

On completion of the task, discreetly reverse rolls and return to the training centre by an alternate route.

Travel safely and enjoy.

Central discussion

- How did it work out?
- What were your feelings?
- Exchange of practical tips
- What can be done independent (and safe!) by a Deafblind client and what not
- Use of the white cane

The trainer supplies with practical experiences.

Note: this course is not mentioned as a professional mobility course. It only makes professionals aware of the problems of Deafblind people in situations in and outside the house.

7.4 Organisational information and advise

In this concept is chosen for practical ADL and Mobility situations.

The situations can be transformed, taking the circumstances of the location into account.

7.5 Useful additional literature, sources, links

Orientation and Mobility tips are mentioned in enclosure 4.

8 Partners in care

Trainer: professional in deafblindness

8.1 *Aim of this chapter*

The professionals know where to find support and services for persons with ADB

8.2 *Required media and material*

- Leaflets of institutes for Deafblind (national)
- List of websites and addresses of organisations who support Deafblind people (national)
- Paper with international websites, by example:
www.deafblindinternational.org
www.adbn.org
- Computer/internet

8.3 *Methodology*

The trainer gives an overview over the provisions for Deafblind people in his country and of the organisations of clients.
He gives information of the care system for people with acquired deafblindness.
A list of organisations, including websites, is hand out to the professionals.

Make clear what the possibilities of the institutes for VIP are. Make clear what support you need of organisations of Deafblind.

Inform the professionals about the way clients are organised.

Stimulate the professionals to have a look at the website to have a good impression of the support people with ADB can get. If there is enough time student can take a look at the website during course. Therefore computers are needed.

8.4 *Organisational information and advise*

See 8.3

8.5 *Useful additional literature, sources, links*

National resources

9 References

American Foundation for the Blind; What to Do When You Meet a Deaf-Blind Person?; New York 1986

Göransson L.; Deafblindness in a life perspective in: Strategies and Methods for Support, 2008; www.mogard.se

Information Center for Acquired Deafblindness; Six booklets: Theory and methods; Receiving a diagnosis; Getting support; Being active; Getting an education and work; Narratives of everyday life; Herlev 2008; www.dbcent.dk

Sauerburger, D.; Independence Without Sight or Sound Suggestions for Practitioners Working with Deaf-Blind Adults; New York 1993

Interesting websites:

- www.deafblindinternational.org
- www.deafblind.com
- www.rnib.org.uk
- www.sense.org.uk

Appendix 1

Programme

DAY 1			
Themes	Content	Trainer	Time
Introduction	Introduction of trainer/s and professionals & housekeeping issues		0.25h
Overview	Overview of course contents, delivery structure and expected outcomes - questions		0.25h
1. Simulation of deafblindness	Professionals to undergo simulated deaf blindness exercise One person is client, the other companion Discussion and creation of mindmap in small groups by professionals about their reaction to this exercise? What is acquired deaf blindness? Approach necessary in working with people with acquired deafblindness (attitude, time, circumstances, environment)	Trainer of deafblind people	1,5 h
2. Short introduction in hearing impairment and introduction in deafblindness	Hearing impairment Overview and questions Practical problems associated with hearing impairment What is a hearing aid? What is possible using a hearing aid, what is not possible? How to use and clean a hearing aid? Why do some people with hearing impairment not use a hearing aid?	Logopedist/audicien/	1 h
LUNCH			
3. Aids/tools	Information about assistive devices (waking up, doorbell, telephone, computer etc.	Specialist	1 h
4. Deafblindness	When is one considered deafblind? Approach necessary in working with people with acquired deafblindness. Films and story of client who has personal experience of deafblindness Overview of main causes of acquired deafblindness Two examples in more detail: - Usher syndrom Age related deaf blindness Overview of special problems – practical and psychosocial (1+1 ≠ 2) What support is needed? Short term and life long	Trainer/ client	1,5 h
Review	Review of day, questions and answers and overview of next day on course		0.25h

DAY 2			
Themes	Content	Trainer	Time
Overview	Overview of today's course questions about previous days course	Trainer	0,25
5. Communication	Meeting and greeting a deaf blind person What does it mean to grow up deaf? Communication issues Communication using a hearing aid Communication via an interpreter. Introduction to sign language(fully language) and manual language(post lingual communication for DB). Goal: become aware of the possibilities, no training. Practical work: writing capitals in the hand, the tactile way of communicating that everyone can learn in a short time. Other communication devices Overview of alternative communication methodologies	Trainer/specialist in communication Person with ADB for practical examples	2,5 h
LUNCH			
6. Activities in daily life and mobility	What daily living problems can be helped by ADL training What training is available? Practice with assistive devices (waking up, doorbell, telephone, computer etc.) Practical activities Overview of mobility training issues when working with deaf blind person Instruction for guiding a deaf blind person Overviews of other issues in relation to mobility Particular points of attention Practical exercise.	Trainer	2,5 h
6 Partners in care	Which services can be given by an organisation for vis.impaired people to Deafblind people? Information, training and support available for professionals When you need to involve other specialists and where you can access them Services and support available locally and nationally for people with acquired deaf blindness. Service providers and peer support groups.	Trainer	0,25 h
7. Evaluation	Review of the course; evaluation form	Trainer	0,5 h

Appendix 2 Tips for contact

(chapter 2)

People who are deafblind are limited in their information, communication and mobility, so they can not take part in the social community without adaptations in and around their environment. People who come into contact with a deafblind person could feel unaccustomed and a bit unsure how to act sometimes. The tips below will make the first contact and association easier.

1 To approach

- Always approach a person who is deafblind from the front. In this way the remaining sight and hearing can be used optimally
- Announce your presence by calling the person by his or her name and shaking his or her hand. He would want to know who you are and he can make clear to you in which way you can communicate with him.
- Use his or her remaining sight and hearing, and the available optical and hearing appliances (hear it, ring control)
- Let the deafblind person function as independent as possible by asking him which help he wants.

2 Communication

- Look for a quiet spot and turn off background noise (radio and TV).
- Take your time, realise you need more time than with any other person.
- Make sure that the deafblind person is positioned with his back to the light (concerning dazzling), and that the light is in your face (concerning reading your lips).
- Look at the person while speaking.
- Speak quietly and articulate clearly.
- Do not yell. When you are yelling, you will never be audible for a person with impaired hearing.
- Use short and uncomplicated sentences and words
- Do not put your hands in front of your mouth when speaking (concerning lip-reading).
- Do not change the subject too suddenly - insert a small break first.
- Use different words after replying twice.
- When necessary, spell out names and names of places when they are difficult to hear.
- When necessary, use other communication techniques:
 - - Writing: in black book, on a white-board, with block-system characters in your hand. Or hold the hand of the deafblind person and write block-system characters on the table with his finger.
 - - Spelling out words with your fingers: in your hand or in the air.
 - - Braille communicator.
 - - Assisting gestures for yes and no. (yes = tap on the palm of the hand, no = stroke the palm of the hand.)
- Someone with a visual and hearing impairment has to guess a lot what is said. Thus ask frequently if he can repeat what you said, so you know for sure that you are talking about the same thing.

- Especially in big groups, keep contact with the person concerned to prevent confusion and the feeling of being left alone.

-

3 Accompaniment

- Always ask in which way somebody wants to be accompanied.
- To walk arm in arm, offer your arm. Ask him or her to hold your elbow loosely or to put his or her arm through yours. Realise that some people who are deafblind have balance impairments.
- Take the first step yourself so the deafblind person can follow your moves. Never push somebody ahead of you.
- Discuss up front the location you want to reach and what is going to happen over there.

4 Activities

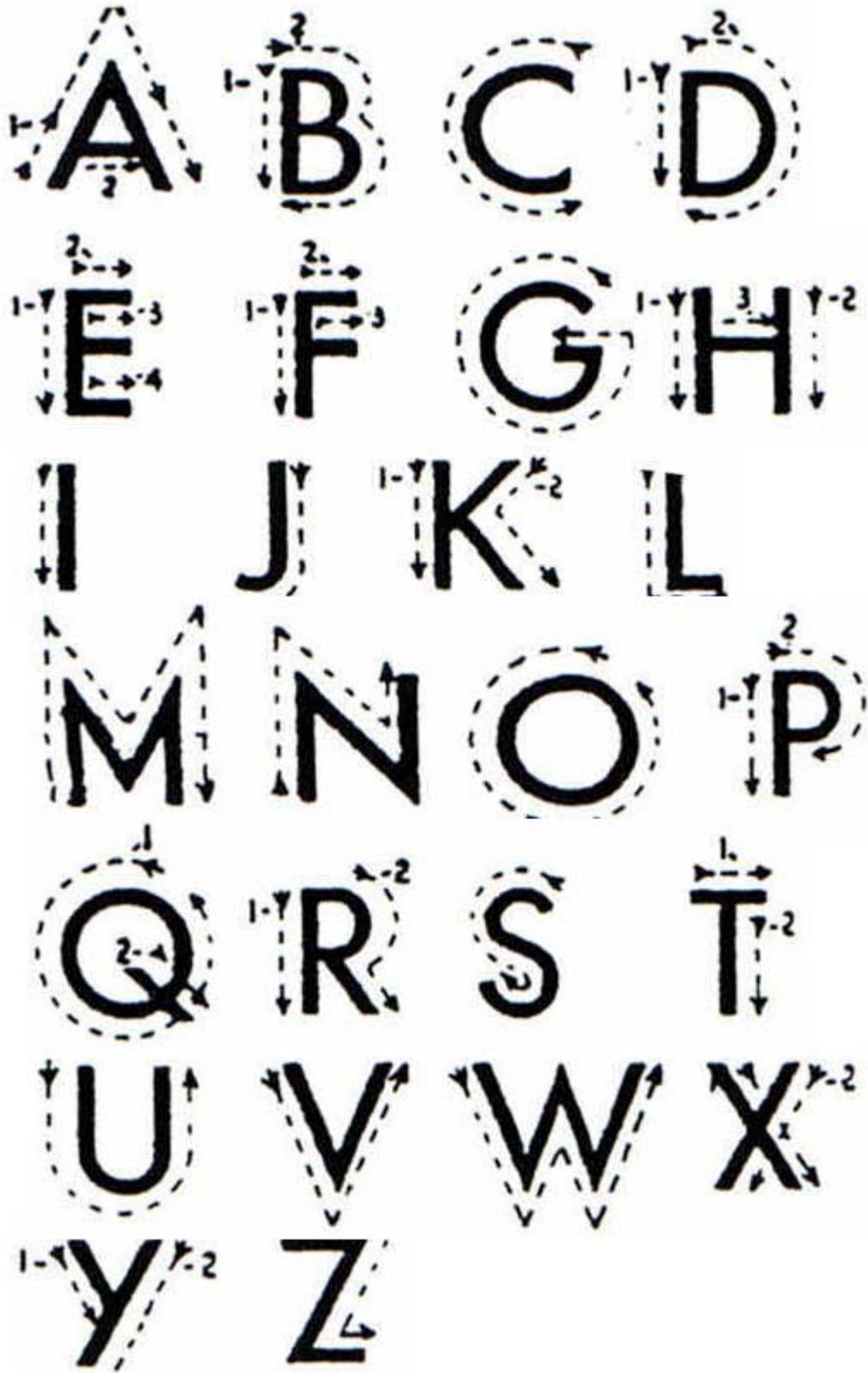
Always give someone as many opportunities as possible to be active himself. For example with the following activities:

- Domestic jobs.
- Handicraft and hand work, weaving, moulding, and (adapted) party games.
- Use of the computer for gaining information and communicating.
- Raiding and writing Braille, and exchanging letters in Braille.
- Taking care of plants and pets
- Maintaining and supporting telephone contacts if someone has the appropriate appliances.
- Exercising outside: walking, cycling on a tandem, shopping, gardening, trips and sports

5 Realise the following

- A person who is deafblind mainly uses his other senses like touch, smell and taste. So make sure that you do not smell of garlic or other unpleasant smells for example.
- Every person has his own personality, wants and needs. A deafblind person is somebody who is capable to think and act himself.
- A deafblind person needs to be informed actively and given information, even when it is about daily news and information.
- The meal is an important event for deafblind persons. It provides a form of time classification for the day. Having dinner is a form of enjoyment (taste and smell). So spend much care on it. Tell what dishes are on the table and where they are located on the table. Do not just dish up for somebody, but ask if help is needed. Tell where the different foods are located on the plate.

Appendix 3 Capitals in the hand



Appendix 4 Tips for orientation and mobility

Deafness and blindness have great consequences for orientation and mobility. The degree of both limitations, and to what extent the client uses his remaining sight and hearing, determine the client's possibilities. The bigger the limitation, the less is possible. What someone can achieve is determined individually, depending on the personality and the living environment.

The period needed to achieve the goal is usually longer and much more intensive than with the target group of the visually impaired. Learning O&M-skills requires a lot of effort from the client's concentration and memory. A big motivation is thus needed. Co-operation and asking the environment for help is of essential importance to achieve the desired goals.

Problems during the instruction

- Communication is different and is more difficult.
- More balance problems (Meniere, Usher 1).
- Paying more attention to the walking pose is necessary
- Remaining sight and remaining hearing can be disturbing (disturbing noises) but also needs to be exploited for learning to use all possibilities optimally.
- Possibilities for learning routes are limited because particular routes are not available for a client with impaired sight and hearing because of road safety.
- It is very difficult to change fixed routes.
- A high level of concentration is necessary, not every client is able to realize this..
- People with a visual and hearing impairment can over-estimate themselves or can be very afraid and insecure about going outside alone. Over time, they go outside less and less, until they are not going outside at all anymore. Working on this requires a lot of effort from the mobility instructor and from the client.

Points of attention for during instruction/guiding

- Take care for professional mobility training!! Deafblind people need to experience in a professional way their possibilities and limitations.

In general for guiding:

- Give the client as much information as possible in advance at home so you can communicate in a quiet environment.
- Stand out of the sunlight, but with light on the face of the guide concerning lip-reading.
- Discuss signals that may be used on the way. For example the letter 'W' (wait) on the shoulder in case a passer-by starts talking to you and you can not communicate with the client for a moment.
- Do not communicate with the client with the visual and hearing impairment limitation while walking but stand still.

Accompanied walking

- In accompanied walking it is important that others are being informed and motivated on how they can offer guidance to people with a visual and hearing impairment: use the same routes, provide information in a way which can be understood by the client, mention changes.
- Physical contact is important, as verbal communication is largely unusable and determining signals provides more security.
- Encourage the use of a white stick when the client is walking arm in arm: in this way the client receives more information and will be able to orientate himself more independently.