Care with Vision

Understanding and helping people with an intellectual and visual disability

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Cover Illustration: Lida de Zeeuw (www.lidaline.com)

The illustration: The child's face is painted in the pupil of an eye. It is a child with a visual disability as the child uses one eye to look at the ball and grasps next to the ball when reaching for it. From the child's perspective the child comes from the dark into the light where he/she can be 'seen', noticed, observed or assessed by the caregiver, teacher or other professional. On the other hand the caregiver, teacher or other professional looks through his/her own eye at the child wanting to provide the special care the child with a visual disability needs. The ball offered by the caregiver symbolises supporting and enhancing interaction and play (i.e. learning about the surrounding world) with persons with multiple disabilities. If you look carefully on the left side of the child's arm you will notice that the artist painted an ear. By extrapolating the ear the artist underlines the importance of giving attention to all the child's senses: sight, hearing, smell, tactile senses. Looking through the pupil of an eye at the child, symbolises a number of things: look carefully and work systematically to provide the daily care persons with visual and intellectual disabilities need and systematically evaluate problems that may occur. In other words: work with 'vision'.

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Preface

In 1998 two colleagues, Paula Sterkenburg and Trudy Arentz visited South Africa. They visited several schools and group-homes for persons with special education needs. In their report on the visit they wrote:

> "The need for knowledge and experience is huge. An interest in expertise exists on eye tests, especially for persons with intellectual disabilities as well as the influence of the visual disability on the development, behaviour and daily life of the client".

This visit laid the foundation for a project, which was financed by the Bartiméus Association. The aim was to exchange expertise with professionals and practitioners in South Africa. Later the VU University Amsterdam - and PAOS-funds (Post-Academic Education – Post Academische Beroepsopleiding) also financed the project. The initial and basic involvement eventually became a long-term project of cooperation between Bartiméus, the VU and the South African National Council for the Blind (SANCB).

By applying the 'Train-the-Trainer' approach, knowledge and expertise was shared with more than 125 professionals, initially only from South Africa, but later also from countries in Southern Africa (Lesotho, Malawi, Swaziland, Zambia and Zimbabwe). During 7 different courses the students developed their knowledge and skills on diagnoses, contact with, and education of persons with both an intellectual and visual disability. The aim of the lecturers - Trudy Arentz, Paula Sterkenburg and Joop Stolk - was to guide students to apply the acquired knowledge in their work situations and to disseminate it into their own schools and regions. Finally, some of them have become trainers themselves and are now able to train other students. The team from Bartiméus and the VU can, when necessary, still be consulted. In this way the knowledge on how to serve people with special needs is being shared freely with professionals and practitioners in this part of the African continent.

To better equip the new trainers, and also to share the experience and knowledge worldwide, this book has now been compiled. Newly trained persons and also other interested professionals or practitioners will be able to use this resource. It can be used as a 'Manual for Trainers', which is the result of close interaction between the team and the students.

The International Council for the Education of People with Visually Impairment (ICEVI) regards this project as an excellent tool to improve the care of one of the most vulnerable groups of people also in South and Southern Africa.

The course is in line with the South African Ministry of Education's goal to include children, also 'minority groups' with special needs, into the mainstream education system. Further, the course and book is an indication of how Bartiméus is able to present itself as a national and international expert organisation. A further result is that relations between South African organisations and the VU University have been strengthened.

I would like to thank the SANCB in Pretoria for organising and accommodating the courses. My appreciation also goes to the Athlone School for the Blind in Cape Town. Without the support and enthusiasm of the SANCB and Athlone School this project would not have been so successful.

Our gratitude goes to those who provided funds, in particular the Bartiméus Foundation for providing a large part of the funds needed for the project and the book, as well as the VU University and the Post-Academic Education Fund (PAOS-fonds), for sharing the financial burden. In addition, we are also grateful towards Bartiméus and the VU University for enabling their staff members to spend time in South Africa, sharing their academic knowledge and expertise.

A special word goes to the three lecturers: Trudy Arentz, Paula Sterkenburg and Joop Stolk. Due to their unceasing enthusiasm, their perseverance and their enormous effort, this project has been a great success.

With the publishing of the Manual in book form the project has formally come to an end. However, Bartiméus still receives requests for training in other parts of Southern Africa and for support to professionals following advanced studies. Still being available to support and assist the process of dissemination of information continues!

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Acknowledgments

This book is the result of the joint effort of specialists from
- Bartiméus - Doorn (Trudy Arentz and Paula Sterkenburg); and the
- VU University of Amsterdam - Department of Clinical Child and Family Studies (Paula Sterkenburg and Joop Stolk).

We wish to thank those who, in various ways, contributed to our work in South Africa. We are indebted to:

- All the caregivers, teachers, social workers, ophthalmologists, child psychologists and other professionals who participated in the courses in South Africa. They inspired, stimulated and supported our work. We were impressed by their eagerness to improve their work.
- Marlies Raemaekers, MA, Director of Bartiméus, who lectured with us during some of the courses and who also contributed substantially to the financial support of this project.
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- Obert Maguvhe, PhD, successor to Dr Schoeman at the SANCB who, as a blind person himself, was strongly committed to our 'joint' cause.
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- Bartiméus, for contributing the lion's share of the costs for our project. Two other organisations shared the costs by providing substantially in the form of subsidies. We thank the Board of the Department of Clinical Child and Family Studies of the VU University, Amsterdam, and the Board of the Post-Academic Education Fund (PAOS-fonds), Leiden, the Netherlands.

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Part I

Frame of reference

Chapter 1

General introduction

1.1. The aim of this book

This is not an ordinary book. *Care with Vision* is not intended merely to be read, but also to be acted upon! In addition to sharing knowledge regarding the assessment of visual disabilities in persons with learning difficulties, this book also focuses on the careful elaboration of psychological evaluation. During psychological assessment the goal is to gain information concerning the problem presented by the client or the client's parents/caregivers/teachers, as well as the client's disabilities and possibilities and his/her environment. By assembling this information and interpreting it in a systematic way, the most appropriate intervention can be advised. This process of assessment and evaluation is meant to give a well-considered answer to the client, parent, caregiver or teacher. This method of psychological evaluation is described in this book as the 'Step-by-Step' model.

Care with Vision has a threefold goal. The first goal is to share knowledge concerning visual disabilities among persons with learning difficulties and to provide the 'Step-by-Step' model as a resource to improve the process of diagnostic evaluation of professionals themselves. The second goal is to provide material on visual disabilities in persons with learning difficulties that can be used when sharing the knowledge regarding the 'Step-by-Step' model with colleagues. The third goal is to provide material that can be used during a course on visual disabilities related to persons with learning difficulties and psychological evaluation, using the 'Step-by-Step' model. Therefore, this book covers a full curriculum or teaching programme for professionals working with people with multiple disabilities, i.e. both intellectual and visual.

1.2. The development of this book

During our first visit to South Africa, one of the first questions put to us as professionals working in the care for the multiply disabled, was: 'How can we understand and help Sophine, a girl aged 14. She is blind and isolated from her peers. She always sits on her own with her hand over her eyes. As teachers we want to teach her new skills but she does not participate in activities'. This question marks the start of developing course material with the aim to share knowledge and experience with caregivers, teachers, social workers, ophthalmologists, child psychologists and other professionals from South Africa, Lesotho, Malawi, Zambia and Zimbabwe. We noticed the need for working with guidelines for clinical assessment and psychodiagnostical evaluation.

In co-operation with the South African National Council for the Blind in Pretoria and the Athlone School for the Blind in Cape Town, we developed a syllabus on the causes and nature of visual disabilities, on educational and therapeutic programmes for these clients, and on understanding, helping and supporting parents of children with such multiple disabilities

This course material was shared with 124 caregivers/teachers during seven separate courses over a period of seven years (2000 – 2006) - and is now assembled in this book. This makes this book a special publication: it is based on co-operation with many highly motivated caregivers and teachers, who were anxious to improve the quality of their work as fully committed professionals. The idea was that caregivers and teachers who participated in the course would pass on their newly attained knowledge and skills to colleagues, based on a ‘train-the-trainer’ principle. In other words we focused on training professionals in such a way that they themselves could then train their colleagues. To equip them for this task, the participants in the courses received the content of the course in print, supported with DVDs. The course material and fragments from the DVDs are combined in this publication *Care with Vision*.

The course material focused on the education and support-services for persons with a visual and intellectual disability also referred to in this book as ‘persons with multiple disabilities’ - people who are blind or have a visual disability according to the criteria of the World Health Care Organisation (see Chapter 2) in combination with learning difficulties. But, the application of the ‘Step-by-Step’ model can be generalised to care and special education in general.

1.3. The contents of this book: an overview

In part 1 of *Care with Vision* (Chapters 2 and 3) we focus on information on visual disabilities in persons with learning difficulties. The goal is to share (background) knowledge on the basic concepts of a visual disability. The prevalence of visual disabilities in persons with learning difficulties is mentioned and information is given on the most common eye abnormalities and eye-diseases. Information is also given on the possible causes for eye disfunctioning and on cerebral visual impairment (CVI). CVI is a visual impairment not caused by a disfunctioning in the eye itself, but malfunctioning of the visual pathways in the brain. Furthermore, information is given on recognising a visual impairment during daily care for persons with learning difficulties. The goal of the third chapter is to try to understand the impact of visual disability on the way of living and behaviour of persons with learning difficulties.

Part 2 (Chapters 4 to 8) describes in detail the application of the ‘Step-by-Step’ model for psychodiagnostical assessment and evaluation. Furthermore, specific ways in which the client can be supported are described. In Chapter 8 the reader is guided to understand and help parents who are in need of support. Often the emotional problems and educational needs of parents are overshadowed by the problems of their disabled children. This seriously complicates the process of providing education and support. Therefore, parents and their children should be considered as an inseparable entity, and we should not only be concerned about the needs of the children, but also about the needs of their parents.

1.4. Guideline for using: *Care with Vision*

We suggest that, when you read this book, you work through the book from Chapter 1 to Chapter 8, as the different chapters have a special order. Part 1 starts by giving information on the visual disabilities and their influence on behaviour (Chapters 2 and 3). Part 2 focuses on the ‘Step-by-Step’ model. Chapter 4 is meant to explain the ‘Step-by-Step’ model. Chapters 5, 6 and 7 show how the ‘Step-by-Step’ model is used when dealing with complicated problems. Chapter 8 describes how the model can be used to help parents who experience difficulties with the care of their child with learning difficulties.

Furthermore, every chapter provides case studies and, where applicable, DVD-material is added. As the goal of this book is to improve one's own professional capacities in psychological assessment, exercises are provided throughout the book. When working through *Care with Vision* on your own it is advisable to stop your reading, to do the appropriate exercise provided, and then to continue. You will find it a practical book, motivating you to participate by doing the exercises and using the DVD-material.

The next goal of this book is to provide material so that the knowledge and the process of working with the 'Step-by-Step' model can be shared with colleagues. Thus, you can use this book for workshops. You can use the material from the book in your workshops. For example Chapter 3 is a chapter you can use for a workshop on 'understanding visual disabilities'. However, it is advisable to first use Chapter 4 as an example for the 'Step-by-Step' model before using the more difficult material and cases (Chapters 5 – 8). During workshops you can use the exercises provided in this book, as well as the added DVD-material.

The third goal is to provide material for a 10-day course on 'visual disabilities in persons with learning difficulties, assessment and evaluation: the 'Step-by-Step' model'. During such a 10-day course you can work through *Care with Vision* form Chapter 1 to Chapter 8, using the exercises and assignments as well as the added DVD-material. It may also be advisable to order some of the DVDs as noted in the appendix (in the appendix you will find an order form). Furthermore, the content of the book may be changed to suit your course, and course themes can be added.

We wish you all the best in sharing your knowledge and experience with your colleagues.

Chapter 2

Visual problems in people with learning difficulties

Introduction

Silidile

Silidile is a girl, 6 years of age. She was born in Johannesburg, South Africa and has Down's Syndrome. She has two siblings, a brother and a sister, both with no disability. At the age of two she was operated on both eyes to remove congenital cataracts (density or cloudiness of the lens in the eye). She wears spectacles with very thick lenses. Every year she visits the ophthalmologist for an examination. The ophthalmologist confirms that everything is fine and that the operation was a big success. Her spectacles are replaced from time to time. She does not squint. There is no reliable information on how much she can see, because her developmental delay makes it difficult to assess her vision.

Silidile attends a school for children with a learning difficulty (special needs education). The teacher noticed that she shortens her viewing distance when she looks at her book. She has trouble working within the lines in an exercise book and she is unable to colour neatly within the lines of a picture. She often confuses the different characters and she cannot easily pick up objects. She has delayed fine motor development. Often she does not recognise people or objects, although sometimes she does. She is able to find her way around the school, enjoys playing on the playground and does not bump into objects or people.

However, the teachers noticed lately that Silidile no longer enjoys doing her schoolwork. Her work is untidy and she is not interested in anything. When she performs a task she needs a lot of time before completing the task. She often asks for help and teachers describe her behaviour as "claiming their attention". When she does not get the attention she wants, she immediately becomes angry, starts crying and often hits the other children. She continuously asks what the teacher is busy doing and frequently gets up from her chair to see for herself, even though this is not allowed. Furthermore, she touches everything with her hands, also the objects belonging to the other children. On many such occasions her behaviour has caused problems in the classroom. When the teachers unexpectedly ask her something, she does not respond. Therefore the teachers describe her as a disobedient child. They noted that she gets upset when there is a lot of noise in the classroom. She also shows 'claiming behaviour' during, for example, a sporting event. This kind of dependent behaviour irritates the other children.

In conclusion, Silidile seems not only to be very stubborn, but also dependent on others. She easily gets upset and angry and is not interested in the tasks she has to perform.

Her teachers would like answers to the following questions:

- How can we help her to become more independent?
- How can we make her aware that the short viewing distance at which she does her schoolwork aggravates her posture problems – her back, neck and shoulders – and that she is also spoiling her eyes?
- How can we help Silidile to concentrate on her tasks and increase her working speed?
- What can we do to improve her stubborn and sometimes aggressive behaviour?

A possible visual disability?

There are a number of facts that could indicate a possible visual disability. The following behavioural conditions could be indications of a vision problem:

- The shortening of the viewing distance
- Unnecessary and excessive touching of objects
- Slower working speed
- Her dependency during, for instance, sporting events (thus, when in unknown territory)
- Her difficulty in recognising people and objects
- Her delayed fine motor control
- Her difficulty in discriminating between different characters, as well as colouring between the lines of a drawing

Other signs indicating a possible visual disability are:

- Silidile was born with cataracts, which interfered with her visual development. The cataracts were removed at the age of two, but the most important part of the development of seeing, in small children, normally takes place during the first weeks and months after birth. Important to note is that, although Silidile wears spectacles, this does not necessarily mean that the visual disability has been resolved.
- The ophthalmologist was not able to assess her vision, because of her learning difficulties. Silidile confuses the different characters on the vision test chart. To understand Silidile's behaviour, it is important to determine her visual acuity (vision) and the effects of a possible visual disability on her behaviour. If we are able to understand her behaviour we can recommend guidelines for her daily care and help to change her development.

Care for people with multiple disabilities

Years ago there was no special care for people with multiple disabilities. The care they received was based on the most obvious disability, or the one that was first noticed, for example intellectual or physical, or only hearing or visual disability. Often additional problems were vaguely taken notice of, without further specific attention for e.g. additional visual and/or hearing disabilities. These disabilities were frequently not even recognised. The reason was that there was little knowledge available regarding the assessment of visual functioning (or hearing disorders) in people with a learning difficulty and about the influence of visual- and/or hearing disabilities on their daily life, development and behaviour. During the past ±15 years assessment material, as well as increased knowledge regarding visual functioning and hearing disabilities have become available. This also includes knowledge on the influence of those disabilities on daily life, development, behaviour, possibilities and limitations of people with an intellectual disability. In this chapter we will give a brief overview of some of the possibilities available for the assessment of visual functioning. Why is specific care of people with both an intellectual and visual disability so important? Why can we not just give proper care for people with learning difficulties, who incidentally also have visual problems?

Gunther (2004) provides answers to these questions as he describes specific education, support and care for persons with a visual, hearing and/or intellectual need. He explains that:

- When a person has two or more disabilities, each disability has a huge influence on the well-being of the person;
- Each disability requires its own form of special education, care and support, as well as the ability to learn to cope with it;
- The support and care of only one of the disabilities cannot be given properly, because of the influence of the other disability(s).

Thus: the support provided for only one of the disabilities is not sufficient when people have more than one disability.

People who cannot see have to use their intelligence, memory, verbal expression and capabilities to obtain information and to communicate with others. Someone with a learning difficulty cannot use some, or all of those compensation techniques, or cannot use them effectively. On the other hand, someone with a learning difficulty also uses his vision (and other senses) to explore and learn. He learns by observing people, observing the way others handle objects or cope with circumstances. When one has a visual disability, an important compensation technique, the ability to see, is not available.

Thus, for a person who has a learning as well as a visual disability, two very important compensation techniques are either lacking or affected: seeing and cognitive functioning. Having more than one disability leads to a more complex life and to fewer possibilities to compensate. Good insight into the compensating needs of a child with multiple disabilities will enable one to provide the special care needed.

Unfortunately visual (and hearing) problems are very common in people with a learning difficulty. Living with these disabilities are even more difficult when the support given is focused on only the known problems, for example, on the intellectual disability or the lack of motor control, because often the sensory disabilities are not known, noticed or understood. Expectations and support have to be adjusted according to the level and abilities of the person with a multi-disability.

Recognising multiple disabilities can contribute to early and specialised interventions. Not recognising the different disabilities may lead to under- and overcharging and thus to psychological and behavioural problems.

2.1. Standards concerning visual disability

The standards concerning visual disability are based on two components: *visual acuity (vision)* and *visual field.*

What do we mean by ***visual acuity (vision)*****?**
Visual acuity is defined as the capability of recognising two different points lying very close together as separate points. The closer together the points are, the higher the visual acuity. Or translated into Snellen values (the reading chart ophthalmologists and optometrists use to define visual acuity): when someone is able to distinguish a character size 7.5 by 7.5 mm at a

reading distance of 5 meter the visual acuity is 5/5 or 1.0. The average visual acuity of the "normal" eye is 1.0. Young adults are often able to recognise much smaller characters; therefore they have a higher visual acuity. The visual acuity can also be less than 1.0. The characters have to be bigger, or have to be offered at a closer distance for recognition.

In the test using the Snellen chart (see chapter 4.4.) the visual acuity is indicated by the number of lines the person is able to read at a reading distance of 5 meters. A person with a visual acuity *less than 0.3* (<0.3) is indicated as visually impaired. Vision can be affected by eye diseases as well as brain disorders.

What do we mean by ***visual field*****?**
Visual field is how we view our environment. Fixating our eyes on one particular point, detail can be seen, but we have a vague image of the environment. This means that we are able to notice objects and persons within the environment but we cannot recognise them, or see the detail of the objects or persons. Therefore we have to turn our eyes to the person or object and focus our eyes on the person or object. This total overview of the environment, including the central part we are focusing on, is called our visual field. Our visual field helps us to notice what is happening in our surroundings and can for example provide us with information in case of danger, or attract our attention when someone or something is approaching.

The normal visual field is about 180° in the horizontal sphere and about 130° in the vertical sphere. The visual field can be affected by eye and/or brain disorders. When the visual field is smaller than 30° (<30°) in each direction, we speak of a visual disability.

Some persons have a combination of loss of both visual acuity and visual field.

The World Health Organisation has defined a visual disability as:

Visual disability	**Visual acuity**	**and/or**	**Visual field**
Normal (no visual disability)	≥0.3		≥30°
Low vision	<0.3 and ≥0.05		<30° and ≥10°
Social blindness	<0.05 - LP+		<10°
Total blindness	no light perception		(LP=)

In other words:

- A visual acuity of 0.3 means that for recognition of symbols, the symbols, characters or pictures of the test chart have to be 3 times bigger than in a visual acuity of 1.0, or have to be brought 3 times closer to the person.
- A visual acuity of 3/60 (0.05) means that the person is able to count fingers, not on a 60 meter distance which is normal (vision 1.0), but at a distance of 3 meters. When the person has to come even closer than 3 meters to count fingers we speak of social blindness (visual acuity <0.05).
- You can point out a normal visual field as follows: a person can see his own hands at 90° to each side of the head. Above the eyes the normal visual field is 60° and beneath the eyes (lower field) about 70°. A decrease to 30° to each side of the head indicates a visual disability and a visual field less than 10° is called tunnel vision.

These two criteria, visual acuity (vision) and visual field are very important for measuring visual functioning. These figures indicate the severity of the visual disability within the definition of the WHO criteria. However, for a musician or a policeman, a visual acuity of 0.5 can be a much greater problem than a visual acuity of 0.2 in a person whose main hobby is taking long walks. How a person experiences his visual problems depends on personal circumstances, such as his needs for seeing detail, but also his own persistence, as well as on the adjustments that can be made and the support and encouragement or stimulation of his environment. For a person who likes walking or cycling low vision is less of a problem than tunnel vision, the lack of having an overview.

To understand the way someone with visual disability functions, the relevant information concerning the cause and consequences of the visual disability should help, as well as the influence it has on one’s life (development and behaviour). Accurate and extensive assessment will be necessary to discover what the implication of the disability is. Unfortunately, the necessary information to assess the visual functioning is not always available. This can be because there are no ophthalmologists or optometrists in the neighbourhood that have the equipment and experience to measure visual acuity and visual field in people with an intellectual disability. Special tests are needed, especially when the person is not able to speak or point out what he is able to see. Later on in this book you will learn more about the special tests needed. Of course it is good to know the results of the visual acuity and visual field tests, but it is even more important to know about the impact of a visual disability and to act according to this information.

If it is not possible to have a visual assessment done, you have to learn to recognise which signs might indicate a visual disability, through close observation of the person and the experience in working with visually disabled people. Doing tasks while being blindfolded yourself (simulating a visual disability) can enhance one’s awareness of the problems a visually disabled person can encounter. In this book many signs will be mentioned.

2.2. The prevalence of visual disabilities in people with learning difficulties

The prevalence of visual disabilities is high all over the world, although the figures differ from country to country. In the Netherlands, the most common problems are age-related disorders. The prevalence of visual disability increases when people get older. Cataract (a cloudy opacity of the lens of the eye) is a common problem in elderly people but can easily be corrected. In the Netherlands, in “normal” children, the prevalence of visual disabilities is about 0.2%, in elderly people without an intellectual disability up to 2%. A congenital eye disease often affects children more; whilst in adults we see many acquired abnormalities such as cataract or a visual disability as a result of diabetes or glaucoma (high eye pressure). The exact figures from other countries are not available, but especially those from the developing world are not reliable, because many people with a visual disability have never seen an ophthalmologist, and are “unknown”. River blindness is common in certain parts of Africa, as well as blindness caused by a vitamin A deficiency. In 2002, of the 6200 million people of the world, an estimated 320 million people were affected by a visual disability. In this group 37 million were blind (visual acuity <0.05). Of this number, 75% of the blind people live in Africa, South and East Asia and in the Western Pacific.

Regarding people with learning difficulties in the Netherlands, we see totally different figures regarding the incidence of visual disabilities. If we include all levels of developmental delay, we see an average incidence of almost 20% (Van Splunder, 2003). In the group of severely and profoundly intellectually disabled people, the prevalence of a visual disability is higher than 70%. So there is an extra high risk in the group of intellectually disabled persons.

Note: the incidence of hearing disabilities should also not be underestimated. Approximately 20% of adults with an intellectual disability in the Netherlands also have a hearing disability and about 5% are deaf-blind.

Silidile

Silidile was born with a cataract and was operated when she was 2 years of age. The most important part of the development of sight takes place straight after birth and during the first few months. Because of the cataract, there was a severe delay in her visual development, which unfortunately can never be (fully) regained.

The prevalence of visual disabilities

- What do you think is the most common cause of visual disabilities in children and adults in your own country?
- What is the estimated incidence?
- What do you estimate is the prevalence on visual disabilities in people with learning difficulties in your country?
- Do you think that visual disabilities in persons with an intellectual disability are recognised?
- Can you find information about these subjects on the Internet and also from your National Institute for the Blind?

2.3. The normal and abnormal eye

To be able to understand the abnormal eye and visual disabilities it is necessary to have some information about the normal eye, the causes of specific eye-conditions and eye-malformations, as well as the possible change in a person's behaviour and attitude due to the visual disability. A few examples of malformations will be described. More in-depth information can be obtained from ophthalmologists or optometrists. Information on specific eye diseases is also available on the Internet.

General knowledge of ophthalmology can help one to understand the nature and cause of a visual disability. A comparison will be made between a normal eye and a few of the abnormalities that may occur in an eye. The eye-abnormalities that will be described may occur in all people, young and old, but are far more common in people with learning difficulties. We will give a very brief explanation of the eye, but we believe, enough to provide insight in the malformations that may occur.

The eye is found in the eye socket and is protected by the socket bones. The normal size of the eyeball is approximately 24 mm in diameter. The ***sclera*** is the very tough outer layer, seen as the white part of the eye. In front of the eye we see a little round and clear or transparent window, the

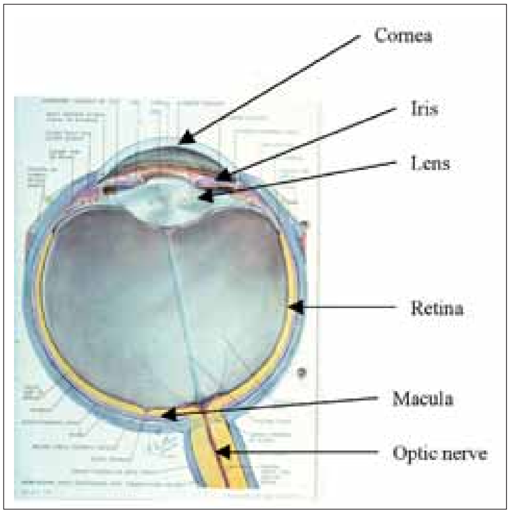


Figure. 2.1: A cross-section of the normal eye

cornea. The ***iris*** is the coloured part of the eye that can differ from light blue or grey, to almost black, depending on the amount of pigment in the eye. In the centre of the iris, we find the ***pupil,*** an opening that allows light impulses to enter the eye. The pupil will increase or decrease in size, depending on the brightness of light that enters the eye. In bright light (sunny weather) it will decrease. In dull light or during the evening when it is dark, the pupil increases to allow more light to enter the eye. Its function can be compared to that of the diaphragm of a camera. Behind the iris we find the ***lens***, which is also completely transparent. The thickness of the lens can change, so we can, normally, always focus a sharp image on the central the retina, called the *macula.* The space between the lens and the cornea is filled with a clear fluid, the *aqueous humour*. In the back of the eye we find the ***retina***. Behind the retina we find the *choroid*, consisting of blood vessels that feed the retina and drain away waste products. The vitreous body fills the space between the lens and retina*.* This body is filled with *vitreous humour*, a clear, thick, jellylike, material that keeps the eyeball in shape and all the parts of the eye in place. If some of this jellylike material leaks, the whole eye may collapse.

The ***retina*** consists of 10 layers. In the outermost layers you find the photo-receptor cells, the cones and rods. They absorb light and convert it into electrical impulses. All the neurons from the cones and rods gather in the ***optic nerve*** that transports information to the brain, where the interpretation of what is seen, takes place. These impulses will be translated by the brain into details such as movement, colour, shape, etc. The cones are responsible for seeing detail and colours and are mostly concentrated in the central area, the macula, which is the point of sharpest vision (important for seeing small details). The cones function in bright light, while the rods function at dawn and at night. The rods are also responsible for peripheral vision. They are located mainly towards the front in the curve of the retina. With the rods one cannot see details and colours. We have about 120 million rods and 6 million cones.

Each eye is connected to **six *eye-muscles*** (Figure. 2.2.), which are responsible for all the eye movements, so that the eyes can look up, down or sideways and focus together on one particular point. It is necessary that the cornea, lens, aqueous humour and the vitreous humour are all transparent, so that the light impulses (visual information), coming from the surroundings, can enter the eye without obstacles and can be focused on the retina.

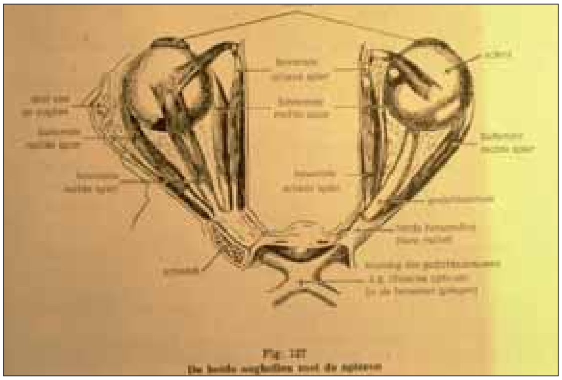


Figure. 2.2: Eye muscles

Figure 2.3. The normal eye

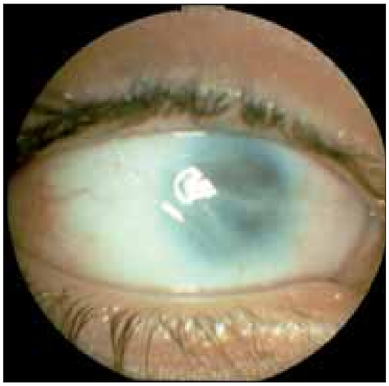


Figure 2.4. A blind eye with a totally non-transparent cornea

If there is any cloudiness, we would not get a clear image on the retina and the visual information, which is transported to the brain, will be of lesser quality or may even be non-existent. This can lead to a visual disability or blindness, as shown in Figure 2.4.

Figure 2.5. Keratoconus

Figure 2.6. Keratoconus, dense cornea

Keratoconus (Figure 2.5 and 2.6) is a cone shaped cornea (anyone can get a keratoconus, but it's quite common in people with a learning difficulty, especially Down's Syndrome). For a comparison of keratoconus and the normal eye see Figure 2.3 and 2.5. The cone shape of the cornea can grow bigger. As a result the cornea is "stretched out" and liquid can enter from the eye into the cornea and cause scars Kammerwassereinbruch). Some of the fluid can be "pumped back" into the eye again. But if this happens repeatedly the cornea can even be totally cloudy. A cloudy or cone shaped cornea can hinder or spread the light entering the eye. This may lead to visual impairment and can also cause behavioural problems because of light sensitivity (light hindrance). Light sensitivity may be experienced when looking through a dirty or a frozen windowpane of a car when the sun is shining on the windowpane. The light that shines in is irritating and blurs your vision. You can clean a windowpane, but not the "window" of your eyes. People with an intellectual disability might refuse to go outside on a sunny day, because of this light hindrance. Parents, teachers or caregivers may label this as a behavioural problem, because they do not understand why he/she refuses to go outside.

Figure 2.7. Clear lens

Figure 2.8a. Cataract after eye trauma

Figure 2.8b. Cataract due to ageing

A ***cataract*** (opacity or clouding of the lens, Figure 2.8a and 2.8b) can have different forms and may lead to a visual disability or even blindness. A cataract can often be treated with an operation. The cloudy lens will be removed and replaced by an artificial lens. After surgery, spectacles may be prescribed.

Insight in the reason why someone has a visual impairment is more difficult when the eye abnormality is situated in the deeper parts of the eyes. These eye malformations are not visible from the outside. So knowledge about signs that may indicate a visual disability may help to identify eye abnormalities. After identifying a possible visual disability the necessary action can be taken, such as asking help from a person who is specialises in visual assessment and observation or by asking for an assessment by an ophthalmologist.

In the following pictures frequently appearing eye-diseases in people with learning difficulties will be shown. Of course they can also occur in people without learning difficulties.

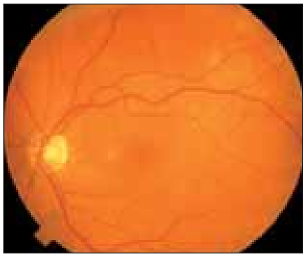


Figure 2.9. Normal retina

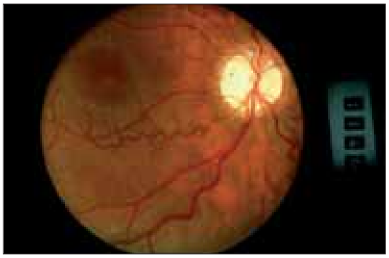


Figure 2.10. A pale optic nerve

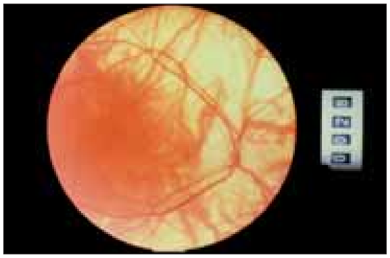


Figure 2.11: Albinism

Figure 2.9 shows a ***normal retina*** with a normal nice pink/orange colour, normal sized blood vessels and a ***normal optic nerve*** (slightly pink).
In the case of ***optic atrophy*** the optic nerve can be less pink or even totally white (Figure 2.10). This indicates that the transfer of visual information from the retina to the brain is damaged to some extent. The transfer of information may be slower, incomplete or even non-existent.

Figure 2.11 shows the retina of a person with ***albinism***, with very little pigmentation in the eyes and which normally leads to the loss of visual acuity. This condition (lack of pigmentation) can be present in the skin as well as in the eye. Albinism will not be explained in-depth, as the combination of albinism and an intellectual disability is very uncommon. The picture is just an illustration to show the difference between a normal retina and abnormalities due to a lack of pigmentation.

Figure 2.12. Tumour

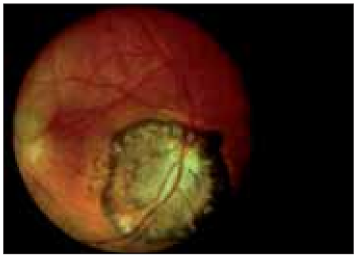


Figure 2.13. Toxoplasmosis

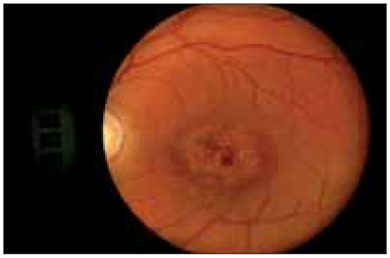


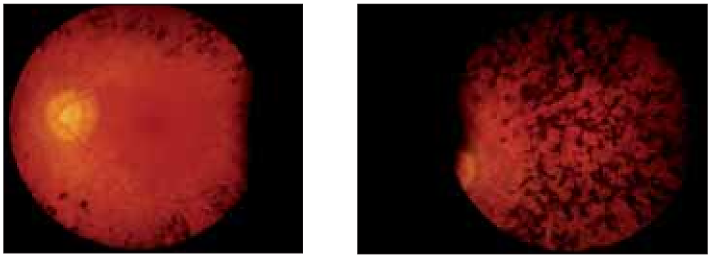
Figure 2.14. Macula degeneration

Figure 2.12 shows a retina with a tumour, a disease that can also affect the eye. Figure 2.13 shows a retina with a big scar because of ***Toxoplasmosis***, a parasite carried by cats, which can affect human beings. When infected it is often hardly noticed, but when a woman is pregnant this parasite can affect the brain and/or retina of the unborn child.

Where the retina is damaged it is not possible to receive and transfer visual information from the damaged parts to the brain. This normally leads to the loss of visual acuity and/or visual field, and in many cases, to light sensitivity or low vision.
As explained before, the 6 million ***cones*** are the receptor cells, which are responsible for colour vision, vision in normal (day)light and detailed vision. The highest concentration of cones is in the macula (see Figure 2.1.) and that is the reason why the macula is so important for seeing details. The concentration of cones is the highest in and near to the macula.

The ***rods*** are the receptor cells, responsible for vision in dim light. These 120 million rods are distributed throughout the whole retina, except the macula. It takes a while before they adapt to darker circumstances, which is the reason it takes a while to see something when walking from a very bright environment into a dark or dusky room. This is called dark adaptation. When the cones are damaged we have problems seeing colours and detail (especially when the macula is damaged) and we lose a part of our visual acuity. When the rods are damaged we have trouble seeing in twilight and darkness, since adaptation in the dark is disturbed. We can also see an (increasing) loss of visual field. When the cones are first damaged we will lose the central field (macula region), and when the rods are damaged we see a loss of the peripheral field, outside the macula.

Macula degeneration (Figure 2.14) also results in loss of visual acuity, and a loss of the central visual field. Often vision of about 0.1 will be left. When a person looks straight at an object, which is normal visual behaviour, he will not be able to see any detail. He has to turn his head to observe things or persons with the peripheral field, which leads to a blurred image. That leads to the inability to see detail, difficulty in recognising objects, faces and facial expressions. It also leads to not making eye contact, which is often interpreted as being impolite or autistic behaviour.



Figures 2.15 and 2.16. Retinitis pigmentosa, early and late stage

In ***retinal dystrophia***, a degenerating malformation of the retina, the rods and cones lose their function. ***Retinitis pigmentosa*** is one of the eye-diseases that show progressive loss of the function of the photoreceptors. Retinitis pigmentosa is a rod-cone dystrophy because first the rods lose their function and afterwards the cones. In the early stage you may find clotting of the pigment in the peripheral range of the retina, so the light sensitive rods first lose their function which leads to loss of dark adaptation (seeing in twilight and dark, night-blindness) and the loss of visual field, leading to tunnel vision. In the end often the cones also lose their function, which leads to total blindness. Retinitis pigmentosa is a disease that is quite common amongst people with learning difficulties. One of the most common syndromes in South Africa with retinitis pigmentosa is Bardet-Biedl Syndrome. Retinitis pigmentosa affects people at different stages. Some persons with this syndrome become blind at a very young age, others during their teens. Some may remain partially sighted and may still have tunnel vision into their forties or fifties.

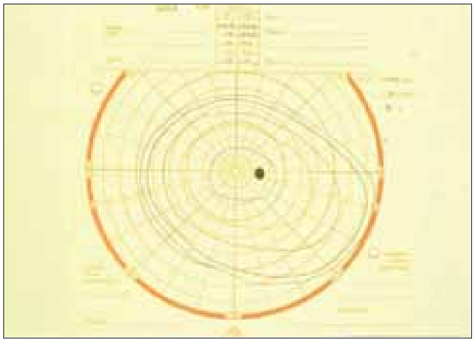


Figure 2.17. Normal visual field of one eye

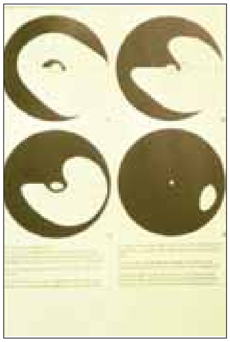


Figure 2.18. Loss of visual field in glaucoma

Cone-dystrophy usually occurs between the first and third decade of life with day-blindness, aversion to light, loss of visual acuity (macula function) and colour blindness.

Glaucoma (high eye pressure) leads to the typical loss of the visual field. Figure 2.17 shows a normal visual field (of one eye) and in Figure 2.18 the black (= blind) areas show the sequence of the loss of visual field. An unknown high eye pressure will only be noticed when the loss of visual field is already in an advanced stage. So it is a sneaky disease, especially because it is painless. For that reason, everyone over 45 should have regular tests to measure and control the eye pressure. Only in acute glaucoma with a sudden and very high eye-pressure, patients suffer from pain, headache, nausea or vomiting. The eyes are red and the cornea looks hazy. They should be treated immediately, because the eye-pressure is very high and will soon lead to a severe loss of visual field, or even blindness. Untreated or untreatable glaucoma will lead to blindness.

Treatment of high eye pressure consists of the use of eye-drops (for the rest of one's life) and if necessary, laser treatment or an operation. The damage caused by glaucoma is irreversible.

It is impossible to mention and show all the eye abnormalities and consequences of the abnormalities. If there is any suspicion of any abnormality or lower vision, an ophthalmologist should be consulted. We are aware of the fact that this is not always possible. Sometimes the cause of the intellectual disability is known. The consequences of the malformations, belonging to the cause of the intellectual disability, can be studied via the Internet or found in medical literature. If the ophthalmologist finds any malformations, please ask for a detailed explanation of all the consequences for the client and his environment and what treatments or adaptations are possible or necessary.

Other visible eye abnormalities

Strabismus (squint) Normally both eyes focus simultaneously on an object. In some cases we see a squint of one eye, called strabismus. The affected eye is pulled to the nasal side or inside (convergent, esotropia) or the outside (divergent, exotropia) and unable to look straight at objects. This happens when some of the eye muscles do not function in harmony or when one of the eyes has an eye abnormality. These are the most common forms of strabismus. It is also possible that one of the eyes is standing higher or lower, sometimes combined with a squint inside or outside. The eye with a squint has most of the time a lower vision (amblyopia) than the non-squinting eye. Please note, that when one of the eyes has a squint, the brain receives two images but blocks/suppresses the weaker image. The squinting eye becomes "lazy" and may lose (part of) its function. We realise the explanation about a squint and amblyopia is very brief, but we only want you to be aware what a squint is and what can cause it. A squinting eye doesn't necessarily lead to a visual disability, as long as the not squinting eye has good vision.

Nystagmus The eyes sometimes make involuntary eye movements, called nystagmus. This movement can be jerky or rhythmic. Nystagmus can be horizontal or rotating, and sometimes vertical. Nystagmus can be the cause of lower vision, but an abnormal vision can also lead to a nystagmus. Nystagmus cannot be corrected. Sometimes the nystagmus can be less when the person turns his head (torticollis) into a certain direction.

2.4. Refractive errors

In conclusion we will have a look at refractive errors, even though refractive errors do not have to be an indication of a visual disability. As long as correction of the refractive errors (spectacles, lenses, laser) give a vision higher than 0.3, we do not speak of visual disability (according tot the World Health Organisation).

Sometimes, especially in people with learning difficulties correction of the refractive errors improves visual acuity, but they still have low vision. Or sometimes wearing spectacles is absolutely impossible. However, it is always worth trying spectacles. Do not all people, including those with an intellectual disability, deserve equal opportunities?

What is meant by refractive errors and what is the cause of a refractive error?

The most common eye problems are refraction errors. Normally the light rays from an object outside the eye are bent to focus exactly on (the macula of) the retina. This leads to a sharp image of what we see. This is called emmetropia. Most of the people are emmetropic or have very little refractive errors, so correction will not be necessary. To imagine what it means the light rays are bent, think of a stick you put in clear water. It seems the stick is broken on the water surface, but it's not. The image looks that way because air and water bent the light in a different way. This is the same in the eye. The cornea, the lens and the fluids in the eye bent the light onto a focus point.

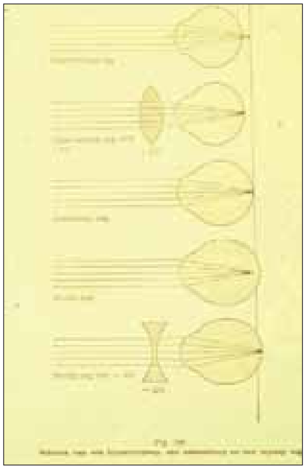


Figure 2.19. Emmetropia, hyperopia and myopia

When the light rays that enter the pupil are not focused on the retina, but focuses somewhere in front of it (the 4th image of Figure 2.19), we speak of a ***myopic eye***. The eye is a little bit too long and these people are called ***nearsighted***. That means, without spectacles, their near vision is better than their distance vision. This can be corrected by providing them with ***minus lenses*** (in their glasses). See the last image of Figure 2.19.

In ***hyperopia,*** the light would be focussed "just behind" the retina instead of on the retina (the 1st image of 2.19). By using a ***plus lens*** *(the 2nd image)*, the light will be focussed onto the retina and provide a sharp image. When someone is hypermetropic he can often focus the light on the retina by accommodation. This means that he can focus his eye lenses by making them thicker (plus lenses). Especially babies have the ability to adapt their focus. Focussing nearby all the time can make a person tired and may result in headaches.

When people get older (> 40-45) they lose their capacity for accommodation and have trouble reading (***presbyopia***). Their arms will "become too short" to read properly because they have to hold the book further and further away to read. Reading spectacles (plus-lenses) or bifocals will help. People with an intellectual disability often cannot read but they may need the "reading" spectacles for building puzzles, drawing and looking at pictures, etc.

For more information on refractive errors see: www.visionchannel.net

Note: wearing spectacles (or not wearing spectacles) does not give any information about the presence of a visual disability!

2.5. The visual field

As mentioned before, not only visual acuity is important in visual functioning. The optic nerve that leaves the eye goes to the optic chiasm in the brain. Part of the optic nerve crosses in the chiasm; the left part of the retina of each eye is connected to the left part of the brain. The left parts of the retina receive the information from the right part of the visual field, which is shown in Figure 2.20. Likewise, images from the right part of the visual field of each eye are received at the left part of the brain. (Compare it to being spastic: damage in the left part of the brain can lead to problems in the right arm and/or leg).

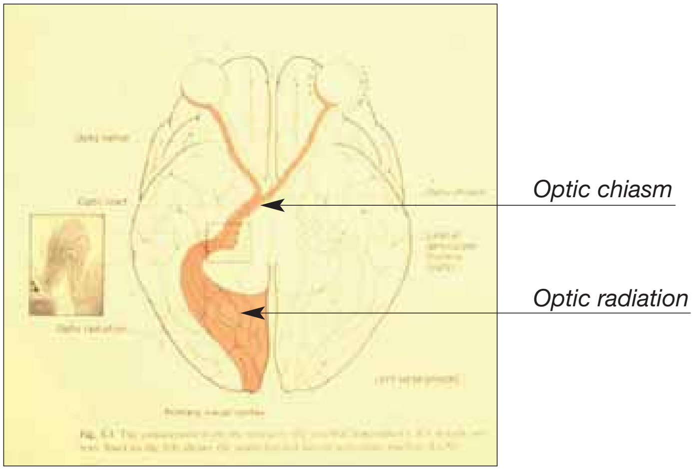


Figure 2.20. Visual field

Again, information from the right side of the visual field is projected onto the left side of the right eye (nasal side) and the left eye (temporal side). This information is gathered in the brain on the left side. So the information of the left side of the left eye is processed directly to the left side of the brain, while the information of the left side of the right eye is crossing in the optic chiasm. Because of the images of those parts of both eyes are transported to the same part of the brain, through the optic radiation, we "see' the two images simultaneously as one, seeing "depth" (stereopsis). This is why we develop good eyesight in both eyes. As mentioned before, in a squint one of the images will be more blurred and the brain will suppress the worst image, the one of the squinting eye, resulting in, most of the time, amblyopia of this eye.

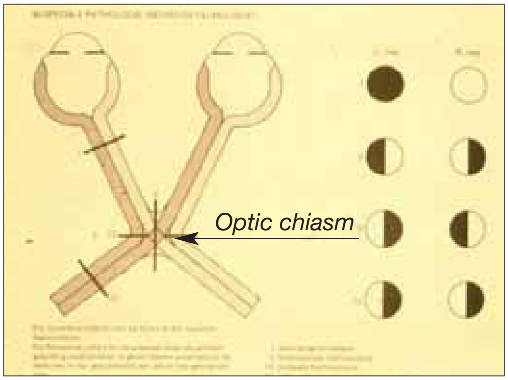


Figure 2.21. Obstruction of visual pathways and loss of visual field

Figure 2.21 gives an image of the loss of visual field, depending on the position of the damage in the brain. Before the chiasm, where part of the information of both eyes is crossing to the other half of the brain, an obstruction will lead to a blind

eye. When the damage is in or behind the chiasm, there is a loss of a part of the visual fields of both eyes, as showed in the circles on the right side of Figure 2.21. This will again be explained in paragraph 2.7.
Thus, obstructions of the visual pathway can lead to various losses: loss of vision, loss of visual field or both and therefore, this may lead to different kinds of visual disabilities.

2.6. Risk factors related to visual disabilities

People with visual disabilities are found in all countries of the world. Furthermore, more or less the same eye conditions cause most of the visual disabilities. However, the extent to which each condition contributes to visual disabilities in a country or region differs. In Europe the consequences of diabetes and glaucoma are important risk factors, while in certain parts of Africa, the lack of vitamin A, trachoma and river blindness are much more common. In Asia there are many people with untreated cataracts. However, all over the world children with developmental delay and adults with learning difficulties are a large group that are at risk for being born with, or acquiring, a visual disability, as mentioned in paragraph 2.2.

Eye and visual abnormalities are often caused by brain damage, certain Syndromes (like Down's Syndrome) and degenerative diseases. The abuse of drugs and alcohol and HIV infections are further risk factors for the unborn child. People with learning difficulties, especially in countries with highly developed care systems, live longer and are therefore at risk of visual disabilities due to ageing factors that cause visual disabilities. First, a summary of possible risk factors will be given. Secondly, examples on risks on visual disabilities will be given regarding the intra-uterine infections and intoxication and regarding Syndromes. However, the focus of this chapter is only to give an overview. For more information, please consult the Internet and or other publications.

In pregnancy and delivery

Congenital (= inherited) factors may be the cause of visual disabilities. Visual disabilities are often found in people with:
- Down's Syndrome, Bardet Biedl Syndrome
- Leber's Disease (these persons do not always have a learning difficulty), Peter's Anomaly, Peter's Plus Syndrome
- Disorders of metabolism like: leucodystrophia, Neuronal Ceroid Lipofuscinosis (NCL), mucopolysaccharidoses

Intra-uterine infections can cause a lot of damage. The earlier the foetus is exposed to viruses, parasites or toxic substances during pregnancy, the bigger the more severe the damage will be, to both the brain and the eye.
Examples are:
- Rubella (German measles)
- Toxoplasmosis (a parasite appearing in cat stool)
- Drugs and Foetal Alcohol Syndrome

During birth there can be many complications such as:
- Asphyxia (lack of oxygen), leading to cerebral palsy
- Cerebral (brain) haemorrhage
- Premature birth, long-term respiration

Acquired eye disorders (eye disorders obtained later in life)

- In certain Syndromes, such as Down's Syndrome:
  - Cataract (opacity of the lens)
  - Keratoconus (distortion or deformation of the cornea)
  - High myopia (in need of high minus glasses)
- Age-related disorders (ageing):
  - Cataract
  - Glaucoma (high eye-pressure)
  - Diabetic retinopathy
  - Macula degeneration
- (Automutilation / self-injurious behaviour, like head banging)
  - Cataract
  - Detachment of the retina

Acquired brain damage

- Asphyxia (lack of oxygen):
  - Near-drowning
  - Near-cot (crib) death
  - Epileptic seizure
- Meningitis, meningo-encephalitis (sometimes after vaccination)
- Head trauma
  - Accidents
  - Cerebral haemorrhage, cerebral infarct
  - Non-accidental injuries for example, child abuse and Shaken Baby Syndrome
- Tumour of the brain, brain surgery

Some examples of intra-uterine infections and intoxication

As mentioned earlier, the focus of this book is to give an overview. Therefore, only a number of examples are provided. The features that will be discussed are not complete and are not always present in every community. Information on many more Syndromes and conditions can be found via the Internet and in other publications.

Rubella Syndrome The cause of Rubella Syndrome is an active rubella infection in the mother during pregnancy. The earlier in pregnancy the rubella infection occurs, the more it affects the unborn child, especially during the first 3 months. Many of the children affected by this infection have learning difficulties, growth retardation, heart defects, sensory neural hearing loss and microcephalus (small brains). Ocular abnormalities are conditions such as: retinal pigmentation, microphthalmus (very small eyes), cataract, glaucoma, keratitis (inflammation of the cornea), and corneal scarring. Many children with these conditions have a tendency to eye-poking (putting a lot of pressure on the eyes by pushing hard with their fingers). Rubella vaccination has dramatically reduced the incidence of the Rubella Syndrome in the Netherlands.

Toxoplasmosis Intrauterine toxoplasmosis can cause chorioretinitis (inflammation of the retina) and intra-cranial calcifications and is acquired by eating uncooked or undercooked meat or contact with contaminated cat faeces. Besides chorioretinitis we see microphthalmus, cataracts, optic atrophy, and panuveitis (an infection of the total eye). Chorioretinal scars (see

Figure 2.13) are often located in the macula, which leads to vision loss and (often) to nystagmus.

Other intra-uterine infections that may have ocular manifestations are:

- Cytomegalovirus
- Herpes simplex
- Syphilis

These infections may cause chorioretinal-scarring, cataracts, microphthalmus (no microphthalmus in syphilis)

Foetal Alcohol Syndrome (FAS) Alcohol is nowadays the most reported poison to which the foetus can be exposed. One out of every six cases of cerebral palsy is estimated to be the result of (heavy) alcohol exposure during pregnancy. Growth deficiency, diminished brain cells and intelligence, malformation of the brain, ectrodactyly (underdeveloped fingers and toes), congenital hypotonia, low birth weight and a cleft lip may occur in persons with this Syndrome. Ptosis of the eye-lid (hanging of the eye-lid), microphthalmia (very small eyes), chorioretinal atrophy (the retina is damaged), optic nerve hypoplasia (underdevelopment of the optic nerve), are all possible ocular features.

Drug toxicity Drugs such as ethambutol, quinine, antileukemics, corticosteroids, (that are used as medicine) can cause ocular abnormalities such as cataracts and nystagmus. Recreational drugs may also cause ocular malformations.

Non-accidental injuries: shaken baby Syndrome, child abuse These conditions cannot be ignored by people concerned with child health care, because of the dramatic increase in reported cases. About 40% of all physically abused children have acquired learning difficulties due to brain damage and ocular complications such as lens dislocation, retinal detachment, scleral ruptures, and intra-ocular haemorrhage.

Examples of Syndromes

Bardet-Biedl (and Laurence Moon) Syndromes Eight different forms of Bardet-Biedl Syndrome have been identified. Bardet-Biedl and Laurence-Moon Syndrome are closely related. Bardet-Biedl can be identified by aspects such as obesity, polydactyly (extra digits) in about 60% of cases, mild learning difficulties, and in all cases progressive retinal pigmentation and dystrophia (retinitis pigmentosa). Myopia, astigmatism and nystagmus often occur. It is a disorder with a wide variety of outcomes. In Laurence-Moon Syndrome we do not see polydactyly and obesity, but these children have a short stature. There are also other symptoms identifiable in both Syndromes, but these are the most common.

Retinal dystrophy (retinitis pigmentosa) This condition has a great effect on visual acuity and visual fields. The dystrophy affects the rods and the cones of the retina. That means that firstly the rods will be affected which will lead to a concentric loss of visual field and the loss of dark adaptation (seeing in twilight and dark). At a later stage, loss of the macular function will follow, and visual acuity is further decreased.

Most patients will have vision less than 0.1 by the age of 30. Eventually they may become totally blind. The loss of visual field and dark adaptation in an early stage can easily be misinterpreted.

When there is not much visual loss, the person affected can unexpectedly notice small particles, but bump into other people or into objects because he does not see them, or he may ignore someone because he does not notice the other person. He may experience better sight on a sunny day than on a cloudy day. He will always switch on lights and is reluctant to switch the light off, even after given instruction to do so. The reason is that he, in order to use his remaining vision optimally, really needs very good light.

Down's Syndrome This is the most common condition of human malformation in Europe. It is caused by a malformation of the 21st chromosome. The characteristics are: mental deficiency, hypotonia with a tendency to keep the mouth open and a protruding tongue, a small stature, hyperflexibility of the joints, and many other abnormalities such as cardiac problems.
Ocular abnormalities that may occur are:

- High myopia, but sometimes hypermetropia, in 70%
- Strabismus in 45% of cases
- (Congenital) cataract (fine lens opacities in 59% and acquired in 30-60%)
- Keratoconus
- Nystagmus in 35%
- Blocked tear duct in 20%
- Chronic keratopathy, because of not closing the eyes completely when sleeping.

Every newborn child with Down's Syndrome should have ophthalmologic supervision and should be checked for refraction anomaly, strabismus (cave: amblyopia), cataract (which often appears at an early age), and keratoconus.

Leber´s Amaurosis: infantile rod-cone dystrophy Leber s Amaurosis is a rod-cone dystrophy, which presents itself at birth or during the first few months after birth. In some cases it is progressive. It is an inherited disease and a common cause of blindness, which leads to poor vision and nystagmus, roving eye movements, poor pupillary responses to light and eye-poking. In the retina we notice (not always right after birth) a pale optic disc, thin vessels and signs of periretinal pigmentary retinopathy. Later on, enophthalmus, keratoconus and cataract can be seen, which may occur because of eye-poking. Learning difficulties are frequently reported.

Examples of neurometabolic diseases

Neuronal ceroid lipofuscidosis One of the first features of this hereditary disease is the deterioration of visual functioning through retinal degeneration and maculopathy, as well as seizures and intellectual regression. There are 4 different forms, depending on the age when the first symptoms occur:

- Age 8 - 18 months - Infantile NCL, Haltia-Santavuori disease;
- Age 2 - 4 years - Jansky-Bielschowsky disease, late-infantile NCL;
- Age 4 -10 years - Batten Spielmeyer Vogt, juvenile NCL.
- Adulthood – Kuf's disease

Gangliosidosis There are many different forms; one of them is Tay-Sachs disease. It leads to an accumulation of GM2 gangliosidos in the neurones of the brain and elsewhere. Children with this condition present the following signs early during their first year of life: loss of acquired skills, blindness, seizures and being spastic. These children normally only reach the age of 4.

Examples of other conditions which can cause an intellectual and visual disability:
Hydrocephalus Increased pressure in the brain, due to excessive brain fluid, can lead to damage of brain tissue and also of the optic nerve. This normally causes loss of visual field and loss of visual acuity.

Cerebral Palsy A group of conditions which are not progressive, but motor control is affected, due to damage in the areas in the brain which control motion. Intelligence is not always affected, but sometimes hearing is. Visual disabilities can range from strabismus, refractive errors to loss of visual field, reduced visual acuity and visual agnosia (not able to recognise people or objects).

2.7. Cerebral Visual Impairment (CVI)

Visual disabilities can be caused by different problems in the eye. We have already looked at some of these problems, such as keratoconus, glaucoma, retinitis pigmentosa and cataract. However, it is possible that visual disabilities are not caused by a problem in the eye itself, but by a problem in the visual pathways in the brain. This is called a ***cerebral visual impairment (CVI).***

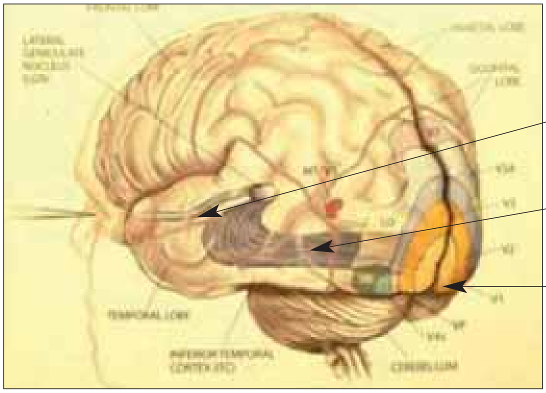
Seeing is not only the perception of light rays or patterns in the eye, but also the transmission of these stimuli to the cerebral nervous system (physiological process). In the brain the stimuli have to be translated into images, movements, colours, etc. Understanding visual information is a complex process that takes many steps, such as:
- Separating foreground from background
- Seeing colours and forms
- Recognising forms
- Perceiving different parts as one entity
- Recognising images and faces
- Understanding the meaning of the images

Seeing is a learning process. Under normal conditions, visual acuity increases very quickly after birth. At birth babies are able to see the difference between light and dark and movements. Babies already look at faces, even though they cannot see details because the visual pathway is still immature. Very soon they can make eye contact and after two months the baby smiles, imitating the smile on the faces of other people. Looking at things is a stimulation for the maturing of the eyes and (visual part of) the brain. The brain has to organise all the visual information in a way that we can recall it and learn to remember and recognise images.

The maturing of the eye (size, retina) and the visual pathways are associated with the development of visual functioning. When building up visual information in the brain one need eyes and visual pathways without obstructions.

Cerebral visual impairment, therefore, can express itself in many different ways, not only in lower vision or a loss of visual field, but also in higher visual perception disturbances, for instance: not recognising objects (visual agnosia) or (the expression of) faces, or problems in orientation. Problems may also occur in exterminating a certain object when many objects are put together (crowding).

For example: when you put five objects on the table with a big space between them it may not be difficult to pick up a favourite toy. But when the objects are put very close to one another or in a heap, these objects are noted as one object and a favourite toy may not be recognised. This may become a problem for children when they start to learn to read. Two or three letter words may not be a problem, however, longer words may be impossible to read. Also note, that CVI does not always come with an intellectual disability.



Optic nerve

Optic radiation

Primary visual cortex, V1

Figure 2.22. The visual pathways, from the eye through the brain (Zeki, 1993)

Causes of cerebral visual impairment
Cerebral visual impairment are disturbances (disorders) in seeing, caused by damage to the visual system beyond the optic chiasm, the place where the optic nerves cross and the optic tracts start, leading to the optic radiation. The small line on Figure 2.21, coming from the eye, leading into about the centre of the brain is called the optic nerve. It ends in the chiasm, where part of the nerves cross, and after that it is called the optic radiation, leading to the primary visual cortex in the brain (V1). From there, visual information is transported to different parts of the brain. Matters such as motion, colour, shape, face recognition, etc. More information can be found in Zeki (1993).

CVI can have different causes, such as:
Developmental and structural defects, for example when a child is born with malformation of the brain, similar to hydrocephalus, when there is an obstruction in the brain so that the liquid cannot be drained, or a child is born with microcephaly, an underdevelopment of brain tissue.

Acquired defects *may be:*
- Infantile encephalopathy: pre- and perinatal problems, such as asfyxia, birth palsy.
- Post-natal problems, such as asfyxia, caused by (near)drowning, near crib-death.
- Trauma (accidental, non-accidental)
- Inflammation, like meningitis, encephalitis
- Impaired metabolism
- Degenerative diseases
- Epilepsy
- Hydrocephalus
- Cerebral haemorrhage, brain infarction
- Brain tumour

In children the main problems that occur around birth (prematurity, asfyxia), can cause Cerebral Visual Impairment. Prematurity can lead to periventricular leukomalacia (PVL). This is when damage to brain tissue occurs around the ventricles and cavities that are filled with liquid. There is a close relation between the ventricles and the optical pathways because they are so close to each other, and the optical pathways are very sensitive to the lack of oxygen (ischemia). Ischemic damage in children born at term is often seen as unilateral brain infarction at the optical cortex, while in PVL both sides of the brain are affected, which increases the risk of getting CVI.

In children with cerebral palsy, visual impairment occurs in more than 70%. The visual pathway in the brain is a big part of the cortex. So, if any damage occurs to the brain, parts of the visual pathway are often affected.

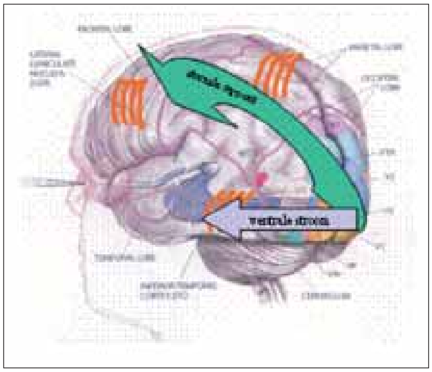


Figure 2.23. Ventral and dorsal stream of visual information

Figure 2.22 and 2.23 show the visual pathways of the brain.
The visual cortex is divided into many different parts, such as:
V1: primary visual cortex, receives all visual input
V8: processes colour vision
MT/V5: detects motion

Figure 2.23 also shows the submission of all the gathered information in a ventral stream: the area for what it is (recognition) and a dorsal stream: the area for where it is (location). Damage to the ***ventral stream*** on the right side of the brain causes problems in recognising faces, understanding of facial expression and route finding. On the left side it causes problems in recognising objects and forms and this side is important for reading. Damage in the ***dorsal stream*** causes problems in getting an overview and making a selection in visual information, simultaneous perception (processing information from different senses at the same time), integration with the motor system, moving in (a 3-dimensional) space, knowing where you are.

Symptoms
The symptoms of PVL and local damage show various differences.

Symptoms	Local damage	PVL
Nystagmus	Rare	30 %
Optic atrophy	Rare	Regularly
Cerebral Paresis	40 %	80%
Squint	Rare	Often
Hydrocephalus		In 30%

Because of the damage to the visual pathways and/or the primary visual cortex, visual acuity is decreased and often we see loss of visual field. Often the loss of visual field is found in a concentric loss thereof. Sometimes we see a hemianopia, (loss of half of the visual field) or

sometimes a loss of the lower part of the visual field.
Because of damage to the connections to the frontal cortex, (cortex at the level of the forehead), where we find the centre that controls the eye-movements, there are problems with fixation and the smooth movement of the eyes. Failure to accommodate (vary the thickness of the lens in the eye to see nearby) may also occur sometimes.

When the (pathways to the) higher visual centres are damaged, we see a visual-cognitive problem such as “where” something is and “what” it is. The “where” centre gives information on the location of an object in space, whether it is moving or not and the orientation of an object. This part of the brain is also active when a person moves. The “what” centre becomes active when we have to recognise objects and faces and it has a close relationship to our memory. If those higher visual centres of our brain are damaged we have problems in orientation, recognition (faces, objects, characters, reading), simultaneous perception and seeing depth.

Visual problems in CVI

Primary visual cortex:	- decreased visual acuity, sometimes blind sight (knowing there is something there, without really seeing it) - loss of visual field: concentric loss hemianopia loss of the lower visual field
Visual-motorcontrol:	- fixation problems - problems with smooth pursuit and fixation - nystagmus - squint - accommodation problems
Visual-cognitive: (interpretation)	- disturbed simultaneous perception, crowding - disturbances in seeing depths - problems in the perception of movements - orientation problems - disturbances in recognising forms and faces - problems with reading

In a child born with CVI we often see none or very little visual reaction in the first months after birth. After that it looks as though there is some visual perception in the peripheral visual field and the child is able to follow slow movements. Striking features may be visual inattention, inadequate fixation and looking away from offered objects. Some children constantly gase or stare at the lights. A child may have problems finding an object and looking at it.

The integration of visual information with motor movements or listening (hearing) at the same time, is difficult. At such moments, visual information shuts down. The visual input is not the most important information people with CVI get, because it is often not understood. Hearing or feeling is more important because it is better understood.

What kind of treatment can be offered? In children with low visual reaction visual stimulation is an option to try to improve visual attention. However, one must be very careful in order to prevent over-stimulation because many children may have problems in simultaneous perception. Furthermore, people working with a child with CVI should be informed of the consequences and possible adjustments to the environment. Objects should be offered one at a time. The objects should not be too small and should have a high level of contrast. Photographs are often too difficult to interpret, because there is too much information on it. Using pictograms can cause problems because people with CVI can have difficulty in translating 3-dimensional information (e.g. a car) into 2-dimensional information (the picture or drawing of a car). Use big objects, bright colours, slow movements, give verbal information and allow using taste, smell and touch can teach the child the difference.

Conclusion: a few examples of possible visual disabilities

Marjory

Marjory is a young woman of 19. She has slight learning difficulties. She attended a special school; she can write her own name, recite the alphabet, but is unable to read. She now works in a sheltered workshop and lives in a group home with 5 other women of her age.

Marjory is overweight and has extra fingers on her hands, but no extra toes on her feet. She can build puzzles with small parts. She enjoys making cards and watching television.

There are a few things the caregivers are concerned about and which they do not understand:
The first thing Marjory does when she arrives home is to switch the lights on in every room she enters
Even though she can do detailed work, she often bumps into furniture or overlooks things on the table, while eating. Sometimes she sees her caregivers; sometimes she only notices that caregivers are in the vicinity when they start talking. It seems as though she ignores people. Her friend gets frustrated if she feels ignored. Marjory always says she really did not notice the other person and that she does not ignore people, but this is difficult to believe.

A visual disability?

Discuss the following questions:
1. Thinking of what you have learned so far: how can Marjory’s behaviour be explained?
2. Does her behaviour remind you of a certain kind of visual disability?
3. Does her behaviour remind you of a child you know?
4. How can you examine the possible cause of the problem?

Charles

Charles is a boy age 7. He has Down’s Syndrome and attends a school for special education. When reading, he constantly shortens the viewing distance considerably - up to 10-15 cm from his work. Even though his teacher continuously asks him to sit up straight, he does not obey. When he makes eye contact with others, he comes very close to them. It looks as though he wants to force his teacher and parents to give him more attention. His teachers and even his parents do not appreciate this behaviour. When making eye contact with him, they often see a strange “eye-shaking”.

A visual disability?

Discuss the following questions:
1. Can Charles' behaviour be explained now that you have learned about Down's Syndrome and visual impairment?
2. How would you explain his behaviour?
3. Does his behaviour remind you of a child you know?
4. Would you refer him to an ophthalmologist?

Michael

Michael is a boy of 3. He was born at 30 weeks and had a lack of oxygen (asphyxia) during and after birth. He has epilepsy and cerebral palsy. He can not walk, he uses a wheelchair. He does not have fine motor skills. He can use his hands and grasp for things with his full hands, but he is unable to pick up small things with his fingers. He does not make any eye contact. He hardly looks at objects and is often only alert when he hears sounds. When his parents talk to him he enjoys funny voices. He prefers toys that make a noise, and does not like cuddly toys at all. He sometimes reacts very jerky and starts crying when he is touched.

A visual disability?

Discuss the following questions:
1. Start by making a summary of Michael's specific behaviour.
2. Thinking of what you have learned so far: how can Michael's behaviour be explained?
3. Does his behaviour remind you of a child you know?
4. What can be done to help Michael?

First complete the above assignments before reading the following text.

In the first case (Marjory) a brief example is given of a person with a Bardet-Biedl Syndrome. Her wish for switching on the light can be explained because she has retinitis pigmentosa with loss of visual field and dark adaptation (night blindness) and therefore needs more light. Because of the loss of visual field she sometimes bumps into people and objects. Often she doesn't notice all the people around her. Because her central vision is not affected (yet) she is able to see small detail.

The second case (Charles) is a description of a child with high myopia which explains his reduction of distance not only to his schoolwork but also to persons and objects. Sending him to an ophthalmologist or optometrist for prescription of glasses would be wise.

The third case (Michael) is an example of a child with a cerebral visual impairment. His behaviour may indicate that the cause of his visual disability may not be his eyes but due to damage to the visual system beyond the optic chiasm. This can lead to the loss of visual field and visual acuity. Missing the overview in your environment can lead to being touched unexpectedly, because you didn't see the person coming closer. Because hearing is more important than seeing he prefers toys with noises.

Chapter 3

Understanding the impact of a visual disability

Introduction

In the previous chapter we provided important information on vision and on the causes and symptoms of visual disabilities. This information is important to understand visual disabilities, which persons with learning difficulties may have. However, is this information enough? We do not think so, because we have not yet discussed the impact that a visual disability may have on the daily life of a person with learning difficulties. In this chapter we will focus on this fact, in order to gain a better understanding.

To attain this goal we will use clips of films to explain the impact of a visual disability. We will also include assignments, which you should complete. In order to help you understand the impact better through personal experience, you will, for example, make use of simulation spectacles.

3.1. Visual acuity: 0.1

To better understand the effect of visual acuity, the DVD ‘0.1 Visual acuity’ will be used. With the aid of a special adjusted camera we can see ‘through the eyes of a person with a visual acuity of 0.1’. This is just an example as not everyone with a visual acuity of 0.1 experiences the world in exactly the same way, seeing that the nature of eye conditions may differ.

0.1 Visual acuity

Frans Gunther & Jan IJzerman

While looking at the DVD note the effect of this visual disability on daily life functioning.

Discussion

1. Imagine you have a visual acuity of 0.1, what would this mean in your daily life?
2. Which tasks may be influenced by the 0.1 acuity?
3. What is the impact of the 0.1 acuity?
4. Is it possible to reduce the impact of the 0.1 acuity?

3.2. Experiencing a visual disability by using simulation spectacles

The DVD “0.1 Visual acuity” may help you to get a better understanding of what a person with a 0.1 visual acuity may see. Now we take a step nearer to a real life experience of having a visual disability, by putting on a blindfold or simulation spectacles. The spectacles may simulate tunnel vision, hemianopia or near-sightedness. With distorted vision caused by the spectacles, we shall perform a number of everyday tasks. Afterwards we will discuss what it was like to have a “visual disability”.

Simulating a visual disability

1. Participants can do the following exercises while they wear simulation spectacles or a blindfold:
   - walk to the door
   - walk to a chair and sit down
   - colour a picture
   - cut figures out of paper
   - pour tea or water into a cup or glass (be careful with warm tea!)
   - find and recognise a person in the room
   - feel and identify different objects
   - have a conversation with someone

   For greater effect the light can be switched off or there may be a lot of noise.

2. Report on the experience:
   - How did you find your way to the door, table or chair?
   - How did you find the glass or jug? How did you manage to pour water into the glass / tea into the cup?
   - How did you recognise where you were?
   - What did you do to compensate for your lack of clear vision?
   - Which compensations did you use while doing the following:
     - colouring
     - cutting out figures
     - walking and finding your way
     - recognising a person
     - pouring tea or water
   - What does it feel like to talk to someone you cannot see?

3. Discuss how the points mentioned below may influence the experience:
   - colour
   - contrast
   - shortening viewing distance
   - using other senses
   - illumination / lighting
   - time
   - repetition
   - noise or sound ‘pollution’

To a very limited extent and in an artificial way we have experienced what it means and how it feels to have impaired vision. Of course this is only a weak reflection of the reality people with visual disabilities live with. After all, it is impossible to experience what the world of a person with a visual disability is really like. Sighted people still function from their own experience as sighted persons. They know the world the way it really is, although everyone experiences the (visual) world in a different way.

Sighted people have learned to find their way, solve their problems, and to adapt to a changed environment, etc. based on visual clues. They know how to differentiate between objects, how to analyse visual impressions and experiences. They develop a memory based on visual impressions. However, a person born with a visual disability has always experienced the world in a totally different way than sighted people, but for him/her that world is reality. Ask a pupil with low vision whether he can see the picture of a tree on the wall. The pupil will, almost always answer 'yes'. He sees something, and when the teacher tells him that it is a tree, he believes that the object with the brown and green colours is a tree. The question is, will he recognise it again?

> Does he see the leaves and the detail that make that tree different from other brown and green objects?
>
> or
>
> Will a white object on a dining-room table always be a coffee mug? Is everything on a plate edible?

3.3. Signs related to a visual disability

People with a visual disability often have a certain way of reacting. To recognise the specific behaviour more easily, we make use of a checklist, which focuses only on the visual, visual-motor and behavioural aspects. Please note that this checklist is not a complete list and that the signs only provide clues for use during the assessment process. Visual signs give a stronger indication of a visual disability than visual-motor and/or behavioural signs. The signs will be divided into the seven dimensions of human functioning:

1. Physical

- In some syndromes a combination of a physical as well as a visual disability is common, for example persons with Bardet-Biedl Syndrome.

2. Visual

- *Visible eye malformations*
  Some examples of visible eye malformations are: a (completely) white cornea, a very mature cataract (grey or yellow looking pupil), and a cone-shaped cornea (keratoconus), micro-cornea (very small eyes) or macro-cornea, the (total) absence of an iris.

- *Deviant eye movements*
  Recognisable are the quick, often horizontal, involuntary eye-movements called nystagmus. To try to compensate for, or diminish these movements, as the head is sometimes held in a different position (torticollis). Caregivers may misinterpret this position of the head as being stereotype behaviour or the result of a motor deficit.
  Wandering eye-movements - this is when the eyes move in all directions, without focussing on a person or on specific objects.

- *Squint*
  Young babies often show a squint, especially when they are tired. When they grow older the squint usually disappears. If the squint is permanent, the squinted eye usually has a lower visual acuity than the non-squinting eye. Sometimes the squint is alternates from one eye to the other. Most of the time both eyes have equal vision. Having a squint does not mean the person has a visual disability. In many cases the non-squinting eye has normal vision. A thorough visual assessment should provide the information on the visual acuity.

- *Not looking directly at an object or strange ways of looking at objects*
  Someone may have a strange way of looking at objects. When a client does not look at the object he is handling, it is often interpreted as a lack of motivation to look, or of being disinterested. Not looking at an object is also often seen in people with cerebral visual impairment. They look at an object, turn their head away and than grasp for it. In the same way clients who are unable to make or sustain eye contact, are mistakenly called autistic, frightened, impolite or shy. Not looking at an object is almost never without reason, for example a client may have specific problems in the central part of the retina which means he can only see with the non-central part of the retina, and therefore has to look sideways at an object in order to see it. Sighted people may find this very strange.
  Sometimes it's easier to detect objects when moving the head. This can be mistaken as stereotype movements and behaviour, but it is in fact an effective way to see clearer.

- *Difficulties with some visual tasks and not with other tasks*
  People may say: "You are wrong; this client is not partially sighted. Look, he can easily find his way in the home". Caregivers may not understand a client having problems with some tasks and not with other tasks. For example, a child or client may easily discover a little toy on the table, but is unable to find a big teddy bear in the cupboard (for instance due to crowding!). This can also be because different tasks demand different visual abilities. Visual functioning also depends on circumstances such as illumination, contrast and colour. For example, you do not need to see small detail in order to walk around objects without bumping into them. You only have to detect the object, and that does not need much vision. In familiar rooms, people with a visual disability often rely on their memory. In contrast with orientation in space, other tasks require the recognition of form and detail, such as looking at pictures, building a puzzle or cleaning a bedroom. However, signs can be ambiguous. Try not to jump to conclusions too quickly.

  Also be aware of the fact that some clients are able to pick up little pieces from the table or the floor, and then also bump into persons or objects. It is not because they are inattentive, but because they have a very limited visual field, or may have tunnel vision. People with CVI often demonstrate change in visual (and other) behaviour, because of change in awareness.

- *Brief "viewing" behaviour*
  People may have a strange way of looking at objects: they may look at an object very briefly, turn their head away and grasp for the object with the entire hand. Such movements are not visually controlled; they are unable to keep their focus on the object. They show short viewing behaviour, which is often misjudged as not being interested. In CVI we often see that clients have problems with eye-movements, holding fixation and reaching at the same time.

- *Short viewing distance*
  Partially sighted people may have a strong preference for looking at objects from a very close distance – to see the detail clearer, although being very close to an object may influence the overview of the presented visual information. However, when clients look from a close distance, especially at people or the possessions of others, they are sometimes regarded as being too inquisitive or “being nosy”, which is a wrong interpretation of this behaviour. Shortening the viewing distance is also seen in people who are extremely short-sighted and should make use of “minus” spectacles.

- *Difficulties seeing in the dark or in bright light*
  It may be an indication of a visual problem when a person has difficulties to function in bright light, in shimmering light or in the dark, or when the brightness of the light suddenly changes. Partially sighted people are sometimes unable to adjust to changed brightness of light as quickly as normally sighted people (one of these occasions is discussed in Chapter 2, the Bardet-Biedl Syndrome with the retinitis pigmentosa and the problems in dark adaptation). People with cataracts or keratoconus will most of the time avoid bright light, because it limits their visual functioning. They are hypersensitive to light, while others with very low vision may like to “play” with light by looking into the sun or a bright light, because it gives them a visual sensation.

- *Crowding*
  People who suffer from “crowding” can pick up an object found on a table, but have difficulty in finding the same object in a crowded environment with a lot of visual information. They may also have problems with reading: when they have to read 2 or 3 letter words they encounter no problem, but it’s impossible to read longer words. Crowding can be a big problem for people with CVI.

- *Visual agnosia*
  This is the inability to recognise faces or objects, due to CVI or acquired brain damage. However, people with this problem are often able to recognise objects by feeling, hearing, tasting and smelling. They can recognise people by their voices, footsteps, jewellery, and perfume or by specific habits.

3. Auditive

- *Avoiding noisy surroundings, or complaining when there is too much noise*
  Some clients not only claim certain places in a room, but they also avoid noisy surroundings. They easily become stressed in noisy situations, because the noise complicates their acoustic orientation. They find it difficult to distinguish between what they need to hear and what not. They then lose their understanding of what is happening around them and may also be unable to distinguish who is talking to whom. They fear such situations and can even walk away and withdraw from a social environment to the safety of a quit place.

4. Motor

- *Difficulties with eye-hand and eye-foot coordination*
  Examples of problems with coordination are seen amongst clients who have difficulty in grasping, for example, when they drink tea. To compensate and reach the object they make a

so-called “parachute-movement” around the cup and close their hand over it when they feel it, instead of reaching for the ear of the cup. Eye-foot co-ordination problems may be clear when a client shows fear for instance when approaching stairs, where there is a difference in height, a change in colour or texture of the floor. ‘Shuffling’ can also indicate a visual disability: by keeping the feet as near as possible to the floor the client obtains important information about the change in height or texture. Sometimes they refuse to wear shoes, because without shoes they can feel the floor. Keeping contact with the floor can also indicate where they are walking on stone, grass, sand, or carpet.

- *Difficulties in orientation*
  In a familiar environment the influence of a visual disability on the client’s orientation is limited, due to a combination of memory, the use of other senses and, if present, the use of visual clues. Visual detection is possible with very little visual acuity, because of the client’s ability to recognise colour and light-dark shades. Difficulties in orientation are mostly seen in an unfamiliar environment, or after changes have been made to a familiar environment. Furthermore, persons with CVI may also have difficulty with orientation, even though they have good vision and a full visual field.

5. Cognitive

- *Recognising objects*
  Another sign of a visual disability may become clear when a client makes extensive use of his/her sense of touch to examine objects or people. By touching an object the client acquires information of its shape, weight, stability, etc. Furthermore, by manipulating and shaking the object, the sound, smell and taste will give useful information in recognising the object. People smell, walk and touch differently, so this can also convey information about the person approaching.

6. Behavioural

- *Showing fear*
  When a client with a limited visual field or very low vision is approached from the side the client may get a fright or show no or even late response. Without having the correct information these signs can easily be misunderstood.
  People with CVI may show different visual behavioural reactions – at times they may react in one way and then at other times in a totally different way. Possible reasons may be that they are tired or distracted by noises. Also their alertness is changing during the day, possibly due to epileptic activity.

- *Specific preferences regarding activities*
  Persons with a visual disability will not spend time on hobbies that require good visual abilities. When they avoid visual tasks the “lack of interest” can easily be contributed to their intellectual limitations. But it can also be a sign of a visual disability. We often see a striking contrast between the client’s interest in visual tasks and non-visual tasks. For example, a client spends most of his time listening to music, but never watches (or perhaps only listens to) television programmes.

  Clients who develop visual problems when growing older can show a sudden change in their interest in hobbies and activities: for example, when they stop doing needlework or building puzzles. The question needs to be asked: Could it, for example, be the result of a cataract, or a need for “reading” spectacles, or is there another visual problem?

- *Self-stimulating or stereotype behaviour*
  The kind of activities someone is interested in, or the kind of stimuli he responds to, provide important signs. Because people with multiple disabilities lack important (visual) information, they can develop self-stimulating or stereotype behaviour. They may listen to their own sounds, wave with their hands and fingers in front of their eyes, rub on surfaces, poke in their eyes, display self-injurious behaviour or may be lost in their own thoughts.

- *Preferring a specific place in the room*
  Claiming a specific place in the room may be another sign indicating a visual disability. A person may choose a chair, often in a corner or next to a wall, or with their back to the wall or window. In this way they are able to enlarge their ability to observe and see or hear the surroundings or avoid light hindrance. Choosing a ‘safe’ chair prevents unexpected approaches or contact. Sitting with his/her back to the window can minimise direct light falling on their eyes, for example, in case of a keratoconus or cataract.

- *Limited initiative and motivation in developing self-help skills relevant to the client’s level of development*
  Persons with both intellectual and visual disabilities often show limited initiative. This lack of initiative can be a way to ascertain the help of caregivers in, for them, difficult situations. However, some clients are unable to develop self-help skills due to the nature of their multiple disabilities.

7. Relational

- *Dependence*
  Persons with a visual disability may show signs of dependence, asking for help in situations in which they may be expected to be self-supportive. They may, for instance, follow the group, taking little initiative.

Summary

From the information provided in previous paragraphs, one can distinguish certain behavioural traits indicating visual disabilities, such as fear, refusing to go outside in sunny weather or when it is dark, avoiding noisy surroundings, withdrawal, resistance to engage in activities related to visual tasks, and self-stimulating behaviour.

However, there also may be other signs such as:
- A compulsive way of ordering the surroundings: the client has a strong need for a structured environment in order to know where to find objects. They may be upset when the environment is changed unexpectedly.
- Reacting slowly and taking a long time to perform a task.
- A decline in will-power to be self-supporting.

DVD: Signs of visual impairment

Joleen Braams, Harry Hofman & Jan IJzerman

While looking at the DVD note different signs indicating a visual disability as discussed earlier in this chapter.

Discussion
- Give examples of children or adults you know who show some of the signs mentioned in this chapter.
- Do the signs presented in this chapter help you to better understand clients with odd behaviour?

3.4. Efforts to compensate for visual disabilities

Some persons with visual disabilities will use every possible strategy to gain as much visual information as possible by using their remaining vision as accurately as possible. Their strategy may be to shorten the viewing distance, take the time to observe, repeat the observation, improve contrast, reduce the amount of (minute) detail, increase the size of the image, and use additional illumination. Furthermore, the use of the other senses (touch, taste, smell and hearing) are important ways to gain useful information. They can also ask for information over and over again.

Compensating for a visual disability

1. Think of one particular child or adult with a (possible) visual disability.
2. Have you noticed whether the person uses compensating behaviour (smelling, tasting, feeling, hearing, memory, asking, and structure)?
3. Is it possible that some of the tasks or expectations can lead to frustration and behavioural problems? Are these tasks or expectations indications that the person is overestimated in his/her abilities?
4. Do you think that adjustments should be made during tasks?

People are not homogeneous and therefore there will be a great difference between two persons with the same (ophthalmologic) eye condition, the same visual acuity and visual field. The way persons experience their visual disability depends on the person, for example, on his/her self-determination and persistence, and also on the support and encouragement given by other persons in his/her surroundings. Where one person may feel extremely limited by a visual disability and will sit in a corner and show little initiative, another person will go bike riding or even run a marathon, or even work full-time and enjoy life as much as possible.

Knowledge about the cause of a person’s visual disability and the consequences for his/her development and behaviour may help to have adequate understanding of his/her abilities and limitations, also in respect of complex learning difficulties. For example, someone with a CVI often cannot make proper use of his or her sight. Possible causes are:

- The processing of visual information in the brain is disturbed and so are the eye movements.
- People with a cerebral visual impairment have brief viewing behaviour (visual inattention).
- In many cases, but not always, the most important compensating sense – hearing - is very well developed. The person will react to every little sound to obtain information. When the hearing is triggered the visual information is blocked.

In some cases a visual disability caused by ophthalmic malformation cannot be cured and therefore adaptations may support visual functioning. In case of CVI there is no cure, so adaptations are always necessary.

3.5. Persons with visual and intellectual disabilities need specific care

Providing specific care for persons with visual and intellectual disabilities requires that the realities of the person's disabilities are considered. In other words, parents, teachers and caregivers should respond adequately to the specific needs of multi-disabled persons. Thus, caregivers have to compensate for the negative effects of the disabilities and focus on the client's abilities.

Caregivers can provide specific care in the following ways:

- *Adjust the tempo of the care-giving process*
  Persons with multiple disabilities need more time to respond to questions, remarks or assignments. They also need more time to perform their tasks.

- *Provide clues for the disabled person to connect to information*
  A clue may help the client to recognise the caregiver. A deaf-blind child, for example, can identify the caregiver by associating the jewellery or aroma with the person who will provide the care. It is advisable that caregivers wear the same jewellery and/or perfume every time they work with their clients.

- *Provide a predictable and safe living environment*
  A predictable and safe living environment can be provided, for example, in the following ways: avoid changes in the living surroundings e.g. moving the furniture; provide bright contrasts and good illumination; keep the home tidy by placing objects in the same spot (the remote controls, toys, plates, cups, tables, chairs) etc. By naming every person you are talking to, everyone in the room will know who is speaking to whom. You can give information by saying that you are entering or leaving the room and by telling why you are in the room and what you are doing. Do not touch partially sighted or blind people unexpectedly.

- *Stimulate independence*
  The client may become as independent as possible when daily living skills are taught.

The remaining senses and the cognitive processing of clients with a visual disability can be stimulated in different ways:

- *Remaining vision*: Residual vision can be stimulated for example by providing magnifying spectacles, a reading loupe, and additional light. The use of a white cane can help the person to move about independently from one place to another. To use these aids adequately persons (with learning difficulties) need special training. In many cases clients with learning difficulties will not be able to use these aids.

- *Remaining other senses*: The senses of hearing, smell, touch and taste should be stimulated. For example, give the client the opportunity to smell and taste the food before starting the meal; feel the towel and smell the soap before washing, etc.

- As *reducing unnecessary sounds* may support other senses, these unnecessary sounds can be reduced in the following ways: turn off the radio while you are having a meal, give the client the opportunity to wash without the presence of other clients in the bathroom. In other words, support the client by creating a quieter environment.

- *Cognition:* Cognition can be stimulated by often repeating what is said or offered (by smelling, tasting, and holding it) and then gradually adding new information. Learning new skills needs repetition especially for persons with a visual disability and a learning difficulty.

- *Self-confidence:* Self-confidence can be stimulated by teaching the person to master self-help skills.

Persons with a visual disability need specific care. When they have an additional learning difficulty they need even a more “specific” specific care. To give specific care, adjustments should be made in the daily care programme.

We will now discuss possible adjustments to the specific care programme. The accompanying exercises are included to give ‘non-disabled persons’ the opportunity to experience the world of persons with a visual disability. These experiences may stimulate you to make the necessary adjustments and provide special care.

1. Adjustments regarding attitude

A caregiver with a sensitive and supportive attitude will prevent, reduce or compensate for the disabilities and focus on the client’s abilities; for example, the caregiver will remove the toys lying around on the floor or warn the child and support him or her to get to the door safely.

The caregivers should exercise patience by not rushing the disabled person, but to help him to discover and adjust to a new environment. The caregiver should encourage the disabled person to find his own way around and provide help by guiding the person in a respectful way. However, sometimes the caregiver should withdraw and give the disabled person an opportunity to find his own way. This will only be possible if the person has the cognitive ability to do so. If the disabled person asks for help the caregiver should respond with understanding and support.

During the following exercises you can experience what it is like when the caregivers either adjust their attitude or are not supportive. During the following exercise you are blindfolded or use spectacles, simulating a visual disability.

Attitude

Experience the way the caregiver helps you in an unfamiliar situation.

Three participants leave the room. They either put on simulation spectacles or a blindfold before entering again. The room setting is changed. Take care not to make too much noise while moving the furniture and changing the room.

The first person with a simulated visual disability enters the room.
- The caregiver shows the "disabled" person how to orientate himself in the 'new' room. This can be done by being either very caring or inconsiderate.

The second person with a simulated visual disability enters the room.
- The caregiver helps this person to find a chair. This can be done by being either very caring or inconsiderate.

The third person with a simulated visual disability enters the room.
- The caregiver helps this person to find his bag/coat. This can be done by being either very caring or inconsiderate.

Discussion
Did the caregiver stimulate the senses and cognitive processing of the disabled person? Did the caregiver:
- Stimulate the use of the remaining vision?
- Stimulate the other remaining senses?
- Provide cognitive support?
- Stimulate self-confidence?

Describe the caregiver's attitude considering the above-mentioned aspects?
- Was the caregiver patient by allowing sufficient time for the activity?
- Did the caregiver provide encouragement?
- Did the caregiver show respect?
- Was the caregiver tolerant?

Repeat the assignment but now keep in mind the way in which you stimulate the remaining senses and support the cognitive process, as well as the way in which you have a supportive and understanding care-giving attitude.

In summary, to provide specific care the caregivers should be aware of their attitude towards the disabled person. The caregivers should:

- *Be patient:* Be patient and give the disabled person the necessary time to orientate in a new situation.
- *Be encouraging:* After helping someone to find his/her way, encourage the client to find

his/her own way around. This encouragement should be given by verbally motivating the person to take initiative and by giving him or her time to respond. Give compliments and be supportive.
- *Show respect:* Speak in a friendly and caring way and when you touch the disabled person, prevent a harsh and unexpected touch.
- *Be tolerant:* Being tolerant will encourage the disabled person to take initiative, while intolerance will cause stress or anxiety and thus the disabled person will make mistakes and feel insecure.

2. Adjustments regarding mobility
Specific care implies that the caregiver is aware of the mobility skills of the disabled person. The caregiver should:

- *Guide from a close distance*
  There are different ways to guide a person who is visually impaired. One way is to walk a small step ahead of the sighted person. By doing so, this person can follow you and sense your movement. Also the disabled person can walk one step behind the sighted person with a hand on the sighted person’s shoulder or elbow. A verbal warning can be given by the sighted person when the disabled person approaches obstacles, people, doorsteps, etc.

- *Guide the disabled person from a distance*
  By giving verbal instructions or by making other sounds, for example by patting on the table, the sighted person can direct the visually disabled person to find his way to the table.

- *Be patient*
  Allocate time for the person to orientate himself, especially in strange situations or surroundings. By walking slower you allow the visually disabled person more time to gain the necessary information.

- *Support the use of the remaining senses*
  If possible, give the person the opportunity to use the remaining senses: hearing, touch, taste and smell.

- *Adjust surroundings*
  Make it easy for the person to find his way on his own, for example by placing a mark on the wall of the corridor, or on the floor. Or allow the disabled person to always use the same chair, situated on the same spot in the room.

- *A safe spot*
  When the visually impaired person is seated against the wall or in a corner, no one can unexpectedly approach this person from behind or from the side and therefore avoid getting a fright or having to be on guard all the time.

- *Adapt care to the specific disability*
  In the case of a reduction of the visual field, it is better to approach the person from the front than from the side. Or, in the case of a right-sided hemianopia it is advisable to approach this person from the left side or from the front to prevent unexpected touching, which might cause anxiety. In such cases it is advisable to let the person sit in the room on the side where the hemianopia manifests, facing the wall.

Mobility

Experience what it feels like to be guided by a person who is patient and caring as well as by a person who is impatient and indifferent.

Both the caregiver and the person with a simulated visual disability walk downstairs. The caregiver uses different ways of guiding the person with the simulated disability, for example by either being caring, indifferent or careless. Vary the way you touch the “client” for example: hold him firmly, pull him along or ask him to put his hand on your shoulder. Obstacles can be described verbally or the “client” can be allowed to touch the obstacles, for example a banister. While doing this exercise **always take care and prevent accidents**.

Discussion
What did the person with the simulated visual disability experience as positive and as negative?

Describe the caregiver’s attitude considering the earlier mentioned aspects?
- Was the caregiver patient by giving sufficient time for the activity?
- Did the caregiver provide encouragement?
- Did the caregiver show respect?
- Was the caregiver tolerant?

Discuss the influence of the caregiver’s attitude on your own feelings of well-being and behaviour as a “client”.

In summary, always guide the person with a visual disability in the way the disabled person prefers to be guided. If the person cannot talk, observe if the disabled person gives you the impression that he/she feels safe. To support self-competence rearrangements in the house or around the home may be necessary. To stimulate and support mobility the attitude of the caregiver is decisive.

3. Adjustments regarding communication

Specific care includes that the caregivers are aware of their communication skills. The caregiver should:

- *Start and end all contact*
  Use the visually disabled person’s name and inform the disabled person about your presence. Always verbally or non-verbally explain what is going to occur. When leaving the room announce the departure and the expected return. Remember to mention the name of the person in the room to whom the conversation is addressed, whether it are caretakers, parents or clients. Also provide verbal information on persons entering or leaving the room and what these persons are busy with.

- *Keep contact*
  When a crowded area is entered you can keep in touch with each other, for example, by asking the disabled person to hold your elbow.
  When you are continuing the conversation, commenting on what you are doing, or by singing, you can keep contact with the visually disabled person, even if you are in a separate room.

- *Give information*
  As the visually disabled person may miss many visual clues it is important to describe what is happening, what you see and notice.

- *Use communication aids*
  In some cases communication aids can support the (visual) and cognitive processing of the visually disabled person. For example, enlargement of objects, pictures or prints may be supportive. Additionally touch or smell can be added.

Communication skills

Experience what it feels like when care is given without adequate communication skills.

The sighted person gives the person with a simulated visual and physical disability (not being able to use hands) a glass of water without explaining what can be expected.

Discussion
1. Was attention given to attentive communication skills?
2. Describe the caregiver's attitude considering the earlier mentioned aspects
   - Was the caregiver patient and giving sufficient time for the activity?
   - Did the caregiver provide encouragement?
   - Did the caregiver show respect?
   - Was the caregiver tolerant?
3. Describe what it feels like to be the visually and physically disabled person. Did the caregiver's attitude have any influence on your attitude towards the caregiver?
   Repeat the assignment. Give the "client" (simulated disabled person) a glass of water and now use adequate communication skills.

By being aware of the missing information that a person with a visual disability experiences, the caregiver can support the disabled person in the following manner: by the way contact is started and rounded off; by staying in contact even if the caregiver is in another room; by giving (verbal) information to the disabled person and providing the possibility to participate in the conversation or activity.

4. Adjustments regarding activities during daily care
Specific care includes that teachers/caregivers make the necessary adjustments when activities or tasks are performed, to such an extent that the visually disabled person can learn new skills or perform new tasks. For persons with learning difficulties, additional activities should be included in the daily programme to stimulate their development:

- *Stimulate all the senses*
  For example, during story telling the visual, auditory, tactile, smell and taste senses can be stimulated. Stimulation of all the senses during activities can increase understanding and participation. In other words, it may prevent under-stimulation or getting bored.

- *Stimulate movement*
  Add activities to the daily programme which include movement such as a rocking chair, a swing, or holding hands while singing, dancing and moving from one side to the other.

- *Provide strong visual stimuli*
  Make use of strong contrasting colours and adequate light when activities are provided. By doing this, the use of residual vision will be stimulated and there could be more participation during activities. Movement can also give stronger visual information.

- *Be predictable but also elicit participation*
  When activities are provided there should be some predictability as this gives the disabled person a feeling of safety. However, also add small new elements as new activities may stimulate participation and activate involvement.

- *Reduce overwhelming stimuli*
  When too much stimuli are given simultaneously the visually disabled person will not know what to attend to first. This may then support the feeling of insecurity and the disabled person may even become frustrated.

- *Reduce the physical space*
  The visually impaired person will prefer a small room rather than a larger room. It is easier to orientate and to keep track of what is happening in a smaller room than in a large room – for example, persons entering and leaving the room. If you have a choice, teach the person with a visual disability and with learning difficulties in a small classroom. Or provide activities for adults in a small group. It is much easier to adapt to a small room with a small group of children. Caregivers can also create little corners in classrooms for stimulation. Lily Nielsen developed the ‘little room’, a concept for the stimulation of visual and intellectually disabled children. According to her principles, these stimulation corners can be created in a classroom to provide multi-sensory stimulation.

Daily care and activities

Experience what it feels like when no adjustments are made during tasks.

The caregivers give the person with a simulated visual disability toys to play with, or ask him/her to make a drawing or write a letter. While he/she is asked to play with the toys or complete the task, the caregiver talks in a loud voice to another caregiver. The noise made in the room will distract him/her from performing the task.

Discussion
1. How did the "client" (person with a simulated visual disability) react to the noisy surroundings while performing a task?
2. What were the most interesting and stimulating activities?
3. Did the "client" enjoy playing with the toys while the caregiver talked to the other person?

Describe the caregiver's attitude considering the above-mentioned aspects?
- Was the caregiver patient by giving sufficient time for the activity?
- Did the caregiver provide encouragement?
- Did the caregiver show respect?
- Was the caregiver tolerant?

Mention important aspects to keep in mind when activities are introduced. Also mention aspects you want to attend to in your school/ care centre/ class.

In summary, stimulation of all the senses of the person with a visual disability may support further development and prevent boredom or under-stimulation. It also may prevent challenging behaviour. Caregivers/teachers need to apply great creativity to adapt learning and activity programmes.

5. Adjustments regarding the environment

A visual disability may cause a person to be very dependent on other persons. However, people prefer to be independent, even though they have a visual problem. The visually disabled person experiences a level of independence by using low vision aids and by learning to walk with a white cane, if possible. There are also many environmental adjustments that can contribute to more independent behaviour.

- *Illumination*

Good illumination increases the visibility of objects. Specific attention should be given to the adjustment of the lighting in the home, day activity centre or classroom. For example, some visually disabled persons have problems to adjust when they walk from a darker room into the light or from a bright lighted area into a darker area. It is therefore important to try and avoid big differences in illumination. Furthermore, it is better to use fluorescent lights instead of halogen or spotlights. The lights should be turned on all day if the visually impaired person has poor sight or limited adaptation to light (refer to people with Bardet-Biedl). If necessary, use a task light or a little fluorescent table lamp. It is important to avoid direct light caused by open light sources or direct sunlight.

- *Contrasts*
  With contrasting colours it is easier to detect objects, for example:
  - paint the walls and ceilings in a light colour (but not pure white)
  - paint doors, door and window frames in contrasting colours
  - paint the door handle in a contrasting colour
  - place a recognisable object on the bedroom door (visual and/or tactile)
  - use contrasting colours in furniture and accessories
  - put a white plate on a contrasting placemat on the table

- *Orientation markers*
  Specific tactile or audible orientation markers can be used to promote the independence of the visually disabled person. For example: a sound at the end of the hallway or a clock with a loud tick above the chair can support auditory orientation. Additional sound signs can be used outside. Tactile orientation markers are also very useful, such as the use of rubber or corded (ribbed) paving stones to mark crossings. Easy recognisable objects can be placed on the door of the bathroom, toilet or classroom.

- *Environmental sounds*
  Reduction of unnecessary sounds can save a lot of effort, because the visually disabled person can be distracted or confused by too much noise. Always turn off the radio when nobody is actually listening to it or when you are in conversation with someone.

- *Interior*
  Specific care implies that the caregivers should critically look at the interior of the room where the visually disabled person spends most of his time. Can the visually disabled person walk around without bumping into objects? A few suggestions are: keep the interior of the house or classroom unchanged so that the visually disabled person will know where to walk and where to expect obstacles. Take care that the chairs are always at the same place. But, when changes are necessary, make the changes together or guide the disabled person and support orientation in the changed surrounding. Avoid using furniture with sharp edges, and avoid obstacles such as wheelchairs in unexpected places or in walking areas.

Environment

Think about the environment in your school or group home where the visual disabled person spends most of his time.

Discussion
Discuss the following aspects:
1. What is the environment like?
2. Are there obstacles where the visually disabled person can bump into?
3. Are there auditory markers?
4. Is there sufficient illumination?
5. Was sufficient use made of contrasts?
6. Was sufficient attention given for reducing environmental noise or sounds?
7. Was adequate attention given for decorating the interior?

3.6. Quality of daily care

The checklist in ‘Appendix: Chapter 3 and 4(b)’ can be used in every care-giving or teaching situation. It covers seven aspects of daily care: recognition and predictability; living environment; attitude; self-reliance; daily programme; hobbies; and adapted tempo. Every aspect is specified by some points of special interest. With this checklist you can indicate whether specific care is indeed provided.

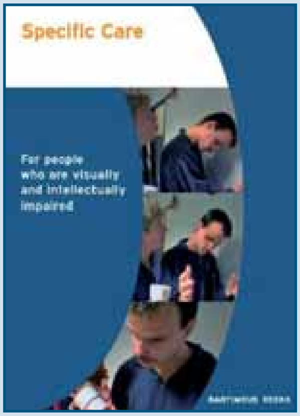
DVD: Specific Care

Frans Gunther & Jan IJzerman

Before watching the fragments form the DVD ‘Specific Care’, decide on which aspects of the ‘Checklist Quality of Daily Care’ you want to focus.

Discussion

1. To what extend was specific care given according to the checklist?
2. Which adjustments would improve the given care?
3. Which ideas are applicable in your daily work?



Conclusion

The exercises in this chapter should improve understanding of persons with visual (and intellectual) disabilities. The increase of understanding may also result in the improvement of the specific care that is given to persons with disabilities. Adjustments made to provide specific care may improve the quality of care and thus the quality of their lives.

Part II

The 'Step-by-Step' model

Chapter 4

Working Step-by-Step: from recognising problems to evaluation

Introduction

An important aspect of someone who works with persons with a visual disability and learning difficulty is to gather information on them in a systematic way. This information is used in helping, teaching and guiding clients. A useful 'tool' in administering this information process is the Step-by-Step model. In this chapter we will present this model, illustrating it with one particular case study - a girl named Suzan. She is intellectually disabled. By using the Step-by-Step model you will professionalise your approach and be able to make more reliable choices and intervene more effectively.

First of all we will introduce Suzan. Then we will present an overview of the Step-by-Step model, followed by a closer look at each step. In the following chapters we will also analyse other case studies, using the same model.

Suzan

Suzan is 15 years of age. She has a slight learning difficulty and lives in a group home. She can read and write. She has a small posture and is slightly over weight. At birth she had extra fingers and toes that were surgically removed.

A few months ago she went to an ophthalmologist. He reported a visual acuity of 0.8 and indicated that the retina showed signs of retinitis pigmentosa. Because Suzan's visual acuity is good, her teachers assumed that her sight is very good. However, the reality is that her vision fluctuates. She normally finds her way around when walking outside and she also performs well when she is busy with her daily tasks. But sometimes she seems to loose interest, is withdrawn, bumps into furniture and persons and is unable to find specific objects. On the other hand, in her own room she easily finds her way. She is known to be very structured in what she does. She always asks the teacher to turn on the lights, as the lights are normally switched off, in order to save electricity. Her teachers do not understand why her behaviour is so unpredictable.

Do you have any idea why Suzan's behaviour fluctuates so much during the day? Do you know her well enough to understand and help her? Probably not, because the information we have is very limited. We have to know much more about Suzan's daily life. To gather this information in a systematic way, we make use of the 'Step-by-Step model' - an 'Educational Assessment and Intervention model'. The steps of the 'Step-by-Step model are described below.

Step-by-Step model of assessment and intervention

Step 1: Recognising educational problems
Step 2: File study and consultation
Step 3: Planning the inquiry
Step 4: Conducting the inquiry
Step 5: Integrating the results
Step 6: Understanding the client and his needs
Step 7: Intervention
Step 8: Integration in daily care and evaluation

In this chapter we will discuss each step of this ‘Step-by-Step model’.

4.1. Step 1: Recognising educational problems

Every life experience, whether it is at work, in sports or in a loving relationship, starts by looking for clues of affirmation to guide one on the way forward. Suppose you meet somebody whom you like at first sight. Almost immediately you look for signs in his or her behaviour that may indicate that this person also likes you too. When you enter a city you visited long ago, you look around for familiar signs. These signs (a tower, a big office building, a bridge, etc.) help you to decide which direction you need to take. When one of the children in your class is listless, you want try and find out what is wrong with your pupil by looking for signs that indicate that the child is ill. You want to know: Is the forehead warm? Is the child running a fever? When he vomits, you wonder whether he drank contaminated water.

Without clues you are uncertain and you do not know what to think and what to do. With the relevant signals, you know how to explore, how to come nearer to your goal or destination. Signals are also crucial in the understanding of educational problems. Let us take a closer look at Suzan again.

Suzan
During a staff meeting, teachers and caregivers discussed the fluctuation in Suzan’s daily performance. Although the teachers gave her more time to complete the given tasks and although they have shown more patience, there was only a slight improvement concerning her unpredictable behaviour. Her problems were not yet solved. They think Suzan is just a stubborn adolescent. Her teacher was asked to write a report on her behavioural problems and it was decided to consult the psychologist.

Selecting relevant signs of educational problems

1. Read the information on Suzan again.
2. Focus on the caregivers' problems with Suzan and on the solutions they suggested.
3. Are there signs that can help you in your understanding of the problem?
4. Why are these signs relevant in this case? Give reasons.
5. Classify the signs you selected according to the Seven Dimensions of Human Functioning (see below).
6. Are there any aspects you have overlooked? If so, complete your list of relevant signs.

Suzan's problems (like all educational problems) are multi-dimensional. In a client's functioning we can distinguish between at least seven different dimensions:

1. Physical
2. Visual
3. Auditive
4. Motor
5. Cognitive
6. Behavioural
7. Relational

When you keep these dimensions in mind, they will help you not to be too selective and to maintain a broad view on your work with persons with intellectual and visual disabilities. Within the Step-by-Step model we focus on each of the seven dimensions.

4.2. Step 2: File study and consultation

The Step-by-Step model is goal-directed. You can use it to select information according to the purpose you have in mind. In this case we want to understand the client's problems. In step 1 you identify signs relating to the problem. In step 2 you try and confirm (or reject) the relevance of these signs while you try to understand the client. Confirmation or rejection of signs can be done in two ways:

1. By studying the client's file.
   Determine whether the information in the file corresponds with the identified signs. Is there information in the file that helps you to understand the client (and the signs) better?

2. By consulting colleagues and members of the client's family.
   After you have studied the file, you may have more questions than before. The next logical step is to consult one's colleagues. Maybe they have information on the client, which you do not have. When working with a multi-disciplinary team, it is possible that one of the colleagues is an expert in diagnosing and helping clients with similar problems. In a certain sense the parents, brothers and sisters of the client are also experts. They know the client longer than any of the professionals. Therefore, they are important sources of information. Make use of them.

In both the file study and the consultations, you are guided by the client's problems. Formulating the initial problem may help you to select information. By doing this, you study the file with relevant questions in mind and you consult your colleagues and the family members with a clear idea on what you would like to know. But what is relevant and what is clear in this context? Let us take a look at Suzan's file:

Suzan

The following information was recorded in Suzan's file: Suzan is the second child in her family. She has a younger sister of 10 years who is not disabled. She comes from a small village and her father is a teacher. When Suzan was two years of age the delay in her development became obvious. Consultation with a paediatrician suggested that she might have the Bardet-Biedl Syndrome, especially because of the extra fingers and toes she was born with. Genetic assessment confirmed this diagnosis. Suzan has a good relationship with her parents and sister. She consults them when needed. In the group home she is interested in other clients and she is caring. There are no motor or auditory disabilities. Her hearing was examined the previous year because teachers questioned her ability to clearly hear the assignments given to her.

There was no information on the Bardet-Biedl Syndrome in the file. An Internet search and consultation with the ophthalmologist indicated that Bardet-Biedl Syndrome presupposes a progressive eye disease. Persons with this syndrome are described as being insecure and emotionally unstable. One of the first visual signs of this eye condition is a loss of adaptation to darkness, which means having trouble to see in twilight and when it is dark. The implication is that good lighting is needed to function well after sunset and in dark areas. There is also a progressive decrease of the visual field, which means a diminishing ability to observe the environment. The quality of light influences the extent of the visual field. Visual acuity can remain quite normal for a long time. In the long run, the visual field will decrease to tunnel vision and the visual acuity will diminish and may even result in total blindness. It seems that the information on Suzan's eye disease can play an important role in her behaviour.

Consultation

Prepare an agenda for the consultation with Suzan's teacher
Suggestions for the agenda:

1. Explain the reasons for the inquiry.
2. Describe the significant manifestations of Suzan's behaviour.
3. Suggestions on how to understand her behaviour.
4. Has Suzan's teacher observed similar behaviour?
5. Ask the teacher what had been done to help her solve her problems.
6. What were the results of these interventions?
7. Discuss the information on Bardet-Biedl Syndrome.
8. Determine the next steps that should be taken.

Practice the consultation with Suzan's teacher in a role-play, making use of the agenda.

In the following text we show an example of an interview with Suzan's teacher.

Suzan

The consultations with Suzan's teachers and caregivers, following the above-mentioned agenda, show the following results:

What are the reasons for the inquiry?

In accordance with the ophthalmologist's findings, we assume Suzan's vision is very good during the day, but we have also observed inconsistencies in her visual behaviour. She can easily find her way when she walks outside. She also participates well when performing her daily tasks. But sometimes she does not seem to be interested, is withdrawn, bumps into furniture and persons and is unable to find the objects asked for. Again and again she asks if the electric lights can be turned on. In her own room she finds her way easily. As teachers, we do not understand why she acts in such a strange way. This situation causes the need for a consultation.

Unpredictable behaviour

Suzan is a nice person. She is a little shy and uncertain, but is always interested in others. Although she can find her way, she often bumps into persons or objects. Some days she has no 'accidents' at all. It leaves the impression that she sometimes does not pay enough attention. That seems very strange, because we cannot imagine that she does it on purpose. She is very organised; everything in her room has its own place. When things are moved around, she gets very upset. This leads to stressful situations for herself and others. Her visual performance can be very high; and then, at times, she acts like almost being blind. Doing detailed work is not the problem. It seems to be more a general lack of attention to what is happening around her. She likes to be close to people, but not when there are a lot of people around, because then she withdraws and leaves the room. When we ask her not to leave, she gets upset and starts crying.

Suggestions for understanding Suzan's behaviour

Well, Suzan is 15 years of age. Even though she has always been very easy going, we think reaching puberty plays an important role. She is often stubborn and gets upset very easily. However, we think this is not the full story. It is impossible to attribute the rapid change in her behaviour only to puberty.

What is done up to now and what are the results?

We are more patient with her; we give her more directions and time. When she wants to withdraw and be on her own, we sometimes allow her to be on her own, but not always because we do not want her to become an outsider. When we ask her why she bumps into persons or objects she always answers that she doesn't do it on purpose, it just happens, because she was not aware of the person or the object. She also says that she is afraid to move about.

Discuss the information on Bardet-Biedl Syndrome

The teacher is given information on Bardet-Biedl Syndrome: Many things in her behaviour could be explained from the information received on Bardet-Biedl Syndrome. People with this syndrome have a progressive eye condition that may lead to blindness. They need a lot of light to be able to see well. Therefore, on a sunny day, when the light is good, it is easy for them to find their way. But when it is dark or when they are indoors, it is more difficult. They then encounter a huge loss of their visual field, which leads to a loss of view of the environment, especially when the artificial light is insufficient. That could be a possible reason why Suzan's performance is often strange in certain circumstances.

The next steps that should be taken
More detailed observation of Suzan's inconsistent behaviour is necessary. She needs to be observed in different situations: at the group home, in the classroom and on the playground. A meeting with Suzan, her parents, a teacher and a caregiver from the home is recommended. The purpose of collecting this information is to improve our understanding of Suzan's behaviour.

4.3. Step 3: Planning the inquiry

The Step-by-Step model is like a jigsaw puzzle. At the beginning, there is a lot of missing information, but, by using the Step-by-Step model, the puzzle becomes more complete. The next step, planning the inquiry, is a significant step in the whole diagnostic process. With the information gained from both the file and the consultations, you should ask yourself: What do I know and what is still unclear? What should I focus on when I continue my investigation?

Discuss the following questions with your colleagues.

What is next?

Summarise the information and prepare the inquiry.
1. What do you know already?
2. What is still unclear and needs further inquiry?
3. Which 'instruments' do you want to make use of during the inquiry?
4. Make a detailed agenda for the further inquiry of Suzan's case

Suzan
Looking at the seven dimensions of functioning as mentioned before, we can summarise as follows:

Physical:	Suzan has been diagnosed with the Bardet-Biedl Syndrome.
Visual:	There are possibly other visual conditions which should be assessed.
Auditive:	She has no hearing problems.
Motor:	Suzan has no motor dysfunction.
Cognitive:	She has a slight learning difficulty.
Behavioural:	There are behavioural problems that currently can not be explained.
Relational:	Overall, Suzan's relationship with her parents, sister, group members/friends, teachers and caregivers is good, but sometimes she is afraid in the company of others and then withdraws. Unfortunately, we still do not know whether Suzan's behaviour is influenced by environmental factors.

Planning an inquiry

Answer the following questions by looking at the above mentioned 7 dimensions:
1. Which dimension needs more inquiry?
2. Which instruments can be used?

When you know what information you need, you have to choose the most suitable methods to obtain the information you need. There are an overwhelming number of methods available in educational and psychological diagnosis. To mention only a few: intelligence tests, adaptive behaviour scales, infant development scales, scales for motor behaviour, visual-motor scales, temperament scales, aberrant behaviour scales, behaviour problems inventories, checklists for challenging behaviour, communication profiles, scales for social-emotional development, personality inventories, assessments of dual diagnosis, depression inventories, dementia scales, etc.

Suzan
Planning an inquiry: There are many instruments that can be used, but in this chapter we limit our inquiry to 3 specific methods relevant to Suzan's case:
1. Assessment of visual acuity and visual field.
2. Observation of visual behaviour, social behaviour and behaviour while performing different tasks.
3. Interviewing Suzan, her parents and caregivers.

4.4. Step 4: Conducting the inquiry

The aim of the inquiry, the fourth step in the Step-by-Step model, is to obtain as much relevant information on the client as possible. The relevance of this information is determined by the outcome of step 3: your agenda for further information (see paragraph 4.3). The inquiry should not start without a sound idea on what you would like to know. Just as important as the inquiry, is the careful and reliable application of the chosen methods of inquiry.

Suzan
The purpose of the inquiry is to observe Suzan's behaviour in situations where no problems occur (mainly outdoors) and in situations where she encounters problems (indoors, in unstructured situations and in situations with many people). Special attention is given to how she looks at and touches objects, as well as her behaviour after bumping into furniture or people. This information will be used to gain a better understanding of Suzan's behaviour. The methods used during this inquiry are: test her visual functions, observe her interaction, and interview her parents and caregivers.

The methods for conducting the inquiry will be discussed in general (in a broader context than only Suzan's case). We shall present an overview of the results of the inquiry in Suzan's case just after the description of each method.

1. Visual assessment

A visual assessment is not only a measurement of visual acuity and visual field. In the next few pages the different aspects of the assessment will be discussed briefly. Some of the tests used at Bartiméus to measure visual acuity will be mentioned, although many more tests are available. Visual assessment in people with a learning difficulty asks a lot of (theoretical and practical) knowledge and (practical) experience. In this chapter, only a brief description is given.

The purpose of a visual assessment in general is to decide how and when to treat eye-diseases, to examine the prognosis of untreatable eye diseases, to examine earlier results and to advise on further testing.

Before starting the visual assessment, information is necessary concerning the client's medical history: the cause of learning difficulties, possible epilepsy, auditory - and physical disabilities, the medication the client uses, etc. Furthermore, information is asked concerning the ophthalmic history, ophthalmic diseases, refractive errors, information about visual acuity, etc.

The assessment results indicate (if possible) the nature of the refractive errors. A possible visual disability is reported, based on the visual acuity, visual field, contrast sensitivity, crowding, visual agnosia, etc. If possible information is given on the cause of the visual disability and on the possible ways of treating the disability. In some cases a diagnosis is made of a possible progressive ophthalmic disease, and an indication is given on the immediate and future consequences of the disease. In case ophthalmological treatment is advisable or needed, or detailed ophthalmological examination required, the client is referred to an ophthalmologist.

The following information is gained from the assessment:
- visual acuity and if possible, near and distant visual acuity
- extent of the visual field
- observing contrasts
- colour vision
- visual ability when it is dusk or dark
- possible increased light-sensitivity
- refractive errors (if possible)
- difference in visual acuity with and without correction of refractive errors

Based on the visual assessment, advice can be given concerning daily activities, adjustments to the environment (light, contrast, size of objects, etc.), adjustment of caregiving or teaching approaches, the approach used to help the client get used to wearing spectacles, and on the implementation of relevant daily living activities within the client's interests and visual ability.

The tests mentioned below are a selection of the most often used tests during assessment of persons with learning difficulties:

Snellen Chart

The Snellen Chart (Figure 4.1.) is used at a testing distance of 5-6 meters and provides information on the clients' visual acuity by using letter recognition. The Snellen Chart can be used if the client can recognise and name characters.

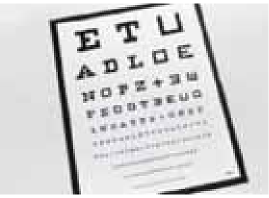


Figure 4.1. Snellen Chart

Burghardt children’s Chart

The testing distance of the Burghardt children’s *Chart* (Figure 4.2.) is up to 5 meters and provides information on form recognition. The Burghardt children’s *Chart* can be used if the client can recognise and name or point out (using sign language) images. The results can give a ‘bit higher’ visual acuity because some images are easy to recognise and the images are quite big, compared to the Snellen Chart.

Figure 4.2. Burghardt children’s Chart

Stycartest: Sheridan test for young children and mentally disabled persons

The Stycartest (Figure 4.3.) provides information on distant vision (up to 3 meters) and nearby visual acuity (25 cm) by recognising forms. The Stycartest can be used if the client can recognise and match or name the characters.

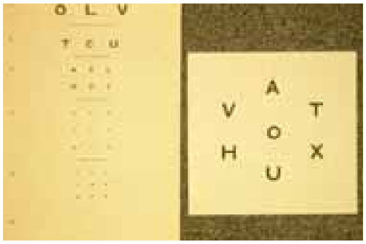


Figure 4.3. Stycartest

LH-test: Lea Hyvärinen

The testing distance of the LH-test (Figure 4.4.) is 40 cm or less, up to 3 meters. The LH-test can be used if the client can recognise, match, point to or name the different symbols on the chart.

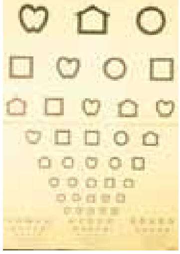


Figure 4.4. LH-test

Cardiff Acuity Test

The Cardiff Acuity Test (Figure 4.5.) is used at a testing distance 50 cm to 1 meter and provides information on visual detection or identification of the marked blocks. The visual acuity can be judged by following the client’s eye-movements if the client can point in a direction of the images or if the client can recognise and name the images.

Figure 4.5. Cardiff Acuity Test

Teller Acuity Cards

The Teller Acuity Cards (Figure 4.6.) are usually used at a distance of 55 cm and are used to measure minimal visual acuity. No recognition is needed as the results are based on the preferential looking method. The results are judged on eye-movements, and if possible on pointing at or verbally indicating the images.

Figure 4.6. Teller Acuity Cards

Hiding Heidi

The Hiding Heidi (Figure 4.7.) is used to assess contrast sensitivity. The test is used at a distance of 1 meter and the cards show different grey levels or contrasts. The results are based on the detected images and judged by client's response. It may be judged on the client's eye-movement (preferential looking) and if possible on the client's pointing at or verbal indication of the images.


Figure 4.7. Hiding Heidi

Recently another useful contrast sensitivity test from Lea Hyvärinen was made available, with the symbols used in the LH test mentioned above.

Other tests

There are many kinds of tests developed for visual assessment, such as the Landolt rings, E-hooks, and Kay Picture Test. Information about these tests can be found on the internet and in the book "*Assessing children's vision*" (Leath, 1999).

Visual field - confrontation method

A measurement of the visual field by using the confrontation method provides information on large defects: hemianopia or quadranopia, concentric decrease, and tunnel vision. The assessment is done by judging the client's reaction on the confrontation method: eye-movements, smiling, pointing at, verbalising, or even avoiding the offered object (see Figure 4.8. and 4.9.) .

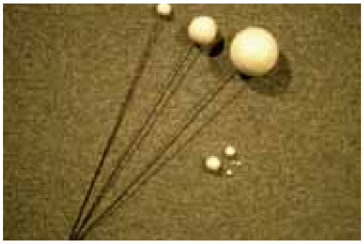


Figure 4.8. Visual field


Figure 4.9. confrontation method

Colour vision

Assessment of colour vision is done by asking the client to name or match the primary colours: red, green, blue and yellow. The results could provide information on a possible central scotoma (maculapathy) or loss of peripheral visual field.

Seeing during dusk and dark: dark adaptation

The assessment results provide global information on dark adaptation by offering white or coloured objects under decreasing light conditions. Your reference has to be your own dark adaptation: as long as you can detect the object, your client has to be able to detect the object (without trying to touch it!). The results may help caregivers and teachers to understand the decrease of the client's visual functioning during dusk and darkness.

Light-hindrance, increased light sensitivity
During the assessment a penlight or another light is used to shine directly into the eyes of the client. Information is then gained by observing the client's reactions. It is important to check the ophthalmic history of the client for more information.

Refractive errors
Refractive errors can be measured by using an autorefractor or a retinoscope with single lenses or lens bar (with or without cycloplegia: eye drops to widen the pupil and decrease accommodation).

Observation
During the visual assessment we also take into account how clients behave during the test. The following information is noted: the way the client makes eye-contact, the client's visual interest, specific behaviour, the client's reaction on (visual) stimuli. We also ask parents or caregivers who join the assessment, to provide information about the person who is assessed.

Suzan: information gained form the visual assessment
Suzan's visual acuity, tested by an ophthalmologist, was almost normal (0.8). Information on the Bardet-Biedl Syndrome revealed that people like Suzan always have problems seeing during dusk and when it is dark and have a decreasing visual field.

The ophthalmologist tested Suzan's visual field with the confrontation method. She brought small objects form behind Suzan into her visual field. Suzan showed no reaction. This assessment showed a decrease of her visual field to 1/3 of the normal visual field (30°). The test was performed during broad daylight.

Having the above information on her decreased visual field Suzan will be observed in different daily life situations. These observations will concentrate on mobility, need for extra light, fear reactions, the way she structures her environment, her ability to perform different tasks in different circumstances and her interaction with others.

2. Observation of interaction in daily living

There are questions you cannot answer without observing your client in daily life situations. Valuable information can be gathered on a person's behaviour by interviewing the caregiver, but then specific information may be missing. For example, as to a client with orientation difficulties: it is important to know exactly in which way the client fails to orientate himself or in which situations he is frightened. What happens in such circumstances? How does the client react to those trying to help him and comfort him? Are there situations where he is more disoriented or frightened than in other situations?

Before you start any observation, you should first concentrate on your client's problems and abilities. You should answer the following questions:
- *What* exactly do I want to observe?
- *Where* will the observation take place? and
- *When* will be the best time to observe the client?

There are no general rules. It all depends on the problems and abilities you want to identify and attend to.

What, where, when? You can only answer these questions by observation in vivo, in the client's everyday situations: When the client wakes up, when he has a meal with his friends, when the child is at school or when the person is at work, in his home environment, when he is with his parents, when he experiences stress or when he is at ease.

Observation presupposes a specific professional attitude. Observation is done by watching the client interact with others in specific situations, *without interpretation*. The strength of an observation is objectivity. You observe the natural interaction of the client. Observing without interpreting is rather difficult. It asks for continuous practice. Try to develop observation skills.

What, where, when to observe

Think of a specific problem of one of your own clients. You would like to know more about the problem and you decide to observe the client.

1. What is the purpose of your observation?
2. What are you going to observe? Why?
3. Where are you going to do the observation? Why?
4. When are you going to do the observation? Why?

Observing Janny

To develop observation skills, we are going to watch the clips on Janny on the included DVD 'Life in sight'. The purpose of the observation is to trace friction in the interaction between Janny and her caregivers.

Divide into groups, each group observing a different aspect of Janny's interaction: visual, auditory, motor, behavioural and relational. Always remember to include the observation of environmental aspects while observing.

1. Observe and note the various (visual, auditory, etc.) aspects of Janny's interaction on the DVD 'Life in sight'.
2. Discuss how the different aspects are interrelated.
3. Is there any friction between Janny and the caregivers?
4. Is there agreement on the cause of the friction?
5. Do you have any idea of the nature of Janny's visual impairment?
6. Which specific information could you (not) get from the observations?

The text below gives an example of the observation done during Suzan's daily life situation.

Suzan

During the observation special attention was given to the different aspects of her behaviour and her living conditions, her mobility, need of light, fear, interaction, and environment. Information gained from the observation can be summarised as follows:

- Mobility: With bright light she moves around easily, does not bump into people or objects. However, in dusk and dark she moves around insecure and tries to shy away from the tasks she has to perform.
- Need of extra light: She performs better when she does her tasks in a (class)room with sufficient light.
- Fear reactions: Suzan shows a startled reaction when people approach her from behind or from the side. This is more obvious in dusk or when it is totally dark.
- Structuring her environment: Everything in her room has to have its own place, and then she can easily find her way around. When someone asks for a certain object like a book or CD, she can find it with little effort.
- Interaction with others: Suzan interacts with her group and participates in conversations. She is interested in others. In situations when they argue or make a lot of noise, she gets restless, withdraws and then goes to another room.

Note: both the living room and classrooms appear to be very dark. When the children get up and move about, they do not place their chairs back under the table. Sometimes a wheelchair stands in the middle of the corridor.

3. Interviewing clients, parents and caregivers

In general, the parents of a client, as well as brothers and sisters, know the client very well. Normally they are knowledgeable on the child's behaviour and as such, a rich source of information which professionals should make use of. Family members may be able to provide valuable information on the client's behaviour, which professionals have never thought of, have not seen or are unable to interpret. The same applies to teachers and caregivers who know clients, based on their daily interaction. For example, a client (let's call him Edward) shares his personal experience with you: “I rarely come in conflict with my parents and caregivers”. But, when his parents tell you about their relationship with Edward, you may get a totally different impression of the situation. “We are often in conflict with Edward. He talks loudly, demands attention and gets upset if we do not attend to his wishes immediately”. In such a case the subjective experience of the parents is totally different from the subjective experience of the client. Therefore, to get a more ‘objective’ impression of the client, it is important to interview the client as well as the parents, caregivers and teachers.

Interviews are just as important as observations, although different. Both are ‘instruments’ that serve different purposes and offer additional information. By interviewing, you can take note of information that you cannot observe. By observing, you gather information on behaviour in a concrete situation. The results from both the observations and interviews are complementary. When results differ, further investigation is needed. For example, when both the client and parents deny a visual problem, but during observation the contrary is observed. For example, the client bumps into objects or has startled reactions when touched unexpectedly. These findings may be important information that needs to be discussed with the client and the parents after having completed the assessment.

It is important to be well prepared before starting the interview. Specify your questions according to the purpose of the interview: What do you want to know and why? Who is best able to answer your questions? What is the best logistical arrangement for the interview?

What to ask and whom to question? How to interview?

Think of a specific problem of one of your clients. You want to know more about the problem and you decide to interview the client himself, a family member, his teacher or caregiver.

1. What do you want to ask? Why?
2. Who are you going to interview? Why?
3. Where is the interview going to take place? Why?

Let us take a closer look at the interview. Do you have an idea of the questions you want to ask? Some examples are given in the appendix to help you make your decisions. Of course, these questions are not the only possibilities and the questions will differ according to what you need to know. Many more and different questions can be added (see appendix: chapter 4(a)).

Example of an interview report: interview with Wendy's caregiver
Personal information: Wendy is 7 years of age. The cause of her severe learning difficulty is not known. She also has epilepsy and is physically disability.
Questions from the caregivers: Can you determine her visual acuity and advise us on the care she needs?

Interview with Wendy's caregiver:

- *Can you describe Wendy as a person? What is Wendy like?* Wendy is a girl of 7 years of age. She refuses to do something she does not want to do. She is very stubborn. Wendy can be a very nice girl. She will sit on your lap where she may even fall asleep. She cannot walk; she crawls all over and uses her own wheelchair.
- *Can you describe what Wendy likes to do during her leisure time?* Wendy likes to watch television. She particularly loves Walt Disney films. She always sits close to the screen. She also likes to sit outside, or else at a window, watching cars pass by. She also likes looking into mirrors.
- *Please describe the problem?* We wonder what Wendy's visual acuity is. We think that she has difficulty seeing objects.
- *In which situation does the problem occur? In all situations, or only in specific situations?* Wendy always sits very close to the television-screen. She gets a fright when caregivers touch her without mentioning her name.
- *When did the problem start? What is the cause of the problem?* She has always reacted in this manner.
- *Have you (or Wendy's relatives) previously asked for help or is this the first time?* This is the fist time we are asking for help. It actually was Wendy's physiotherapist who asked us to examine her visual acuity. We thought her behaviour could be explained by her learning difficulty. However, we did not think that her reactions were caused by a possible loss of sight.
- *How is her contact with others?* She does have contact with others, but not very often. Sometimes she sits in her wheelchair and puts her hands in front of her face. In an unfamiliar situation, she sits with her legs and arms twisted together. She shows behavioural problems when situations are unpredictable. In such situations she screams a lot.
- *Can she make her own choices?* She does make certain choices. We try to give her the

> opportunity to make choices. It seems as if she does understand certain words. When we ask: “Give me your hand please?” she does so.

During the interview you can decide for yourself how specific the questions should be. Sometimes you will need more specific questions, especially when the information is unclear or insufficient.

With this example in mind we should practice conducting an interview by using role play with Barry’s caregiver

Interview with Barry’s caregiver

The purpose of this exercise is to practice an interview yourself. In this interview we discuss Barry, one of your clients. In preparing the interview, you can make use of some of the questions from the list (see appendix 4a).
Divide into small groups for role-play: one of you is Barry’s caregiver and a second-one is the interviewer. Read the information for caregiver and interviewer separately. During the role-play Barry’s caregiver mentions the information that is important to pass on and the

The information as described below can be used for the above exercise. The interviewer can read the ‘information for the interviewer’ and the caregiver can read the ‘information for the caregiver’.

Information for the interviewer
General information: Barry is approximately 30 years of age. He is very social and loves to interact/communicate with others.
Question: Can you determine his visual acuity and give advice on the special care he needs?
Visual acuity: Barry does not wear spectacles. Results of the visual assessment: he has a refractive error of S-11:00 (Myopia); TAC 0.12 (without glasses); TAC 0.2 – 0.25 (with spectacles). Cardiff gives the same results. Visual field: restricted at the bottom (chest part). Contrast is moderate. His left eye turns inward.
Observation: Barry reduces the distance to observe objects. He reacts to sounds in the kitchen and looks around very curiously. He seems to be alert at all times.

Information for the caregiver
Barry is described as a very social man. He is very inquisitive. He is interested in everything that happens in his surroundings and he reacts promptly. Barry has a learning difficulty due to a lack of oxygen during birth. Since the age of three, he does not use any medicine for epilepsy and he has not had a seizure. He has no hearing loss.

His hobby is to play with cards. He does not really look at them, but manipulates them by putting them into a bin and taking them out again. He also likes to play with a ball. He helps tidying up at home, for example, by taking the cups to the kitchen. Barry loves music.

He lives in a very organised home, where everything happens according to a daily routine (getting up, dress, eat, going to the activity centre, lunch, etc.). He follows this rhythm and knows what will happen next. By saying ‘yes’ and ‘no’ he can let others understand what he wants. He uses body language to communicate.

Barry can move around with his wheelchair as well as on his knees on the ground. He is usually positive and optimistic. However, when there is tension in the group home or someone is ill, he reacts immediately. He becomes stressed and depressed.

He loves being with people, getting a hug and chatting, while having coffee. When his father comes to fetch him, he is happy. He recognises persons and prefers some caregivers to others. Looking at his behaviour it can be noted that he sits very close to the television. The holds the cards near his face and does the same with his plate of food. Sometimes he spills his milk. Some meals he prefers to others.

Evaluation of the interview with Barry’s caregiver

1. What did you ask Barry’s caregiver?
2. Summarise the answers.
3. What are the main conclusions?

After this exercise, we go back to Suzan’s case. The results of the interview with Suzan.

Suzan
We asked Suzan to tell us about herself, her likes and dislikes. We also asked her why she asked the teacher to turn on the light. Suzan told us that she liked sunny weather because then she is able to see people and objects in the class or in the house. When she is indoors, she feels insecure because she could bump into persons and objects that were not there before. She often hurts herself, especially when she bumps into the wheelchair. People often react grumpy or angrily and this makes her sad. When she is in a classroom or at home and people shout or are angry, she gets scared. When people talk ’to her’ she answers, but often gets an irritated reaction ‘I was not talking to you!’ She does not want other children to read her books or listen to her CD’s. She asks the teacher to turn on the light because then she can see much better. She likes going home to her parents. During her stay in the group home she misses her parents and siblings.

During the interview with her parents and caregivers, they told us that Suzan’s performance fluctuates considerably at times. They cannot explain this behaviour. They also noticed that Suzan did not like a lot of noise or untidiness in her vicinity. Her parents remembered that her performance was much better a few years ago. They said that their relationship with Suzan had not changed over the years. They described their relationship as warm and understanding.

4.5. Step 5: Integrating the results

Before taking the next step towards the intervention, it is important to integrate all the acquired knowledge: the information from the files and the consultation; the results of the interview(s); the results of the observation(s); and the outcome of standardised tests. In this overall picture the importance of the required information differs. Again you have to select according to the purpose of the assessment. First you integrate your information systematically, followed by a narrative summary.

Integration of information

Integrate the information on Suzan.

1. Summarise systematically.
2. Summarise in a narrative way.
3. Check whether you have included all information.

Complete these tasks before you continue reading.

In the following text we will show how to integrate information by using Suzan's case as an example.

Suzan

Summarise the information systematically

- Suzan lives in a group home.
- She has a slight learning difficulty.
- Suzan has a visual acuity of 0.8.
- Her visual field is 1/3 of the normal visual field (30°).
- Suzan looses grip of her situation when it becomes dusk or is dark.
- When she fails to see somebody or something she gets angry or scared.
- Noise scares her.
- She dislikes quarrels and anger.
- She has her own leisure-time activities.
- She has a good relationship with her parents and caregivers.

Summarise in a narrative way

From the visual assessment, observation and interviews, we gathered the following information: Suzan's visual acuity is good enough for detailed tasks. Her visual field is very limited. Her performance depends on a well illuminated environment. She finds it difficult to get a full picture of her surroundings. She does not like too much noise and prefers a structured and organised environment. She has a good relationship with her family. It is necessary to explain and inform others about her needs, abilities and limitations. Suzan likes to draw, build puzzles, and listen to music, watch television, and page through picture books. She does not like to clean-up or wash dishes.

After this fifth step of the Step-by-Step model we know enough of Suzan's problems and abilities to take the last, crucial step towards the intervention.

4.6. Step 6: Understanding the client and his needs

The first five steps in the diagnostic process: recognising the problem, file study and consultation, planning, inquiry and integration of the results have been discussed. Now we take the sixth step: 'Understanding the client and his needs'. This is a critical step. On the basis of the results of the inquiry, the person executing the assessment (with the help of others) decides what help is needed. This decision requires an optimal identification with the client and a careful representation of his interests.

- The person executing the assessment tries to bridge the gap between diagnosis and intervention. The relationship between a professional and a client is like standing at opposite sides of a river. The professional will never understand his client if he or she observes the client from a distance, 'from the other side'.
- Bridging the gap between facts and insight. Facts are important in professional care, but mere facts do not automatically lead to the understanding of a client.
- A professional person tries to understand his client by identification. Identification implies that you ask yourself: who is my client, how does my client feel, what are my client's wishes, what are my client's personal needs?
- To facilitate identification, the professional tries to verbalise these personal needs in the client's own words. Doing that, the professional forces himself not only to optimise identification, but also to represent the personal interests of the client during the whole process of diagnosis and intervention.
- Identification (I try to understand you as much as possible) and representation (I speak on your behalf) is especially important when you work with persons with (severe) disabilities. They cannot speak for themselves, so you have to speak on their behalf. You act as their spokesperson or their representative.

Suzan's 'need for assistance'

1. What does Suzan need in her daily life?
2. Identify with Suzan.
3. Represent her in formulating her need for assistance.
4. Formulate her needs for assistance in her own words.

Complete these tasks before you continue reading.

On the basis of the preceding steps and in particular on that of the integrated results (step 5) the professional formulates a so-called 'need for assistance'. This will be explained by using the case study: Suzan.

Suzan

My name is Suzan. I am 15 years old and live in a group home together with 6 boys and girls. During the weekends and holidays I stay with my parents. At home and in the group home I have my own room. I keep my room tidy and organised. I go to school. There are 40 children in my class. I like to draw, build puzzles, listen to music, watch television, and look at picture books. Sometimes I work in the vegetable garden. I do not like housekeeping. I feel uncomfortable when it is very crowded. I do not like sunset and darkness, so I always turn on the light. My friend Ann also lives in the group home. Sometimes she helps me with the housekeeping, because she likes doing that. I wish I would not bump into everything. I wish everything was more organised around me. I hate people getting angry with me. I would like to have the lights turned on all the time.

Understanding Suzan's needs in this way is, as we will see later, an essential starting point for the intervention process.

4.7. Step 7: Intervention

1. Goal-setting

The starting point for the intervention is the need of the client, formulated on the basis of the results of the inquiry. The first step in the intervention process is to set goals for the intervention. Setting goals is indispensable. If you do not set specific goals, you will not be able to check the progress of your intervention and you will never be able to prove whether your intervention was successful or not. It is very important to avoid unrealistic goals because they may be harmful for the client. They may also be harmful for the caregivers, because unrealistic goals arouse unrealistic expectations, resulting in disappointment and stress.

Some 'rules' for goal setting:

- Goals should fit the client's needs. Avoid setting goals according to your own ideas, needs and ambitions.
- Goals should be realistic. You must be able to reach a particular goal within a realistic time schedule and with workable methods.
- Goals should be concrete, so avoid abstract reasoning or vague language.

Goal-setting for Suzan

1. Try to set the necessary goals for Suzan.
2. Check whether your goals are set according to Suzan's needs?
3. Is your set of goals concrete enough?
4. Why do you think your goals are realistic?

Complete these tasks before you continue reading.

In the following text we show how goals can be set in Suzan's case.

Suzan

- Accept the fluctuation in her performances.
- Provide the necessary circumstances for good performance.
- Respect her wish to be alone sometimes.
- Change your way of communicating with her and others to make things more predictable. Tell her what is going to happen next.

- Help her to be proud of her strengths, her many hobbies and the way she makes choices, like avoiding a crowded environment.
- Help her to compensate for her weaknesses by providing extra light and giving her more time for the different tasks.
- Arrange things conveniently for her. Always move the chairs back under the table and store the wheelchair in the same place. Provide guidelines and teach her how to use them. Give Suzan a place of her own in the class and living room where she will have a good view. Provide extra light.
- Give Suzan the opportunity to put her belongings back where she wants them to be so that she can organise her own world.
- Give extra guidance when she is working in the garden.
- Prevent conflict by giving her teachers and classmates' information concerning her visual functioning and limitations.
- There will be a progressive loss of her visual field. Therefore, regular testing will be necessary as well as guidance concerning the acceptation of the progressive loss.

2. Selection of methods
The next step in the intervention process is to select the methods that can be used during the intervention. There are many methods available. The following are examples of the different methods:
- Guidance in daily activities
- Adapting activities
- Mobility training
- Skills training
- Stimulation of visual, verbal, motor, and auditive development
- Training of communication skills
- Environmental changes
- Providing the client with the necessary aids (hearing aids, spectacles, white cane)
- Providing counselling, for example, concerning loss of visual abilities
- Providing behaviour modification, play therapy, family therapy, or integrative therapy.

The selection of the most effective methods is crucial. How do you choose the best one? Generally speaking, methods should compliment each other. They must match the client's needs, the goals set and the professional abilities of caregivers and teachers. Methods must provide new opportunities for development. They also need to be understood and accepted within a reasonable time. All professionals and family members have to use the new methods in the same way. Therefore, they all have to be well informed. The caregiver or teacher must have the necessary professional skills to apply a particular method.

Another important aspect of the selection of methods is the unity of intervention. Sometimes it is better not to focus your intervention on the client, but rather on changing the environment. Should a child have behavioural problems, you can opt for indirect help with his parents as the main focus of intervention. For instance, you can teach parents to communicate with their child in a different way.

How to help Suzan?

1. Which methods will you choose to help Suzan? Why?
2. Why do these methods match Suzan's needs?
3. Do they also match the goals for intervention?
4. Which professional skills are needed to help Suzan?

Answer these questions before you continue reading.

In the following text we give an example of the methods that can be used to help Suzan.

Suzan

- Guidance in daily activities: due to the reduced vision and the prognosis, she has to be taught how to use her hearing and tactile senses.
- Adapted activities will be necessary in future.
- Mobility training: guidelines in the class and at home and provision of sufficient light.
- Training of other skills should also be done in the future.
- Training of communication skills: teachers and caregivers have to learn to communicate very clearly, for example, by always mentioning the person's name they are talking to.
- Managing the environment: refrain from changing the environment continuously.
- Providing of aids (hearing aids, spectacles, if necessary, white cane): making use of the white cane when necessary.
- Providing the possibility for counselling concerning her progressive visual loss.

3. Planning

Before you start the intervention, careful planning is necessary. Note who will be responsible for the intervention? Who has the necessary time to help the client? Decide when the intervention is to start. That will depend on the time needed for careful preparation, but sometimes you have to start almost immediately. Decide where and at what time the intervention will take place. Calculate the cost (or for extra costs). Decide whether supervision is necessary and if so, who will supervise the caregiver, teacher or the counsellor?

Suzan

The psychologist will write an intervention programme and will focus on: guidance of daily activities, mobility training, and the training of caregivers to communicate effectively and on managing the environment. When Suzan's visual functioning deteriorates special attention will be given to the adaptation of activities and to provide her with relevant aids, for example, a white cane.

After having discussed the programme with the parents, caregivers and teachers, this programme will be applied in the classroom, group home and at home. The programme will start soon after this discussion and will be evaluated monthly. In the beginning no extra funds will be needed. However, the use of efficient light will increase the energy bill. The psychologist will supervise the activities of the caregivers.

4.8. Step 8: Integration in daily care and evaluation

1. Integration in daily care

A point of special interest in this last phase of the helping process is the integration of the successful aspects of the intervention in daily care. Unfortunately there is always the risk that the results of a helping process are limited to the setting and time of the intervention, especially when the intervention takes place in a therapy-room and not in the real life situation. Generalisation of the results has to take place, for example, from therapy to daily care, or else the effect of the intervention will soon be lost. Therefore, the responsible professionals must give concrete guidelines to parents, caregivers and teachers to apply the relevant information obtained during the whole process, from diagnosis to intervention. These guidelines must also be carefully recorded in the client's file.

Guidelines for daily living
Which guidelines (based on your understanding of Suzan's needs) would you give to Suzan's caregivers? How would you communicate these guidelines with the caregivers? Answer these questions before you continue reading.

Suzan

The guidelines of the programme are explained to and discussed with the parents, caregivers and teachers. Guidelines for the implementation of the programme are not necessary. Parents, caregivers and teachers can always consult the psychologist.

2. Evaluation of the process

After intervention and sometimes also during intervention, evaluation will be necessary. This evaluation is an important feature of all professional work. It is a way of self-criticism, an invaluable characteristic of a good professional. You can evaluate the diagnostic and the intervention process in various ways. Some points of interest are:

- The quality of the diagnosis: It is possible that you may discover a blind spot in your diagnosis during the intervention, or you are forced to concentrate on more aspects of the problem.
- Understanding: Has your understanding of the client been deepened? In which way?
- The needs of the client: You have to check whether these needs are really fulfilled.
- The goals of the intervention: Are all the goals or only some of them attained?

Try to evaluate the helping process every three weeks together with the people mostly involved and over a longer period (about three months) within the lager group. Is there any visible progress over a longer period of time? Discuss the guidelines (based on the diagnosis and the intervention) with your colleagues. Are the results as intended? Try to learn from success and disappointments to improve or stabilise the helping process.

Suzan

In Suzan's case the intervention will be evaluated every three weeks within the three months period following the introduction of the programme. If necessary, adaptations will be made. Only caregivers who are mostly involved will participate. The psychologist will arrange the evaluation. Later on the frequency of the meetings will decrease to once a month.

As an example of systematic evaluation we present and practice a checklist for the quality of daily care (see appendix: chapter 4(b)).

Quality of Suzan's care

1. Select the seven aspects of the 'Quality of life' checklist (see appendix).
2. Prepare an interview with Suzan's caregiver about the quality of her care.
3. Thinking of Suzan: what should one ask her?
4. Assess the quality of care given by Suzan's caregiver'.

Complete these tasks before you continue reading.

Suzan

Questions to Suzan's caregiver on the quality of care given:

- Making the environment predictable and safe: Do you use adapted communication? In what way? How do you protect Suzan from getting a fright due to sudden approaches?
- Is the living environment a friendly and safe place for Suzan? Is the environment predictable? How do you use light and contrast? What do you do to provide a safe environment without objects she can bump into? What do you do to prevent noise pollution?
- Does the environment and caregivers address both disabilities? Do you make positive contact with her? Do you take time to make contact with her?
- Have independence and self-reliance been taken into consideration? Do you give her opportunities to make choices on what she wants or does not want? Can she perform tasks in her home or at school that boost her self-esteem?
- Daily programme: Is her daily programme adjusted to suite her abilities and not overloaded?
- Are arrangements made for leisure time? What activities does she take part in during her leisure time? Is there social interaction?
- Are there moments during the day when she can rest, or be on her own when she wants to?

From the interview with the caregiver we concluded that they already take care of a lot of things. They allow Suzan to make choices, guide her into mastering new tasks, take time and have positive and stimulating talks with her. However, caregivers and teachers know little about her visual disability. They need more information on this. In that way her habit of "withdrawing" herself from noisy or unpredictable situations will be better understood and accepted. Adjusting the environment in terms of the lighting, contrast, guidelines and structure in the placement of furniture will need more attention.

Conclusion

In this chapter we described how you can examine the client's problem by working from diagnosis to intervention in a systematic way. The Step-by-Step model can help you to organise information and to apply it for the well-being of your client. In the following chapters we will present three other case studies to illustrate how a professional person can fulfil his or her core business in helping people in a well-considered and sensitive way.

Chapter 5

What is wrong with Moses?

Introduction

To apply the Step-by-Step model in our own work demands a lot of practice. Therefore we are going to apply it in the following case study:

Moses

Moses is a man with an intellectual and visual disability. He has Down's Syndrome and is 36 years of age. He wears glasses (minus 15 on both eyes). He visited his ophthalmologist during the previous year and no change to his spectacles was recommended.

Moses lives in a group home with 5 other men. He works in a sheltered workshop where his main activity is counting and wrapping screws and nails. He also helps with cleaning, making coffee and doing the dishes. His work has always been very precise. He travels on his own by bus. At the bus stop many different busses come and go, but because he can read and knows the bus number and destination, he knows which bus to take and where to get off the bus.

At home he likes to help cooking the evening meal. He also enjoys watching television, building puzzles, writing letters to his family and reading short stories. He is also able to go to the supermarket on his own to buy groceries.

Moses' behaviour is always friendly and helpful. He is almost totally self-supporting. He can wash and shave himself, get dressed and make his own choices on what to wear. He is always neatly dressed and knows how to match and wear different combinations. He makes his own bed and cleans his own room with a little help from his caregivers. Moses' parents both passed away, but he and his younger brother, Michael, meet every fortnight.

Unfortunately, Moses' behaviour changed over the last four months. He is grumpy in the mornings, and does not want to get up. He walks with an untidy beard, he wears strange combinations of clothes and his clothes are often dirty. He frequently shows up very late for work and other appointments. He gets extremely upset when the supervisor of the workshop confronts him about his late coming. He then says he couldn't find the bus, or that he was on the wrong bus. Despite his changed behaviour, his work is still very accurate.

At home he hangs around, shows less interest in building puzzles and writing letters. He is often caught in arguments with his group members and caregivers. Sometimes when he goes to the supermarket he returns with no groceries at all. He is upset and angry when arriving home. Sometimes he brings groceries home, but has bought the wrong items. When his caregivers ask him why he brings the wrong groceries he strongly insists that those were the groceries specified on his list.

His caregivers are worried. They do not understand why he reacts in this strange way and they would like to know the reason for his changed behaviour. They wonder what is wrong with Moses. They do not understand his behaviour.

To find answers, Moses' behaviour will be examined using the framework of the Step-by-Step model.

5.1. Step 1: Recognising behavioural problems

The Step-by-Step model is an educational model for diagnosis and intervention. We distinguish four different characteristics:

1. Educational diagnosis and intervention are aimed at the interaction between parents and children and between professional educators and their clients. The cause of some of the problems is intrinsic (for example a cognitive disorder in the case of autism), but that is not the only reason for a child's behaviour. You always have to look broader at the way interaction takes place; the way people (educators and children) influence one another.

2. Educational diagnosis is descriptive and interpretive. Classification of symptoms in Syndromes (like in the DSM-IV – the Diagnostic Manual of Mental Disorders) are useful, but the core business of a caregiver or a teacher is to give a precise description of the child in interaction with his/her parents, siblings, teachers, and so on. The nature of the interaction is then followed by a careful interpretation of the child's behaviour.

3. Educational diagnosis and intervention is based on an intimate knowledge of the client. The pedagogue/caregiver/teacher should not only know the client from the results of the standardised tests, but also from personal communication and interaction.

4. Educational diagnosis and intervention is multi-disciplinary. The pedagogue, caregiver, teacher, etc. are assisted by the expertise of other professionals: psychologists, psychiatrists and social workers.

Let us now apply these principles in recognising Moses' problems.

Important signs in Moses' behaviour

1. Read the information on Moses again.
2. Are there signs that can help you in your understanding of the problem?
3. Why are these signs relevant in this case? Explain your answers.
4. Classify the signs you selected according to the seven dimensions of human functioning (see chapter 3).
5. Are there dimensions you have overlooked? If so, why? Complete your list.
6. Do the signs which you have selected, fit with the first two characteristics of educational diagnosis?
7. What is the implication of characteristic three and four for your next steps?

Moses' behaviour problems are two-dimensional: behavioural and relational. There is a sudden decrease in self-care: clothing, washing and shaving. In addition, there is an increase in relational problems. Moses is grumpy and when he is frustrated by something or somebody else he immediately gets upset and angry. There are no indications of auditive and motory problems or increased visual problems. These aspects seem to be absent in his behaviour.

There are also no signs indicating negative environmental factors in the development of his behavioural problems. There is no further information on the interactional character of Moses' behaviour. The description of his behaviour is minimal. Besides, we do not know whether the information is based on systematic, multi-disciplinary and personal knowledge.

5.2. Step 2: File study and consultation

In step 1 you classified relevant signs in Moses' behaviour, but your knowledge of his daily life and his behaviour problems is still fragmented. You need much more detailed information to understand him. Generally speaking, there are two sources of information in this early phase of an inquiry: (1) information from his file; and (2) consultations with caregivers and members of his family.

Unfortunately the quality of information in Moses' file is very limited. The information is outdated, poorly recorded and fragmented. So we have to depend on the additional information of those directly involved in his care. Which means, that you need to consult them?

Let us have a closer look at the preparation for the consultation. But first try this on our own.

Consultation: what and who?

1. Read the information on Moses again.
2. What additional information do you need?
3. Make a list with relevant(!) questions.
4. Who will you ask for this information? Why?
5. Who is best trained to gather the information?

Before we start a consultation we have to answer at least three questions:

What information do we need?
Before and during a consultation (in general and also in Moses' case), keep the following points of interest in mind:

- In what kind of situation does the problem occur? In all situations, or only in some specific situations?
- How long does the problem last? When does it start? What is the cause of the problem?
- A professional person does not only focus on the problems of the client. One also takes into account the strengths of the client and the strengths of the social context. Maybe it is even more important to know what the protective factors are in a particular situation, than to know all the weaknesses.

- Has the client (or his relatives / caregivers) previously asked for help or is this the first time? If so, what was the effect of the help previously given?
- Why is the client referred?
- How does the client manage his problems?
- How do his relatives, teacher, etc. manage the problems?
- Do they understand the problems?
- How do the client's siblings, friends, classmates, etc. react to his behaviour?

From whom would you like to gain more information?
With the problems of the client in mind you have to carefully select those relatives and caregivers that are best informed and who know the client from daily interaction.

Which member of the team will gather the information?
With a list of relevant questions in mind and on paper, the consultation can now start. No matter who you are, you are seldom in the position to do the consultation totally on your own. In Moses' case the psychologist in the team (let us call her Sarah) takes the lead. She was chosen, because she has known Moses for a very long time. Besides, she is an experienced staff member. Sarah plans a consultation with the senior caregiver in Moses' group. He knows Moses best of all.

Consultation: what and how?

1. Prepare (in small groups) an interview with Moses' senior caregiver: what questions do you want to ask and in which way will you ask the questions?
2. Put your plan in action by interviewing the caregiver (in a role play)
3. Write a report on the consultation. Concentrate on Moses' core problems.

After the interview, Sarah adds a detailed report to Moses' file (comparable with your own report). She summarises the main results of her consultation in the following way:
- The most important aspect of Moses' problems is a decline in his functioning, loss of memory and orientation, and his conflict with others.
- These problems are not situation specific. Moses shows this behaviour in the group home as well as at work. It is not known whether the problems manifest themselves also at his brother's home.
- The nature and level of the behavioural problems is not stable, it seems to get worse over time.
- The senior caregiver fears the problems are the first symptoms of Alzheimer Disease, which is quite common among people with Down Syndrome at Moses' age. If it is indeed a case of Alzheimer Disease, the prognosis is unclear. It is uncertain how quick Moses will become demented.
- The loss of memory, the disorientation and the conflicts are aggravating for both Moses and other members of the group.
- The senior caregiver rules out a visual problem, because a year ago the ophthalmologist did not report any problem with his eyes.
- Moses is no longer the friendly, helpful man he used to be. He is unhappy and makes others unhappy.

Consultation - team discussion

1. Compare your own report with the summary in Sarah's file.
2. Are you missing something important?
3. Do you think Sarah lacks important information?

Sarah's report is discussed with the team (psychologist, pedagogue, caregivers and staff of the sheltered workshop). The result of the discussion is that a closer (and broader) look at Moses' problems is indicated because:

- Dementia as a cause is still hypothetical.
- The context of the problems is still unclear: What are his exact problems? When and where does Moses show these problems?
- When and where does conflict with others arise?

Conclusions: Dementia must be checked. Moses' conflict with others must be described. His brother's view on the situation is needed. A new test of his visual acuity is advisable.

5.3. Step 3: Planning the inquiry

Sarah is asked to complete Step 3 – planning the Inquiry. Before she starts her inquiry, she asks Moses' brother for consent. He is Moses' legal representative, because his parents have passed away. Sarah also asks Moses' daily caregivers for their help as their information is crucial. It is essential that his caregivers cooperate and feel respected. Their involvement is indispensable during the whole process, from beginning to end. Sarah plans thoroughly for her investigation and makes the necessary arrangements.

What steps should she follow?

- Consider the possible link between Moses' behavioural problems and the first symptoms of Alzheimer Disease.
- Observe Moses in specific situations where his behavioural problems (in interaction with others) are most apparent.
- Interview Moses' brother and the supervisor of the workshop on his behavioural problems, especially in his interaction with others.
- Test a possible decrease of his visual acuity.

A detailed agenda is drawn up before starting the inquiry: Indicate what has to be done, when, and who is responsible for what. It is crucial to manage the inquiry in the best possible way, in order to attain clear and meaningful results.

5.4. Step 4: Conducting the inquiry

There are three crucial points in the inquiry into Moses' behaviour problems:

- The decrease of his daily functioning
- His conflicts with others
- His visual acuity

1. How to inquire about these problems?
   By testing for a possible development of dementia: Sarah makes use of several instruments: the Dementia Questionnaire for People with Mental Retardation (DVZ), the Peabody Picture Vocabulary Test (PPVT), the Wechsler Intelligence Scale for Children (WISC-R), and the Multidimensional Observation Scale for Elderly Subjects (MOSES).

   Some of the tests are validated translations of American tests and others have been developed in the Netherlands. Together they measure different aspects of problematic behaviour: long-term and short-term memory, orientation in time and space, word and sign recognition, etc.

   People with (a developing) dementia show an increasing lack of purposefulness in their functioning and their ability to anticipate fails more and more. With the loss of these (intellectual) skills there is a shift from problem-centred to emotion-centred coping. This causes a change in attitude and sentiment. These aspects of Moses' problematic behaviour should be tested too.

2. *By observing Moses in interaction with others* in three problematic situations:
   - waking up in the morning (washing, getting dressed, having breakfast),
   - travelling to his workshop, and
   - spending leisure time with his friends.

   The results of the observation should then be compared to situations when Moses is alone in his room, and at his ease. The observations focus on Moses' actions and reactions and on what happens before and after the problem situation occurred.

3. *By interviewing his brother and his supervisor on their observations* concerning Moses' behaviour problems and their possible explanations and ideas on how these can be prevented.

4. *By testing Moses' visual functioning*.

Sarah will do all the psychological testing, observations and interviewing. The visual functional assessment will be done by an ophthalmologist.

A summary of the results of the inquiry:
1. Tests show no clear-cut drop in memory. His short and long-term memory is still according to his cognitive level. There is some indication of disorientation in time and space. Moses is able to function in a goal directed way and to anticipate events. There is a shift from problem-centred coping to emotion-centred coping. This leads to negative reactions towards him by others. Although there are some indications of dementia, at this moment the results are not convincing enough to confirm that Moses has dementia.

2. Observations show that Moses cannot find his way in the group home. When his clothes and other belongings are not in their usual place, it is very difficult for him to find them. On his way to his work he cannot see the bus number and the direction of the bus. He cannot decide which bus to take. When he hesitates, he misses the bus and consequently arrives

too late for work. When they watch TV at his group home, Moses sits right in front of the screen. This irritates the others and many quarrels follow.

3. Moses' brother does not experience any problems with Moses. They are always very close and he helps Moses with almost everything. Nevertheless, he is concerned. He is convinced something is wrong with Moses' eyes. He observed that Moses falls more often than usual and complains that he cannot read things.

4. The ophthalmologist's visual assessment now shows that Moses' vision is very weak, weaker than was realised. He cannot observe detailed pictures (for example, puzzles). He becomes uncertain when the surface changes. The most alarming result of the visual acuity test is that the lenses of Moses' eyes are getting dense (opaque).

When considering all the results of the inquiry, we can conclude that there is one main cause for Moses' problems: the cataract (both eyes). The development of a cataract explains Moses' problems in the morning when in a short period of time he has to find his way from his bedroom to the bathroom, dress correctly and be on time at the breakfast table and bus stop. Not being able to read the bus number causes him to arrive late at his work.

Moses' sight worsened dramatically, causing his disorientation. He tried to mask his inability, which resulted in his failing to get up in the morning, his unwillingness to go to work and his disinterest in his hobby, building puzzles. But he could not explain why he reacted in this way. As Moses could not cope with criticism he felt irritated and often quarrelled with his groupmembers and caregivers. His behaviour problems can be explained as being the outcome of an unnoticed decrease of his visual acuity.

5.5. Step 5: Integrating the results

Before you take the next step towards intervention it is important to integrate all the results. This means the integration of the information on his file, the interviews and observations and the outcome of the standardised tests. In this overall picture not each peace of information is equally important. One has to select the information and focus on the purpose of the diagnosis.

Integration of information

1. Summarise the information systematically.
2. Check in groups of two whether all relevant information is captured.

5.6. Step 6: Understanding Moses and his needs

Remember the importance of this sixth step. You will be able to bridge the gap between the results of the inquiry (the diagnosis) and the intervention. In this step, it is important to identify with Moses. Moses can best be understood by identifying with his needs, and by putting his strengths and weaknesses into 'his own words'

Moses' 'need for assistance'

1. Which methods would you choose to help Moses?
2. Why will these methods address Moses' needs?
3. Do they match the goals of the intervention?
4. Which professional skills are needed to help Moses?

5.7. Step 7: Intervention

The seventh step in the assessment and evaluation processes can now be taken. It is called intervention. Moses' needs are the starting point of the intervention. Before intervening, we need to set goals for the intervention. As we have seen in the preceding chapter, good goals that address the client's needs are realistic and concrete.

Goal-setting for Moses

1. Set the necessary goals for the intervention.
2. Is your goal-setting according to Moses' needs? Check this.
3. Is your goal-setting concrete enough?
4. Are your goals realistic?

The next step in the intervention process is the selection of methods. They must address the client's needs (see chapter 3). Consider which form of intervention will solve the problem. In other words: How can Moses be helped?

How to help Moses

1. Which methods would you choose to help Moses?
2. Why will these methods address Moses' needs?
3. Do they match the goals of the intervention?
4. Which professional skills are needed to help Moses?

Results of the intervention:

1. Moses underwent successful surgery for the cataracts in both eyes. His visual acuity improved.
2. One of the caregivers, Marjory, helped Moses to (re)organise his daily activities: wake up, wash and dress, enjoy breakfast, go to work and come home again, and pursue his hobbies. She also helped him to co-operate with his friends. The information on this 'reorganisation' was then discussed with the supervisor at his work. Consequently, also at work, adjustments

Guidelines for a proper approach

Suppose you are Moses' caregiver and suppose Moses had to undergo surgery: What guidelines would you develop regarding Moses' rehabilitation in the group home and at his workshop?

were made.

5.8. Step 8: Integration in daily care and evaluation

A point of special interest in this last phase of the helping process is the integration of the successful aspects of the intervention in his daily care. The results obtained by applying the Step-by-Step model are collated in a detailed report written by one of the members of the multi-disciplinary team. In the report all the information gathered, serves as 'guidelines for adequate special care'. The report is also sent to and discussed with Moses' brother and specific advice and guidelines are added.

Guidelines for daily living

Suppose you are Marjory and you are going to discuss the guidelines you and Sarah developed with your colleagues. Organise a role play 'transfer of guidelines' and check afterwards whether your colleagues picked up the information and are motivated to put these guidelines into practice.

We have not yet reached the end of this last step. Using the guidelines in the near future is not enough. Moses will still need special attention from all the caregivers for a considerable time. Moreover the acuity of Moses' eyes should be checked regularly, considering the possibility that a new cataract could develop.

Conclusion

When we first met Moses, his case seemed very complex. It really was complicated, but in a different way to what we thought at that time. At first, his caregivers thought it was obvious that Moses has Alzheimers, because all his problems pointed in that direction. The test results showed that Moses did not develop dementia. He happened to have a cataract (both eyes) and almost all his problems could be explained as a result of the cataracts.

What we learned from this case study is that we should not take it for granted that our first thoughts on a client's behaviour are correct. A level of caution is always advisable. We should use the Step-by-Step model to work systematically through the evidence. It is important to note that in all assessments, visual functions should always be checked.

Chapter 6

Support and care for persons with multiple disabilities: never say ‘never’

Introduction

In chapter 4 we presented the Step-by-Step model to systematise the process of intervention. In the following case study we are going to guide you to apply this knowledge in concrete situations. We will identify Mary’s need for help by following the Step-by-Step model.

Mary

Mary is 55 years of age. She has a severe learning difficulty. She is also physically disabled and cannot walk. The causes of her disabilities are not known; all we know is that she has been like that since birth. Because she cannot walk, she either crawls or is moved around in her wheelchair. Her caregivers have not mentioned any challenging behaviour.

Every year each participant in the group home is assessed and evaluated and the care programme is adjusted if necessary. During the latest evaluation the caregivers mentioned that where Mary often used to page through her picture books in the past, she now prefers to be outside, looking at the cars that pass by. She also prefers staying in a separate room instead of being with the others in the living room. Her caregivers describe this change in behaviour as very strange. Her current behaviour does not correspond with the activities she used to enjoy for so many years. They wondered why she shows this change in preference.

Because many of the caregivers are middle-aged and need spectacles for reading and writing, they wonder whether it was not caused by a change in Mary’s visual acuity or, because she may also have a cataract just like Patric who lives in the same group home - Patric is also 55 and has Down’s Syndrome.

6.1. Step 1: Recognising Mary’s problems

To really understand the problem, we have to look at the broader context to avoid making a mistake by only looking at the symptoms. If we do not have a holistic approach and get to the core of the problem, we can easily make mistakes and a wrong diagnosis can be made. If that is the case we may start with an intervention programme that is not effective. To prevent this from happening we will start by exploring the signs mentioned to by the caregivers.

Important clues of Mary's behaviour

1. Read the information on Mary again.
2. Are there signals that can help you to understand the problem?
3. Why are these signals relevant? Give reasons for your answer.
4. Classify the signals you have selected according to the six dimensions of human functioning (visual, auditive, motor, behavioural, relational and ecological - see chapter 4).
5. Are there any of these dimensions that you have overlooked? If so, why did you not notice them? Complete your list.

Complete these tasks before you continue reading.

Mary

The relevant signs according to the six dimensions of human functioning in Mary's case are:
Visual: No information is available concerning her visual behaviour. However, her caregivers noticed that she behaves in a strange way. Mary no longer wants to "read" her picture books and only wants to sit outside and look at the cars passing by. They think that the cause of the change in her behaviour may be because of a visual problem, a cataract or just the need for spectacles.
Auditive: No auditive screening has been done.
Motor: Mary is physically disabled.
Behavioural: No challenging behaviour has been observed, only a change in her behaviour.
Relational: No information is available on the relational aspect.
Environmental: No information is available on the environmental aspect.

It is important that we consider all relevant signals and take all aspects into account. You should always consider if you might have overlooked any of the dimensions.

Mary

It is clear that Mary's caregivers are concerned about her, because she no longer pages through her picture books which she loved to do. On the other hand, it is possible that their observations are not really objective; perhaps they are just scared that they have overlooked a visual problem (as was the case with Patric). More information is needed. At this moment there is yet a lot we do not know. We need to know more about her hearing, her contact with other people, her likes and dislikes, as well as her surroundings.

6.2. Step 2: File study and consultation

As mentioned in step 1, Mary's behaviour has changed. This behaviour cannot be fully explained with the limited information we have. We need more information on all the different aspects. Therefore, in Step 2, we will focus on obtaining more information by conducting a file study and by consulting her caregivers and family members.

Mary
Unfortunately Mary's father passed away when she was 45 and her mother, when she was 48 years old. She has no siblings. The only remaining family contact is an aunt who normally visits Mary on her birthday. Mary has quite a number of caregivers; some of them know her for only about one year, but there is one caregiver who has been working with Mary for the last 12 years.

Consultation: what and who?

1. Read the information on Mary again.
2. What information is still outstanding?
3. Make a list of relevant questions that you want to ask.
4. Who are you going to put these questions to? Why?
5. Who is best suited to collect the information?

Complete these tasks before you continue reading.

Mary
What information on Mary do we still need and what questions should we ask?
- What do you mean by the statement that she pages through her picture books? What does she really do with the book? Where is the book when she uses it? Can she hold the book on her own? Can she turn the pages of the picture book by herself?
- When was the fist time that you noticed that she does not "read" the books any longer? When looking back, what do you regard as the cause of the problem?
- What does she enjoy doing? What are her strengths?
- Did the caregivers previously asked for help? If so, what was the response?
- Why has Mary been referred? Are there specific reasons for referring her for intervention at this stage?
- Were there any changes in her life or in the group home just before caregivers noticed that she did not "read" her picture books any longer?
- How does Mary react emotionally in different situations and towards different caregivers? Are there any changes in her reactions?
- How would you describe her relationship with her caregivers, group members and aunt? Does Mary turn to someone specifically when she is distressed or when she has emotional problems?
- Are there any changes in the environment, for example, lighting?

From whom would you like to gain more information?
We need to ask the caregiver who knows her well to provide more information, but need to also get information from a medical team.

Which member of the team will collect the information?
The team will work together to find answers regarding Mary's changed behaviour. Because the psychologist has an overall picture of all the clients in this group, she should collect the information and report to the multidisciplinary team.

Consultation: what and how?

1. Prepare an interview with Mary's senior caregiver: what would you like to ask and what will your approach be?
2. Interview the caregiver (making use of role-play).
3. Prepare a report on the consultation. Concentrate on Mary's core problems.

Complete these tasks before you continue reading.

Guidelines for interviewing the caregiver:
Make an appointment with the caregiver and ask for a private place to interview her.
Start with an 'open' question, for example: How would you describe Mary?
Ask for examples when answers are given to the questions.
Ask for detail when answers are given - use when, where, who, how, why?
Ask questions about Mary's strengths, interests, hobbies, etc.
How did Mary 'read' the picture books? Did she turn the pages, turn the book, and recognise the pictures? Is there a difference in the way she currently handles the books?

The results of the interview (consultation) can be reported as shown below.

Mary

The psychologist gained important information from both the file study and the interviews. Mary's senior caregivers, a physician and a physiotherapist, were interviewed. The following information was obtained:

- Mary lived with her parents until she was 22 years of age. As it became very difficult to give Mary the necessary care, she was placed in a group home. To give Mary the opportunity to get used to her new home, the process of placement first started with weekend visits to the group home. Gradually the frequency and the length of the visits increased. Her parents were very concerned and caring. Mary coped well with the gradual change in the situation. Later Mary stayed in the group home and only visited her parents during weekends. At the end she moved in and lived here for the last 15 years.
- When Mary's father and later her mother passed away, caregivers helped her to work through the loss. They accompanied her to both funerals and talked to Mary about her loss. The caregivers used rituals: lighting a candle, followed by talking about her father and her mother, and ending the ritual by singing a hymn. Although it is not clear whether Mary understood what happened, her caregivers got the impression that at first she was sad. By repeating the ritual she seemed to cope well with the absence of her parents. After some time the frequency and the length of the rituals declined and eventually stopped. At the moment she reacts in a positive way and seems to be a happy person.
- It recently struck her caregivers that she does not use her picture books as often as she used to. They thought she needed reading spectacles , due to her age - she is 55 years of age. They thought that she might even have a cataract.
- During the interview the senior caregiver mentioned that she no longer reacts in an alert way when her name is called. The caregivers think that, as she becomes older, she may also have a hearing disability.

- No visual acuity or hearing tests had been done before. When the senior caregiver was asked how she previously reacted when she was called for lunch or dinner, she mentioned that she normally responded promptly but lately she no longer reacted in that way. She only reacts when the caregiver is quite near her.
- Mary is healthy. Although she has epilepsy, no incidents have been reported during the last 13 years. She always has a good appetite and is hardly ever ill.

Consultation - team discussion

1. Study the summary carefully.
2. Is there important information that is still outstanding?

Complete these tasks before you continue reading.

Mary

The report written by the psychologist was discussed in the team. The team members noted that important information was still missing. The report did not include information on her visual acuity and her hearing. The team decided that assessment of her hearing and vision was needed and therefore appointments were made with an optometrist / ophthalmologist for visual assessment, and with an audiologist to conduct hearing tests.

6.3. Step 3: Planning the inquiry

Assessment of Mary's vision and hearing has to be done. As the assessments will be strange and new to her, the caregivers wanted to know how Mary could be helped and prepared for the assessments. The following arrangements were made:

- The assessments will be done in the doctor's room. The medical unit is not an unknown location for Mary as, during the past years, she had visited the doctor occasionally for small problems like a scar on her arm, a skin infection, etc. Her caregiver will accompany her.
- Mary's favourite teddy bear and another toy will be taken with to make the visit as positive and enjoyable as possible.
- She will be told about the assessment the evening before. Although the caregivers do not know whether she will understand what is going to happen, they hope that by informing her about the assessments, she will be prepared and that she will cooperate.
- They will explain briefly that the doctor will take a look at her eyes and ears. This brief explanation will be repeated a few times during the morning.

6.4. Step 4: Conducting the inquiry

An optometrist / ophthalmologist conducted the visual assessment. Later the hearing assessment was also done. The following is a summary of the results of the assessments:

Mary

Visual acuity

- TAC: 0.06 near sightedness (without spectacles), Mary can point out where the pictures are on the chart. She was not able to mention the pictures so it was not possible to measure distant vision.

- Candy beads: She picked up a number of very small candy beads – but had done it by touch, not by sight.
- No spectacles are needed for distant vision (emmetropia).
- TAC: 0.5 (with “reading” spectacles, S+2.00).
- Visual field: may be restricted, but because she reacts so slowly, it is not clear to what extent.
- Contrast: Moderate
- Light sensitivity: No
- Nystagmus: None.
- Eye movements: Correct.
- Lenses: Right eye clear, left eye very small cataract.

Reaction of the caregiver
The caregiver was surprised with the severity of Mary’s visual disability and the change in her ability to see closely with the “reading” spectacles. Mary displayed no problem when the spectacles were put on.

Hearing assessment
The tests showed that Mary has a hearing deficiency.
Hearing loss: 30 dB in both ears.
As she will have difficulty to hear in a crowded room, hearing aids were prescribed. She is able to hear her caregiver during individual sessions, but is unable to understand or hear properly when there is excessive noise.

6.5. Step 5: Integrating the results

The next step is to integrate all the results. It is important to be selective when considering information. The most important elements of information should be noted:

Integration of information

1. Summarise the information systematically.
2. Check in groups of two whether the information is complete.

Complete these tasks before you continue reading.

Mary
Mary’s age and disabilities are important factors. Her behaviour was explained as being related to loss of visual ability. Because of her lack of reaction when her name was called, it was thought that she might also have a hearing problem. No hearing test was previously done. However, both visual and hearing test were reported during the inquiry (see paragraph 6.4).

The vision test indicated that if she would use “reading” spectacles, her visual acuity and her near vision would improve from 0.06 without spectacles to 0.5 with spectacles.

Her low visual acuity (0.06) because of presbyopia (needing reading spectacles when getting older) combined with the slight cataract seem to explain her loss of interest in her picture books.

Her interest for the cars driving by may be due to the combination of a number of factors such as being able to see a big object, contrasting colours and the movement of the cars.

When people are in need of reading spectacles like Mary, most of the time their distant vision is not a problem. Unfortunately her distant vision could not be tested, because of her inability to name pictures or symbols.

The hearing tests indicated that Mary needed a hearing aid. Her hearing loss may have caused her disinterest in group home activities and may explain her preference to sit outside or in a separate room, instead of enjoying the social engagements in the living room. She may have been unable to hear and understand what is spoken.

6.6. Step 6: Understanding Mary and her needs

In Step 6 you should imagine that you are Mary, and then describe her needs and emotions.

Mary's 'need for support'

1. What does Mary need most of all?
2. What does she need in her daily life?
3. Identify with Mary and write a paragraph starting with 'I am Mary. I am….' Represent Mary by formulating her 'need for support'. Describe her need for support in her own words.

Complete these tasks before you continue reading.

Mary

I am Mary. I am 55 years of age. I live in a home with 9 others. I know my caregiver very well. Her name is Ann. Ann is very friendly and helps me. All the other caregivers are also caring and loving. Lately I cannot see as clearly as I used to, especially when I look at nearby objects. I wish someone could help me. I would like to see clearly again, because I enjoy reading my picture books. I also notice that I do not hear the songs on the radio as clearly as I used to. I do not hear when my caregivers call me for lunch. When I am outside I can see the caregivers come and therefore I do not have to be on alert all the time. I will have to get used to hearing and visual aids, and this will be a new experience for me.

6.7. Step 7: Intervention - Getting used to spectacles and hearing aids

In step 7 we are going to look at possible interventions. Firstly we will start by setting the goals that should address Mary's needs.

Goal-setting for Mary

1. Set meaningful goals for Mary's programme.
2. Will the goals address Mary's needs?
3. Are the goals concrete and specific?
4. Are the goals realistic?

Complete these tasks before you continue reading.

Mary

There are two main goals for Mary's programme:

- Mary must learn to wear her spectacles when she "reads" her picture books.
- Mary must learn to always wear her hearing aid.

Please note: These goals may not be realistic - we do not know if Mary will be able and willing to use her spectacles and her hearing aid.

For these reasons our goals should rather be:

- Mary uses her spectacles when she is 'reading' her picture books. She wears her spectacles for as long a period as possible.
- Mary uses her hearing aids as long as possible during daytime.

To achieve these goals, special programmes will have to be developed. A special programme is important as the client may show resistance to using spectacles or hearing aids by taking them off all the time, or by even throwing them away. To overcome this resistance, the client has to 'get used to wearing spectacles' and has to 'get used to using hearing aids'. The main goal is that Mary will use the spectacles and hearing aid in situations in which she really needs them.

As Mary has problems to hear and understand others and this is hindering her in her daily functioning, getting used to the spectacles and hearing aid should be the highest priority for the intervention programme. If she gets used to her spectacles and hearing aids she will enjoy looking at the picture books once again, while listening when the caregiver reads to her.

It is important that she be taken through a programme which has especially been developed to help persons with a hearing loss. This programme is known as 'Getting used to hearing aids', and is useful in the following situations:

- When the client moves from one situation with little noise to the next with a lot of noise.
- When the client feels insecure when he/she hears sounds he/she is not used to.
- When the client dislikes having the hearing device his/her ear.

She also needs another programme 'Getting used to Spectacles'. This is useful in the following situations:

- If the client has never used spectacles before.
- If the client dislikes having objects on or near his/her face.
- If the client dislikes new experiences or situations. Using spectacles can make the world look different and it sometimes takes a while to get used to this different world. For some clients it

can take a while to get used to spectacles, while others accept their spectacles straight away.

- If the client has trouble coping with the change in visual stimuli.
- If the client does not experience the change from vague to sharp images as an immediate advantage.
- If the client experiences very little change when using the spectacles, due to other visual disorders.

Guidelines for a proper approach

Suppose you are Mary's caregiver. Mary has to get used to using hearing aids and spectacles. Which guidelines would you develop and use?

Answer the question before you continue reading.

Mary: Hearing aids

For Mary to get used to the hearing aids, her caregivers will have to be motivated to help her. The device should be fitted carefully and the batteries checked regularly.

Getting used to hearing aids

General guidelines: Before fitting hearing aids, a person should be available who is able to effectively and very quickly help solve problems that may occur during this initial period. During this period a few common problems may be encounter, such as not being able to fit the device, or running out of charged batteries.

The client may experience the initial use of hearing aids as somewhat uncomfortable. It may have taken a long time before the hearing disability was diagnosed and the client may have forgotten what it is like to have "normal" hearing. (Note: hearing with hearing aids never accurately replaces normal hearing as sounds differ from the sounds we are used to). Further, voices and noises may seem very loud and different when one uses hearing aids for the first time.

The experience of getting used to hearing aids differs, compared to that of getting used to spectacles. When a client uses spectacles for the first time, they most often experience the difference right away, but with hearing aids, the client has to get used to hearing sounds in a different way. The longer the hearing aids are used, the more the client will like them. But getting used to the new devices demands patience. Getting the full benefit from hearing aids may take time.

To get used to the hearing aids the use of the device can be built up slowly. For instance: first give the client the opportunity to listen to everyday noises, using the device. Then try using it during conversations in a quiet room. Next, move to conversations in small groups. Then motivate the client to use it outside. Finally, the client can be motivated to use it in a noisy place like a restaurant.

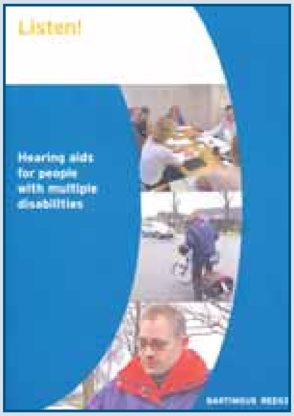
The secret is to gradually build up the length of time during which the hearing aid is used. Daily use of the hearing aids should help the client to get used to the device. If the client uses it all day, every day, straight away, then the ear mould can cause a sore in the ear. Also be aware of the possibility that one's ears can be irritated when the aid does not fit correctly. Battery strength should be checked daily.

DVD: LISTEN! Hearing aids for people with multiple disabilities

Josje Kingma, Saskia Damen, Ruth Schelfhout & Jan IJzerman

Look at the DVD and see how clients are helped to get used to their hearing aids.

What are the important aspects when helping the client to get used to hearing aids?



Mary: Spectacles

For Mary it will be best to use a flexible spectacle frame with a soft nose pad and soft ear bends. Real glass is dangerous and heavy, so it is better to ask for synthetic glasses. Her caregiver will have to clean the spectacles regularly as Mary will not be able to do so. Without regular cleaning, the spectacles will be of little use. The spectacles should fit properly and should not be too tight against the side of her head or behind the ears or too loose so that the spectacles slip down her nose. Mary will not like to wear spectacles that fit uncomfortably.

Getting used to spectacles

General guidelines: There are three main guidelines for getting used to spectacles: gradual adaptation, awareness and positive conditioning.

Gradual adaptation
One of the elements of gradualness is that there should be no pressure on the client to use the spectacles. The client should be given the time he needs to get used to use them. Situations in which it is necessary to work with another approach will be discussed later.

When goals are set, take care that these goals are a combination of a number of small steps. Sometimes it can take years to teach a person with a learning difficulty to take a new route when walking, or to develop certain skills. Most often these persons are taught by mastering many small steps, one at a time. Getting used to wearing spectacles is also a process that can take a very long time. When we start with the programme we should discuss the benefits of wearing the spectacles, in which situations the spectacles will be provided, but also how often and for how long the spectacles will be used. It is important to increase the frequency and the duration of wearing the spectacles. The frequency and duration can be increased as long as the client does not show resistance.

Sometimes the client enjoys wearing spectacles. In these situations the use of the spectacles are welcomed, so the duration of wearing the spectacles can be build up much quicker. Sometimes a client even wants to wear them all day, right from the start. In some cases the client can become overwhelmed by all the extra visual information. Therefore you have to frequently adjust the programme, based on the abilities of the intellectually disabled person.

Should there be any sign of resistance; take one or a few steps backwards. Revert back to the time before the client showed resistance and then gradually continue the adjustment programme. It is actually similar to a desensitisation programme, which is often given to persons who suffer from a phobia.

It is possible that in some cases, due to persistent resistance, no progress is made. The client then, for example, only wears the spectacles while being at the day activity centre or when he is walking outside or when watching television. We believe that in such cases it is better that the client experiences good eyesight in particular situations or for only short periods per day, then not wearing the spectacles at all.

When the resistance continues, it may be better to stop for a few weeks and then start again. The client may then accept and use the spectacles. The expectation is that if spectacles will improve the client's vision, this benefit will eventually motivate the client to use them more often or permanently.

Awareness

It is important that the client is made aware of the reason why he should wear spectacles. If the client can speak and understand verbal information, the caregiver can explain the importance of wearing spectacles. For clients with less understanding of verbal information the use of spectacles can be supported by continuously using the same words when the spectacles are offered: 'We are going to put on the spectacles and look at the nice pictures' and then hand over the spectacles or put them on. By always repeating the same words and acting in the same way the client will gradually understand what the caregiver wants. Clients who do not understand speech at all have to learn the importance of the spectacles by often noticing the difference between clear and unclear vision. By repeatedly watching movies or looking at photos, building puzzles or by going for a walk with and without spectacles, the difference will become clearer and the client will then be encouraged to use them. During the programme, the caregiver can create different situations and provide different activities in which the client can experience seeing with and without spectacles (unclear and clear). For persons with a lot of resistance, it is preferable not to increase the range of experiences, but rather to try to increase the duration of wearing the spectacles during a single of a few activities.

The client can be made more conscious about his spectacles by giving him/her the opportunity to put on or take of his spectacles by himself/herself, if that is possible. It is important to avoid any kind of force or pressure. If you do use force or pressure the client will most certainly increase his resistance and then the goal of 'getting used to the spectacles' will not be attained.

When a client is not able to express his experiences verbally, you have to get information from mimics, body language or observe change in behaviour. Continuous observation of the client while he wears the spectacles can provide information and clues should be reported.

Positive conditioning
When the client is trained to use the spectacles in a positive and enjoyable environment, it will increase acceptance. The client will learn to associate wearing his spectacles with pleasant experiences. Caregivers know during which situations the client feels most relaxed and which situations are most enjoyable. Also ask the person who has the best relationship with the client to start with the programme. This person's attention will be very stimulating and motivating for the client.

Another situation in which spectacles can be offered is, for example, when the client can look at himself in a mirror.

When choosing the activities, consider the following:
When the client is far-sighted (in need of + spectacles) the client will have the most positive experience and experience the best results if the spectacles are provided during activities such as building a puzzling, looking at pictures, and while performing pleasant tasks.

For a client with near-sightedness (need of – spectacles) activities in which there is a greater distance to the object, will give the best results, for example, while watching television, walking, following the caregiver or while sitting on the couch and looking outside. These clients are used to close distances to objects. While wearing the spectacles they will get used to looking at objects further away. If caregivers are aware of this, they can keep it in mind while continuing with the programme.

When spectacles are provided for clients with unequal refraction errors (astigmatism requiring cylindrical refractive correction), the client will, at least in the beginning, experience the world in a distorted way - everything looks distorted. For these clients it is better to first provide an activity in which they are not mobile as this may be frightening. For these clients the programme should include activities in which the client sits down while working or being involved in activities. To get used to these spectacles, the client can best use them all day long – at least as long as bearable -, right from the start of the programme. After a day or two, the distortion will disappear.

In situations where the client is far sighted due to his age, (presbyopia) one should offer reading spectacles only – not only meant for 'reading' but also for performing 'nearby activities' such as colouring pictures, building puzzles, etc. If he already uses spectacles, one must choose between having two pairs of spectacles and change them when the activity is changed, or bifocals or multifocals. Often multifocal spectacles are not provided, as it is very difficult to get used to these kinds of spectacles. The optometrist or optician should give advice.

DVD: Getting used to glasses

Paula Sterkenburg & Jan IJzerman

Look at the clips from the DVD ‘Getting used to glasses’ and see how clients are helped to get used to the glasses.

What are the important aspects when helping the client to get used to spectacles?

For more information on the use of spectacles see: Bijker, De Zeeuw, & Sterkenburg (2002), De Zeeuw, Sterkenburg, & Bijker (2002), and Sterkenburg (2002).

6.8. Step 8: Integration and evaluation: never say ‘never’

In step 8 of the Step-by-Step model, results are collected and a detailed report is compiled by one of the members of the multidisciplinary team. In the report the goals and results are evaluated. The report is sent to and discussed with Mary’s aunt and also with her caregivers. This report should indicate the results of the special programmes being used to help someone get used to spectacles and hearing aids. Which problems were encountered? What observations were made concerning Mary’s behaviour? Is there a difference in her behaviour before and after implementing the different programmes? What were the shortcomings of the different programmes?

Mary

Considerable success was noted when the programmes on getting used to hearing aids and glasses were offered to Mary. However, she does not wear her hearing aids all day, or use her spectacles in all situations where she could benefit from them. To encourage her to continue on the road to acceptance, caregivers will have to create opportunities to motivate Mary to use her aids. They will also have to check that the hearing aids work properly. Furthermore, Mary’s eyes should be tested regularly and special attention should be given to check the possible further development of the cataract. Her hearing should also to be tested on a regular basis.

Challenges regarding ‘getting used to hearing aids’

Mention some of the challenges that she may encounter while ‘getting used to hearing aids`.

Complete this task before you continue reading.

Challenges: Getting used to hearing aids

Sometimes the client will only use the aids when someone is around, or when one motivates the client to use the hearing aids. It is therefore preferable that the programme starts with providing hearing aids in situations where there is a caregiver available, for instance during a meal, during an activity or while taking a walk. If the hearing aids are not spontaneously used all the time, then it should be used when a caregiver is available.

Caregivers are often not aware that the batteries of the hearing aids are flat and need replacement. Therefore they do not understand why the client does not want to wear the hearing aid. Special attention should be given to this aspect. Timetables should be used to ensure that a caregiver regularly checks the quality of batteries.

Sometimes clients will gladly use their hearing aids in a quite place or when they are listening to music or watching TV, but prefer not to use the aids in a noisy environment.

Challenges regarding 'getting used to spectacles'

Mention some of the challenges that she may encounter while 'getting used to spectacles'.

Complete this task before you continue reading.

Challenges: Getting used to spectacles

In some cases clients will only wear the spectacles during activities where their parents or caregivers are present and motivate them to use the spectacles. It is therefore preferable that the programme starts with the use of spectacles in one-on-one situations or activities, such as building a puzzle, walking or looking at pictures. If the spectacles are not used in other situations, then at least they are used during sessions when the caregiver is present.

In some cases the use of spectacles does not mean the client's visual acuity increases dramatically. In some cases the vision can improve from 0.1 to 1.0 (10% to 100%) but in other cases the improvement may only be from 0.05 to 0.15 (5% tot 15%). In this latter case the person will still be visually impaired (<30%). With the spectacles the client will still have low vision and therefore the vision will remain blurred. Spectacles are provided because the client will be able to observe more detail. However, it may take time before the client realises that the spectacles improves his/her vision.

For some clients it can be frightening to see so much information and detail at once with their new spectacles. The new situation may be overwhelming, especially for persons with myopia (short sightedness). It may be frightening as the client was used to focusing on a 'nearby' world with "little" information. To prevent resistance it will be better for these clients to have a programme which is stretched over a long period of time and with minimum time pressure.

The same can be said in the case of elderly persons, because they may be less flexible in adjusting to the higher level of stimulation. It is therefore better to restrict the use of the spectacles to certain activities. Sometimes myopic clients want to wear their spectacles the whole day, right from the start. In that case, allow them wear their spectacles if they want to.

Possible challenging behaviour may be the reason why there is hesitation to start with the programme. However, not being able to see well can also provoke or increase challenging behaviour. It is therefore important to carefully consider whether it is wise not to start with the programme.

Conclusion

For persons with multiple disabilities, appropriate aids can be provided to improve their quality of life. Most people can get used to using their spectacles or hearing aids, therefore: if you do not try, you will never know. More often than expected, persons with serious sensory impairments may surprise you. So never say never!

Chapter 7

Understanding behavioural problems: an attachment-based intervention

Introduction

Tony

Tony is 7 years of age when he is admitted to the department of psychotherapy at Bartiméus. He lives in a home-care centre and has no contact with his parents or with his foster-parents. At the time of his admission he has a developmental age of about 18 months. Tony has a severe learning difficulty and is blind. Although he is not physically disabled he often bumps into objects. He is unable to talk.

His parents and caregivers are unable to understand his needs. At the time of admission he showed serious aggressive self-injurious behaviour and had difficulty to sleep. His reactions were and are unpredictable. He will suddenly burst into tears and hurt himself as well as others. He is then inconsolable and it is hard to calm him.

The reasons for his behaviour are a mystery and he obviously found himself in a deadlock situation. His caregivers try to help him to change his behaviour, by giving him toys to play with, expecting that he will not harm himself. That does not work as he throws the toys away.

Tony's behaviour is similar to that of Mariëlle, the girl on the DVD titled 'Attachment: a psychotherapeutic treatment'.

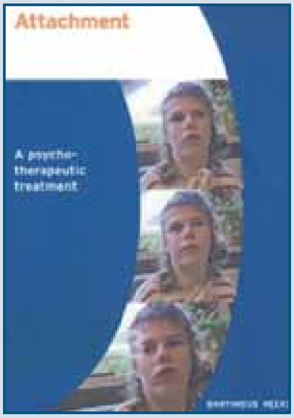
DVD: Attachment: A psychotherapeutic treatment

Paula Sterkenburg & Jan IJzerman

The fragments of the DVD 'Attachment: A psychotherapeutic treatment' shows treatment given to Mariëlle. She reveals similar challenging behaviour as Tony. To get an impression of the challenging behaviour Tony's caregivers have to cope with, have a look at the very fist part of the DVD (first ± 2 min. of the total DVD). Turn the sound off so that the text does not distract your attention.

We will discuss the DVD when we look at Step 7 (Intervention).

While looking at the short clip, note the challenging behaviour and discus how this behaviour corresponds with Tony's behaviour.



7.1. Step 1: Recognising Tony's behavioural problems

Using the Step-by-Step model, we shall work through Tony's case. The fist step is to select relevant clues of his educational problems.

Selection of relevant clues of behavioural problems

1. Read the information on Tony again.
2. Concentrate on the caregivers' problems with Tony and on the solutions they try to find.
3. Are there clues that can help you in your orientation towards understanding the problem?
4. Why are these clues relevant in this case? Motivate your answer.
5. Classify the clues you have selected according to the six dimensions of human functioning: visual; auditive; motor/medical; behavioural; relational; and environmental.
6. Are there dimensions you have overlooked? If so, complete your list of relevant clues.

Complete these tasks before you continue reading.

Tony

The following are relevant clues:

Visual:	Tony is blind, his behaviour confirm this: he bumps into objects and uses his tactile sense.
Auditive:	Nothing is mentioned about his auditive functioning. Although there are no clues that indicate an auditive problem, it cannot be excluded.
Motor/medical:	Tony has no physical disability.
Behavioural:	His behaviour is challenging for both himself and his caregivers.
Relational:	He does not respond to the guidance and comfort given by his caregivers.
Environmental:	The case study on Tony does not provide any environmental information. Therefore, this aspect needs further investigation.

Why are these clues relevant in this case?

The clues that stand out are that he has a visual disability, and the fact that he does not respond to the guidance and comfort given by his caregivers. An overview of the revealing facts given above immediately provides the starting point for further investigation:

Visual:	Is Tony totally blind?
Auditive:	Does he have an auditive disability?
Motor/medical:	Can his behavioural problems be caused by pain?
Behavioural:	What is the real cause of his behavioural problems? When does he display the challenging behaviour?
Relational:	Are there caregivers with whom Tony has a meaningful relationship? Are there any indications of attachment relationships in his life?
Environmental:	Is his environment adapted to his disabilities?

Towards the next step

1. According to you, what are the possible reasons for his self-injurious / challenging behaviour?
2. Who would you like to consult on this matter?

There are many different paradigms/models for looking at self-injurious/challenging behaviour. Looking at Tony, a few of these perspectives of his self-injurious/challenging behaviour could be due to:
- Physiological/medical reasons,
- Acquired ‘learned’ behaviour, or
- Disturbed attachment development.

A hypothetical example:
Physiological/medical reasons - his blindness: Tony can show self-injurious behaviour because he gets a fright every time he is touched unexpectedly. As he does not notice his caregiver approaching him, he may react by scratching the caregiver. This happens because of a fright, or stressful situation.

Acquired ‘learned’ behaviour: Tony learned that when he does not want to go outside he succeeds in that by scratching or pinching his caregivers. Time and time again his caregivers will then leave him in his room. He learned that by doing so his own wishes are fulfilled and that he can manipulate them.

Attachment development: The caregivers are not able to guide and comfort Tony when he reveals his challenging behaviour. The challenging behaviour also seems to be unpredictable. Sometimes Tony displays this kind of behaviour towards a caregiver he hardly knows, as well as to the caregivers he knows very well. The consequence of his behaviour is that all caregivers keep him at a distance and do not invest in a relationship with him. The sad part is that he has never had a caring parent and has not learned to adjust his emotions with a relationship with an attachment figure.

As we believe that all challenging behaviour has some meaning, it is important to examine the possible reasons for this behaviour. Through a model of systematic analysis we can come to possible explanations for the challenging behaviour.

It is very important to start from within a broad conceptual framework as to this behaviour. Therefore, to gain more insight in the occurrence of self-injurious behaviour among persons with visual and learning disabilities, we conducted a study at the Visual Advisory Centre (VAC), Bartiméus (Sterkenburg & Arentz, 2000). The psychologists of this centre were asked to make the medical and psychological files and the detailed written reports available of those clients with self-injurious behaviour. These reports were written over a two-year period, 1998-2000. A compilation of these reports provided the following information:

- the findings of the optometrists who assessed the visual functions;

- the findings of the ophthalmologist who did the medical-ophthalmic assessment;
- the findings of the observation of the client from an educational and caring point of view;
- the findings of the psychologist who did the behavioural assessment and evaluation.

The definition as mentioned in the 'Challenging behaviour scale for people with a learning difficulty' (*Storend Gedragsschaal voor Zwakzinnigen*, or SGZ, Kraijer & Kema 1994) was used as criteria for self-injurious behaviour. Examples were: head banging and injuring, scratching, pinching, biting, hitting, pulling of hair, eye gouging, etc., to such an extent that when one would do it, he would hurt himself.

The files of the first 20 clients that complied with the criteria were included in the study. Of them, 9 were men, 11 were women and the average age was 37 years – ranging between 16 and 58 years of age. They were grouped in the following groups based on their learning difficulties: 3 persons had a light and moderate learning difficulty, 9 were intellectually severely disabled and 8 intellectually profoundly disabled.

In an earlier study Claessens, et al. (1993) studied 1,135 persons who displayed self-injurious behaviour for more than three years. The results of this study are shown in Figure 7.1. The self-injurious behaviour of the 20 visually impaired clients in the VAC-study is also shown in Figure 7.1. The clients in the VAC-study showed approximately the same challenging behaviour as the self-injurious behaviour of the persons mentioned in Claessens's study. However, Claessens et al. (1993) did not mention eye gouging and screaming as self-injurious behaviour.

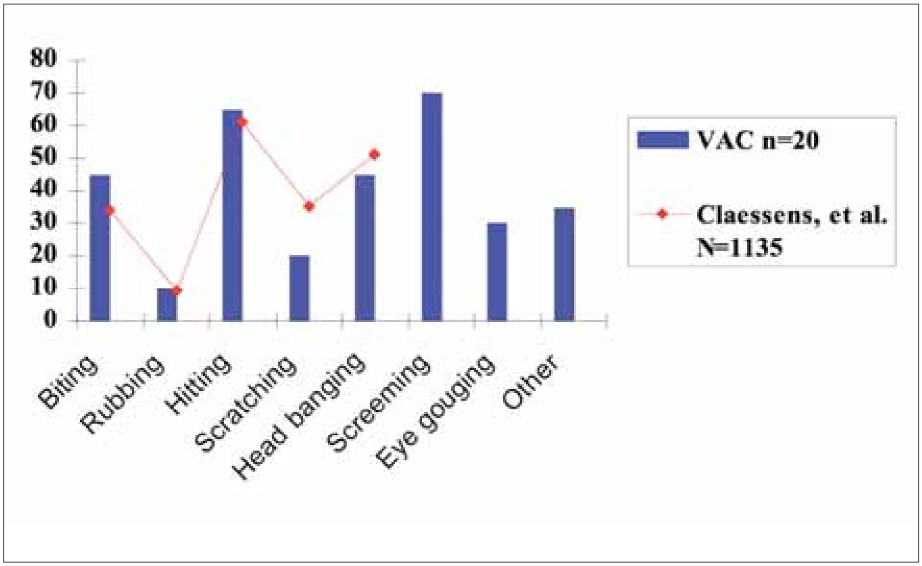


Figure 7.1. Self-injurious behaviour as indicated in the study by Claessens et al. (1993) N=1135 and the 20 clients in the VAC-study.

To determine the etiological reasons for the self-injurious behaviour in the VAC-study, we looked at the reasons given in the client's own care programme and the reasons given by the psychologist as noted in the psychologist reports.

Figure 7.2. shows the seven most frequently mentioned etiological reasons for the self-injurious behaviour in the client's own care programme and in the reports written by the VAC

psychologists. The etiological factors mentioned in the care-programme, which corresponded to the factors mentioned in the detailed VAC-reports, were: psychological factors, restless ambiance / over-stimulation, communication and indistinct care. The differences between the care programme and the VAC-reports were: physiological factors, boredom / under-stimulation and disturbed attachment.

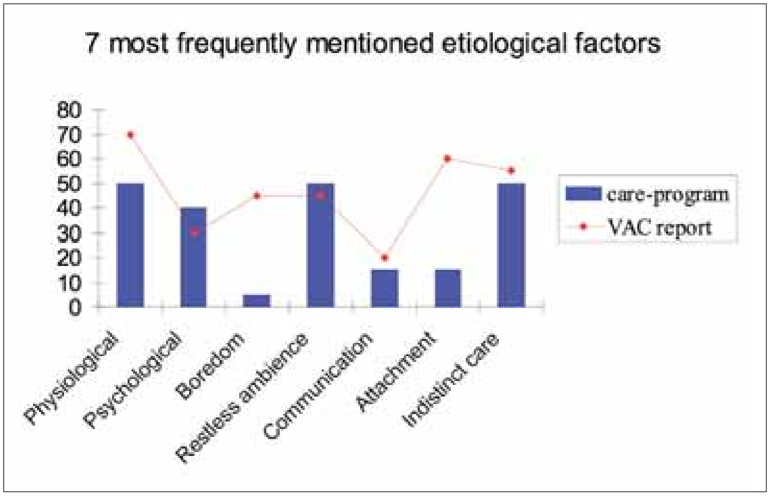


Figure 7.2. The seven most frequently mentioned etiological reasons for self-injurious behaviour as noted in the client's own care programme and in the report written by the psychologist working at the Visual Advisory Centre (VAC), Bartiméus.

In 70% of the VAC-reports the psychologists mentioned physiological factors as etiological factors that contributed to self-injurious behaviour, for example, inflammation in the eyes or in the ears. Further, anxiety due to visual loss and possible flickering due to retina detachment were also mentioned as possible factors that contributed to self-injurious behaviour. Physiological factors were less often mentioned in the client's own care programme than in the VAC-reports.

In 45% of the VAC-reports boredom or under-stimulation was mentioned as a cause. Clients were bored because they seemed to be under-stimulated due to their visual disability. Boredom was seldom mentioned in the client's own care programme.

In 35% of the cases, hearing disability or possible hearing loss was mentioned, but the hearing was not tested. This indicates that the care programme had not always provided the care needed.

In 60% of the VAC-reports, disturbed attachment was mentioned as a cause for the self-injurious behaviour. Attachment disorders may arise, for example, when parents or caregivers are unable to connect to the needs of the child. Early separation because of extended hospitalisation, for example, can also be an impediment to developing a relationship. These aspects, together with discontinuity of care, are mentioned as important risk factors for attachment disorders in the care for persons with multi-disabilities (Janssen, Schuengel & Stolk, 2002). In 15% of the client care programme, compared to the 60% mentioned in the VAC-reports, a problematic emotional development or an attachment disorder was mentioned as ethological factor, contributing to self-injurious behaviour. Therefore it seems that self-injurious behaviour, due to the development of disturbed attachment, may have been neglected in 45%

of the cases where self-injurious behaviour was present. These results suggest that with all the case-studies of clients with multiple-disabilities who have severe challenging behaviour, a problematic development of attachment should be examined as possible ethological factor.

In 80% of the cases the caregivers did not recognise the visual disability and consequently the clients were under-stimulated. The finding also indicated that in 80% of the cases too little specific intended care was given.

7.2. Step 2: File study and consultation

When one wants to better understand self-injurious/challenging behaviour, physiological problems, psychological factors, boredom/under-stimulation, restless ambiance/over-stimulation, communication, attachment and indistinct care, are all factors that should be examined with every case-study.

What would you like to know?

1. Looking at the reasons for Tony's challenging behaviour, what would you like to know about him and his surroundings?
2. Mention the different ways of gaining the information you need.

Complete these tasks before you continue reading.

Looking at the information we have on Tony and the possible reasons for his self-injurious behaviour/challenging behaviour, we may need more information on the following aspects:

- *Physiological problems*: Does Tony experience any pain or physical discomfort?
- *Psychological factors*: What is his level of functioning? Is he depressed or did he suffer a traumatic experience?
- *Boredom/under-stimulation*: Is there sufficient stimulation during both his day- and evening programme? Do the activities correspond with his abilities and interests?
- *Busy/noisy environment or over-stimulation*: What does his living environment look like? Does he experience anxiety due to a noisy environment?
- *Communication*: Do people communicate with him on his level and to the abilities or limitations of his senses?
- *Attachment*: What do we know about his fist years of life? Did he have a sensitive and caring attachment figure? Was this figure available when he needed the person? Does he have a caring attachment figure at the moment? What does his relationship with this person look like? Is there someone who can comfort Tony when he is anxious or stressed? Is there someone who stimulates his development in a sensitive and responsive way?
- *Indistinct care:* What is the quality of the daily care he receives? Are his care-programme and caregivers sensitive and responsive to his needs?

In Tony's case, information on the possible reasons for his self-injurious behaviour may be gained from medical assessments, observations, functional behavioural assessment, interviewing caregivers and parents and by conducting a psychological assessment.

Tony: file study

Tony was born after a pregnancy of 7 months. He is blind from birth and has no light-perception. He is blind because he was exposed to too much oxygen in the incubator. Because of symptoms of insomnia, an EEG was taken to verify whether he had epilepsy. The results from the 24-hour EEG showed that during the evenings and nights there were epileptic activities. However, the neurological assessment did not clearly indicate a connection between his insomnia, fluctuating moods and epileptic activity. Furthermore, it was noted that functional auditive tests were done and no hearing loss was indicated.

Within a few weeks it was clear that the quality of care given by his mother was insufficient. At three months of age he was placed in foster care. Later he was placed in another foster family, but this family could also not provide the care needed. At age five, he was placed in a home-care centre.

Already while staying with the first foster family, Tony suffered form insomnia or sleeplessness. It was noticed that when he was awake during the night, he would make a lot of noise and would scream and shout. It seemed as though he felt very lonely and anxious. This challenging behaviour got worse as time passed.

Tony enjoys sitting on the lap of the caregivers at the home-care centre. He enjoys this physical contact. When his caregivers cannot provide the physical contact he so clearly asks for, he bites his own hand. When he is stressed his caregivers cannot comfort him.

Tony does not have contact with other children in his group. However, he enjoys: having a shower, bathing, swimming, and listening to music.

7.3. Step 3: Planning the inquiry

At this step we need to ask ourselves: What exactly do we know and what is still unclear? What should we focus on when we continue the assessment?

What do we do next?

Draw up a detailed agenda for the further study of Tony's case
1. What is known?
2. What is still unclear and needs further inquiry?
3. Which instruments should be used?

Answer these questions before you continue reading.

Tony

What do we know about him?

Looking at the six dimensions of functioning, we can come to the following conclusions:

Visual:	The information in his file indicates that a functional visual assessment was done and that he is blind.

Auditive: Functional auditive tests were done. He has no hearing problem.
Motor/medical: He has no physical disability.
Behavioural: He shows severe challenging behaviour, hitting and biting himself and others, screaming, and bang his head.
Relations: He is only focused on his caregivers. He does not have contact with the other children in his group home. His caregivers cannot comfort him when he shows challenging behaviour. His caregivers are afraid that Tony may hurt them.
Environmental: Tony has a history of pathogenic care; he has had many different caregivers.

What is still unclear and needs further investigation?
Physiological problems: Does Tony experience any pain or physical discomfort?
Psychological factors: What is his level of functioning? Is he depressed or did he suffer a traumatic experience?
Boredom/under-stimulation: Is there sufficient stimulation both during the day and in the evening?
Noisy or busy environment/over-stimulation: What is his environment like? Does he experience anxiety due to a noisy environment?
Communication: Does communication take place on his level?
Attachment: Is he able to distinguish between different caregivers? Does he single out a specific caregiver when he feels anxious or when he explores his environment?
Indistinct care: What is the quality of care he receives daily? Are his caregivers sensitive and responsive?

Which instruments should be used?

- *Physiological problems: Do*es Tony experience pain or physical discomfort? Caregivers will be asked to fill out the pain checklist (Terstegen, 2004). The general practitioner should be consulted concerning any possible physical discomfort.

- *Psychological factors*: What is his level of functioning? Is he depressed or did he suffer a traumatic experience? To determine his level of functioning, his IQ can be tested. This can be done by using the Social Competence List, which can be used to indicate IQ (SRZ: Sociale Redzaamheidsschaal-Z, Kraijer & Kema, 1994). During the interpretation of the results the diagnostician should keep in mind the necessity to correct the data for the visual disability, as the person may have lower scores due to his visual disability. A depression checklist can be used to determine whether Tony suffers any degree of depression. An interview with caregivers can provide information on any traumatic experiences during his past.

- *Boredom/under-stimulation:* Is he sufficiently stimulated? Tony will be observed in both the day-care activity centre as well as in his home environment. During the observation a time score will be kept to record in which activities he becomes engaged and for how long.

- *Noisy or busy environment/over-stimulation:* What is his living environment like? Does he experience any anxiety because of a very noisy or busy environment? During the observation a thorough report on the environment will be done. An 'ABC-analysis' can be done to gain more information on his predetermined behaviour.

- *Communication:* Does communication take place on his level? His way of communicating with caregivers will be observed and analysed.

- *Attachment:* Are there indications of a reactive attachment disorder? To get an indication of a possible reactive attachment disorder, screening lists such as the 'Behavioural Signs of Disturbed Attachment in Young Children' can be completed during an interview with the caregivers (Boris & Zeanah, 2005) (see appendix: Chapter 7(a)). The 'Clinical Observation of Attachment' (Boris & Zeanah, 2005) (see appendix: Chapter 7(b)) can also be used. These results will be presented to the psychiatrist who will, by following the American Academy of Child and Adolescent Psychiatry (AACAP) practice parameter, confirm or reject the diagnosis based on the 'Reactive Attachment Disorder'.

- *Indistinct care:* What is the quality of the care that he receives on a daily basis? Are his caregivers sensitive and responsive? During the observation the quality of care that he receives will be noted by using the Quality of Care Checklist (see appendix: Chapter 3 and 4(b)).

7.4. Step 4: Conducting the inquiry

The aim of the inquiry, the fourth step of the Step-by-Step model, is to obtain as much relevant information as possible on the client. In step 3 we noted that a series of instruments would be used in Tony's case:

- Pain checklist (Terstegen, 2004).
- Consultation with the general practitioner.
- IQ test: Social competence list (SRZ: Sociale Redzaamheidsschaal-Z, Kraijer & Kema, 1994).
- Depression checklist.
- Interview with caregivers concerning possible traumatic experiences, as well as his relationship with his caregivers, 'Behavioural Signs of Disturbed Attachment in Young Children' (Boris & Zeanah, 2005) (see appendix: Chapter 7(a)), and Clinical Observation of Attachment (COA) (Boris et al., 2004) (see appendix: Chapter 7(b).
- Quality of Care Checklist (see appendix: chapter 3 and 4(b)).
- Observation concerning the possible over and under-stimulation during activities, a very noisy or busy environment, and the level of communication.

The results form the instruments used in the assessment can be summarized as follows:

Tony

- *Physiological problems*: Does Tony experience pain or physical discomfort?
  The results on the pain checklist indicated that he did not experience any pain. The general practitioner could also not find any indication of physical discomfort.
- *Psychological factors*: Is he depressed or did he suffer a traumatic experience?
  The score on the depression checklist gave an average score, indicating no clear sign for depression. The caregivers mention that they are not aware of any traumatic experience and

that no traumatic accident was reported.

- *Boredom:* Is there sufficient stimulation at all times?
  His day- and evening programmes were examined. While the caregivers were engaged in either cooking or household activities, there were long periods of time when no toys were given to him to play with or no other activities were provided. When the music he liked to listen to, stopped, it often took a long time before his caregivers would notice and change it. The stimulation of his tactile senses could also be improved.
- *Noisy or busy environment:* What is his environment like? Does he experience anxiety due a very noisy or busy environment?
  The observations showed that the environment had not been adapted to cope with his blindness. The environment was noisy, and that caused a loss of orientation and as a consequence, it affected his ability to find his way around the group home. This may explain why he often bumped into furniture.
- *Communication:* Does communication take place on his level?
  A special communication system was developed for Tony in accordance with his communication level. For example: when communicating with him, the caregivers would use different objects to distinguish between his morning and afternoon programme. They would do the same before changing to the next activity, by allowing him to feel a specific object and thus indicating which activity will follow.
- *Attachment:* `What do we know about his fist years of his life? Did he have a sensitive and caring attachment figure? Was this figure available? Was there a caring attachment figure available later during his life? What are the results obtained by using the ‘Behavioural Signs of Disturbed Attachment in Young Children’?
  His parents could not give Tony the care he needed. Tony was placed in foster care where there was no attachment figure to provide the sensitive and responsive care he needed to become securely attached.
  His history can be described as a history with pathogenic care according to the DSM-IV environment criteria for Reactive Attachment Disorder (RAD). Furthermore, the ‘Behavioural Signs of Disturbed Attachment in Young Children’ indicated a disturbed attachment: a score of 32 points. During the Clinical Observation of Attachment (COA) there was no difference in his behaviour towards the most well known caregiver and that of a stranger.
  All the results were presented to the psychiatrist who integrated the results with his own assessment (following the AACAP practice parameter). The psychiatrist concluded that Tony had a Reactive Attachment Disorder as described in the DSM-IV.
- *Indistinct care:* What is the quality of the daily given care? What is the quality of the daily care he receives? Are his caregivers sensitive and responsive to his needs?
  The results from the checklist showed that Tony received an adjusted daily- and communication programme, but that there was room for improvement. Multi-sensory stimulation should be added, especially during his free time. The caregivers have a supportive attitude, but, as his behavioural problems are so severe, Tony is unable to build a secure relationship with his caregivers.

7.5. Step 5: Integrating the results

For the integration of all the results, we need to make a narrative summary of the known information.

Integration of information

1. Integrate the information on Tony
2. Check whether it is complete

Complete tasks 1 before you continue reading.

We are now ready to integrate the information: as an example a summary is given below.

Tony

Tony is a boy of 7 years of age. He is blind from birth and has a severe learning difficulty. He has no physical or further sensorial disability. His severe challenging behaviour includes self-injurious behaviour and aggressive behaviour towards his caregivers. During his life there has been no attachment figure and according to the DSM-IV criteria, he has a history of pathogenic care. The test results indicate an attachment disorder. The psychiatrist confirmed RAD.

He lives in a group home where his caregivers are supportive. However, during the day he shows signs of boredom. His environment seems to be very noisy, making it difficult for him to orientate himself in his home. He has no contact with other clients. He enjoys listening to music, swimming, having a shower, and bathing.

7.6. Step 6: Understanding Tony and his needs

In this step we try to place ourselves in the shoes of the client. We will use all the information we have and put it into words, as though it was Tony himself talking. We will verbalise the possible feelings which Tony may experience. This provides insight into the client and may influence the choice of the intervention followed (step 7).

Understanding Tony's needs

Use all the information you have available. Now write down in Tony's own words, his needs, wishes, problems, etc.

Complete this task before you continue reading.

Tony

I am Tony and I am 7 years old. I enjoy sitting on the lap of my caregivers. Sometimes I feel very unhappy. During such moments I do not know what to do. I hit or bite my caregivers, because I feel helpless and unhappy. I try to keep contact with my caregivers because I feel so insecure when they are not around. On the other hand, even when they are around, I am unhappy and feel insecure. Actually, there has never been a special person with whom I have felt safe and secure at all times.

I feel so insecure because I cannot see if the caregiver is in the room or not. When I do not hear the caregiver, I feel as though I am the only person in this world - I feel so lonely. In the group home I am often bored. I cannot find my way around when the others in my home make a lot of noise. I really need someone who understands me and can help me to feel more secure. I hope that my caregivers can make me feel more at home and give me the care I need.

7.7. Step 7: Intervention - Integrative Therapy for Attachment and Behaviour

The development of secure attachment is a difficult process for multiply-disabled children and calls for special attention, as the combination of disabilities may present a higher risk for insecure attachment. Highly insecure or even failed attachment to parents, presents an important risk factor for psychological stress and the development of psychopathology, especially in cases when children are unable to cope with life's stress on their own (Schuengel & Janssen, 2006). In severe cases, psychotherapeutic intervention may be necessary to attain an attachment relationship, in order to build on this relationship to improve social behavior.

Research on integrative treatment, starting with an attachment-based approach and completing the intervention with behaviour modification, showed that this Integrative Therapy for Attachment and Behaviour (ITAB) was effective. The clients showed, over a period of time, significantly less challenging behaviour (Schuengel, Sterkenburg, Jeczynski, Janssen, & Jongbloed, 2008). This study also indicated that with time, the clients showed greater attachment behaviour in times of stress towards the attachment therapist than towards the control therapist. Physiological measures indicated that the clients experienced less stress during stressful situations when the behaviour modification was given by the attachment therapist, rather than given by the control therapist. The attachment figure was found to be a buffer against stress (Sterkenburg, Schuengel, & Janssen, 2008).

ITAB, as described in Sterkenburg and Schuengel (2008), consists of three phases:

- *Phase 1 is the attachment therapy.*
  This first phase is based on Bowlby's (1984) description of the development of attachment. First (phase 1.1), the therapist provides sensitive and inciting responses with the aim of making contact with the client. Next (phase 1.2), mirroring and synchronising is added to stimulate communication. Then (phase 1.3), the therapist stimulates exploration of the environment, providing a secure base, and providing comfort when exploration results in anger or anxiety. By providing and using a secure base, the client will develop a stable mental representation of the attachment relationship. Then the propensity increases to seek contact with or to be in proximity of the therapist when the client feels stressed or fearful. This propensity is called attachment.
- *Phase 2 focuses on behaviour modification*.
  The aim is to teach the client new and socially acceptable behaviour. Only social reinforcements are given such as affectionate pats and hugs (physical contact), approval and praise (verbal contact), and considering the client's visual disability when the social rewards are chosen.
- *Phase 3 focuses on generalisation.*
  The secure base with the therapist is used to facilitate the seeking of contact with other caregivers. After some time, the sessions are reduced and the therapy stops. The caregivers

continue to invest in the bonding with the client through sensitive responsivity. The therapy ends when the transfer of information to the caregivers is completed, and when the caregivers invest in the contact with the client and when they stimulate the client to continue on the road to further development.

The ITAB is illustrated in the DVD ‘Attachment: a psychotherapeutic treatment’ (www.bartimeus.nl).

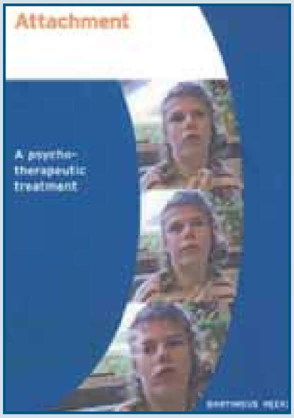
DVD: Attachment: a psychotherapeutic treatment

Paula Sterkenburg & Jan IJzerman

The DVD gives an overview of this treatment

On the DVD added in this book you will find short clips from the DVD.

Look at the phases of the Integrative Treatment for Attachment and Behaviour (ITAB) as reported on the DVD.



Tony
Tony received ITAB, similar to the case described in the DVD ‘Attachment: a psychotherapeutic treatment’. The effects were the same: his challenging behaviour decreased already within the first phase of the treatment. The decrease continued during the second phase in which he learned new and appropriate behaviour. For example, he learned that he could ask his caregiver to put on his favourite music, instead of using self-injurious behaviour.

After completing the last phase (phase 3: generalisation), his previous challenging behaviour was hardly ever noticed again. He sometimes even walked to the kitchen to ask his caregivers to change the music. It became clear that listening to his favourite music could help give his own positive interpretation to his free time. At the end of the treatment it was easier for caregivers to build a relationship with Tony. These more positive relationships resulted in making time to play with him or to give him a nice body massage (multi-sensory stimulation). He even started enjoying the contact with the other clients living in the house together with him. For example: one afternoon, when the caregiver entered the room, he was enjoying some music, while sitting hand in hand next to Marcus, another client.

7.8. Step 8: Integration in daily care and evaluation

Tony
After completing phase 3 of the ITAB, the psychotherapy was rounded of. The caregivers realised that they had to continue to build on their relationship with Tony and that they should

stay sensitive and responsive towards him. The absence of relationships or harsh and insensitive caregiving might once again result in challenging behaviour. As he, at the end of the intervention showed interest in relationships and enjoyed the company of other persons, it became much easier for caregivers to invest in this relationship.

When the caregivers realised that the environment was very noisy, they attended to this aspect by turning off the radio in the hallway and by taking a client who would make a lot of noise, for a walk after dinner. These interventions also contributed to even better special care.

The treatment was effective. At the end of the treatment Tony hardly ever showed challenging behaviour, he looked for his caregivers when he experienced stress, and enjoyed having a relationship with others. At the end of the treatment his caregivers introduced activities to stimulate the use of his tactile senses. He actually started showing more interest in these activities.

Conclusion

After having completed steps 1 to 6, it was clear that for Tony, the intervention would include individual therapy. The 'Integrative Therapy for Attachment and Behaviour' was conducted as described in Step 7. Research indicated that this treatment is effective for clients such as Tony (Sterkenburg, Janssen, & Schuengel, 2008), resulting in the possibility that the daily caregivers can provide their care in an even better way.

The authors want to state that not all the facts as described in Tony's case, are factually true. Information from different cases was combined to give you a hypothetic impression of how one works through the different steps of the Step by Step model . However, the information provided in the DVD as well as the cases described in the research articles, are factually true.

Chapter 8

Parents in need of support

Introduction

In this last chapter we will not focus on the children or clients, but on their parents in particular. We will try and be more aware and thus sensitive towards the emotional impact of having a child with a disability and towards the impact of raising a child with special needs. For many caregivers this is a challenge. In general it is easier for them to identify with their clients rather than identifying with their clients' parents.

When a caregiver tries to understand the feelings of a parent, he soon discovers that all parents differ. Each parent has his own particular life experiences. Parents are not the same or experience the same kind of feelings. The attitude and feelings of a parent towards a child with a disability are influenced by their cultural and family background.

To improve our understanding of a parent's needs, we are going to try and answer a very fundamental question concerning parenthood: *'What do children mean to their parents?'*

What do children mean to their parents?

The following are a number of examples to illustrate the answer to this question:

- Some woman or men cannot have children. Some accept this, but others do all they can to become pregnant: lengthy medical tests, far-reaching investigations, surgery, artificial insemination, etc. are done. Why do couples go through all of that? Why is it so important for them to give birth and nurse a child?

- Nothing attracts more attention in the media than the maltreatment of children, e.g. news of a child that is killed by his parents, or sexually abused or battered. Apparently nothing else hurts our feelings more than doing wrong to children. Why? What does a child mean to us?

- During a research project, many fathers and mothers were interviewed on the emotional and psychological impact of loosing a child through mortal illness or because of a fatal accident. At the end of one such interview a mother said: "There were many, many difficulties in my life, but nothing compares to the loss of one's child. It is very bad, a severe shock indeed. You never forget it. Even years later the memory stays with you, day and night. Nothing can be worse…" Do we understand why nothing in life is worse than loosing one's child?

- The desire to have children happens to be a worldwide experience and affects people of all ages. In the Bible, for example, we have striking illustrations in the lives of Sarah and Abraham and their grandson Jacob and his wife Rachel. Rachel was desperate when she could not give birth to a child. "Give me children", she cries out, "or else I die". She wanted to become a mother; otherwise her life will have no meaning at all (Genesis 30:1). In the Book

> of Samuel we are also confronted with that strong desire for a child. In the Temple of Jerusalem, Hannah laments being childless and asked God to give her a child (1 Samuel 1: 1-20).

Most people have a desire to have children. They want to share their lives with their children. Children seem to have a special meaning to them. What is this special meaning? Why would some couples do anything to become pregnant? Why are most people shocked by the news of a child being abused or killed? Why do parents say that the death of a child is the worst thing that can happen to a person?

The value of parenthood

What, according to you, is the meaning children have for their parents? Try to give at least five answers.

Answer this question before you continue reading.

The value children have – is there a common ground?

In a classical research project of Hoffman and Hoffman (1973), parents were asked what it means to them to have children. Nine different answers were given:

- A child confirms your adulthood
- In a child your life continues
- A child gives depth/meaning to your life
- A child strengthens your marriage
- A child keeps you young; you do things you otherwise would not do
- A child stimulates your creativity
- A child proves your (sexual) potency
- A child gives you status
- A child is a guarantee for the future

Compare the answers given in the research project to your own answers. Is there any common ground? What are the differences? Can you explain these differences?

The meaning that children have for their parents is not identical. On the contrary, meaning is interwoven and almost always linked to personal life experiences. That explains why the meaning children give to their parents changes as times changes and varies amongst people from different religions and social classes.

Questions, questions…..

Imagine you are expecting a baby or that your wife is pregnant. Soon you will become a mother or a father. What will it mean to you to have a child?

Imagine that the baby is severely disabled. What effect will that have on you?

In the light of the nine answers given in the Hoffman and Hoffman research project, what will it mean to you to have a disabled child?

Does that help you to understand why parents are almost always disappointed when a child is born with a disability? Try to explain your understanding of the situation.

To conclude: a child with a disability does not meet the ideals and expectations of the parents. That is why parents find it difficult to accept their child and its disability. It is very difficult for them to keep aloof from their personal life values and that of the people around them. They are disappointed, because the child is different to what they longed for.
Of course, parents differ in their response to the birth of a child with a disability. Some (seemingly) accept their child quite easily. Others start a life long struggle with their negative feelings towards this fact and/or the child. However, it is always important when meeting a father or mother of a child with disabilities, to keep in mind that they may find it very difficult to accept and to raise a child with disabilities. It has an emotional and psychological effect on them. We therefore have to be sensitive to these problems when we work with parents.

In the lives of parents of children with disabilities we can distinguish four different problem areas – problems on the emotional, value, psychological-educational and practical levels.

Emotional problems in accepting the disabled child, manifests in:

- *Denial*: “Believe me, my child has no disability…You see, my first child was slow in his development too…I am the person who knows my child best…better than any doctor”
- *Anger:* towards others (husband, wife, family, doctor, God). “He does not understand me…They all let me down…What a blunt and arrogant doctor he is…O my God, why?”
- *Guilt*: “What did I do wrong? It is my fault that he is disabled. My wife blames me for his disability, because there are two other children with disabilities in my family”
- *Disappointment*: “We expected a healthy child…Our dreams for the future are scattered. Sometimes I imagine she is not disabled...”
- *Concern about the future*: “How will the child develop? How can we stimulate his development? Will he/she ever be able to live an independent life?”

Problems regarding values: concerning the meaning of life and the meaning of parenthood (see: Stolk, Boer, Seldenrijk eds. 2000) “What is the meaning of my life now? Will it be possible to change my goals in life after the birth of this child? Does the life of my child mean anything in society?”

Psychological-educational problems: One of the reasons why parents find it difficult to raise a child with disabilities is because they develop differently. They are different to other children they know - slower and often not pleasing. “How can I stimulate my child?…I really do not understand why he does not react to things. What is good and what is not desirable when caring for my child? My sister is very good in raising her children. Other parents appreciate her advice, but she does not understand my child. I cannot share my problems and feelings with anybody. My child is different. I have a desire to have somebody who understands my child and is willing and able to give me advice”.

Practical problems: There are many problems that parents have to cope with, for example: feeding the child; carrying him or picking him up; finding proper schooling and transport; being exhausted and in need of rest.

Prepare an interview

To put this knowledge on parenthood into practice: you have to make preparations to interview a mother of a child with multiple disabilities (using role-play). Ask her to tell you about her child, herself and her family life. Prepare the interview with great care. Keep the four problem areas in mind. What do you want to know and ask? In which way can you be sensitive towards the mother? Compile a report on the interview and evaluate the outcome with others to get feed-back. In which way is your knowledge of parental problems on the increase?

In the following scenario we will focus on the third problem area, the educational problems of parents. By using the Step by Step model, we will try to diagnose and understand the problems of the mother of a child with a severe learning difficulty and find a way to support and assist her.

Dirk

Dirk is twelve years old and has multiple disabilities. He has intellectual, physical and visual disabilities. He has the developmental level of a ten months old baby and has no verbal communication. Fortunately he has no hearing problems. Caring for Dirk is difficult. To alleviate the pressure on his parents, Dirk lives in a group home for children every alternative week; the other week he stays at home where Dirk’s parents try to do what they can, but they are exhausted. Caring for him becomes more and more difficult and challenging.

To pick him up when he has to be washed and dressed is a burden for his mother, Kate. His parents have very little contact with him. Communication is limited. For his mother this is a source of intense disappointment and sorrow. But there is also another problem, during interaction with his mother; Dirk often bangs his head against the wall or an object. He often moans and whines. However, this he only does at home. His mother feels that she has completely failed in caring for him and that it might be better for Dirk to live in the group home permanently. But that is a very difficult decision: leaving one’s own child in the care of strangers. Dirk’s mother discussed her problems and doubts with the director of the group home. She promised Dirk’s mother to help her as much as possible.

Suppose you are Laura, the director of Dirk's group home. You promised his mother to help her. You know how important it is to understand her problems before giving her advice. You cannot work on the basis of superficial knowledge of her problems. You decide to work through Dirk's case by making use of the Step-by-Step model. To understand his mother's problems you start with the first step:

8.1. Step 1: Recognising problems

Recognising Dirk's problem

With the conversation with Dirk's mother in mind, select some relevant clues in her story on the following topics and questions to start with:

- Read the information on Dirk and his parents.
- Concentrate on the problems which his mother experiences.
- Which clues can help you in your understanding of the problems Dirk's mother encounter?
- Why are these clues relevant in this case? Explain and use examples to illustrate your answers.
- Categorise the clues you selected in the four problem areas mentioned.
- Are there problem areas you have overlooked? If so, complete your list of relevant clues.

Complete these tasks before you continue reading.

The core problem for Dirk's mother is her inability to understand him and the reason why he bangs his head. Her problems are mostly on the relational aspect of his upbringing (see chapter 3). It is important to find out whether there are other relevant aspects, such as visual and auditive, that need attention.

8.2. Step 2: File study and consultation

In completing the information on Dirk's mother, it is also necessary to refer to Dirk's file. Some of the facts given are:

Dirk

"Dirk communicates on a non-symbolic level… Caregivers suspect Dirk has seizures… This was not confirmed by medical examination… Dirk is an easygoing boy who needs much affection… Dirk's mother is exhausted and depressed… It is expected that in the near future Dirk will permanently live in the group home".

The main topics discussed during the consultation

The following are possible topics to discuss when consulting Dirk's mother and father:
- Lack of communication
- Head banging
- Moaning and whining
- Moving to the group home
- Emotional problems

Possible topics to be discussed when consulting Dirk's personal caregiver:
- Level and means of communication
- Possible differences between behavioural problems at home and in the group home

Prepare an interview with the mother, father and caregiver with these topics in mind. Be aware of the emotional impact of your questions. Be as concrete as possible This information is needed to understand Dirk's mother and her needs.

An example of the summary of the results of the consultation is provided below.

Dirk

Dirk's mother mentioned that she has no contact with him. She finds this very difficult, although she desires to have contact with him. "This lack of contact is my main problem, believe me. Sometimes I can only cry". Dirk's father is worried about his wife's problems. He tries to help and support her as much as possible, but because of his work, he is away from home quite often. He sincerely hopes it will be possible to keep Dirk at home. Communication between Dirk and his caregivers in the group home is limited. Nevertheless, they are able to communicate with him during daily activities such as eating, bathing and walking. "We know what he needs and we just explain what is going to happen next", they report. In the group home Dirk's behavioural problems are not serious.

8.3. Step 3: Planning the inquiry

There are at least two strong indications for further research:
- There is a striking difference between Dirk's behaviour at home and in the group home. The difference between his mother and caregivers may indicate that a solution of the main problem can be found at home.
- Both Dirk's father and mother are motivated to keep Dirk at home.

Conclusion: there is hope of a solution for this serious problem. Laura, the director of the group home, continues her search for understanding, by completing the next step in the Step-by-Step model: Planning an inquiry. With the information from the file and the consultation in mind you should prepare an agenda for the inquiry.

Planning the inquiry

- Draw up a detailed agenda for the further investigation of Dirk's case.
- What do you know and what is not yet clear to you?
- How are you going to get the information you need?
- Which instruments do you want to use?

Compare your planning to that of Laura's.

Laura's planning of the investigation:

- We know there is a difference between the communication and the behaviour problems at home and in the group home. Why do the caregivers seldom report problems in communicating with Dirk and why do they not report head banging, moaning and whining? This seems to be related to the caring situation at home. Are there significant differences in the way Dirk's mother and his caregivers at the group home care for him?
- These questions can only be answered by observing the real life situation. Observation reports may make it possible to compare how Dirk's mother and how his caregivers communicate with him. By observation one can determine whether the head banging, moaning and whining is aggravated by the situation.
- Caregiving situations will be registered with a video-camera. Video clips of 20 minutes will be taken in two situations (during bathing time and in a playful situation), at home as well as in the group home.
- To identify possible differences and similarities in the behaviour of the mother and caretakers in both situations, the observations will be analysed carefully by a health care worker.

8.4. Step 4: Conducting the inquiry

The observations were executed as planned. The presence of the video camera had no influence on Dirk. His mother, however, was very stressed both during the washing and clothing situation. She was complemented and thanked for giving the health care worker the opportunity to do the observation and to use a video camera.

8.5. Step 5: Integrating the results

Dirk

Summary and results of the observations at home and in the group home:

- Dirk listens to what his mother does.
- When she moves he 'follows' the sounds he is hearing.
- There is no indication in his mother's behaviour which shows that she realised that Dirk was listening to her.
- Dirk bangs his head when he does not know what is going to happen next.
- He laughs when his mother speaks to him during close contact.
- Caring for Dirk seems to have become a routine for his mother as she does not speak very much and there are long periods of silence.
- Dirk's mother seems to be sad and withdrawn.

- No behavioural problems were observed in the group home with the exception of head banging when Dirk's caregivers were busy preparing the meal or when they were helping to put the other children to bed.
- Four characteristics of the caregivers' communication with Dirk were observed: (a) they speak to him, keeping at a close distance; (b) they make it possible for him to predict the forthcoming activities, (c) they support activities verbally and (d) they direct the activities.
- There is a lot of close contact between Dirk and the caregivers.

8.6. Step 6: Understanding Dirk's mother

This sixth step in the Step-by-Step model is a vital point. By using the available information one must decide what kind of help is needed. This asks for the optimal identification with the client (Dirk's mother) and a careful representation of her interests.

To facilitate this, the professional team tries to 'translate' the facts (the result of the inquiry) into needs, and puts this in the client's own words (the starting point of the helping process).

Need for assistance

You represent Dirk's mother. Formulate her 'need for assistance' in her own words on the basis of what you know of her and her son.

Note, this is only an exercise or example, in real life one would actually know much more about a client than we describe in this case

8.7. Step 7: Intervention - Video home-training

When you understand the mother's needs, you are able to explore the best way she can be helped. It is not a solitary decision of the caregiver, teacher, counsellor or therapist. As professional you always come to a conclusion after a conscientious, non-directive exchange of thoughts with the client. Helping somebody means working together.

In this case, Laura (after consulting her colleagues and reaching a mutual agreement with Dirk's parents) started with the training of communication skills. By comparing the communication skills of the mother and the caregivers, the necessary goals for the intervention were set.

Setting of goals for the training of communication skills

Try and set at least five concrete goals for the training of communication skills.
Are these goals in accordance to the mother's needs? Are these goals realistic and concrete?

After the setting of goals, you are ready to select a proper method for intervention. This method should match the client's needs, the goal of the intervention and the professional abilities and skills of the caregiver, teacher, therapist, etc.

Methods must match

In communication, which method of intervention should one choose? Give an outline of the expected results of the training of communication skills. Does the method match the needs of Dirk's mother and the goal of the intervention? Which professional skills are needed to help Dirk's mother?

Dirk's case is based on a case study in a Dutch project called 'Video Home-Training for parents of an impaired child' (see Dekker, Biemans, 1994; Weiner, Kuppermintz, Guttman, 1994). This Video Home-Training method focuses on the training of communication skills with both the parents and other family members. Before following Dirk's mother in this training, some information is given on the Dutch Educational Home-based Assistance in general, and on Video Home-Training in particular.

1. Helping parents at home

The burden of raising a child with a disability can be made easier in different ways: by the practical and emotional support of the family members, neighbours and friends, by giving education and care in schools and day care centres, by placing a person with disabilities in a group home, etc.

In the Netherlands (and many other countries) more and more parents ask for help, not only for their child, but also for themselves. They want to keep their child at home as long as possible. They only want to accept a group home as a last choice. But keeping their child at home is only possible when help is given in their daily environment where problems occur and solutions can be found and implemented. This resulted in the formulation of several new methods of home-based assistance.

The main characteristics of home-based assistance
- *An intensive intervention* (once a week for two to five months, depending on the complexity of the problems).
- *Assistance at home* (always in the real life situation of parents and children).
- *By active participation of a skilled trainer* (who participates in the usual family activities).
- *Directed to improve the parents' action* (observing the child, interpreting his behaviour, taking initiative and reacting in an appropriate way).
- *By 'social learning'* (the trainer acts as model).

Advantages of home-based assistance
- *Diagnostic considerations:* The behaviour of people is affected by their environment (social rules; arrangement of space and time). 'In vivo' observation offers more reliable information on the problem situation.

- *Therapeutic considerations:* Care is more effective if it is applied to the daily life of clients. Advice is directly linked to the specific situation. Clients do not have to work through abstract or general information.
- *Relational considerations:* Parents feel more comfortable in their own environment. That is why the trainer does not ask parents to come to his office. Instead, he visits them at their home. There the trainer serves as a model for the parents in difficult real-life situations. He gives the client the feeling that he understands the difficulties they encounter as parents and that he does not distance himself from the situation.

The following are target groups for home-based assistance:

- Families with psychological-educational problems, caused by intellectual, physical, visual, or other disabilities of their child. The development of the child is often delayed and disharmonious. That makes it difficult to understand the child's needs.
- Families with psychological-educational problems caused by cultural disadvantages. The lifestyle and the communication style in the family is a stumbling block for the children to attune to the school programme. The assistance focusses on broadening the cognitive potential of children with special needs.
- Families with many problems, varying from marital problems, conflicts between parents and children, maltreatment, malnutrition, neglect and physical abuse or sexual abuse.

2. Video Home-Training

There are different methodologies of home-based assistance. Every methodology has its specific theoretical orientation (learning theory, attachment theory, system theory, intergenerational theory, etc.) and is suitable for different kinds of problems (psychological, educational, communicative, sensory, autistic, etc problems).

A very popular method in the Netherlands is Video Home-Training, based on ethnology and communication theory. An ethnologist observes animals and human beings in their natural environment. Threvarthen (1989) a human ethnologist from Scotland, observed newborn babies in interaction with their mothers. He found that even in the first two weeks there is an active interaction between the two: babies take the initiative to communicate with their mother by looking, "talking" and using body language. The mothers spontaneously react by babbling, touching, using body language etc. In this way they stimulate each other to communicate, because they both enjoy it.

The initiators of the 'Video Home-Training' used the results of these observations to develop a specific method of home based assistance, based on the following principles:

- Good care presupposes good communication.
- Every parent desires good communication with his or her child.
- Every parent has the ability to communicate.
- All children (even children with severe learning difficulties) communicate.
- Communication problems pose a problem in raising children.
- The cause of educational and behavioural problems is often due to the inability of parents to cope with the need of their child for communication, exploration and development.
- Video Home-Training aims to assist parents in communicating with their child by using video feed-back.
- Involvement with the aim of assisting parents to communicate well.

- Good communication starts with the detailed observation of verbal and non-verbal communication of the children.
- Good communication presupposes adequate use of communication clues.

Video Home-Training takes place in everyday situations involving parents and children. The video trainer makes a video-clip of about ten minutes. The trainer and parent watch the scene very carefully and repeatedly if necessary. The home trainer mentions the parent's good communication, ignoring the less fortunate clues. He helps parents analyse their communication carefully and helps them to observe the effect of the communication on their child. Again and again the trainer stresses the importance of using some specific communication clues: two basic clusters; four communication patterns and fourteen elements. With the use of the video clip, the parents are taught in an indirective way to use these clues to stimulate communication with their child. By doing that, contact is restored, the quality of their relationship improves and this results in the stimulation of the child's development (see Dekker en Biemans, 1994).

To facilitate our communication with parents we make use of the so-called "communication clues with clusters of communication patterns and elements" (Table 8.1.). It is essential that every hometrainer masters these clues. We first give an overview of the clues, followed by a explanation of the different sections.

Clusters	**Patterns**	**Elements**
1. Initiative and reception	Attention	Turning towards Looking at Friendly intonation Friendly expression Friendly posture
	Tuning	Joining in Agreeing Naming Confirmation
2. Exchange in a circle	Arranging of a circle	Involvement Look around Confirming reception
	Turning	Take and give a turn Distribution of turns
	Cooperation	Working together Helping each other

Table 8.1. Communication Clues (Dekker en Biemans, 1994).

Communication Clues (Dekker en Biemans, 1994).

- The basis of all communication is initiative and reception. Normally children take the initiative all day long. Parents should learn to recognise these initiatives and communicate with the child, showing that his initiative is appreciated and answered. Parents should learn to be active and also take initiative and stimulate social interaction.
- There are two patterns of communication in this cluster: attention and tuning.
- Parents give attention by turning towards the child, looking at him/her, displaying a friendly intonation, friendly expression and friendly posture.
- Parents tune in by joining in, agreeing, naming and confirming.
- The communication clues in the attention pattern are relatively passive. By tuning in, parents have a more active role. Both attention and tuning are meant to communicate: “I am interested in you, I like you”
- Attention and tuning can break a negative spiral.
- Exchange in a circle. Parents learn to communicate in a way that the social development, the cooperation between the children and within the family improve.
- By forming a circle (the equivalent of attention in a group) parents show that they are also involved in what their children do together. Parents learn to observe the initiatives of their children and to stimulate these initiatives.
- Turning: parents are taught to give all family members the same amount of attention.
- Cooperation: communication isn’t just about verbal contact. Doing things together and helping each other is just as important. Parents are taught to notice cooperation and to stimulate it.

3. Hometraining with Dirk’s mother

After this intermezzo on the home-training method, we go back to step 7 (intervention) of the Step-by-Step model. Back to Dirk’s case.

After consulting Dirk’s mother, Laura, the director of the group home, proposes to start Video Home-Training. Dirk’s mother agrees. She does not expect much of the intervention, but “you can always try…” she says. The first goal of the home trainer is to restore contact between the mother and Dirk. We watch the video process and try to recognise the main characteristics of the method (production: Stichting Lichaamstaal © 2002). There should be no problem to understand the video, because most of the communication is non-verbal.

What is notable?
In the first video clip we see Dirk’s mother washing him. What is noteworthy against the background of what you know about Dirk and his mother and the method and goal of the intervention?

Noteworthy in this first video clip:

- Dirk listens to what his mother does - that means he communicates in his own personal way.
- He bangs his head when he does not know what is going to happen next, or when he is left alone.
- His mother does not help him to expect what activities will follow.

- His mother is rather passive
- She does not communicate with Dirk.
- Dirk continues wth the banging of his head.

What does Dirk need?

Watch the first video clip again and try to answer the following questions:
Observing Dirk, what are his needs?
Are these needs met by his mother?
Observing Dirk's mother, what does she need?
What would you advise Dirk's mother in terms of communication clues?

Guidelines for Dirk's mother with reference to the first video clip:

- Try to understand what Dirk needs in this specific situation
- Tune in to Dirk's needs
- Support him verbally (guiding, explaining, affirming, telling where you are going, where you are, what you are going to do, etc.)
- Make use of different communication clues of cluster 1
- Take and give turns in your communication with Dirk
- Direct activities
- Watch Dirk's reactions to check whether you are on the right track
- Try to enjoy the communication with Dirk

After the first hometraining session Dirk's mother was surprised by Dirk's ability to understand her. At the same time, she is ashamed of herself. "Why could I not notice his needs earlier? I used to act that way in the past, but I thought Dirk is older now and it is not necessary anymore. I did not realise that he is no more than a one-year old child in the body of a twelve-year old boy".

In the next five training sessions the Video Home-Trainer motivates the mother to keep in touch with Dirk's needs and to make use of appropriate communication clues. In the next video clip we see Dirk's mother washing and dressing him again. A lot has changed, there is a remarkable difference.

Communication and behavioural problems

Watch the interaction between Dirk and his mother. Which communication clues does his mother use to support him? What has changed in the interaction between Dirk and his mother?

Possible answers:

- The mother verbally explains her activities. This is exactly what Dirk needs. His mother tells him where she is going, where she is, what she is doing. She guides him, explains and reassures him.

- This is not only good for Dirk, it is also good for his mother. After many years she again enjoys the contact she has with Dirk.
- The amount of moaning, whining and head banging has reduced consirerably.
- Dirk has to wear his splints, but he does not like them. He bangs his head for a moment, but his mother tells him that he will get a reward if he wears the splints. Dirk calms down.
- Dirk opens the door while his mother helps him by guiding his hand and reinforcing him verbally. Dirk is very proud.
- Each day is ended with a ritual: Dirk's father walks into the room with him. They 'fly' and Dirk's father puts him to bed.

After seven sessions, the hometraining with Dirk's mother is finished. The home trainer gives her a booklet with general information on Video Home-Training and with the main guidelines in caring for Dirk:

- Recognise Dirk's needs.
- Notice what Dirk wants to say by watching his body-language and non-verbal communication.
- Verbalise what he 'says'
- By verbalising all actions, he learns to understand the situation and knows what is going to follow.
- Keep eye-contact and auditive contact as much as possible, otherwise Dirk 'looses' you because of his visual disability.
- Guide his attention and activities
- Be friendly in intonation, expression and posture
- Touch, cuddle and fondle him
- Praise and reward him
- Always realise he is still a very small child with the needs of a baby.

8.8. Step 8: Integration in daily care and evaluation

Now the last step in the Step-by-Step model: at the end of the last session, the home trainer discusses the training process with both the father and the mother. Dirk's mother is very enthusiastic. She feels and knows she is able to take care for Dirk again and (unexpectedly) even enjoys it. There is no urgent need anymore to institutionalise him. His father is grateful too. He notices his wife is far less stressed and he is very happy his son can stay at home for a longer period. His wife told him everything about the hometraining and he picked up some valuable ideas for his own interaction with Dirk.

The Video Home-Training was completed, but not the intervention. After one, two and four months, the home trainer will visit the family again to check whether they are still able to handle Dirk and whether they continue applying the communication principles.

Conclusion

A client is never an individual: children have parents, wives have husbands, and everybody is part of a community. Every person with a disability is related to someone who is very important to him. Do not forget a child's parents. Do not look at parents as people that hinder you in your work. Parents need your attention and help as much as the children you care for. Parents should be seen as partners in close cooperation (collaboration) with professionals. This cooperation implies respect and sensitivity for the problems and questions of the parents.

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Appendix: Chapter 3 and 4(b)

Checklist Quality of Daily Care (CQDC) for persons with visual and intellectual disabilities

This checklist covers seven aspects of daily care: Recognition and predictability; Living environment; Attitude; Self-reliance; Daily programme; Hobbies; Adjusted tempo (Gunther, 1994; Hofman, 2001). Every aspect is specified by some points of special interest. With this checklist you can indicate whether a specific aspect of daily care is indeed given (when needed!). The different points of interest remind us whether the needs of a client are indeed fulfilled.

Making the environment predictable and save for the client
- Recognising the person (voice, jewellery, photo, clothing, aroma, objects, way of making contact)
- Recognising the room (odour, colour, contrasts, markers, sounds, objects)
- Recognising objects (enlargements, contrasts, touching, smelling)
- Recognising the daily programme or activities (referable objects, repetition, pictures, beginning and ending rituals for activities)
- Recognising the day and time (by telling what day it is, using a calendar, ticking clock)

Recognising the social interaction (telling what's going to happen, who you are talking to)

2. Is the living environment a friendly and safe place?
- Predictable
- Enough light, lightning, avoid light hindrances
- Safety, no unexpected objects, obstacles
- Effective contrast
- Noise reduction
- Enough space to move around

3. Are both impairments considered in the care-giving process?
- Work unhurried when care is given, take time
- Make contact, use beginning and ending rituals
- Give physical care in the correct way
- Positive care

4. Is independence and self-reliance taken into consideration?
Making choices whether care is necessary or not
Encouraging independence as much as possible
Allow client's to make their own choices

5. Daily programme
- Are the provided activities suitable for the person?
- Are adjustments necessary and have they been made?
- Are there tasks in the home that the impaired person is able to do?

6. Are arrangements made for spare time?

- Does the person enjoy the activities?
- Does the person have the possibility of having contact with others?
- Are the activities that are provided, adjusted to suite the person's disability?

7. Are there moments during the day when the person can rest?

- Is there a quiet place where the client can sit and be on his own?

Appendix: Chapter 4(a)

Possible questions for a diagnostic interview

Questions in general

- Will you please describe the problem(s)?
- In which situation does the problem(s) occur? In all situations, or in some, or specific situations?
- How long does the problem(s) last? When did it start? What is the cause of the problem?
- What are the strengths of the client?
- What are the strengths of the social context (teachers and caregivers)?
- How does the client cope with his problem(s)?
- Has the client (or his relatives) previously asked for help, or is this the first time?
- Why was he referred at this stage? Is there any specific reason?
- How do his relatives, teacher, etc. manage the problem?
- How do the client's siblings, friends and classmates react to the problem?
- Do they understand the problem?
- Can you describe how much the client can see and observe, or what he cannot see?
- What specific care is given to this (visually / auditory impaired) person?

More specific questions

Visual behaviour
- Does the person make eye contact?
- When does he see an object? Does the person get a fright when touched?
- Does the person see objects from a certain direction sooner than from another direction?
- Are there any behavioural differences during the day or at night?
- Does the child show problems walking form a dark room into a brightly lit room or when the child is walking from a dark room into direct sunlight, or the exact opposite?
- Does the child prefer certain colours?
- Does the child have favourite places in the home?
- Does the child recognise objects or find objects when they have fallen?
- Does the person watch programmes on television? Where does he/she sit while watching?

Orientation and mobility
- Is the client well orientated or does he/she have any problem?
- Does the person fall or bump into objects?
- Does this person make use of his/her hands to feel where they are going?
- How does he behave in an unknown environment?
- Does the person have problems climbing stairs?

Compensating the possible visual impairment
- How does the person use the remaining senses? Hearing, touch, smell, taste?
- How does the person use his/her memory?
- How important is the context in which things happen?

Communication

- How does the person cope with change?
- When does the person become stressed?
- How does the person communicate?
- How does the person show feelings and emotions?
- Can he/she be on his/her own?
- How does he/she react in a group?
- Does the person sit all alone or does the person talk to the others?
- What is the living situation like?

Behaviour

- What are his/her hobbies?
- Is there an object that the person prefers?
- Does the person have stereotyped behaviour?
- Are there behavioural problems?

Changes

- Are there changes in the daily functioning of the person?
- What can the person do or no longer do?
- How does this person react to changes in his/her life?

Developmental history

- What is known about the development of the person, how he/she was raised at home, school, etc.?
- Were there important experiences that took place in his/her life? How did he/she cope?

Appendix: Chapter 7(a)

Behavioural signs of disturbed attachment in young children
Boris & Zeanah (2005)

Affection
Adaptive: Showing affection within a range of interactions.
Maladaptive: Lack of affection interchanges within a range of social settings, or "pro-miscues" affection with relatively unfamiliar adults.

Seeking comfort
Adaptive: Seeking comfort from a preferred adult caregiver.
Maladaptive: Lack of seeking comfort when hurt, frightened or ill, or else seeking comfort in an odd or ambivalent manner (e.g., *increased* distress when the child does not seek comfort).

Reliance on help
Adaptive: Willingness to seek help from preferred caregivers when problems are too difficult to solve alone.
Maladaptive: Excessive dependence on caregiver or inability to seek and use supportive presence of attachment figure when needed.

Cooperation
Adaptive: Generally cooperative behaviour towards the caregiver.
Maladaptive: Pervasive, or fearful over compliance to the caregivers instructions ("compulsive compliance") or lack of compliance to the caregivers requests and demands.

Exploratory behaviour
Adaptive: Uses attachment figure as a secure base from which to venture out and explore novelty in environment.
Maladaptive: Failure to check back with caregiver in unfamiliar settings after venturing away, or almost complete unwillingness to leave caregiver to explore.

Controlling behaviour
Adaptive: Little evidence of behaviour directed towards controlling of the caregiver.
Maladaptive: Over-solicitous and/or age-inappropriate care-giving behaviour by the child toward the caregiver, or excessively bossy or punitive control of the caregiver by the child.

Reunion responses
Adaptive: If distressed, seeking comfort from attachment figure, or, if not distressed, establishing reconnection through nonverbal or verbal communication, with positive result or sharing what exactly the child experienced during the separation.
Maladaptive: The failure to re-establish interaction after separation, including the deliberate ignoring or avoiding behaviour, intense anger, or obvious lack of affection, or the failure to resolve distress caused by separation, or any evidence of disorganized attachment behaviour.

Response to strangers
Adaptive: Initial resistance to social engagement, which is more noticeable in unfamiliar settings.
Maladaptive: Immediate engagement without initial wariness, extensive physical contact without referring to the caregiver, the willingness to leave the caregiver and accompany a stranger without protest.

Appendix: Chapter 7(b)

Clinical Observation of Attachment (COA)
Boris & Zeanah (2005)

Episode 1: 5 minutes
Clinician observes parent-child “free play.”
Note especially familiarity, comfort, and warmth in the child as he/she interacts with the attachment figure.

Episode 2: 3 minutes
Clinician first talks to, then approaches, and then attempts to engage the child in play.
Most young children exhibit some resistance, especially initially, when engaging with an unfamiliar adult.

Episode 3: 3 minutes
Clinician picks the child up and shows him/her a picture on the wall or looks out of the window together with the child.
This increases the stress for the child. Again, note the child’s comfort and familiarity with this stranger.

Episode 4: 3 minutes
Caregiver picks the child up and shows him/her a picture on the wall or looks out of the window together with the child.
In contrast to the stranger picking up the child, he/she should obviously feel more comfortable during this activity.

Episode 4a* 1 minute
Child is placed between the caregiver and the stranger and the unfamiliar object (e.g., scary/exciting) - the remote-controlled toy is introduced.
Child should seek comfort, preferably from the parent. If interested, rather than frightened, the child probably shares a positive affection towards his/her parent.

Episode 5: 3 minutes
Clinician leaves the room.
This separation should not entice much of a reaction in the child, as the clinician is a stranger.

Episode 6: 1 minute
Clinician returns.
Similarly, the child should not be much affected by the stranger’s return.

Episode 7: 3 minutes
Caregiver leaves the room.
Child should definitely take notice of the caregiver’s departure; though not necessarily show any obvious distress. If the child is distressed, the clinician should comfort the child a little.

Episode 8: 1 minute
Caregiver returns.
Child's reunion behaviour towards the caregiver should be congruent with the separation behaviour. That is, distressed children should seek comfort and nondistressed children should re-engage positively with the caregiver when introducing them to a toy or activity or talking to them about what occurred during the separation.

*Optional episode.

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3	0.1 Visual Acuity (English: 1996)	10 minutes	€ 11,50 (postage excluded)
3	Signs of visual impairment (English: 2002)	26 minutes	€ 20,- (postage excluded)
3	Specific care for people who are visually and intellectually impaired (English: 2001)	28 minutes	€ 20,- (postage excluded)
4	Life in sight (English: 1998)	3 parts of 20 minutes each	Only available on request
6	Listen: Hearing aids for people with multiple disabilities (English: 2006)	15 minutes	€ 15,- (postage excluded)
6	Getting used to glasses (English: 2002)	23 minutes	€ 20,- (postage excluded)
7	Attachment: a psychotherapeutic treatment + Guidebook to the DVD (English: 2006)	28 minutes	€ 20,- (postage excluded)
8	Zorg in de Zoeker Order from: Stichting Lichaamstaal, Holstraat 15, 6017 AC Thorn (tel: +31 (0)475-562473) (Only available in Dutch: 1997)		

* The *video's* for the following films are only available as long as stock lasts:
- 0.1 Visual Acuity
- Getting used to glasses
- Sign of visual impairment

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About the Authors

Joop Stolk, (PhD), studied at the Faculty of Psychology and Education of the VU University of Amsterdam. Up to his retirement in 2007, he worked as an associate professor at the Department of Clinical Child and Family Studies at the this university. His research focussed on the education of children with severe dual disabilities and on the development and evaluation of methods supporting parents of disabled children. He published many articles and books on these subjects and on ethical problems in the care for families with a disabled child. After leaving the University, he was appointed 'Knight in the Royal Order of Orange-Nassau'. In cooperation with 'Woord & Daad', a Dutch organisation for childcare in developing countries, he recently started a project in Sierra Leone to train teachers in recognising, understanding and fulfilling the needs of traumatised children.

Trudy Arentz received her education in ophthalmology at the University Hospital in Nijmegen. She works at Bartiméus in the Netherlands as a technical ophthalmic assistant/optometrist. Since 1994 she has specialised in working with people with (severe) learning difficulties and with acquired brain damage.
Besides the assessments on visual functioning and advice on the influence of the visual impairment on the client and his environment, she trains and coaches new colleagues. She is also involved in training physicians, who specialise in working with people with an intellectual disability. One of her other tasks is to train parents, caretakers, teachers etc. in visual impairment. From the start she was one of the lecturers in the "train the trainers" project in South Africa.

Paula Sterkenburg, (PhD), completed her MA in clinical psychology in 1991 at North West University in Potchefstroom, South Africa. From 1992 to 1993 the focus of her MA study at Utrecht University in the Netherlands was on developmental psychology. Since 1991 she worked, first of all as caregiver and then later as health-care psychologist and therapist at Bartiméus, an organisation that aims to improve quality of life of blind and visually impaired persons by providing personal advice, guidance and know-how. Since 2001 she has been lecturing at the VU University of Amsterdam. In 2008 she completed her PhD research on 'Intervening in Stress, Attachment and Challenging Behaviour: Effects in Children with Multiple Disabilities'. For her applied research she received the first Award of the 'Dutch Association of Health Care Providers for People with Disabilities' in 2007.

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