Expertise and education

Active Learning

Making contact by playing and discovering the world.

A method for children and adults with PIMD and visual disabilities, and their support networks.

Martien Rienstra

Theory book

“Since I am unable to come to the room, the room must come to me.”
(Dr Lilli Nielsen, 1992)

Credits
While the utmost care has been taken to create this edition, the authors and publisher cannot be held liable for any incomplete or incorrect information contained in this book.

Photos
Kirsti Boessenkool, Erik Reker,
C. Çiblak and others.

Layout
Weijsters & Kooij vormgevers.

Formatting
Makes Sense design.

Translation
Gijs Hulscher & Christine Gardner.

Visio, Communications Department,
PO Box 1180, 1270 BD Huizen.

Contents

Introduction

In the 1990s, I visited a day-care centre for children with multiple disabilities in the Dutch province of Zuid-Holland. The centre's therapists had integrated the Active Learning approach, which had been developed by Dr Lilli Nielsen, and they had organized a seminar for all who were interested.

Active Learning focuses on the client, their support network, and the physical environment. The goal of Active Learning is to stimulate the client to make contact with his or her immediate surroundings. Clients can learn that they can influence their surroundings by being more active and taking initiative.

I was deeply impressed by this seminar. I thought it was really wonderful that the environment of these children had been designed in such a way that they were being stimulated as much as possible to experience things throughout the entire day.

In 2003, I started working at Visio, and there I again encountered Dr Lilli Nielsen's Active Learning approach. Dr Nielsen wrote important things about supporting the kind of clients I would be working with – clients with a visual and intellectual disability.

Over the years, I have used Active Learning in practice, and I have increasingly noticed how valuable the method can be for clients and their support network. Active Learning can give valuable and stimulating meaning to the many idle moments at a day-care group.

It is always better when a client is doing something – because the environment has triggered them to act – rather than being idle (withdrawing into themselves, lapsing into stereotyped movements, or developing self-injurious behaviour).

I used a questionnaire to ask colleagues at Visio who worked with the same type of clients about their awareness of and experiences with Active Learning: 70% of them had heard of Active Learning, but only 15% of them had access to information about the method, and 64% said they wanted to learn more about Active Learning.

It turned out that there were specific Active Learning materials available at various Visio facilities – the Little Room for instance – and that these were frequently being used, yet knowledge about the underlying method was lacking.

It is high time to make Active Learning available to a broader audience.

At the beginning of 2017, the project group Active Learning was started, with the goal of implementing the Active Learning method within Visio. Various Visio subdivisions are represented in the project group: Education, Residential & Day-care, and Rehabilitation & Advice. This book provides the theoretical basis for the implementation of Active Learning.

Martien Rienstra

How to read this book

This book is about Active Learning, a support method for clients with profound intellectual and multiple disabilities (PIMD) and visual disabilities and their support network. Active Learning was developed by Lilli Nielsen, a Danish teacher, trainer, advisor and psychologist (PhD). Partly because of translations of her work into German and English since 1990, she has become known to a wider audience.
This book offers a description of her theories, and their application in practice, adapted to diagnostic tools and support guidelines as they are being used in the Netherlands today. Beside this theory book, there is also an Active Learning workbook, which provides practical tips and examples.

The definition of Active Learning is:

To facilitate the client to actively make physical contact (with objects, materials, and people) through means tailored to the client with the goal of stimulating and expanding the client's awareness of their options for acting and making contact.[1]

An impression of Dr Nielsen, based on her life and legacy, is given on page 8 and beyond. Dr Nielsen conducted and published most of her research in the last 20 years of last century.

Especially in recent years, there has been more attention and recognition for the complex problems of people with PIMD and visual disabilities. In this chapter, new insights will be linked to Dr Nielsen's findings in the late twentieth century.

In chapter 1, a picture is sketched of the client, who is the focus of this book and is also at the centre of the method. Active Learning attaches great importance to the client's own input.

In chapters 2 and 3, the emotional development of clients with PIMD is discussed. These chapters will show how firmly functional capabilities are based on emotional development and what problem behaviour can arise if there is a discordant profile. The way the support network makes contact with the client can have a positive impact on the difference between 'doing and coping with the consequences'.

Chapters 4 and 5 discuss functional development (moving, looking, acting), and the role these functional capabilities play in becoming an individual are examined. There are various reasons why the functional development of clients with PIMD and visual disabilities can stagnate.

---

[1] This definition was drawn up by Martien Rienstra, March 2016-May 2018

It is often difficult for clients to start moving and to explore their environment. Consequently, clients could miss out on fundamental experiences, and they might not be fully aware of their own possibilities.
Various tools have been developed based on Active Learning that offer the client a tailored range of activities, allowing them to actually gain these experiences.

In chapter 6, we discuss how Active Learning can be used to support clients. Interventions are arranged in accordance with the International Classification of Functioning, Disability and Health (ICF) model. Guidelines are provided for the implementation of the discovery and treatment phases.

We have provided several descriptions of cases throughout the text to illustrate the theory.
The book concludes with an afterword and a bibliography. An observation form was created by the project group to assess the options for Active Learning. You can find this form in the appendix of this book.

Lilli Nielsen

Lilli Nielsen was born on December 21, 1926, on the Danish island of Bornholm. She died on June 24, 2013. She was the second child in a family of seven; four of her siblings were born blind. From the age of 7, she cared for a younger blind brother.
After secondary school, she started working as a teacher at a nursery school, and later at a hospital; occasionally, she was hired to teach blind children.

Later, Lilli Nielsen studied psychology, and went to work as a trainer and consultant at Refsnaesskolen, the Danish national institute for blind and visually impaired children.
In 1988, she received her PhD from Aarhus University in Denmark. Her publications, which have been translated into English and German, are also from this period:

- 'The Comprehending Hand' (1976). This book is about how important grasping and grabbing is for blind children to come into contact with their environment.
- 'Spatial Relations in Congenitally Blind Infants' (1988). This is her doctoral research into the possible effect of the Little Room on the development of spatial relations in children with Cerebral Visual Impairment.
- 'Are You Blind?' (1990). This book examines the emotional development of visually impaired children. Dr Nielsen identifies an imbalance in what a child can handle emotionally and the functional demands that are placed upon them.
- 'Space and Self' (1992). This book examines the use of the Little Room and the effect of its use on the development of sensory integration, object permanence, self-identification and spatial relations.
- 'Early Learning Step By Step' (1993), This book examines various skills, such as chewing, eating, and dressing oneself. The process of learning skills is described step by step.
- 'Functional scheme : levels 0-48 months: functions, skills, assessment, learning, reassessment' (2000). This book provides tools to analyze in detail the visually impaired child's skills, behaviour, and ability to learn.

Dr Nielsen visited the Netherlands in 1992 at the invitation of two Dutch organizations for people with intellectual and visual disabilities. As a result of this visit, Dr Nielsen's Active Learning was translated and implemented in the 'Zintuigelijke Stimulering' (sensory stimulation) method.

In 1998, this method was described in ‘Behandelvormen voor ernstig meervoudig gehandicapten (Forms of treatment for PIMD)’ by Nakken et al.[2] In this book, various treatment methods widely used at the time were assessed by a group of parents, a group of professionals, and a group of scientists. The sensory stimulation form of treatment received positive feedback, and the method has made its mark on various care centres. Active Learning has a far more prominent role at Visio South than at other local branches of Visio. Outside Visio, the method has led the Esdégé Reigersdaal institution to develop the ‘play path’ – an extensive observation list intended to identify options for playing.

Dr Nielsen went to great lengths to make Active Learning accessible to a wider audience, among other things by attending international conferences and through her publications. At www.lilliworks.com, the geographical distribution has been mapped.

Dr Nielsen was quintessentially someone who took an evidence-based approach. It was only later that more scientific research was conducted on people with a visual and intellectual disability, leading to an increased appreciation of the complexity of this group.

Since the start of this century, research has been conducted in the Netherlands into the effectiveness of support for people with PIMD (since 1993 by Vlaskamp et al. among others); research is also being conducted into the socio-emotional development of people with intellectual disabilities (among others by Došen, 2009). Diagnostic tools and treatment guidelines have been developed based on the outcomes of these studies. Resulting from the findings of professor Vlaskamp, the University of Groningen started follow-up studies on people with PIMD.[3]

Distribution of Active Learning across the world (source: www.lilliworks.org)

Professor Annette van der Putten has included the chapter ‘Supporting movement: motor activation’. In this chapter, she underlines the functional and purposeful use of motor activation in the client's daytime programme.

At the Bartiméus Foundation, Paula Sterkenburg has conducted research into bonding and contact in children with a visual and intellectual disability. She identified the frequent occurrence of behavioural problems in these clients and developed Integrative Therapy for Attachment and Behaviour (2007).[4]

---

2 Nakken, Reynders, Vlaskamp, & Procee, 1998 | 3 Maes, Vlaskamp & Penne (e d.), 2012
4 Twint & de Bruijn, 2014

Thanks to scientific research, making and interpreting a diagnosis has now become more refined and reliable. In addition, it has led to more knowledge about the effectiveness of support and the way it should be provided.

With regard to supporting clients with PIMD, support methods such as the following can be useful:

- 'Ervaar het maar' (Go ahead and experience): a methodical approach to stimulating motor abilities, senses and communication. This method offers sensory activities to the client, and themed boxes with a variety of sensory materials are used.[5]
- 'De kracht van eenvoud' (the power of simplicity): a movement programme that boosts the development of people with PIMD in a simple yet well-thought-out manner.[6] In this programme, a large measure of involvement of the client, who can assert their own influence, plays an important role – the client puts something in motion and receives a reaction to that action.
- 'Goed leven' (Quality of life) is an approach to care and support, in which development thinking and the values and practices of LACCS (a Dutch method for supporting people with PIMD) are central. LACCS is a Dutch abbreviation which stands for Physical well-being, Alertness, Contact, Communication and Stimulation.[7]
- The 'Circle of Security' was introduced by Glen Cooper, Kent Hoffman & Bert Powell (1998). This method provides guidelines for addressing the needs of children. In this context, 'secure base' and 'safe haven' are the key concepts for the optimal response to the initiatives of the child.[8]
- In 2011, Paula Sterkenburg published the book 'Vertrouwensrelatie voor Ontwikkeling' (Development through a relationship of trust): a workbook that provides starting points for the building of a relationship of trust with children or adults with PIMD.

Despite these new insights, the ideas of Dr Nielsen remain valid. In her publications, she specifically addressed the problems of children and adults with multiple and visual disabilities and the way they make physical contact with their environment. She describes how the hands are the most important instruments for making contact, what influence the environment has on this contact, and how this process is influenced by emotional development. Through the publication of her findings – mainly evidence-based practice – Dr Nielsen has made an important contribution to the care for children and adults with PIMD and visual disabilities.

---

[5] Koeleman, 2005 | [6] www.emgplatform.nl | [7] De Geeter & Munsterman, 2015
[8] Zaal, Boerhave, & Koster, 2009

The Client

1.1
Introduction

This book focuses on those clients who are visually impaired, have intellectual disabilities and often motor disabilities as well, and whose developmental age does not exceed two years. In professional literature, these people are described as having severe and multiple disabilities (SMD), or profound intellectual and multiple disabilities (PIMD).
Platform EMG, a Dutch organization for parents, healthcare professionals and everyone else who is involved with people with PIMD, offers the following description of this group:

"It is hard to give an accurate description of children and adults with severe or profound intellectual and multiple disabilities. Their IQs are below 25 and they have a wide range of additional impairments, which they can barely compensate for, or not compensate for at all; additionally, they need round-the-clock care and supervision. But despite their disabilities, they also have potential! This potential is increasingly being discovered by parents, healthcare professionals and others involved. People with SMD never cease to surprise us with what they can do. An IQ of 25 or below cannot be measured with a test; for this reason, healthcare professionals often refer to the developmental age – which can be reasonably accurately determined through extensive and prolonged observation. The developmental age of people with severe or profound intellectual and multiple disabilities is at most 24 months; however, their chronological age can greatly exceed their developmental age. Additionally, they experience complex problems in such areas as communication, use of their senses, health and mobility."

In 2003, Dr Van Splunder conducted a study into the prevalence of visual impairment in people with intellectual disabilities. His research involved 1,500 people with intellectual disabilities, and found that 19% of them had a visual impairment.
The Dutch Guidelines Database[9] reports the following on this subject:

"The prevalence of low vision or blindness in people with severe or profound ID ranges from 30% to 92% in professional literature. It should be noted, however, that the highest percentages were found in institutions for people with profound ID. Refractive disorders, cataract and cerebral visual impairments are all diagnosed frequently."

Furthermore, the aging of people with intellectual disabilities is a factor that naturally deserves consideration: 25% of the Dutch population is expected to be over 50 years old in 2020.[10] The prevalence of visual impairment increases with age.
In this book, we use the term 'clients' for children and adults with severe or profound and multiple intellectual disabilities and visual impairments.

1.2
Visual impairment

Not being able to see the surrounding world, or not being able to see it sufficiently, has a

---

[9] https://richtlijnendatabase.nl/richtlijn/visusstoornissen_revalidatie_en_verwijzing/visusstoornissen_bij_verstandelijke_beperking.html | [10] Limburg, 2007

profound impact on the desire to interact with that world. Making contact with the objects and materials there is much less automatic.

The ability to gain insights into everyday actions, which play a major role in that world, is also limited. Incentives and intrinsic motivation to grab objects are often absent in people with visual impairments. Many clients receive too few visual stimuli to prompt a change of their body position or to give meaning to objects.

Visually impaired people are not (or not sufficiently) triggered to imitate, to move towards something, or to grab something that is just beyond their reach. For these people, it is difficult or impossible to perceive and visually follow their hands, yet these very hands are the key instruments with which they can interact with their surroundings.

Because there is little or no contact with the immediate surroundings, awareness and understanding of those surroundings is hardly established, if at all. If an object cannot be seen or felt, it becomes very difficult to learn to understand that an object stands on its own – independent of the person observing it. And this is where the difficult development of object and person permanence begins for visually impaired children. These difficulties affect many areas of development, such as bonding between parent and child, language, interaction with others, the development of their own unique identity, and the courage and desire to move about.

Sighted children between the ages of 9 and 18 months learn that objects exist, even when they are not touching them. At the age of about 9 months, a toddler might randomly come across their favourite cuddly toy; six months later, they start to realize that it still exists even if they cannot see it, and a little later, they can actively go looking for it. Object comprehension and object permanence are crucial for the process of differentiation between the 'self' and the world beyond.

Visually impaired children usually focus more on auditory and tactile stimuli. Auditory input only occurs if an object actually makes sound. However, most objects and materials in the child's world are silent unless they are interacted with: the TV turned off, mum reading a book, the biscuit tin in the cupboard, or the cat sitting on the windowsill. A child's environment only occasionally provides auditory input, for instance when people or objects move. Consequently, visually impaired children receive a minimum of auditory information about their immediate surroundings. This way, sounds do not contribute to the development of object permanence. The development of object permanence in a visually impaired child is only stimulated when a parent actively keeps making auditory contact with their child, or when a certain object provides continuous auditory input, for example a ticking clock. An important condition for this is, however,

that a child is able to give meaning to the sound he or she hears.
Tactile input from objects only occurs when they are touched, or when passive contact is made with something in the immediate surroundings. The tactile input stops when the child drops the object or changes position. Only when a child accidentally comes into contact with the same object again do they learn something about object permanence – the fact that the object continues to exist even if it can no longer be felt. This principle applies equally well to people; object permanence and person permanence develop side by side.

For children who cannot actively move towards something by themselves, it is even more difficult to understand that objects or people have not simply vanished when there is no auditory or tactile information.

1.3

Profound intellectual and multiple disability and visual impairment

Although visually impaired people have the physical abilities to move about, to pick up objects and to explore, they often do not seem to use those abilities. The people around them have certain expectations of them, but somehow meaningful actions do not get off the ground. They seem to reject making contact with objects and taking purposeful actions.

These people might:

- withdraw their hands when something is offered for them to experience;
- not experience physical contact as soothing;
- show only limited facial expressions;
- display stereotypical behaviours, for instance waving their hands or making unceasing finger movements;
- make little contact with objects or materials, but make a lot of physical contact with their own bodies;
- touch objects very briefly and then continue flapping their arms or walking about;
- make negative physical contact with others or with themselves without an apparent reason (e.g. hitting or pinching);
- resist and try to counteract movement initiated by someone else.

This behaviour is often difficult to understand. The feeling may arise that you cannot make contact with the person and that you do not know where to start or what objects or materials you can offer. The person may make you feel insecure or give you the feeling that you will never get it right.

When Dr Nielsen observed this behaviour in certain children in the 1980s, she looked into possible causes and treatments. Closer observation of this behaviour prompted her to ask why one child acts in a way that is in accordance with their emotional developmental age, and another child doesn't (regardless of their chronological age).

It is her hypothesis that the level of emotional development is the determining factor for behaviour. "*Perhaps*", she states, "*their level of emotional development is holding them back from functioning at the actual level of their intelligence.*"[11] As a result, there seems to be a discrepancy in some children, and much less so in others because they are functioning more in line with their developmental age. This has prompted the development of an approach and treatment method that aim to connect the functional and emotional levels.

Koen is a 9-year-old boy; he is legally blind from birth and has an intellectual disability. He likes to lie on his back on the floor with his head raised and his fingers close to his mouth. Koen's fingers and head are in constant motion and frequently and purposefully seek contact with each other. He has a reasonable degree of control over his gross and fine motor skills, and has no contractures that prohibit free movement. There are always objects worth experimenting with close by.
And yet Koen prefers to lie on his back on the mat with his head raised and his fingers moving close to his mouth.

---

[11] Nielsen, Are You Blind?, p 15

Emotional development

2.1
Introduction

Development of your own, independent personality starts with awareness of the distinction between yourself and your surroundings. Awareness of the distinction between your body and the physical environment makes you see yourself as an individual – a person capable of influencing their own environment. In chapter 3, the influence that 'making physical contact with the nearby space' has on becoming an individual is discussed at length.

However, the surroundings do not only consist of materials and objects, but also of people. Socio-emotional development comes about through interaction with others.

In the Netherlands, Professor Anton Došen has extensively researched socio-emotional development, and he has described the various phases of that development in detail.

His system of classifying behaviour can provide guidance when observing people with PIMD and visual disabilities.

Dr Nielsen underlined the importance of emotional functioning and the discrepancy that can exist with respect to cognitive and/or motor functioning. In her book, 'Are You Blind?', Dr Nielsen discusses the way in which children seek contact with their environment (objects, materials and people), and she describes how this behaviour provides insight into the emotional development of children. Based on emotional development, she has formulated five different approaches, which will be discussed in this chapter.

2.2
Four phases

0–6 Months

In the very beginning, there is an interplay between a baby's inner needs and the way his or her caregivers react to those needs. Out of the warm, familiar environment of the womb, a baby suddenly has to cope with a cold and motionless world where there is no longer constant physical contact with their mother. A baby needs the first six months to adjust to life outside the womb. Professor Došen calls this phase 'the first adjustment phase'. In this phase, babies are completely dependent on their caregivers. Contact with the immediate surroundings (objects, materials and people) is made through the near senses (touch, smell and taste). This sensory input is integrated in the brain. A baby does not yet experience their own body as a whole; there is no sense of distinction between body and surroundings.

To illustrate the way babies make contact in this phase, Dr Nielsen points at a baby's directionless reaching for and taking hold of their caregivers' clothing or hair. The sounds or throat sounds that a baby makes and their crying and babbling are also intended to result in contact. By looking

---

12 Zaal, Boerhave, and Koster, 2008

around, picking things up, grasping things and letting go, babies learn the difference between themselves and the world around them: ‘this is me, and that is you’. The better babies can make that distinction, the more aware they become of their own actions and the more complex these become. Dr Nielsen links this phase of development to the behaviour of an adult client. However, when a 35-year-old who is at this phase of development ‘grabs’ or ‘babbles’, that makes a totally different impression on their surroundings than when a baby does these things. After all, physical strength and the ability to produce sound have developed in adults. Moreover, to people nearby, this behaviour is often unpleasant (shouting) or frightening (reaching, grabbing or pinching). Clients often get a negative response to this behaviour, while they are merely seeking contact on their own emotional level.

Furthermore, clients often make no distinction between the use of hands or mouth when examining objects. Due to the client’s visual impairment, they might continue to use both hands and mouth for a long time to examine objects. In the case of boredom or frustration, there is a risk that a biting habit could develop.

6–18 Months

Babies gingerly start to explore the world around them and they take the first steps to becoming independent human beings. They start to use their motor abilities to explore their own bodies, and they learn that their bodies enable them to pick up and examine objects – some objects make sounds, others are soft to the touch, and still others can give babies great joy when they put them in their mouth. When examining objects, a baby learns that there is a difference between what they do with their own body (very direct feedback) and what they do with objects. Babies learn that they can employ their own body to explore their immediate surroundings with all its materials and objects. A little later, children start to use objects to make contact with other people. For example, they may throw something away and wait for the other person to pick it up, or they may show something and then continue playing.

Professor Došen calls this phase the ‘first socialisation phase’ – the bonding between parent and child is at the heart of this phase. Children start to develop a burgeoning awareness that there is a distinction between their body and their immediate surroundings. Toddlers enjoy contact with people but also with objects and materials. There is beginning, but still limited object permanence at this point.

Dr Nielsen uses the example of a child nestling on an adult’s lap to illustrate the way a child seeks contact at this phase. The child would like nothing better than to sit there all day. The toddler offers the adult all kinds of objects, to share their enthusiasm about those objects. When the adult does not respond, the child touches the adult with the object, or makes a sound with it, hoping to draw the adult's attention. Gradually, a child will learn to move about and to climb onto an adult's lap and back off again. Toddlers give objects to others, but often they also quickly take them back.

Toddlers start to realize that they can influence their world and that there is a difference between themselves and that world. Step by step, the foundation for the development into an individual is laid.

Some clients who are in this phase may have turned attracting attention into a full-time job. During the day, they may, for instance, regularly hit the table at which they are sitting with their hands or with a toy. The people who are close to these clients are by no means always able to effectively respond to these requests for help. As a result, the hitting behaviour could overshoot its original purpose – which is to announce: 'hey, hello, here I am' – and could slowly turn into a habit.

Clients in this phase often do learn to examine their own bodies; however, due to their underdeveloped motor and visual skills, they are not able to explore their surroundings – unlike toddlers, who do so ceaselessly. On the emotional level, most clients do not progress beyond this phase; awareness of the distinction between their own body and their immediate surroundings is barely established, if at all.

18–36 Months
In this phase, toddlers gain more and more control over their motor skills and they learn to move about. Toddlers also learn that there is a difference between 'mine' and 'thine'. This distinction teaches them that they have their own part in the world, and they learn to rely on themselves.
Professor Došen calls this phase the 'first individuation phase'. In this phase, object permanence develops and toddlers become aware of their own self. Toddlers influence their physical surroundings in a way that is increasingly purposeful and deliberate. Dr Nielsen illustrates this phase using the example of a child giving one of their toys to an adult for safekeeping. Children at this phase also start playing games that involve hiding things and rough-and-tumble play. Children take the first steps on the path to acting independently. Rules and boundaries are important in this phase.

Most clients lack the motor, visual and cognitive skills required to reach this phase of emotional development.

3–7 Years
Professor Došen calls this phase the ‘first identification phase’; it focuses on the forming of the self. A child will start to use the word ‘I’ to refer to themself instead of their name; the child is the centre of their own world. There is a growing understanding of how the world works and what actions are required on a daily basis. Children become more and more aware of the way in which they can have an influence on their surroundings.

2.3
Visual impairment

In the contact with their caregivers, visually impaired babies lack certain information. Their inner needs are satisfied by their caregivers, and interaction is focused on smell, touch, sound and movement. This kind of interaction is sufficient in the first phase. Owing to the lack of visual input, babies explore their own body less and less when they are a few months old; after all, they have little or no ability to see their hands moving toward each other, or their feet – which may be fun to grab – and as a result they need more time to get to know their own body.

The reciprocal nature of a shared smile is another thing that is often absent in the contact between a visually impaired baby and their caregiver. This baby learns less to use their smile consciously in the interaction with their caregiver. The visually impaired baby experiences the reactions of their caregiver in a passive way.

The baby becomes acquainted with their environment mainly on the basis of auditory stimuli. Auditory input plays an important role in functional development, but of course it plays a role in emotional development as well. A visually impaired child’s auditory orientation is much less visible to the people around them than a sighted baby’s visual orientation. In other words, it is easy for the people around a sighted baby to notice when he or she is looking at something; however, when a visually impaired baby is listening to a sound, this is not nearly as noticeable. The invisible nature of a baby’s auditory orientation evokes much less response from the people around them; after all, it is unclear if the baby is listening in the first place – and if they are, to what sound.

It is important to expose visually impaired children to a wide variety of different sounds and to explain those sounds. In addition, it is helpful to let the child experience that they can cause sounds themselves. For this, some basic motor skills are required, but there is certainly an obvious role for caregivers and the client support system to make this possible. First and foremost, the child’s environment needs to be designed in such a way that a child can easily cause these

sounds. A Resonance Board is a useful tool for this purpose (see page 43).
Visual games based on taking turns, such as peekaboo or smiling, have to be replaced with auditory or tactile ones: making and imitating sounds, laughing out loud, or rolling a ball that makes sound towards the client.

2.4
Making demands

Human development is partially shaped by interactions with the surroundings, in which parenting plays an important part. From a certain age onwards, making demands is an important means to teach children things.

Making demands starts in a fairly easy way at the emotional age of 10 to 15 months. There are certain rules, but a child at this age primarily learns to explore the limits of the rules, and they receive guidance in this from their parents – without any coercion. This way, young children not only learn that there are rules to follow, but they also learn to deal with rules and demands.
Because of this interaction – the freedom to take the initiative about whether or not to participate and by doing things together – a child gradually learns new skills. Parents mostly just supervise and their interventions are proactive: when a child is allowed to eat by themself, parents make sure that there is a large bib under the child's plate because they know that their child is going to spill. When a child is playing, we expect them to be only briefly interested in something and that they will throw toys around. So we give them toys that can survive a fall, and we make sure that there are no easily broken objects in the child's vicinity.

When the child grows up, interventions focus more on cooperation, for instance when building a block tower: 'look I'm laying down this block; will you lay down the next one?' Interventions also focus more on restrictions. For instance, parents could tell their child 'no, that's not allowed', when they put everything they stumble upon in their mouth. Gradually, a child gets used to the demands of their environment, and they learn to comply. If the child does not, parents intervene and help the child to abide by the rules.
Clients whose developmental age is not in sync with their emotional age are at some point also confronted with demands: 'don't throw that', 'don't put that in your mouth', 'go on, pick that up'. However, they are often not able to respond adequately; their emotional developmental age is not sufficient to meet these demands. They do not understand the difference between 'you' and 'me', and they have not yet built up confidence in their own abilities nor their abilities to influence the world around them. We run the risk of asking too much of these clients. Consequently, some clients might seclude themselves, increasingly upsetting the balance between success and failure. In that case, they could even stop employing the skills they had previously mastered, and they no longer try to see what

works and what does not. Subsequently, every demand could lead to a fear of failure, negating every intention to take the initiative.

It is important to reflect on whether the demands made suit the emotional age of the client. Professional caregivers will have to be conscious of the kinds of demands they make – even if they are only made in passing.

It is striking that visually impaired clients are often reluctant to use their hands in a functional manner. Their fine motor skills are usually well developed due in part to contact with their own bodies and in part due to stereotyped movements (if those are present). Despite that, they avoid examining surfaces with their hands or contact with objects in their surroundings. Sometimes, visually impaired children as young as 10 months display this behaviour. This reluctance may have come about when these clients were faced with demands or when they came into contact with all kinds of objects for which they were not yet ready ('here, touch this, this is a ball').

When she worked with these clients, Dr Nielsen did not say things like: 'come on', or 'go on, grab it'. Instead, she demonstrated what sounds objects could make, and she explained what was happening. It was then up to the client to decide whether to make contact with these objects or not.

2.5
Stereotyped behaviour

Dr Nielsen interprets stereotyped behaviour as a cry for help – a message that says: 'Can't you see that there's something wrong in my life?'
It is then up to the client's support system to accurately interpret the behaviour.
Stereotyped behaviour could come about because clients were forced to examine objects or because they were not allowed to explore things on their own terms. By forcing clients to experience something, they are robbed of their own initiative. The feedback clients receive through 'forced cooperation' is totally different from feedback clients receive when left to explore on their own – on their own terms and at their own pace.
As a result of the clients' visual impairment and owing to the fact that they experience only limited enjoyment from exploring, they have only their own bodies to do something with.
Since they experience a limitation in what they can do with their own body, they may start hitting themselves or fiddling with their hair, fingers or clothes. If a client gets used to these types of actions, they may start repeating them more and more often. At a certain point, these activities could turn into the manifestation of stereotyped behaviour. For these clients, repeating the same actions/activities over and over is better than doing nothing at all – for them, stereotyped behaviour has become an expression of loneliness.

Dr Nielsen stressed the importance of accepting stereotyped behaviour as an integral part of a client's being. This behaviour has become so fundamental to the client that it has become part of their personality. If one disregards or tries to stop this behaviour, one also disregards the client's personality. The aim of the treatment of stereotyped behaviour is often to try to prevent the repeated movements or to take away the object with which the stereotyped action is carried out. In order to prevent stereotyped movements, which could lead to self-harm, some clients are given arm or elbow splints. According to Dr Nielsen, these methods are a rejection of the client's personality; it is like saying 'I don't like you the way you are'.

Dr Nielsen recommended going along with the client's stereotyped behaviour by imitating the client's movements or using the same object as the client to imitate the sounds they are making. This acknowledges the stereotyped behaviour as part of the client's personality. Furthermore, the client's interests are shared, and in due time, new stimuli can be added to the familiar sounds and movements.
Sometimes, the client's surroundings can be changed to let the stereotyped movements generate different sounds. The stereotyped behaviour will then automatically lead to a different experience.

Clients can sometimes relapse back into stereotyped behaviour. That behaviour can provide a comfort zone and a base from which to initiate other activities.

Ans van Eijden (clinical psychologist at Visio) has described four different theoretical perspectives from which to view stereotyped behaviour[13]:

- **developmental perspective** (the neuromuscular system is immature, and stereotyped movements are the result of the pursuit of sensorimotor input).
- **behaviourist perspective** (stereotyped behaviour brings about pleasant sensations: getting attention or using the behaviour to withdraw from unpleasant situations. This is the reason the behaviour persists).
- **functional perspective** (stereotyped behaviour arises through understimulation or overstimulation. Alertness and tension are regulated by the repeated movements).
- **neurobiological approach** (stereotyped behaviour is a side effect of damage to the central nervous system).

Blind children who also have an intellectual disability more frequently display stereotyped behaviour. When these children engage in more physical activities, the stereotyped behaviour decreases.
The most common stereotyped behaviours in blind and partially sighted children are rocking the upper body, head banging, and pressing and poking eyes.

---

[13] Ans van Eijden, 2015

Doing and Coping

3.1
Introduction

In 'Are you blind?', Dr Nielsen describes an educational treatment programme which consists of five phases of treatment. The level of emotional development always determines the choice of technique to be used. The way in which materials or objects are offered, and the nature of contact between the client and their caregiver, differ with each technique.
Dr Nielsen applies this approach to clients whose emotional and functional levels of development are far apart. The hypothesis is that the client’s emotional ability to react to their environment stands in the way of the development of their functional actions in that environment. In contemporary Dutch professional literature, this discrepancy is called 'kunnen en aankunnen' (doing and coping), meaning that actually being able to do something (functional development) does not necessarily mean that one can also cope with the consequences of those actions (emotional development). This is especially true for those clients who are the focus of this book.

A client may, for example, bang on a table because they are seeking contact (first socialisation phase). Subsequently, the client’s negative behaviour may result in a verbal reproach. However, because they are functioning at the emotional level of a one-year-old, they are not able to change their behaviour. As a caregiver, it is especially important to offer proximity and limitation at this phase.

Dr Nielsen began her treatments with a lengthy interview with caregivers and parents. Next, she extensively observed the client in question, employing 60 to 70 different objects that were suited to the various levels of emotional development. The tactile and auditory characteristics of the objects were such that they encouraged the client to explore and examine.
In order to arouse the client’s curiosity, both familiar and unfamiliar objects were used. Dr Nielsen was in the same room as the client, and she ‘played’ with various objects. She talked about the objects she was playing with, described the sounds the objects made, or what they felt like. She then left it to the client to take the initiative to participate. The level of emotional development determined the choice of objects to be used, the layout of the room, and which guidance technique to employ.

This introduction took many hours because, at the end of the twentieth century, there was much less data available about what clients were capable of. The decision on which technique to use was made based on this introduction.

Today, we know more about our clients. We have, for instance, information about a client’s developmental age and motor abilities. An observation form has been created to aid in the implementation of the Active Learning approach (see appendix). The form mainly focuses on the way clients make contact with their immediate surroundings; it is used to gather the missing information needed to implement Active Learning.

Dr Nielsen's educational treatment programme consists of five different phases of guidance techniques:
1) Offering
2) Imitation
3) Interaction
4) Sharing the work
5) Consequence

Clients with severe multiple and visual disabilities usually stand to benefit the most from the techniques utilised in the offering and imitation phases.

3.2
Offering

Some clients never make contact with objects; their desire to explore may be underdeveloped. They might be at a level of emotional development which focuses mainly on the primary needs (first adjustment phase). They could also have developed a reluctance to explore because they were frequently forced by others to touch unfamiliar objects.

In this phase, clients mainly focus on their primary needs. Clients have not yet learned to employ their own bodies to explore (at least, not on their own initiative).

As a professional, you are often inclined to guide a client's hand to a particular object or material ('Here is the chair/tap/nappy/fluorescent mirror carousel'). On making verbal or physical contact, you would also expect this person to make contact with you. And before you realize it, you may have just touched the client to greet them. But hang on… the client is supposed to be in the driver's seat in this phase! It is the caregiver's job to make objects in the vicinity of the client as interesting as possible, and then to wait for the client to take the initiative to make contact with them or with the object.

Using the techniques from the offering phase, clients who make little to no contact with objects in their immediate surroundings can be triggered to actually make contact. When utilising this technique, the caregivers should absolutely not call upon the functional skills of the client. Instead, it should be all about the client themself and their intention to make contact with the caregiver or the objects.

When a client shows initiative to make contact, it is important to respond as if it were entirely normal for them to do so. Praising the client excessively might make them reluctant to show initiative – although it may be very hard not to give excessive praise, because when a client shows this initiative for the first time, you may

feel like leaping for joy.
The offering phase focusses on researching the client's preferences, their reaction to sounds in their immediate surroundings, the way in which they make contact and which initiatives they show.
If the client withdraws, this too should be respected, for this is also a way of taking initiative. Some people are mainly focused on physical contact, often matching their emotional level. As a caregiver, it is important to participate in this contact, but afterwards, you should return to the objects and toys.

On this subject, Dr Nielsen remarked: *"Children cannot develop on physical contact alone; they have to experience objects and have to learn to experiment with them."*[14]

Dr Nielsen sometimes offered this treatment up to three times per day and sometimes for more than an hour at a time, depending on what the client wanted. She would bring a wide variety of toys and objects that she had selected based on the emotional level of the client; these materials prompted the client to experiment, explore and compare.

Dr Nielsen: *"When a client cannot explore on their own, or if they show no interest in the world around them, they are completely dependent on adults to design their environment in such a way as to trigger them to go exploring.*[15] *I invite the client to come and sit next to me; if the client refuses, I join them on the floor. If the client leaves the room, I will not encourage them to return. I will simply continue playing in the hope that they decide to return. While playing, I observe whether the client is at all interested in having contact with me."*[16]

"If the client's developmental age is 12 months, I will play like a 12-month-old. I will rummage about in a box filled with toys, or I will tap an object on the floor. Occasionally, I will drop an item, sometimes close to the client, sometimes a bit further away. I constantly keep in mind that the client is blind: I use objects that make sound, objects that give a sound when they are taken apart. In order to allow the client to imitate me, I will place a box with objects in front of them. I will create an atmosphere which is totally free of any demands, allowing the client to play.
If the client shows interest, I will tell them about the object; however, I will not comment on their actions – I let the client decide what to do with the object. And if they throw the object away, or if they put it in their mouth, my response will be to describe the sound: "That makes a nice sound when it hits the floor/your teeth". Everything I do is an offer, and it is up to the client to decide what to do with it."[17]

3.3
Imitation

For sighted people, the imitation phase is an important phase in their development, during which they acquire new skills and hone existing ones.
Imitation is a tough skill to master for our clients due to their partial or total lack of visual input.

---

[14] Nielsen, Are You Blind?, p 63 | [15] Nielsen, Are You Blind?, p 64
[16] Nielsen, Are You Blind?, p 62 | [17] Nielsen, Are You Blind?, p 67

When someone performs a certain action, our clients cannot see it at all, or not sufficiently. Consequently, they are not triggered to imitate those actions, and they have to be encouraged in another way.

The technique of imitation is intended to increase the client's interest in nearby activities and to strengthen their ability to take the initiative.

Imitation can be encouraged by demonstrating an action (accompanied by sound), and subsequently performing the action together with the client, for example crumpling paper into a ball, or banging two blocks together. Doing these actions together provides tactile, auditory, proprioceptive and kinaesthetic stimuli. When working with visually impaired clients, it is important to explain what you are doing; you can explain using complete sentences or just key words – for most clients, the latter are often easier to understand. So do not say: 'here it is, take it', but instead say: 'for you', or 'take it'. Additionally, it is important that everyone interacting with the client expresses things in the same way.

The sounds a client makes are often unrelated to the world around them. They mainly use their own bodies to produce sounds, such as clapping, grinding teeth or babbling. To us, this could look like stereotyped behaviour. A client can learn to link the actions of an adult to the sounds those actions make. The client can learn this by making sounds with certain objects, registering them, and recognizing them when they are made by someone else.

Dr Nielsen imitates the actions (or stereotyped behaviours) of the client, and, after a while, she introduces slight variations. Alternatively, when the client is playing, she joins in and subsequently introduces small changes. A client's first response is often negative (e.g. throwing the toy away). Sighted clients may also exhibit this behaviour, often eliciting a corrective response, such as, 'not there, but here, put it in the tray'. Tolerating this behaviour and allowing the client to repeat the action can help them build confidence to go a little further. It can sometimes be useful to use two identical objects. Important conditions for success are to remain supportive and to try not to force the client to actively participate.

According to Dr Nielsen, *"Children build their self-confidence in the phases of offering and imitation. Being together with an adult can be enjoyable and exiting, and it can lead to new tactile and auditory experiences. Children learn that they can take initiatives and that initiatives lead to changes in their environment. The more things they can actually do, the more they come into contact with others."*[18]

Various techniques that can be used to stimulate movement interaction in blind and visually impaired clients are described in 'Learning together'.[19] The book also describes the techniques of imitation, and rhythm and timing.

---

[18] Nielsen, Are You Blind?, p 76 | [19] Lee and MacWilliam, 2002

According to Lee and MacWilliam, mirroring is following the child's movements and giving back information about the quality of the movements to the child – their intensity, magnitude, rhythm and tempo. Mirroring is usually done by making direct physical contact with the child and adding appropriate vocalisations to the movement.

Rhythm and timing are used to strengthen the interaction with the child; the pace of the child's movements is matched and reciprocated. Actions such as knocking, tapping, clapping, vocalisations, or the movement itself can all be part of this technique. Both mirroring and rhythm and timing fit in well with Dr Nielsen's imitation phase.

3.4
Interaction

This phase focusses on the specific me-you and you-me situation, where the client learns to differentiate between the different sounds of different people. The client is encouraged to take the initiative during interaction, providing a basis for social development. In this phase, it is important that everyone interacting with the client uses the same approach.
Again, the client's level of emotional development, motor abilities, and personal preferences determine the choice of materials.

It should always be respected if the client withdraws at this stage, and the adult should then return to the stage of offering or imitation. Interaction is all about doing things together – jointly shining a torch through a darkened room, pressing a piano key together, or push-and-shove games that emphasize 'me-you'. This phase is characterised by more interactive games and turn-taking. In verbal contact, the words you and I are used more frequently – 'I'm drinking from my cup', 'you're drinking from your cup', 'I'm putting on my coat', 'you're putting on your coat'. Visually impaired people have sometimes forgotten how to take the initiative – all too often, too much was done for them. It is necessary that their confidence in their own actions is strengthened and any initiative in this direction should not be impeded.

An appeal to cooperation is made at this stage – 'you can help me'. Directly asking 'could you help me with this?' will often be too ambitious because the client will then have to answer with yes or no; instead, a client may help by holding their hands close to the action and so follow certain movements. This requires the actions to be slow-paced and repeated often. Make sure that the client can always take the initiative as to whether to participate.

Playing and learning to explore objects is an important foundation for all kinds of daily skills, such as eating/drinking, getting dressed, opening and closing doors, hanging up a coat, or setting the table.

Nielsen:

> **“At the time we first meet, Jens is 11 years old; however, his emotional age is 6 to 8 months.**
> **He really enjoys cuddling, and he is constantly looking for this kind of contact. He has a well-developed ability to tell where a sound is coming from. That gave us hope that we could teach him to direct some of his energy to other activities than merely seeking physical contact all day long. After a period in which the techniques from the offering phase were implemented, Jens started imitating. He emptied the toy basket, manipulated toys, explored objects with his mouth and hands, and experimented with different sounds. As a result, he was open to the instruction on how to remove objects without triggering negative separation anxiety. I said to him: “I’ll remove the lid from the jar. I want to remove the marbles from the jar.” I noticed him becoming more interested, and I said: “you can help me remove them from the jar”. I brought the jar to his hands and removed the marbles from it, while, at the same time, the jar was touching his hands. This way, Jens received both tactile and auditory information about this action. I tried to avoid contact between his hands and mine as much as possible. As soon as he felt my hands, he wanted to cuddle. I was continuously debating whether a pat would satisfy him or whether he really needed a hug. I said: “Hey, I thought you were going to help me”. And then he returned to the jar containing the marbles. After he had helped me for a while, he could let go of toys by himself.**
> **... Jens became more and more active and he started to develop his own identity. He could now name toys. His need to cuddle became less and less. Sometimes he relapsed and just wanted to be hugged, especially if the material offered no longer sufficiently challenged him.”[20]**

In 'Learning together'[21], the technique of ‘turn-taking’ is described; this technique is about creating awareness of one's own actions. When using this technique, the child's behaviour (movement and sound) is mirrored, and a conversation arises: the child makes a sound, the adult imitates the sound and the child, in turn, responds to the adult’s sound. The child becomes aware of their own sounds through the imitations of the adult. This approach fits in well with Dr Nielsen's interaction technique.

3.5
Sharing the work

According to Dr Nielsen, an elementary level of emotional stability is required at this stage. At this point, a client is open to learning about dependence and independence in relation to others.
At the sharing the work stage, an appeal is made to the client’s interest in engaging in new activities.

---

[20] Nielsen, Are You Blind?, p 79-80 | [21] Lee and MacWilliam, 2002

Daily actions are split out into parts and are divided between the client and the adult. Sharing the work could look like this: ‘I’ll put some porridge on your spoon, and you put the spoon in your mouth’; I’ll put the marble in the cup, you pick it up; you put your shoes on, I’ll tie the laces’. If the client does not want to carry out the action, the adult should revert back to a previous phase (offering, imitation), and client and adult can perform the action part together. It can sometimes take a few minutes before the client carries out their part of the action. A client may learn to independently carry out more and more parts of an action, and by doing so, ultimately learn to complete the entire action on their own. Again, the client should be respected, and they should be given plenty of room to employ their own initiative.

3.6
Consequence

At this phase, the client gets prepared for the demands that will be made upon them in the future.
The client learns to trust themself and, as a result, lays the foundation for making decisions. This technique can be applied at an emotional age of about 2 years.
Through verbal communication, the client is taught that actions have consequences, and that one follows the other, for example: 'if you want to drink, you must first put your cup on the table; if you want a bedtime story, you have to brush your teeth first; if you want to play the piano, you first have to go to the play corner'.

Once the client is increasingly able to meet requests, they may also show more attention and affection or both. For some clients, it can be a real revelation when they find they can carry out a request. If the client becomes more familiar with this concept, they will be able to act increasingly independently. Because the client has become emotionally more stable, they will be better able to deal with far-reaching changes in their life.

Functional development

4.1
Introduction

In this chapter we will address functional actions – being aware of the fact that hands and other parts of the body can be actively employed to make contact with and possibly affect the surroundings. The motor and sensory functions that allow a person to experience things form the basis of functional actions. A stimulating environment is necessary to trigger these functions: if there is nothing to see, you do not learn to use your sight; if there is nothing to do, you do not develop muscle strength and motor coordination. From the moment of birth, the immediate surroundings play an important role in the development of functional actions. The immediate surroundings are not just the physical space (with its materials and objects), but also the people there.

4.2
Being born

The first space a baby experiences is the uterus, which provides continuous feedback on movements of the mother and foetus. In the uterus, babies make both gross and finer motor movements, such as stretching and bending their arms and legs and subconsciously and in an uncoordinated way bringing their hand to their mouth. A foetus has only limited room; it is enclosed in the intimate and flexible space of the womb. After the birth, a baby finds themself in a vast world without any boundaries. Only in the arms of their parents or other adults can the baby again experience a sense of enclosure. Sheets and blankets make up the boundaries in their bed or cradle, although these may disappear at any moment. In such an instance, babies often start looking for the sides of their cradle. When in the playpen, babies usually experience no boundaries because parents often prefer to lay their baby in the centre of the playpen, so that the baby cannot hurt their fragile head. In that case, the baby, with still uncoordinated motor skills, encounters few boundaries. The presence of the grasp reflex makes babies grasp at random objects within their reach, such as mum's hair, a cup, or their own clothes. The reflex action is triggered when something touches the palm of the baby's hand, making the fingers close into a little fist. After four to six months, this reflex disappears, and babies are then capable of targeted grabbing of objects and consciously releasing them.

4.3
Learning to see the surroundings

Visual information is important for any baby. At first, babies mainly use their vision to focus on their mother, her breast, or the feeding bottle; this early use of vision helps to develop visual fixation – the awareness of visual input and the ability to focus on it. After 8 weeks, the development of a baby's eyes allows them to see better at a distance of 1 metre, stimulating the ability to track moving objects. Good visual acuity is established at one year old; however, the ability to see fine details develops further until about the age of four.

By moving their head and by observing their surroundings, babies learn about movements in the surroundings (people moving) and the objects there. Initially, a baby is moved passively through the surroundings, for example on their mother's arm. The baby experiences their immediate surroundings from different angles because they are placed at various locations, such as the playpen or the play mat. Whenever the baby is moved, the new location provides new visual input. A baby learns that objects can disappear from view, but they also learn that they can move their body to visually track objects and, at a later stage, look for objects they have seen before. The visual field is limited at birth; mainly the central field will be developed (45 degrees). A full visual field of about 180 degrees is only established at the age of two. The ability to see and distinguish between colours is absent at birth; this ability will have developed sufficiently when a baby is about 3 months old.

At about the same time, a baby can consciously focus on their hands. Seeing their moving hand accidentally hit a toy is the first step towards targeted movement. Hand-eye coordination plays an important role in making contact with the immediate surroundings.

When babies are four to five months old, they start to reach out for objects, and to compare visual information by shifting their gaze between objects. For example, they might first look at the teddy bear hanging above their head on the play arch and then shift their gaze to the cuddly toy lying next to them.

Shifting visual attention is the third stage of visual development after visual fixation and visual tracking. The baby learns to focus their gaze on something that attracts their attention, for example their mother's voice. At first, the baby's eyes wander about, but they are soon able to shift their gaze quickly and effectively. Let's imagine a child lying in the playpen; at this stage, they will have the ability to fix their gaze on their talking brother, and subsequently turn their gaze back to Ernie, who is hanging from the play arch. They can see where the sound is coming from, and they will attempt to move towards their brother – if their motor skills allow. Visual input greatly motivates babies to act and move.

Not only do visual acuity and the visual field of the child develop in the first few months; the child also learns to give meaning to what they see. Visual stimuli are passed on to the brain through the retina. Next, a complex process of unravelling the visual input takes place in the brain, for example into shape, colour, distance, direction, movement, straight and/or oblique lines, and depth. In a sense, subareas of the brain translate the electrical input supplied by the retina. Only then is it possible to consciously perceive this information and to give meaning to it.

Looking, which only involves the eyes, consequently changes into *seeing*: looking and understanding what you see.

A visually impaired baby lacks the visual information which would normally stimulate them to make contact with their surroundings. Their movements provide tactile information, but they cannot link that information to visual input, or only to a lesser degree. Consequently, a visually impaired baby does not sufficiently learn that they can play a role in their environment. For instance, they do not see that their hand is very close to a cuddly toy, and that they can grab it if they move their hand just a little further. When they are moved through their environment (in their parent's arms or in a pushchair), they mainly receive auditory and motion stimuli. The information a child receives from those stimuli is much less detailed than from visual input.

In addition to ophthalmic problems, people with PIMD and visual disabilities often have cerebral processing problems as well – although the visual stimuli are received, they are not processed. This leads to the following specific visual behaviours:

- limited visual curiosity;
- short visual attention span;
- varying visual behaviour (sometimes visual attention, but at other times little use of vision);
- shifting the gaze is often impossible (visual attention can only be directed at one object at a time);
- it is often impossible to watch and listen simultaneously;
- it is often impossible to look at something and grasp it simultaneously.

In this context, Dr Nielsen writes about preferred senses and 'pathways' (pathways are senses which are either open or closed). She uses the term 'pathway' as a metaphor for cerebral processing problems. The image of the sense as a pathway is used to symbolise a sense that is sometimes able, and sometimes unable to process information, without the presence of a defect.

4.4
Learning to move in the space

After four to six months, the grasp reflex disappears, and babies are then capable of targeted grabbing of objects and releasing them. Seeing an object becomes an increasingly important trigger in taking action. When a child sees a crinkle book and decides to grab it, this leads to the following sensory input:

- **movement** (the experience of how their hand moves towards the crinkle book);
- **sight** (seeing their hand move towards the crinkle book);
- **hearing** (hearing the sound of the crinkle book);
- **touch** (feeling the fabric of the crinkle book).

These various sources of information are combined in the brain and provide a comprehensive picture of how our immediate surroundings look, feel, sound and/or taste. The combination and integration of this information allows a child to use the appropriate motor response. A child is reminded of earlier sensory and motor experiences by the sight and the sound of the crinkle book, making them want to grab it again. Based on those previous experiences, a child knows exactly how far to reach and how big their grip must be to grab the book. A child trains and develops their motor functions (coordination, muscle strength, praxis) by ceaselessly trying to grab the crinkle book.

Visual and motor development enable the development of object permanence. At first, the child accidentally encounters objects when they are using their motor skills to explore – they are visibly happy when they come across their favourite toy by chance. At around the age of 12 to 18 months, a child becomes aware of the permanence of objects, and will gradually start looking for their favourite toys.

The incentive to grab the crinkle book is not present (or to a far lesser extent) in children with PIMD and visual disabilities. Apart from their total or partial lack of visual input, they could also develop a physical inability to grab the book. This way, both the ability to look and to move about are not trained (or to a lesser degree) because the book is too far away to practise visual skills, and it is also too far away to be an incentive to act (reach for it). Moreover, motor skills are not trained because there is nothing that triggers the child to act. The child does not experience the need to roll over onto their tummy or to refine reaching and grasping skills to be able to grab something that was previously out of reach. And when a toy slips from their grip, there is little incentive to pick it up again. For these children, out of sight literally means out of mind.

Reaching for and grabbing things is important to hone motor skills in preparation for the support function. The support function supports a baby when they are lying on their tummy, lifting their head in that position, moving to crawl, and getting up to sit and stand. For babies, seeing objects in their immediate vicinity is an important incentive to roll over, raise their heads and move. Visually impaired children will have to be prompted to move and change their position.

Tummy time is often not something visually impaired children enjoy. Unlike sighted children, that position does not provide them with new information. Sighted children see the world from a different perspective while on their tummies, and that actually motivates them to move – either crawling or shuffling around on their bellies.

Selma Fraiberg[22] described the classic image of the blind child: lying still on their back, with their hands sideways along their head. The blind child had been moving their arms and hands during their first 2 months, but stopped after 3 months, only to start again 4 months later (around 6-8 months old). That same stagnation of development was also observed in leg movements. It takes much longer for blind children to start actively moving by themselves, sometimes even up to 2 or 4 years longer than sighted children.

Selma Fraiberg also links a baby's use of their hands in daily activities and during play to their emotional development. Babies use their hands as an extension of their mouth – mouth and hands are used in the same way to examine objects. A baby gets to know their hands because they appear in their field of view, and they see what their hands are doing and how they grab objects. Blind children do not get this visual input, and they use their hands noticeably longer as extensions of their mouth. Due to the lack of visual information, it is difficult for them to develop the hand into an independent tool, prolonging the symbiotic relationship between hand and mouth. The mouth continues to be an important instrument for examining toys, and the divergence between hands and mouth occurs much later.
Only when a child learns that they can employ their hands and their body to make contact with their surroundings – and also possibly affect that environment – can they begin to see themselves as an individual.

Visually impaired children get direct feedback on their actions through making contact with their own bodies. These actions are often the only activities they truly enjoy. However, that leads to much less refinement of motor skills and a far lower increase in muscle strength.
After all, when a baby only makes contact with their own body, that requires very little variation in muscle strength and coordination.

---

[22] S. Fraiberg, 177

Rosalie has limited motor capabilities. She often sits in her wheelchair during the day. She regularly brings her right hand to her mouth in an uncoordinated way.
Her carers have mounted a fluorescent mirror carousel to the play arch on her wheelchair. Every time she moves her hand to her mouth now, she hears and sees the mirrors move. Each time that happens, she looks at them in wonder and repeats the movement.

4.5
Learning to move through the space

Starting to walk is a crucial milestone for the understanding of the layout of a space and about the relative positions of the various objects there.
By moving about in the space, a child gets to explore what they can do with their body, and their motor skills become more and more purposeful and refined. A child learns about the dimensions of the space in relation to themself, and by moving about, they get to know the various dimensions of things in that space – how tall or long things are and what it means to be under something.
Suddenly, prepositions like ‘on’, ‘under’, ‘behind’, ‘in’, ‘between’, or ‘through’ become meaningful because the child can experience these concepts first hand. Time and time again, small children will hide under a table (a safe space of their own), get into a cupboard, or hide behind a sofa.

By making contact with the space, children learn to perceive themselves as acting individuals; they learn that they can affect their environment, for example by making contact with the people or objects, or by picking up and moving objects.

To a toddler, seeing a small hole or button is an incentive to investigate. Don’t all toddlers seem to know exactly how to use the TV’s power button? There are two important preconditions to performing this independent action: seeing the TV and its power button, and seeing an adult using it. A child is encouraged to refine their ability to grasp when they see breadcrumbs, raisins, or bits of string, eventually leading to the development of the pincer grasp. An interesting sound in another room can be an incentive to investigate – ‘What’s happening there?’ Investigating is only possible if the child has a spatial and visual idea of where that other room might be and how to get there. Toddlers throw toys away, hide them, and then go searching for them. They put their favourite toys in a special place. From the age of 18 months, children build playhouses for themselves, for example under a table, with sheets draped over a clothes horse, or in an old box. Hide and seek and peekaboo are among children’s favourite games, and the ability to see plays a major role in both.

Moving through a space is usually a step too far for clients with PIMD and visual disabilities.

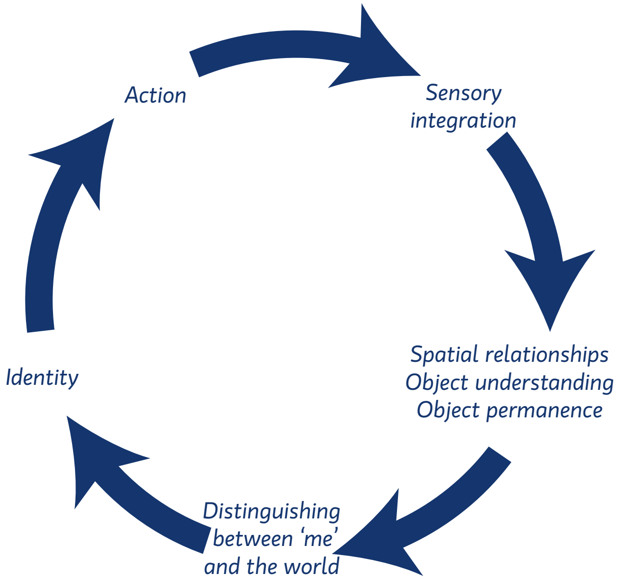
Deficiencies in vision, coordination, and muscle strength hold clients back from moving about. The motor functions of these clients are significantly weaker, restricting their ability to move. At first, sounds can be an incentive to move, but gradually, sounds increasingly trigger the client to stop moving and listen passively. After all, 90% of all sounds are outside their reach, and the client often has little influence on whether a sound is made or not. Clients learn to appreciate the unpredictable nature of sounds – for it is not certain beforehand how long a sound will last, what it will sound like, whether its tone will change, and whether or not it will be repeated.

The multiple disabilities of clients with PIMD and visual disabilities reinforce each other. A client who is visually impaired, but who has no motor disabilities, gets feedback through their own movements; when they bring their hand to their mouth, they receive feedback from their body. When repeating this movement, they increasingly link the tactile feedback to the feedback from the movement itself (proprioceptive input). Clients with motor disabilities are often unable to perform purposeful motor actions, and their movements are uncoordinated. Control of muscle strength is often not attuned to movement. The motor skills of clients who suffer from spasms are often affected by reflexes (sometimes pathological reflexes) that prevent them from bringing their hands to their mouth by themselves. The grasp reflex, too, persists longer in these clients, causing an inability to let go of what they are holding. Their reduced muscle strength makes it harder for these clients to move against gravity; moving their arms vertically is a great athletic achievement for them.

During the first years, the intellectual disability will become increasingly visible. That disability can limit the client's options for compensating. In these clients, the development of communication skills (the understanding and use of language) is slower than in others. Consequently, these clients cannot learn certain skills by means of verbal instruction. Making sense of their surroundings and the various objects there is an even bigger challenge for them.

Additionally, these clients get fewer opportunities to experience things by themselves because they are often placed in a protective environment (e.g. a playpen) where there is much less to experience than on the floor, grass, or sand. Parents and other caregivers are often too protective of these clients; they often respond before the client themself has had the chance to do something or indicate what they want.

The following figure highlights the importance of actions to the development of an identity. The perception of the immediate surroundings changes through functional actions (making contact with objects and/or materials in the immediate surroundings), and the body also receives sensory information about this space. The sensory input is subsequently processed in the brain (sensory integration) and forms, along with motor output, the basis for the development of spatial relationships, understanding of objects, and object permanence. The realization that there is a difference between themself and their immediate surroundings (objects and space) creates awareness and helps to shape their own identity as an individual who knows they are capable of influencing their environment.[23]



---

[23] Nielsen, Are you blind?, 1990

Bringing the room nearby

5.1
Introduction

"Since I am unable to come to the room, the room must come to me." Lilli Nielsen

How can clients (children or adults with PIMD and visual impairments) be triggered to become aware of their surroundings?
How can we enable clients to experience the difference between their own body and their immediate surroundings? How can we stimulate someone to initiate contact if they show almost no initiative themselves?
The room can be brought to the client in several ways, ensuring an optimal stimulation of functional development. When the room is near the client, we refer to it as their 'nearby space' – an environment that is accessible to them (or made accessible), and where they can learn to make physical contact. Some key aspects of the nearby space are:

- **safe and familiar;**
- **stimulating:** the space is tailored to the client;
- **delimited:** the boundaries of the space can be felt;
- **fixed:** objects in the space are fixed in place; only the client can move to another position.

The nearby space is made up of and filled with tangible boundaries, objects, and materials (as opposed to the immediate surroundings, which also include people). In the nearby space, the basis for understanding the concept of space can be formed along with the understanding of the spatial relations between the objects present in that space.

In order to stimulate awareness and exploration of the nearby space, Dr Nielsen designed various 'perceptualizing aids'. These aids are the Little Room, the Resonance Board, and the Position Board, which we will discuss in this chapter. Additionally, there are several other aids that have been developed by others over the past years and that fit in well with the concept of the nearby space. Those aids, too, will be discussed in this chapter.

5.2
The Little Room

The Little Room is a movable room with a back wall, two side walls and a top. Its standard dimensions are 60 cm high, 60 cm deep and 60 cm wide, but other configurations are also available. This small room is placed over a client who is sitting or lying down. This nearby space then provides the client with a safe and sheltered place to explore. The walls of the Little Room can be hung with materials that give tactile and or auditory input. There are often objects suspended from the ceiling with strings or elastic cords. These objects can be moved, but always remain within reach.

There were 40 blind and intellectually disabled children involved in the development of the Little

Room. Their calendar ages varied between 8 and 20 years, and their developmental ages ranged from 6 to 12 months. Almost all of these children became more active than they had ever been before.

The purpose of the Little Room is to allow blind children to experience success with regard to spatial relations, reaching and grasping. The Little Room can also be a valuable aid for children with low vision.[24]

The Little Room dampens ambient sounds and amplifies the sounds that are made in the room itself. This way, the client learns that they can produce sounds through their own actions. Because the objects are hanging at fixed places, the client receives clear information about the boundaries of the space and the location of the objects there. As a result, the client learns about the relative distances between the objects and how they relate to each other. This is what Dr Nielsen calls 'spatial relations'.

Dr Nielsen wrote her dissertation on the effect of the Little Room on the level of activity in 20 children with cerebral visual impairment.[25] Her research shows that children in the Little Room score on average 30 per cent higher on the following aspects:

- **manipulation of objects** (pre-kinaesthetic activities) such as grasping and releasing, grasping and holding, probing with the mouth, transferring objects from one hand to the other, turning objects around in the hand, hitting objects;
- **tactile activities**, such as touching the objects in the Little Room, touching the side walls of the Little Room, groping for objects;
- **auditory activities**, such as reacting to self-produced sounds, specifically grasping purposefully at such sounds;
- **follow-up games**, playing with two or more objects in succession, repeating successive games;
- **positioning activities**, such as checking by rotating the hand, checking the position of objects, comparing the position of objects;
- **repeating actions**, such as repeating immediately after an activity, interrupting an activity for a few seconds.

A small-scale comparative study of blind children and blind children with an intellectual disability showed a similar increase in the above activities in both groups.[26]

---

[24] Nielsen, Space and Self, p 53 | [25] Nielsen, 1989 | [26] Nielsen, Space and Self, p 56

Dr Nielsen identified several stages of exploration of a space.[27] Represented in a table it looks like this:

Stages	Action(s)	Sensory input
First	Uncoordinated movement	Basic tactile, auditory, kinaesthetic* and proprioceptive** input
Second	Coordinated reaching and grasping	More specific kinaesthetic and proprioceptive input
Third	Coordinated reaching, grasping and releasing	Coordinated kinaesthetic, proprioceptive and tactile input
Fourth	Conscious repetition of reaching / grasping / picking up /releasing, and the corresponding tactile and auditory input	Kinaesthetic, proprioceptive, auditory and tactile input
Fifth	Manipulation	Kinaesthetic, proprioceptive, auditory and tactile input
Sixth	Active manipulation in combination with touching and listening	Kinaesthetic, proprioceptive, auditory and tactile input
Seventh	Comparing different objects using active manipulation and tactile exploration	Kinaesthetic, proprioceptive, auditory and tactile input, integrated at the level of actions

* *kinaesthetic means sense of movement; this input is perceived by the vestibular system, also known as the balance organ.*
** *proprioception means awareness of position and direction through senses in joints and muscles.*

Whether someone is able to go through these seven stages (besides their motor capabilities) strongly depends on their level of cognitive and emotional development. Valuable information about which materials and objects are suitable for a client can be obtained through careful observation of how they explore the nearby environment. Those objects and materials can then be integrated into the client's nearby space.

Psychological aspects

The client receives feedback on their own actions through exploration of the Little Room and the objects there. This gradually creates insight into and awareness of their own possibilities. They learn to influence their surroundings; awareness of their own possibilities stimulates initiative. Because the objects in the Little Room do not disappear and remain suspended at the same location, repeated actions yield the same feedback. This creates the basis for the development of the concepts of object understanding and object permanence.

When a client is given an object, there is not the same safe and stable physical environment that encourages the client to repeat actions. Every time someone interferes in the physical environment of a client, the environment changes without the client being able to understand these changes. When the client is experimenting in the Little Room, however, they are in a stable physical environment, and that is why we should limit our interventions to a bare minimum.

---

[27] Nielsen, Space and Self, p 56

Our job is to design the Little Room in such a way as to provide the client with an exciting environment, stimulating their development and desire to make contact. For example, it is important that the client can experience that some objects are unique, and that other objects are identical. That also applies to differences and similarities in sensory input, such as tactile or auditory stimuli.
It is crucial that the client can easily grasp and hold the objects in the Little Room. By making contact with the various objects at different places, the client learns that there is an interrelationship between the objects. In addition, they learn a great deal about their own relationship to objects (spatial awareness).

Kai suffers from hemiplegia; he can use his right arm to a limited extent to reach for nearby objects. He cannot use his left arm for coordinated movements. A set of keys was suspended in the Little Room close to Kai's right hand. When Kai lifted his hand 10 cm, he could feel the set of keys and he could hear the sound he caused. The first few times it startled him, but after a while, a smile appeared on his face.

Designing the Little Room

The Little Room can only be a useful tool if the client enjoys being there and it encourages them to explore. The design of the Little Room should always be tailored to each individual client.

The following are key aspects of the design:

- Objects should trigger multiple senses in order to improve sensory integration. For instance, *the client sees a shiny object hanging from the ceiling. When they touch the object, it rustles and feels smooth to the touch.* The wider the sensory range, the more likely it is that the information sticks.
- The range of objects should provide clear-cut sensory information (object understanding). For instance, the client feels something touching their hand; it feels solid and smooth. They can put their other hand inside it, and they can tap it – it's a cup.
- The various positions of the objects and the space itself should stimulate spatial awareness. From the client's perspective it might look something like this: *'I feel something when I lift my hand up and to the left. Hey, that makes an interesting sound. There is another object when I reach over to the right; oh, that feels soft. How far are they apart? Can I also touch the object on the right with my left hand? How far can I reach with my arm, or do I need to move a bit closer to it?'*
- Clients should get direct feedback on their actions and the sounds they cause. This increases their awareness of how they can influence their environment.

How to hang objects

Objects can be suspended using a length of rope or an elastic cord (either flat or round). An elastic cord has the advantage that it allows the client to bring the objects to their mouth. Elastic cords are available in various thicknesses and their elasticity varies accordingly. Round elastic cords are generally easier to stretch than flat ones. A loop can be tied at the end of the rope or elastic cord, and subsequently be inserted through a hole in the ceiling of the Little Room. A key ring, rod or clothes peg can then be inserted through the loop to fix the object in place while still allowing easy replacement of the object. The length of the string or elastic cord should depend on the reach of the client, their position (either sitting or lying down), and their size. There should not be any objects hanging near the client's head, for that could make him or her feel unsafe.

In addition, objects can also be suspended from the walls of the Little Room. Objects should be placed close to the hands of those clients who do not move much by themselves. This way, even slight movements can create feedback. For clients who are more in control of their movements, objects can be hung in various places, encouraging them to explore the room.

What objects could you hang up?

The most important principle is that being in the Little Room has to be a fun experience for the client. This means that objects that are familiar to them and those they like to play with should definitely be used

For those clients who need some time to get familiarized with new objects, a single new object can be placed among those they already know. Objects have all kinds of characteristics that appeal to the client in one way or another. It is essential to be aware of those characteristics, so you can take them into account when designing the Little Room.

You may consider the following characteristics:

- **manipulability:** is the object suited to the client's motor capabilities? A client who suffers from spasms needs objects that are big and easy to handle, such as a ring. On the other hand, a balloon filled with rice can be easier to handle for a client who has little strength or motor capabilities.
- **tactile input (characteristics and materials):** soft, hard, grainy, angular, holes, brushes, sandpaper, knotted rope, plastic, wood, rubber,

metal. Each object provides its own specific input, has its own structure, weight and shape, and feels either cold or warm to the touch. Clients examine objects not only with their hands but also with their mouth. Many clients have preferences for, or aversions against, certain kinds of tactile input. Both hypersensitivity and hyposensitivity (tactile defensiveness) are linked with the way tactile stimuli are integrated in the brain. When choosing what tactile stimuli to offer, it is important to take a client's hypersensitivity or hyposensitivity (if present) into account.

- **auditory input (characteristics and actions):** pitch (high or low), touch-induced sound (rustling), sound induced by manipulating an object (touching a bell), opening a musical box and listening to its tune, tapping an object against the side wall. Different objects obviously produce different sounds.
  The enclosed environment that is the Little Room amplifies sounds. Moreover, sound can be amplified even further in this small space by the use of a Resonance Board (see 5.3).
- **visual input:** objects that contrast with each other and the surroundings, shiny objects (insulation foil), luminous objects (Christmas tree lights that light up in varying frequencies), alternating black and white objects or just a single black object among five white ones. When the ceiling of the Little Room is covered with a cloth or blanket, the light stimuli in the room become stronger, for example in combination with Christmas lights or a lava lamp. Objects that can move provide visual input, and in the Little Room the client receives strong feedback that they are the one making the object move.
- **input from smell and taste:** scented sachets can be hung in the Little Room; touching them will provide additional input from smell. Materials such as wood, metal, leaves, or sea shells can also provide input – especially when they are fresh from the beach or forest. The sense of taste can be stimulated by hanging edible objects, such as a piece of bread, a slice of apple, or a piece of cake.
- **similarity and difference:** by hanging two identical and two nearly identical objects, the client is stimulated to compare objects and to notice small differences. For example, you could hang two tablespoons and two teaspoons, or a set of keys with a number of identical keys and some unique ones. When a client encounters, for example, two spoons and two nail brushes, they can discover how much objects can differ. Blind clients should be given the opportunity to compare objects at length and to discover even the most minute variations. These clients will gradually figure out where objects are hanging, and they can then actively go looking for them. When that happens, they will have developed a degree of object permanence.

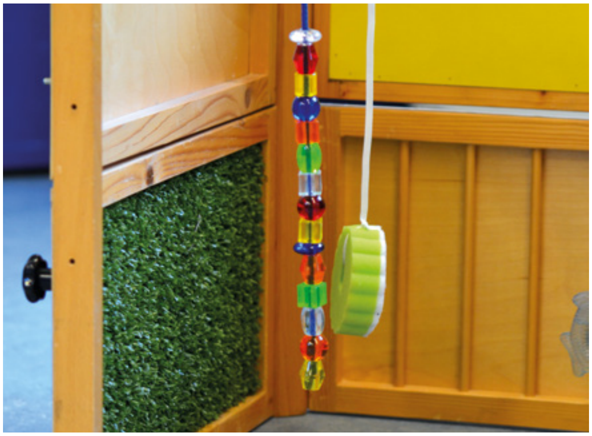
Placing a client in the Little Room

Lying on the back is the most common starting position in the Little Room. That is why it is important not to place the Little Room under a bright light source – beware of fluorescent lamps

on the ceiling or direct sunlight.
When placing a client in the Little Room, it should be tilted onto its back wall. The client should then be laid down in front of the Little Room with their head 30 cm from the back wall. The Little Room can subsequently be tilted back slowly over the client, making sure to avoid objects unexpectedly hitting the client's face.
As soon as the Little Room is in place, it is the client's private space, and outside intervention should be avoided. From this moment on, it is up to the client to initiate movements or to cause sounds. This is the only way the client can become aware of and gain insight into their own actions: this is the basis for the desire to explore and to take initiative.
Some clients love playing in the Little Room from the outset, while others need some time to get used to it (just as they would in any new environment). In the latter case, it is advisable to place the client in the Little Room for only a few minutes at a time. A familiar tune or a familiar object can make the transition easier.

Variety
New objects and situations are a trigger to explore for everyone – whenever we find ourselves at an unfamiliar place, we take careful notice of the new environment. Unfamiliar objects, too, stimulate us to make contact and investigate. That, of course, applies to our clients as well. However, that may get overlooked in the everyday hustle and bustle of a classroom or a residential or day-care group.
This means that objects on a play arch might not get changed for months. Consequently, the client has to look at and feel the same objects for months on end. Their curiosity about these objects will obviously diminish over time.
In that case, there is a significant risk that clients will develop stereotyped behaviours because they are unable to look for variety on their own. After all, clients are only stimulated by those objects they come into contact with that are in their nearby space. To them, all other objects – those that are beyond their reach – simply do not exist.

Some clients need weekly variation, while for others this need only arises after two or three weeks or even a month. When you exchange the old objects for new ones, it is important to leave one or two of the old ones in place. The objects the client is already familiar with serve as a starting point from which to explore new ones.



5.3
The Resonance Board

The Resonance Board is a tool you can use to let the client experience more feedback from their movements through auditory input.
The Resonance Board is a thin wooden board with wooden strips on the underside, elevating the board 2 cm from the ground. Because only the strips are in contact with the ground, and not the board itself, all movements lead to strong auditory feedback. Apart from auditory feedback, movements also cause slight vibrations, which in turn could motivate the client to increase their activity. Clients in day and residential care groups often lie or sit in a supported or fixed position, restricting spontaneous movements and providing little feedback – random movements in an open space mainly provide proprioceptive feedback, and sometimes, if there are boundaries, tactile feedback. While lying on the Resonance Board, the client becomes more aware of their own influence through the direct feedback on the spontaneous movements they make. The client will gradually come to understand that it is they who cause the sounds.
Various materials, such as insulating foil or bean bags, can be laid on the board to encourage coordinated arm, hand, and head movements.
The client's awareness of their own movements can also be increased by suspending items above their head. When a client lies on their front on the board and feels an object and hears a sound when they lift their head, that could motivate them to repeat the movement.

It is important that the client becomes aware that sound is not something they can only experience passively. In that case, the client would remain completely dependent on their environment for auditory stimuli, and the sounds they hear would remain unrelated to the actions that accompany them. Using the Resonance Board, clients can learn that they themselves can play an active role in causing sounds. Additionally, they will learn to link sounds to actions.

In practice, the Resonance Board is often used in combination with the Little Room. The sounds that accompany the client's actions in the nearby space are amplified by the Resonance Board's position off the ground. The enclosed nature of the Little Room amplifies the sounds even further.

5.4
Playing and daily activities

Dr Nielsen emphasized the importance of playing for the development of various skills. The actions involved in playing – grasping, picking things up, manipulating things – stimulate hand function and object understanding. The client learns that the hands are an instrument to come into contact with the nearby space. Through play, clients can explore their own body, and they get feedback on the movements their body can make.

In addition, Dr Nielsen stressed the importance of contact with ordinary objects, such as a cup, nappy or toothbrush.
When a client is familiar with an object, and recognizes it, it becomes easier for them to carry out the action that goes with it. A concept of an object is formed and stored based on information from smell, vision, sound (what does the object sound like?), touch (is the object smooth/rough/cold?) and proprioception (how big/heavy?).
The more multisensory information about an object is stored, the easier it becomes to recognize it later.

Dr Nielsen wanted to guard against clients with PIMD and visual impairments becoming unnecessarily dependent on others. She recommended that these clients be included in daily activities at an early age – much more so than sighted clients. Clients will only imitate daily actions after they have experienced them first hand, and that takes a lot of time and repetition.

Dr Nielsen let clients experience daily activities, such as taking off socks, or fetching a nappy, cup, fork or toothbrush in a playful manner. By letting the client play with a nappy, they get to know and recognize the nappy and the sounds it makes. If the client recognizes the nappy, that knowledge may help them to better understand the process of a nappy change.
This way, the nappy is no longer part of a care activity, in which the client has a passive role, but they learn to understand what causes the sounds that accompany the change. Dr Nielsen attached great importance to the sounds that everyday actions make. Sounds stimulate awareness and insight into daily recurring actions, increasing clients' understanding of what goes on around them.

Over the past 15 years, Total Communication has made extensive use of everyday objects to refer to specific activities:
a nappy represents a change, a bib means a meal, and swim trunks stand for a swim. This way of clarifying situations fits in well with the way a client with PIMD and visual impairments experiences the world.
One of the results of the use of Total Communication is that caregivers have become more cautious when it comes to using everyday items as play materials. For some clients, it could be confusing to be allowed to play with a toothbrush one day and not be allowed to do so the next.

For clients for whom this is not an issue, the use of everyday objects is still a great addition to actual play material. Everyday items can offer a wide variety of stimuli, and that is by no means always the case with play materials. A box with a dishwashing brush, a set of keys (not the toy variety), straws, a hard plastic cup, a spoon, or a shower sponge can all be items a client can really enjoy playing with. Everyday items are widely available, cheap, and easy to handle for the client; that is why Dr Nielsen's idea of using such items for play is still in use. However, the use of these materials is nowadays significantly less linked to daily recurring actions.

Visually impaired clients develop their hand function at a slower pace due to the fact that they make less use of their hands. Exercise builds muscle strength and coordination. Changing position, pressing buttons, playing with blocks, picking up a raisin, pushing something away, getting up to a standing position using the rail of the playpen, eating with a spoon, and so on, all help to train muscle strength and coordination. For visually impaired clients, actions that involve sounds are the strongest trigger to start imitating. The people around the client have an important role in triggering them to start imitating actions.

5.5
The activity box

The activity box is a space with fixed boundaries, and it contains loose objects. The box can be a further step on the path of exploration for clients who have learned to make contact with their nearby space. The activity box is only suited for clients who are able to adopt a stable sitting position next to the box.

The activity box provides the client with a well -defined playing environment. Many actions of the client in the activity box are accompanied by the sounds those actions produce. The objects that fall back into the box cause a different sound than the objects that fall on the floor next to it.

As a caregiver, you can regularly change the content of the activity box. Depending on the client, it can suffice to change one or two objects, while other clients may benefit from the introduction of more new items. Changing items in the box can prevent stereotyped play, or alternatively, offer variations. In any case, the client is triggered to do something with the items in the box, and items can be either picked out or thrown from the box. Besides the client's favourite toys, the box could also contain some items the client is not familiar with. You could also put two or three identical items in the box. In addition, you can fill the box in part with everyday items, such as a toothbrush, shoe, cup, comb, brush, pan, etc. Small materials on the bottom of the box, such as beans, beads or buttons, will stimulate the development of the client's pincer grip.

You can also add more variation by putting shapeless materials in the box, for example rice, beans, or marbles. When a client reaches for and picks up these materials, they often get positive feedback. Moreover, every movement in a box with these materials – coordinated or not – creates auditory and tactile feedback.

5.6
The Position board, activity vest, activity belt and play arch

Not all clients can experience the nearby space using the Little Room. The dimensions of the Little Room could be unsuitable for some clients; other clients dislike lying on their back. It is, nevertheless, important to also provide these clients with a **safe, stimulating, enclosed and fixed** space – a space that does not change when they make contact with it.

We will provide several examples of such a stimulating environment in this paragraph. Some day-care centres, residential care centres and educational institutions are extremely creative when it comes to designing spaces that are beneficial to their clients. They have created their own equipment based on this concept.

Position board

The position board is a simple board with holes in it, allowing for easy attachment of objects. Just like in the Little Room, items can be held in place with a key ring or clothes peg, making it easy to change them.

Activity vest

A client can wear an activity vest over their own clothing. When the client is wearing the vest, their stereotypical movements that are aimed at their body will come into contact with the vest, providing new tactile, auditory, and visual stimuli. Those new experiences will stimulate the client's curiosity and encourage them to go exploring.

Activity belt

An activity belt is a belt or strap with rings to which items can be attached. The strap or belt can be attached to the tray of a wheelchair, and the objects that are attached to it are fixed and cannot disappear from view. Toys can also be attached to the wheelchair tray itself by means of holes in the raised sides of the tray, or by attaching the rings to the tray directly.

Adem is a 38-year-old man. He needs a wheelchair, but he has motor control over his head, trunk and left arm. Adem is a cheerful man; he expresses his feelings of joy by hitting his head or chin hard with his left hand. The blows he deals himself are significant; caregivers who know him well, however, recognize them as an expression of joy.

His game is to swing a scarf through the air. Sometimes, the scarf hits his bald head or curls around his neck. The movements he makes are graceful, and in passing, he occasionally hits his head or chin.

Adem's caregivers wondered how they could help him have fun without hitting himself. We went looking for a solution in which Adem could still enjoy waving his scarf, but with a bit more variation and without the possibility that he could injure himself. At first, we thought about attaching several scarves to a play arch; that way, Adem could still wave the scarves, but he would also experience new movements. However, Adem is too strong for objects to be attached this way; besides, it still allowed him to injure himself.

Next, we strung a strap onto the tray of his wheelchair to which scarves etc. could be attached. Adem seemed to take to this well and started to play with the scarves, but also with insulation foil and a Christmas garland. He grabbed hold of the objects and swung them through the air; however, in doing so, he did not swing near his head, and he did not injure himself as much.

The play arch

The last example to be mentioned here for creating an exciting nearby space is the play arch. Nowadays, many different varieties exist: there are play arches for railed beds (either on a stand or mounted between the rails), play arches for wheelchair trays, stand-alone play arches and even home-made ones. Mounting a play arch is usually not difficult, and activity materials can be changed with little effort.

The Active Learning approach

6.1
Introduction

In the past chapters, the theory behind the Active Learning approach has been discussed. Active Learning was developed by Dr Nielsen in the second half of the twentieth century, and it became available to a wider audience in the 1990s. Over the past 25 years, there have been many changes in care for clients with PIMD and visual impairments. Research and more coordinated diagnostics have provided targeted input for treatments. Visio is also paying more attention to this complex group. The approach that we will discuss in this chapter was developed by Dr Nielsen and has been adapted to the current situation.

6.2
Stated care needs

Active Learning is used in consultation with the client's support system. The fact that the client makes little or no contact with their physical surroundings lies at the core of their care needs. In practice, these needs are often formulated for clients who do not play, or when professional caregivers are uncertain about a suitable range of activities. A client's behaviour could be difficult to understand, or the client could be 'overlooked' because they do not speak up for themselves, which leads to their care needs being formulated by the client's support network or by parents. Clients are unable to express care needs by themselves. Both support network and parents intimately know the client and can formulate the care needs based on their behaviour, or the interpretation of their behaviour.
Care needs can emerge at home, at school, or at the residential or day-care centre. For this complex group of clients, it makes sense to involve the residential or day-care centre or school and parents in the discussion of the care needs.

6.3
The client

Active Learning focuses on clients with:
- a visual and intellectual disability;
- a developmental age of up to 24 months;
- additional motor and/or sensory disabilities.

Actively making contact with objects, materials and people in their environment is not something that comes naturally to these clients. As a result of the client's visual impairment or blindness, they receive few incentives to explore, and their additional motor disabilities hold them back from initiating actions. The client's capacity to compensate is low due to their intellectual disability and low developmental age.

6.4
The approach

Active Learning focuses on the client, their nearby surroundings and their support network.

Making contact with the immediate surroundings is central to the approach. These surroundings consist of materials, objects and people, and through contact, the client learns to explore and recognize their surroundings. Taking the initiative to act is rewarded and provides them with direct feedback. The client has the opportunity to actively go in search of sensory stimuli. If the client had been used to sitting quietly in a corner and withdrawing, they may now increasingly go exploring. By making contact with their immediate surroundings, clients learn to distinguish between themselves and those surroundings, and they learn that they can influence them.

The definition of the Active Learning approach is:

To facilitate the client to actively make physical contact with their immediate surroundings – objects, materials and people – using personalized tools, with the goal of stimulating and expanding the client's awareness of their capacity to act and to make contact.[28]

To adequately tend to the client's care needs, Visio uses the ICF model (International Classification of Functioning, Disability and Health). This model provides guidelines for the organization of information about a client.

6.5
The discovery phase

The goal of the discovery phase is to:

- inform the support network about the methodology and to get it involved;
- gain insight into the way the client makes contact (with objects, materials and people);
- gain insight into the client's capacity to make contact (initiative, sensory preferences, motor capabilities and visual behaviour);
- identify the opportunities present in the client's physical surroundings.

In the discovery phase, contact with the client's support network is very important for the ultimate transfer of recommendations to the treatment phase.

For clients of residential or day-care centres, Visio uses the 'Kijk Zo Kan Het Ook' (this works as well) method.[29] The information collected during the discovery phase is discussed at a team meeting. Based on video footage of the client, the support network and the physical surroundings, the team examines the client's visual problems and the consequences this has for contact, communication, care and activities. The meeting ends with the joint determination of treatment goals; the team can opt to use Active Learning. For example, when the client in question:

- makes little to no contact with their nearby surroundings;

---

[28] This definition was drawn up by Martien Rienstra, March 2016-May 2018

[29] Bokken and Wiersma (2009)

- has many idle moments throughout the day;
- and/or has few options for play and exploration.

If the care needs are Active Learning-oriented, a dedicated exploration will follow to discover the client's possibilities, their support network, and their physical surroundings.

The following elements are addressed during the discovery phase:

- in-depth review of the client's records;
- contact with the support network;
- observations of visual behaviour and the client's capacity to engage in activities and make contact in their daily environment;
- creation of a rehabilitation plan and a support plan.

In-depth review

In order to form an impression of the client, an in-depth review of the client's records is necessary prior to the first contact. This review should encompass at least the report of the client's visual functioning (preferably augmented with observations of behaviour by the behavioural scientist) and the institution's support plan (care plan, individual support plan).

These documents can provide insights into:

- visual functions;
- visual behaviour (requires additional observations by a behavioural scientist);
- the way the client makes contact with materials, objects, and the people around them.

The support network

The support network encompasses the people involved with the client, such as parents, personal caregiver, assistant caregiver and therapists. At Visio, we discuss the information about Active Learning – distributed prior to the discovery phase – with the support network. This information provides the basis for the way the client is going to be observed and treated at Visio. It is important that sufficient support for this foundation is created at the start of the treatment programme, to allow optimal implementation of the recommendations at a later stage.
Additional information about the client is collected during a meeting with the support network. These people know the client well and can provide information about the client's sensory preferences, playing preferences, way of making contact with materials, daily schedule, etc.

Observation of capacity for activities

During the discovery phase, the client is observed in their everyday environment. During the observation, the observer should only be present in the background and be as inconspicuous as possible. The information collected from the in-depth review of the client's records and from the support network is important in determining which setting is best suited for the observation. This could be during 'free play' or during group activities, such as 'snoezelen' (controlled multisensory environment).

If the client does not engage in activities on their own initiative, we may consider, in consultation with the support network, actively instigating contact with objects and materials. During the discovery phase, it is essential to gather information about **how** the client does things, **what** they do, and **where**.
You can find an observation form in the appendix; it is to be filled in together with the support network.

Observing **how** the client does something provides ICF-related information about the client's state of health and functioning. The in-depth review and dialogue with the support network are used to gather information about the client's state of health and functioning. During observation you link this information, which was provided by others, to your own observations and interpretation of the client's actions. You should ask yourself the following questions: what sensory and motor preferences and capabilities do you observe in the client; what is the client's visual behaviour; what is the level of the client's alertness; does the client take the initiative in making contact with their environment, and how do they show that initiative?

Observing **what** the client does provides ICF-related information about the client's level of activity and participation. Ask yourself these questions: what does the client do; which actions do you observe; can they reach for and grasp objects, or do they only touch things by accident? How does the client play; do they use their mouth to examine all kinds of objects; do they mainly make contact with their own body; do they actively go in search of objects? Do you notice the client having fun when making contact with their surroundings? Do you see variation in the movements, or are the movements repeated continuously?

Observing **where** the client does something provides ICF-related information about the external factors that influence the way the client makes contact with their nearby environment and/or their ability to do so. In this context, we mean the client's physical and social environment. Ask yourself the following questions: can you create boundaries at places where the client is often to be found; can you fix objects in place there? Does the lighting there suit the client's needs? At what moments in the weekly programme is there time to stimulate making contact with the immediate surroundings?

6.6
Treatment phase

The discovery phase is concluded with a rehabilitation plan. The agreements are to be noted in the support plan (see appendix), which in turn is used to transfer the work goals.

The following components can be distinguished within the treatment phase:

- treatment goal(s)
- setting
- method
- tools

Goal

The treatment goal of the rehabilitation plan should always be client-oriented and SMART (Specific, Measurable, Achievable, Relevant, Time-bound). It is essential to take very small steps with clients with PIMD, for there is a risk of goals being too ambitious and therefore remaining out of reach. Unattainable goals will demoralize the client and their support network. Owing to the regularly changing composition of the support network, the care needs may not always be recognized and/or endorsed by everyone. This could lead to insufficient consensus and recommendations being followed half-heartedly or not at all. It is, therefore, crucial to have a dialogue about the treatment goal(s).

These are examples of treatment goals:
'In three months' time, client X will have five objects in their nearby space that give them five minutes of enjoyment a day.
In three months' time, client X will make contact with their nearby space multiple times per day.'

Setting

Treatment preferably takes place at a quiet spot in the group or in an adjacent room. It can be helpful to have parents and or other caregivers be present during treatment. In practice, it often turns out that it is not feasible for caregivers to leave the group together with the client. Workloads at day-care centres for adults are often so high that caregivers generally do not have time to play with individual clients in their group. That is why it is important to have a short handover after each treatment. At handover, caregivers should be informed about the client's activities and reactions. Recommendations about stimulating visual behaviour, for instance instigating eye contact during meals, or providing an activity, such as fixing an object to the wheelchair tray and observing whether the client makes contact with it, should also be communicated.

A standard treatment session lasts 45 minutes. Many clients need time to start using their vision and/or to become active. Others need time to get used to an unknown voice or person. The pace of learning, alertness and processing of information are often lower for these clients, and can vary significantly from person to person.
The treatment sessions have both a treatment and an observational character. Owing to the complex nature of this group, training can only have a lasting effect with daily repetition; this is why proper handover between caregivers is essential.

Method

The treatment method adheres to the principles of Active Learning. During treatment, the use of a variety of objects and materials, as well as the interaction between caregiver and client, are both methodical and therapeutical.

Interaction with the client should be appropriate to their emotional development. Depending on the level of emotional development, a choice should be made between offering, imitation, interaction, sharing the work, or consequence (see chapter 3). The choice for one of these techniques should depend on the client's emotional development and their ability and courage to take the initiative: a skill that many clients with PIMD have not managed to master. Resulting from the often-lower pace of the client's actions, the support network will often have directed and/or carried out those actions, without the client having had any active part in them. Clients often take a minimum of initiative, and when they do, this often gets overlooked. During therapeutic interaction, the client is in the lead and the caregiver is mainly a facilitator; it is the caregiver's task to design the immediate surroundings in such a way as to allow the client to take the initiative in making contact with it. This therapy should be hands-off, and your observational skills should be in high gear.

Materials are **offered** methodically and, as always, tailored to the client's preferences and capabilities. The discovery phase should have yielded information about the client's preferred sense, motor abilities, way of taking the initiative, and visual behaviour. Through the support network, information should have been obtained about the client's preferred body position, favourite toys, and their level of alertness. This information is the basis. It is important to further research the motor and sensory capabilities of certain clients. The following methods can be used for this purpose:

- The method 'Ziezo'[30], developed by Visio. Using this method, visual functioning can be set out in detail. This assessment shows to which visual stimuli the client responds, and to what extent.
- The Visual Assessment Scale.[31] This scale can help to gain insight into the viewing level of clients with cerebral visual impairment (CVI) or shifting visual behaviour.
- The LAS list (List for the adaptation of Activities and Situations), which is part of the Personal Activation Programme.[32] This list can be used to gain insight into a client's motor capabilities.

Assessing these clients is not easy. Important conditions for fulfilling the treatment goals are close coordination with the direct caregivers, experience with and affinity for this type of client, and confidence in your own intuition. When a client exhibits complex behaviour, watching video footage of the client together with a behavioural scientist or with the team at the institution may yield valuable insights.

Just like shifting visual behaviour and fluctuating alertness, the receptiveness of other senses can also vary. Whether the client can process the stimuli provided depends on tiredness, pain,

---

[30] Eelman, Kuiper and Steendam, 2014 | [31] Steendam and Wallroth, in development

[32] Hiemstra, Wiersma and Vlaskamp, 2005

other stimuli in the environment, and the time of day. Stimulation of one of the senses could have a positive effect on another sense. Taking the initiative and making contact are often triggered by sound or touch. However, some other clients may only be able to focus on one of their senses at a time – as soon as they hear something, their visual attention disappears. It is important to keep observing which sensory pathway is currently open – ask yourself what sensory input could be usefully provided to allow the client to make optimal contact with their immediate surroundings.

The game box technique can be used to present materials.[33] This technique offers the client ten different objects and registers what the client likes and dislikes. By regularly varying the selection, you can arrive at a selection tailored to the client.

Tools and conditions

Providing boundaries, fixing objects or materials, and providing variation are important ways to stimulate the client to make contact. Employing optimal lighting and contrast is important to clients with low vision.

Dr Nielsen developed the Little Room in order to offer the client permanent boundaries and proximity of objects and materials. For some clients, the Little Room can be a very effective means to stimulate them to make contact. Each of their actions yields optimal feedback. In practice, the Little Room is used mostly with young children with SMD; when combined with a Resonance Board, a truly stimulating environment can be created. The Resonance Board amplifies the sounds caused by the actions of the client. To blind children or those with severe low vision, this auditory information provides especially valuable feedback about their actions. They can endlessly repeat actions at their own pace. Actions that are initially involuntary and undirected may gradually evolve into purposeful actions.

Owing to its limited size, the Little Room is not a suitable tool for a sizable group of clients – a client in a wheelchair with a seating orthosis will usually not fit in the Little Room. Additionally, many clients require specific support, which cannot be provided when they are lying in the Little Room. However, to encourage these clients to act and explore, it is important that they too are provided with boundaries and fixed objects. Other tools have been developed for this group of clients, such as the play arch, the activity vest, the position board, and the activity belt.
At many residential and day-care groups, numerous initiatives have been employed to fix materials and to make boundaries more discernible. For instance, a safety bed can be a valuable means of providing boundaries.

To prevent painful contact with the sides, clients are often placed in the centre of a safety bed as a precaution. The client is consequently deprived

---

[33] Moleman, Van den Broek and Van Eijden, 2009

of tactile information about their nearby space. Decorating the sides with artificial grass, crinkly paper, reflective materials, or the client's favourite toys will make these boundaries perceptible.
Adding extra lighting and optimizing contrast is a significant means to stimulate children with low vision to make contact with their nearby space. A light box or a UV-light box can also be used as a means to stimulate clients to make contact. This is a way to visually enhance the nearby space, making it easier for the client to initiate contact.

Clients cannot indicate when they are ready for a new challenge. Nevertheless, the truth is that after a while, most clients get bored with objects they are very familiar with – overfamiliar objects no longer trigger them to examine, in which case stereotyped behaviour might be just around the corner. There is an important role for the people in their surroundings to add variation. Some clients are triggered to explore by a weekly changing selection of objects, while for other clients, new objects will always have to be offered in combination with their favourite toy.

After a while, it will become clear how the client can make contact with their immediate surroundings: the way they take the initiative, the motor skills they employ, the sensory input they prefer, the way caregivers need to interact with them and the materials and objects that are needed. The next phase is to adjust the client's everyday surroundings – close cooperation with the institution where the client resides is crucial for this. A joint plan for adaptation can be drawn up by means of team training. Video footage of the client can increase support for these adjustments.

Team training

Team training follows after the treatment phase. The following people should be present at the training sessions: the client's personal caregiver, residential and activity caregivers, parents, the client's therapists and physician, and the institution's behavioural scientist. The goal of team training is to jointly take stock of the client's options for making contact with their immediate surroundings; video footage of the treatment phase is an important aid to this process.
Viewing and discussing the footage together creates support and starting points for the implementation of the recommendations.
The training is concluded with a concrete plan for adapting the client's nearby space and their environment, and a time schedule for implementation.

Evaluation

After a certain time – depending on the agreed timeframe – the programme will be evaluated with the support network. The treatment will be discontinued if the care needs have been met.


14
10

Afterword

In recent years, I have immersed myself with great pleasure in Active Learning. It has given me more insights in my work into the capabilities of clients with severe and multiple disabilities. I am convinced that Active Learning is meaningful and valuable for them, regardless of how small progress can sometimes be.
I am delighted that Active Learning has become easily accessible to a wider audience through this book. Furthermore, I hope that the method will inspire other professionals to provide clients with suitable activities, enabling clients to make more contact with their environment.

I would like to thank Visio for the opportunity to translate and adapt Dr Nielsen's theories to the situation in the Netherlands.

Over the past few years, I have frequently talked with colleagues, friends, and loved ones about Active Learning and about the way it could earn a tangible place both inside and outside Visio. Those conversations have inspired me and sometimes yielded valuable and concrete results. Additionally, clients and caregivers have provided me with the opportunity to apply the ideas of Active Learning in practice, and have given me insight into what works and what does not.

I would specifically like to thank a number of colleagues for their involvement:

- The members of the project group: Anouk Dirkse, Marja Knegt, Linda van Oevelen, Tineke Ploeg and Wendy Timmermans – together, we have done a splendid job!
- My colleagues in the focus group: Marjolein Wallroth, Wendy Timmermans and Wilma Verberne. It may seem like quite a while ago, but the foundation for this book was laid there.
- Of course, I definitely want to include Wieneke Huls, Ellen van den Broek, and Dafne Adarkwah.
- I would like to thank Ingrid Jekel for her textual tips and advice.

Thank you, Henk, for your inspiration and support!

www.visio.org/activelearning

Publications and sources of inspiration

Bokken, J., & Wiersema, I. (2009). *Kijk, zo kan het ook.* Sensis.

Burg van der, S., Dijk van, Y., Happee, M., Koelewijn, M., Kunst, E., Pot, B., Ringelestijn, E., & Slikker, P. (2003). *De Speelpoort.* Esdégé Reigersdaal.

Delden van, G. W. (2007). *Kijken door muren.* Visio.

Duijvenboden van, T., Pietersen, M., & Straus, M. L. (2017). *Met het oog op meedoen* (1st ed.). Bartiméus.

Dunn, W. (2006). *Sensory profile-NL handleiding* (Rev. ed., Vol. 1). Pearson Benelux.

Dunn, W. (2013). *Leven met sensaties.* Pearson Benelux.

Eelman, E., Kuiper, M., & Steendam, M. (2014). *Ziezo* (Methodenboek). Visio.

Eijden van, A. (2015, August). *Persoonlijkheidsontwikkeling van jonge blinde en slechtziende kinderen en van kinderen met een meervoudige beperking* (No. 2015-1). Visio. https://www.visio.org/visio.org/media/Visio/Downloads/Rapporten%20webshop/Rapport-2005-3-Persoonlijkheidsontwikkeling-kinderen-def-versie-2015.doc

Fraiberg, S. (1977). *Insights from the blind.* Basic Books.

Froentjes, Y., Juttner, G., & Wijnands, K. (2007). *De Doepoort*. Esdégé Reigersdaal.

Geeter de, K., & Munsterman, K. (2017). *Koffie met een koekje.* De Geeter & Munsterman, orthopedagogen.

Hellendoorn, J., & Scholtens, H. (1991, June). *Stimuleren van communicatie door speelse sensopathische omgang.* NTZ Tijdschrift, 2.

Hiemstra, S..J., Wiersma, L.A., Vlaskamp, C. (2005). *Persoonlijk Activeringsprogramma.* Groningen: Landelijk Kennis Netwerk Gehandicaptenzorg (LKNG). www.lkng.nl

Holtrop, J. A. (1997). *Zintuiglijke stimulering Inhoud en diagnostiek* (Master's dissertation). Unknown.

Koeleman, T. (2005). *Ervaar het maar met… knutselen* (1st ed.). Ervaar het maar.

Kranowitz, C. (2005). *Uit de pas, omgaan met sensorische integratieproblemen bij kinderen.* Nijkerk: Calenbach.

Lear, R. (1979). *Speelhulp voor gehandicapte kinderen : ideeën voor spel en ontwikkeling.* Calenbach.

Lee, M., & MacWilliam, L. (2009). *Learning together: een creatieve benadering van leren voor kinderen met meervoudige beperkingen en een visuele beperking.* Bartiméus.

Limburg, J. J. (2007). *Epidemiologie van visuele beperkingen en een demografische verkenning.* Stichting InZicht. http://www.vision2020.nl/contents/InZicht_rapport.pdf

Maes, B., Vlaskamp, C., Penne, A., & Putten van der, A. J. (2011). *Ondersteuning in beweging: Motorische activering. In Ondersteuning van mensen met ernstige meervoudige beperkingen Handvatten voor een kwaliteitsvol leven* (1st ed., p.). ACCO.

Moleman, Y. H., Eijden van, A., & Broek van den, E. G. C. (2009). *Spelontwikkeling en spelbegeleiding van slechtziende en blinde kinderen.* Visio.

Nakken, H., Reynders, K., Vlaskamp, C., & Procee, A. I. (1998). *Behandelingsvormen voor ernstig meervoudig gehandicapten: een wegwijzer* (1st ed.). Lemniscaat.

Nielsen, L. (1976). *Functional Scheme: Final Skills Assessment.* University of Århus.

Nielsen, L. (1977). *The Comprehending Hand.* SIKON.

Nielsen, L. (1989). *Spatial Relations in Congenitally Blind Infants.* Refsnæsskolen.

Nielsen, L. (1990). *Are you blind?* SIKON.

Nielsen, L. (1992). *Space and Self.* SIKON.

Nielsen, L. (1993). *Early Learning Step By Step.* SIKON.

Oskam, E., & Scheres, W. (2005). *Totale communicatie* (Rev. ed.). Elsevier gezondheidszorg.

Putten van der, J., Houwen, S., & Vlaskamp, C. (2014). *Motorische activering van personen met (zeer) ernstige verstandelijke en meervoudige beperkingen: een teamsport.* Orthopedagogiek: Onderzoek En Praktijk, 53(7–8), 354–367. https://onderwijstijdschriftenplein.nl/tplein/orthopedagogiek-onderzoek-en-praktijk-jrg-53-juliaugustus-2014-nr-7-8/

Splunder van, J., Stilma, J. S., Bernsen, R. M. D., Arentz, T. G. M. H. J., & Evenhuis, H. M. (2003). *Refractive errors and visual impairment in 900 adults with intellectual disabilities in the Netherlands.* Acta Ophthalmologica Scandinavica, 81(2), 123–130. https://onlinelibrary.wiley.com/doi/pdf/10.1034/j.1600-0420.2003.00035.x

Splunder van, J., Stilma, J. S., Bernsen, R. M., & Evenhuis, H. M. (2006). *Prevalence of visual impairment in adults with intellectual disabilities in the Netherlands: cross-sectional study.* Eye, 20(9), 1004–1010. https://doi.org/10.1038/sj.eye.6702059

Steendam, M., & Wallroth, M. (2018). *Visuele Assessment Schaal, Cerebrale Visuele Stoornissen (CVI) bij personen met een zeer ernstige verstandelijke en meervoudige beperking (ZEVMB) Handleiding en invulformulieren.* Visio. https://www.visio.org/visio.org/media/

Visio/Downloads/Rapporten%20webshop/Handleiding-VAS-CVI-ZEVMB.pdf

Sterkenburg, P. (2011). *Vertrouwensrelatie voor ontwikkeling* (1st ed.). Bartiméus.
Stichting Dommelstroom. (producer). (1995). *Waar een weg is, zintuigelijke stimulering bij mensen met een meervoudige beperking* [Film; video cassette].

Straathof, M., Ven van de, I. (1995). *Waar een weg is, zintuigelijke stimulering bij mensen met een meervoudige beperking*. Stichting Maere

Stock Kranowitz, C. (2005). *Uit de pas, omgaan met sensorische integratiestoornis bij kinderen.* Nieuwezijds.

Twint, B., & Bruijn de, J. (2014). *Handboek verstandelijke beperking* (1st ed.). Boom.

Vlaskamp, C., Poppens, P., & Zijlstra, R. (2005). *Een programma van jezelf* (1st ed.). Koninklijke Van Gorcum.

Vlaskamp, C., Wiersma, L., & Hiemstra, S. (2005). *Persoonlijk Activeringsprogramma.* Landelijk KennisNetwerk Gehandicaptenzorg.

Zaal, S., Boerhave, M., & Koster, M. (2008). *Sociaal-emotionele ontwikkeling* (Rev. ed.). https://www.kennisplein.be/Documents/boekje%20SEO.pdf

Zaal, S., Boerhave, M., & Koster, M. (2009). *Hechting, basisveiligheid, basisvertrouwen.* https://www.cordaan.nl/sites/default/files/downloads/boekje_hechting_2009.pdf

Websites we visited and used as a source of inspiration:
www.emgplatform.nl
www.activelearningspace.org
www.lilliworks.com
www.eduplay.nl (vendor of WeesActief Box / Little Room)

Active Learning Observation Form[34]

The purpose of this form is to gain insight into:

1) the options the client has for Active Learning
2) the way the environment can be designed (physical environment)
3) which support techniques best suit the client

After completing this form, there should be enough practical guidelines to create an Active Learning environment for the client. The physical environment can then be optimally adapted to their capabilities. This creates guidelines for the method of support.
The form should be filled in together with parents or a personal caregiver.

Name:
Date of birth:
Date form completed:
Completed by:
Diagnosis:

Mental functions (IQ and EQ):

Personal characteristics/ analytical aspects	Description: circle what applies	Comments
Visual data	Acuity: Contrast sensitivity: Field of View: Visual attention: Capacity for visual fixation: Preferred Eye: left/right Cerebral Visual Impairment: yes/no	
When participant is most alert:	Morning / late morning / afternoon / late afternoon / evening / varies	

---

35 The observation form was created by the Active Learning project group, and it is partially based on the Play Quality List-m.d. found in the book Playing is growing, play development and facilitating play in visually impaired and blind children (Moleman, Van den Broek & Van Eijden, 2009)

Personal characteristics/ analytical aspects	Description: circle what applies	Comments
Preferred pathway to learning:	Touch – sight – hearing – movement – smell – taste	
Specific information about other senses:	Hearing impairment tactile under sensitivity/hypersensitivity – under sensitivity/hyper-sensitivity to movement (explain)	
Health condition:	What health aspects need to be taken into account? (e.g. epilepsy)	
Which parts of the body allow motor activity?	Head – right arm/hand – left arm/hand – right leg/foot – left leg/foot	
The best starting position (for engaging in activities):	Supine – supine supported – prone – prone supported – sitting (unsupported on a mat) – sitting in own chair – standing at standing table – sitting in swing – sitting in bouncing chair – lying in hammock	
Preferred materials:	Hard – soft – chewable – with sound – always plays with the same materials – is stimulated by new materials	
Describe favourite toy or game:		

Personal characteristics/ analytical aspects	Description: circle what applies	Comments
What actions are possible?	Undirected movements – directed reaching and grasping – holding and releasing – combined reaching/grasping/ releasing with corresponding tactile and auditory input – manipulation – manipulation, feeling and listening – object comparison based on active manipulation and tactile exploration	
Does the client show initiative in interaction?	None – makes contact with own body – makes undirected contact with materials nearby – makes active physical contact with materials nearby – actively searches for materials nearby – actively seeks physical contact with people in the vicinity (how?) – actively seeks contact with people in the vicinity to initiate a play action	
Stereotyped behaviour:	Repeats certain physical actions – rocks their body – repeats sounds – always performs the same action with materials – only wants to play with one specific toy in a repetitive manner	

Personal characteristics/ analytical aspects	Description: circle what applies	Comments
Variation of toys:	Chooses different materials on own initiative - varies materials when offered by a caregiver - can only focus on one material at a time prefers to always play with the same material - has difficulty focusing on a particular choice, quickly switches to something else	
Playing area:	Has access to a quiet well-defined playing area – only plays in a space where others are present – lighting in the room can/cannot be adjusted (explain)	
Available materials:	There are/are not enough playing materials available -materials can/cannot be properly fixed in place (explain)	

Personal characteristics/ analytical aspects	Description: circle what applies	Comments
Support technique:	Offering - imitation - interaction - sharing the work - consequence	
Are there idle moments?	Describe these moments: when, and how often per day?	

Active Learning Support Plan

	Description	Evaluation
Problem statement:		
Goal:		
Time(s) and frequency:		

	Description	Evaluation
Playing area:		
Most important aspects from the observation form which have to be taken into account:		
Start date: **Support technique:** **Specific materials:** **Objects:**		
Start date: **Support technique:** **Specific materials:** **Objects:**		

	Description	Evaluation
Start date: **Support technique:** **Specific materials:** **Objects:**		
Start date: **Support technique:** **Specific materials:** **Objects:**		
Start date: **Support technique:** **Specific materials:** **Objects:**		

Notes

Royal Dutch Visio
Centre of expertise
for Blind and partially
sighted people

Visio welcomes anyone with questions about being partially sighted or blind, including those who also suffer from additional intellectual, physical, or sensory disabilities. Visio helps people find answers to their questions about various aspects of their lives, such as aids, education, housing, work or hobbies. Throughout the whole of the Netherlands, Visio staff are expert partners for their clients, residents and pupils, and their networks. Expertise, innovation, passion, and cooperation are at the heart of their efforts.

Active Learning is a treatment method for children and adults with PIMD and visual impairments and a developmental age of 0 to 24 months. The method was developed by Dr Lilli Nielsen (1926-2013) and provides a theoretical foundation with suggestions for practical application. Active Learning primarily focusses on clients who show a low level of activity or who, owing to their disabilities, find it difficult to engage in activities. This theory book examines emotional development, interaction that fits the level of emotional development, and functional development. The book also provides a description of the specific objects and materials that are frequently used with Active Learning. These materials stimulate the client to explore their environment. This helps the client to increase their awareness of their environment, showing them that there is a difference between them and their environment. Beside this theory book, there is also an Active Learning work book and a training programme. For more information please visit: www.visio.org/activelearning

www.visio.org