

**Inaugural lecture**

# **Communication for everyone**

INAUGURAL LECTURE BY PROF. MATHIJS VERVLOED

**Radboud University**



## Inaugural lecture prof. Mathijs Vervloed



In his inaugural lecture, Mathijs Vervloed discusses the challenges involved in research on Augmentative and Alternative Communication (AAC) in children with multiple disabilities.

When speech fails and communication does not occur spontaneously, there are other ways to communicate. However, this requires providing support to both to the child and their communication partners. Communication supporting devices can help with that. The lecture is about choosing particular devices, how to deploy them and whether using them also leads to language. From an orthopedagogical perspective, the author examines the potential of AAC and the challenges present in the diagnosis and treatment of communication problems. He also discusses which language acquisition theories could assist in teaching AAC efficiently

and how research on children with multiple disabilities can contribute to the theoretical understanding of language acquisition in children.

Mathijs Vervloed (1964) studied Orthopedagogy at Utrecht University and obtained his PhD at the University of Groningen in 1995 for research into the cognitive development of children born prematurely. He then worked for 10 years in various positions in disability care for children with visual, auditory and multiple disabilities. Mathijs Vervloed has been associated with Radboud University since 1997. He is a researcher at the Behavioural Science Institute, lecturer in the Pedagogical Sciences programme and director of the Behavioural Science Research Master. The endowed chair in Augmentative and Alternative Communication was established in 2010 and has been held by Mathijs Vervloed since September 2023. His teaching and research remit is 'Augmentative and Alternative Communication in children with multiple disabilities'. The chair is funded by Stichting Milo.

**COMMUNICATION FOR EVERYONE**



# **Communication for everyone**

*Lecture delivered upon acceptance of the appointment as endowed professor in Augmentative and Alternative Communication in children with multiple disabilities at the Faculty of Social Sciences of Radboud University on Wednesday, 26 June 2024*

by Prof. Mathijs Vervloed

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communicatie



voor



iedereen



*Esteemed Rector Magnificus, distinguished audience,*

You have been lured to this auditorium this afternoon for an inaugural lecture titled 'Communication for everyone'.<sup>1</sup> Perhaps when you heard 'for everyone', you thought 'It's nice that it's also for me, but I am not everyone and what is actually meant by this?' Those of you who remember the inaugural lecture and farewell address of my predecessor Hans van Balkom may have understood it as an observation.



Figure 1. Language that does not arrive in speech.

'Language that does not arrive in speech always finds its way out in communication' (Figure 1). Hans called that 'elephant paths'. If you cannot speak, gesture or write, there are always other ways to convey messages: consciously or unconsciously, socially adapted or

<sup>1</sup> I delivered an abridged version of this lecture on 26 June 2024 as an inaugural lecturer on acceptance of the endowed chair in Augmentative and Alternative Communication in children with multiple disabilities, established by Stichting Milo. I would like to thank Stijn Deckers and Judith Stoep for reading an earlier version of the inaugural lecture and giving valuable feedback.

maladjusted, children always find ways to communicate. Incidentally, this is also a modern variant of Paul Watzlawick's first axiom: 'One cannot *not* communicate'.

'Communication for everyone' can also be understood as a question. I only need to change my intonation and pitch. But is communication truly for everyone? Those who work with children with multiple disabilities know that it is not at all self-evident that these children will learn language, whether through speech or gestures. In many cases it is also very difficult for their parents, siblings, teachers or caregivers to understand them and be understood by them.

Communication for everyone is also an appeal. It is an appeal to create situations where communication becomes accessible to everyone, and is understood and usable. Here I would like to draw a comparison with Design for All, the movement to design products so that they are usable to the greatest extent possible by all people, without the need for adaptations afterwards or a special design. Whether that is feasible for communication, I do not know. This also reflects a dilemma faced by therapists. You can use means such as augmentative and alternative communication to make communication accessible, but such a device can simultaneously make communication inaccessible: it may not work, it may come between the communication partners, everyone must first learn to work with the device, or the device may put people in an exceptional position.

In this lecture, I see Communication for Everyone – as an observation, a question and an appeal – as my mission. I will take you on a journey through a world of language and communication for children with multiple disabilities. Like *Milo*, the namesake of Stichting Milo that funds my chair, we are going on a journey (Figure 2).

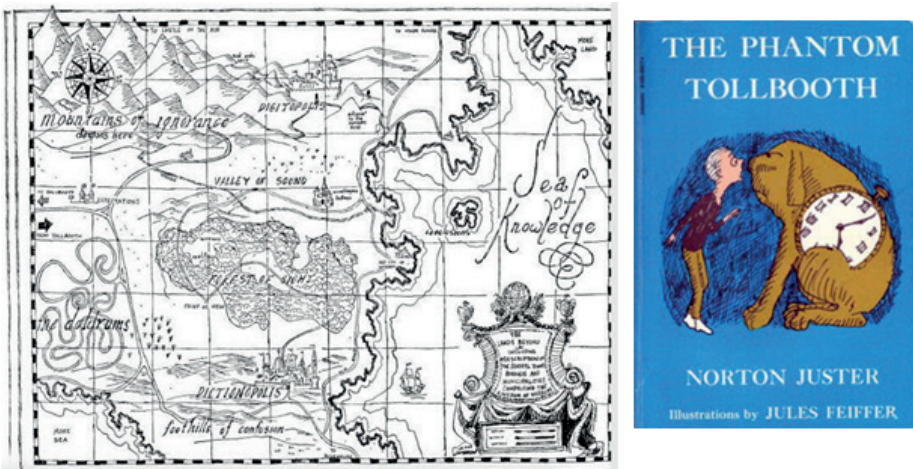


Figure 2. The Phantom Tollbooth.



Milo is the main character in Norton Juster's 1961 children's book *The Phantom Tollbooth*. We do not travel like Milo by toy car through the Kingdom of Wisdom, the Foothills of Confusion, the Mountains of Ignorance or the cities of Dictionopolis and Digitopolis, but we guide Milo through his world and you can come along. Together, we will explore the world of meaning in language. Milo's world is a place where children with multiple disabilities live together with their siblings, fathers, mothers, grandfathers and grandmothers.

On the journey I want to take with you, I will share a lot of facts and ask many questions that I probably do not have answers to either but that are worth investigating. Every now and then I will make an appeal – for understanding, attention, a new goal or to ask a new question – which we can then investigate.

## **Communication for everyone: an observation, a question and an appeal**

Milo is a little boy who does not want to grow up, does not want to learn and is rather bored with life. One day, he finds a large box at home with a strange tollbooth inside. When he enters the land beyond the tollbooth, where everything revolves around words and language, he learns to truly think and discover his purpose in life. The story illustrates the interconnectedness of language, thought and meaning. It is extremely funny and inventive writing that is full of absurd linguistic jokes.

These are today's learning objectives:

- To know (goal) and be able to articulate (the operationalisation in measurable terms of the goal):
  - for whom augmentative and alternative communication is intended;
  - what the three research lines within the chair group are;
  - the challenges we face in researching augmentative and alternative communication;
  - the fascinating insights that research can yield.
- To be able to use one communication supporting device independently in real-life situations.

In addition, I will address the following points:

- What is attention anyway?
- What do interaction, communication and language mean?
- A door.

## Communication as a pedagogical task

Since language and communication always find a way out, we are researching how to enable them in such a way that everyone can learn, understand and sustain them.

I am a remedial educationalist, so the question is what does communication have to do with educating? I do not see communication skills as the ultimate goal of training or education, but as an intermediate goal, just like other skills children need to learn. Especially for children with disabilities, it makes little sense to name concrete end goals of training, suggesting that this socialisation process should result in articulate and independent adults. After all, seeing it this way would mean that many children with disabilities cannot be educated. Ko Kok suggests a much more workable definition of educating (Figure 3):

*Educating involves the relationship between the educator and the person being educated, in which the educator presents themselves as a person, exemplifying their way of being human. This process includes creating an environment that fosters personal growth and managing living situations in such a way that they provide optimal opportunities for self-development.*



Figure 3. Prof. J.F.W. (Ko) Kok (1929-2019).

It is essential that there is a relationship between child and educator, as this provides benefits like basic trust and attachment. Educators create a climate in which children can grow and develop. They achieve this primarily through their personality and by modelling desired behaviour, rather than by directing, drilling or training. A child needs to feel safe, valued and challenged. This is the environment that educators must create.

The phrases 'managing living situations' and 'providing optimal opportunities' echo Vygotsky's (1978) ideas about the zone of proximal development and what educational psychologists call scaffolding, which involves identifying and offering intermediate steps in a stimulating environment to support a child's learning.

Self-development as a goal may sound a bit vague, but this concept is inclusive for everyone. I see concepts like quality of life, social inclusion or participation as concrete expressions of self-development, as a form of well-being. Educating without a fixed end goal does involve specific intermediate goals, such as becoming as competent as possible in communication.

## Augmentative and alternative communication – people first

About whom or what exactly are we talking here? Augmentative and alternative communication includes all facilities, forms of language and devices that support the existing communicative skills, abilities and needs of people with communication disabilities.

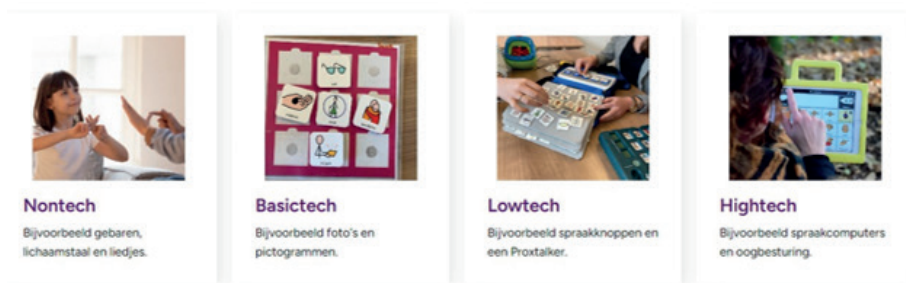


Figure 4. Forms of augmentative and alternative communication.

Broadly, we can distinguish between four types of devices: communication without technical devices and communication with basic, low- or high-tech devices. Figure 4 shows examples. Very often, these devices are used simultaneously or successively.

English speakers use the phrase augmentative and alternative communication for what in Dutch is called 'ondersteunde communicatie' (which literally translates into 'supported communication'). Until recently, like most of you, I was somewhat familiar with the phrase, but did not know exactly what it means and for whom it is intended. That is why I searched the international scientific literature for this phrase. To keep it manageable, I only entered the search term 'augmentative and alternative communication'. I then ran the titles and abstracts I found through a visualisation program (VOSviewer), just to get a better idea of what and whom we are talking about.



Figure 5. Augmentative and alternative communication in VOSviewer.

First, you will notice that all the articles with augmentative and alternative communication in the title or abstract are about individuals. That might seem obvious, but it is not. In disability care, it is good practice not to reduce people with disabilities to their impairments. This is also why I refer to children with multiple disabilities instead of multiply disabled children. The multiple disabilities may distinguish these children from children without disabilities, but the disability is not the only feature that characterises their lives and existence. People with red hair, people of colour or people with an above-average clothing size know what I am talking about.

Highlighting a disability or condition has other drawbacks. Doing so defines someone as deviant, pathological or 'behind', ignoring the concept of natural variation and the fact that group classifications are dependent on place, time and culture, and are therefore fairly arbitrary. If you mainly name the person's disability, the focus overemphasises what someone cannot do rather than what is possible.

That is why it is good practice to use people-first language, like 'children with...' followed by the disability. The choice of terms is highly sensitive. Recently, a reviewer for an academic journal accused me of ableism for using an outdated term. Ableism means discrimination, marginalisation and stigmatisation of, in this case, people with disabilities, irrespective of the intention behind the expression. And my intentions had been well-meaning.

In the literature, people talk not only about individuals but also about patients. This is because augmentative and alternative communication is also widely used for patients with diseases such as ALS, Parkinson's disease, aphasia, multiple sclerosis and dementia. In a medical context, they are referred to as patients. These patient groups are not the focus of my academic chair. Indeed, they differ from most children with multiple disabilities in

terms of when the disabilities manifest. Children with multiple disabilities generally have the disabilities from birth or even in the womb, while the aforementioned patients first learned typical speech and communication and later lost this ability due to an illness. For those patients, the skills of speaking and listening must be accessed through alternative means, but their existing language system can be a foundation. This contrasts sharply with children with multiple disabilities who do not have access to spoken or sign language, and still must learn communication and language.

## The target group: children with multiple disabilities

So, my academic chair focuses on children with disabilities, specifically children with multiple disabilities. There are many synonymous terms used to refer to this group, including 'developmental disability' (highlighted in blue in Figure 5). Such a disability can be single (such as difficulties with hearing, seeing, thinking or moving) or multiple (involving a combination of these single disabilities). Both children with single and multiple disabilities can encounter communication problems that can be alleviated through augmentative and alternative communication.

For Stichting Milo, and therefore also for my chair, our target group is not so much the children with single disabilities, but mainly the children with multiple disabilities of which one is a communication problem. We call this group children with multiple communicative disabilities (MCD). The Milo website describes this as follows (Figure 6):

DOELGROEP

### Voor wie is ondersteunde communicatie?

Bij Milo helpen we kinderen en jongeren die niet of nauwelijks kunnen praten én de mensen om hen heen, ook wel communicatiepartners genoemd. Als je niet of nauwelijks kunt praten, heb je vaak te maken met een communicatief meervoudige beperking (CMB).



Figure 6. The target group for Stichting Milo.

### Heterogeneous target group

The target group consists of children with multiple communicative disabilities (MCD). However, this group is very heterogeneous. Thus, in addition to language and speech problems, children with MCD often also have mental, motor and/or sensory (hearing or vision) impairments, to varying degrees and in different combinations. What the children

have in common is their inability to express themselves through spoken, written or sign language, or to do so adequately. They also often do not understand such language or understand it insufficiently, but this is not necessarily always the case. There are children who understand spoken language well or reasonably well, but cannot express themselves in spoken language. These might include children with severe spasticity. Von Tetzchner and Martinsen (1992) identify a few more groups that can benefit from augmentative and alternative communication (AAC). These include children who temporarily use AAC to communicate, children who are difficult to understand and use AAC to enhance intelligibility, and children for whom AAC is a permanent alternative for both understanding and expressing communication.

At Milo, we not only help the children who cannot speak or sign, but also the people around them, the communication partners. After all, they too need to learn how to communicate when 'normal' talking or signing does not work. It is important to note that AAC is also used when sign language or written language does not lead to communication. To be clear, sign language is a full replacement for spoken language among children who are deaf, so we do not refer to that as AAC. However, other groups of children may use sign language or its components, just like printed or written language, as an AAC tool.

Referring to complex communication needs as 'multiple communicative disabilities' is actually a pleonasm: the word 'communicative' is redundant because it is one of the disabilities. That is why the word communicative is not part of the description of my chair. Instead, it says augmentative and alternative communication in children with multiple disabilities. Still, the addition of 'communicative' could serve an important function, because it highlights the core of the problem that one aims to address, in this case, communication difficulties.

Confusion occurs when therapists and researchers all start claiming their own target group. Here is a not even exhaustive overview of some terms used for the target group of children with multiple disabilities (Figure 7).

The terminology often indicates where the researcher or therapist works. Those who talk about children with 'multiple disabilities with visual impairment' work with children with a visual disability. 'Profound intellectual and multiple disabilities' refers to children with intellectual disabilities. Deaf+ refers to children who are deaf or hard of hearing. In essence, however, these are often the same children.

I would like to call for an end to prioritising one disability over another. The population is already so small. If researchers or practitioners emphasise one disability based on their expertise, because they receive funding from a certain perspective or think that this will make the group more homogeneous, making it less ambiguous to understand, the group will only become smaller. And that really does not solve the problem of heterogeneity within the group.



Figure 7. Alternative terms for Complex Communication Needs.

The group of children with multiple disabilities will always remain heterogeneous. Not only do the children have different numbers and types of disabilities, but there is also a big difference in the extent to which they experience problems. Moreover, especially for language development, it makes a lot of difference whether a child has the disability from birth or acquired it later in life, and whether the condition that led to the disabilities remains stable over time or is progressive and becomes increasingly severe or even leads to early death. AND it matters whether the problems leading to disabilities mainly lie in the senses or motor skills, or mainly lie in the brain. In the first case, there is a problem with the input or output of communicative information, and this is often solvable with technical solutions such as glasses or hearing aids; in the latter case, there is a problem with information processing, for which fewer interventions are available.

### What is a multiple disability?

For me as a remedial educationalist, it is important to describe what capabilities a child has and how their multiple disabilities interact. In that context, various diseases, disorders and disabilities occurring together are not particularly interesting in themselves. This is merely a



case of comorbidity, a stacking of individual conditions. It only gets interesting when there are also multiple disabilities from an orthopedagogical perspective. In this, I follow Han Nakken, former Professor of Orthopedagogy in Groningen. According to Nakken (1993), a multiple disability exists when the assistance, education and interventions normally used for one of two disabilities – each of which could individually lead to a disabled existence – are not applicable because of the other disability. An example: a child with an intellectual disability has difficulty learning based on verbal explanations, but might be able to learn by seeing or experiencing things. If this child also has a visual impairment, seeing becomes difficult, and if this child also has a physical disability, experiencing becomes difficult. A completely new form of teaching and education must be found for this child, and that is precisely what the staff of institutions like Milo are engaged in every day.

## Interaction, communication and language

For the sake of clarity, I will also explain the meaning of interaction, communication and language. That way, at least we will be speaking the same language. Note that other definitions are also possible, but the following functional definitions apply in the context of augmentative and alternative communication (also see Figure 8).

### Interactie:

Wederzijdse beïnvloeding, waarbij de uitwisseling van informatie niet de status van de partners verandert

Axioma 1 Watzlawick:  
Het is onmogelijk om  
niet te communiceren.

### Communicatie:

Een actief proces waarbij twee of meer personen elkaar (intentioneel willen) beïnvloeden om elkaars gedrag, intenties en status van kennis of informatie te veranderen.



### Taal:

Conventionele set van arbitraire symbolen en een set combinatieregels waarmee gedachten, indrukken, interpretaties van de directe en indirecte omgeving in verschillende representatievormen kunnen worden vastgelegd en geuit met het primaire doel om kennis en informatie uit te wisselen, te communiceren.



Figure 8. Interaction, communication and language.

Interaction is mutual influence where the exchange of information and meaning does not change the status of the partners. Sports and dance are good examples of situations where interaction occurs. Working together as in dancing or opposing each other as in boxing are forms of interaction, but that does not yet constitute communication.

In Milo's world, communication is an active process in which two or more people intentionally want to influence each other to change each other's behaviour, intentions



and status of knowledge or information. I question the intentional aspect. In line with Paul Watzlawick's first axiom that it is impossible not to communicate, an intention on the part of the sender of a message is not necessary. Intentions can also be interpreted by the recipient of the message. For instance, most mothers are quite capable of hearing from their baby's crying – which is itself bodily behaviour – whether the child is hungry, anxious or bored.

Language is the use of a conventional set of arbitrary symbols and a set of combination rules to capture thoughts, impressions and interpretations of the immediate and indirect environment in various forms of representation, and express them with the primary purpose of exchanging knowledge and information, of communicating them. For spoken languages, the arbitrary symbols consist of sounds and words, and for sign languages they are hand shapes, hand locations and movements. A set of combination rules refers to grammar, which involves conjugating, inflecting and placing words in the correct order within a sentence. The beauty of it all is that an almost unlimited amount of language can be produced with a limited set of words. It is important to realise that interaction, communication and language are essentially not personal characteristics; they manifest in pairs or groups of people. All three require at least one other person.

## **Skills required for augmentative and alternative communication**

During my inaugural lecture, I showed the audience a short video clip of Tess taken from the Deelkracht website.<sup>2</sup> Tess is a girl with a communicative disability, but she definitely also has communication skills and language comprehension. Tess uses augmentative and alternative communication to express language, employing a high-tech tool – in her case, a speech-generating device. Using augmentative and alternative communication, particularly when it involves devices, can be quite challenging. Users of communication supporting devices need to possess various skills to use them effectively. Especially with the high-tech devices, this requires practice and training.

For some children, spoken or sign language does not emerge spontaneously. These children may benefit from AAC. Not infrequently, and especially with high-tech devices, this requires practice and training. That is the focus of Peia Prawiro-Atmodjo's PhD research. This project is a collaboration between Koninklijke Kentalis and Stichting Milo and is conducted within the Deelkracht programme. Peia discussed this during the symposium. It is a fine example of application-oriented research within which a theoretical model serves as a guide. In this case it is Light's (1989) model. It dictates that successful use of communication supporting devices requires the user to possess skills in four areas:

- 1) linguistic competences, such as being able to determine when to put which vocabulary on the device, navigating the device (knowing what is where) and constructing sentences by placing words in the correct order;

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<sup>2</sup> <https://www.deelkracht.nl/en/>

- 2) operational competences, such as being able to switch devices on and off, operating and maintaining them, programming the device and resolving technical issues;
- 3) social competences, such as being able to ask others questions and answer them, and being able to get the attention of communication partners (e.g. by repeating something or turning up the volume);
- 4) strategic competences, such as explaining to others how to use the device (e.g. with a pre-programmed request asking them to read along and/or asking them to wait patiently until the user has finished drafting a message), using total communication or different modalities (e.g. eye contact, sign language and facial expressions) during communication, and dealing with miscommunication (e.g. by repeating a question, providing additional information or directing the person's attention to the device's screen) (Light, 1989; Light & McNaughton, 2014).

Peia's research also focuses on two other aspects crucial to the success of communication supporting devices: psychosocial factors (e.g. the users' motivation, attitude, resilience and self-confidence) and environmental factors that affect the use of these devices (e.g. acoustics, lighting or the presence of multiple people).

## Culturally sensitive assistance

Let us return to the visualisation of published research on the topic of augmentative and alternative communication. In Figure 9 you can see the collaborative networks between researchers in this field. Americans produce the most publications, followed by researchers from some European and English-speaking countries. The Netherlands plays a modest but structural role. What you see here is characteristic of a lot of scientific research: it is WEIRD. This acronym stands for Western, Educated, Industrialised, Rich and Democratic. And WEIRD research is a problem. For example, it has long been known that a gap can exist between therapist and client in terms of the figurative and literal language they speak.

Therapists tend to be highly educated white, western, verbally adept people, say the average audience at an inaugural lecture, while their clients are not always the same. Publications in psychology overwhelmingly come from WEIRD countries (Henrich, Heine, & Norenzayan, 2010). Henrich and colleagues calculated that 96 per cent of research populations in psychological publications come from countries where 12 per cent of the world's population lives. This leads to bias, misconceptions and prejudices in the diagnosis and treatment of people from ethnic, linguistic, cultural and religious minority groups in particular (also see Garb, 2005).

More attention has been paid to these groups in recent years thanks to the concept of culturally sensitive education and assistance. The question is whether this attention is sufficient to adequately support the parents of clients with auditory impairments, language development disorders and multiple communicative disabilities. It may also

happen that parents born and raised in the Netherlands are not well supported because of bias on the part of therapists. Examples include parents with low socio-economic status, low levels of education or mild intellectual disability, or very young parents or parents who themselves have an auditory impairment or language development disorder. The therapists are rarely part of these groups, may not have an inherent understanding of these people's worlds and may therefore lack a direct connection or rapport with them. From mental health care, we know that the client-therapist relationship is one of the most important predictors of intervention outcomes. That relationship sometimes predicts outcomes better than the content of the intervention itself (Asay & Lambert, 1999). In disability care, and more specifically in AAC interventions, there is a long-term, intensive collaboration between a therapist and a client and their communication partners. It is generally agreed that these interventions are only meaningful and efficient if they align with the client's world (Beukelman & Light, 2020; van Balkom, 2018). For disability care, it is therefore important to understand and, to some extent, respect the client's culture, world and experience. In anthropology and developmental psychology, this phenomenon is known as the developmental niche (Super & Harkness, 1986; Harkness & Super, 1994). In orthopedagogy, it is known as the collective and individual 'story' of the client (Ruijsseenaars et al., 2022). When the therapist and diagnostician do not know the client's developmental niche and their story, there is a high likelihood of errors in making diagnoses, setting priorities for interventions and assessing the abilities of the client and their educators and relatives in carrying out the interventions.

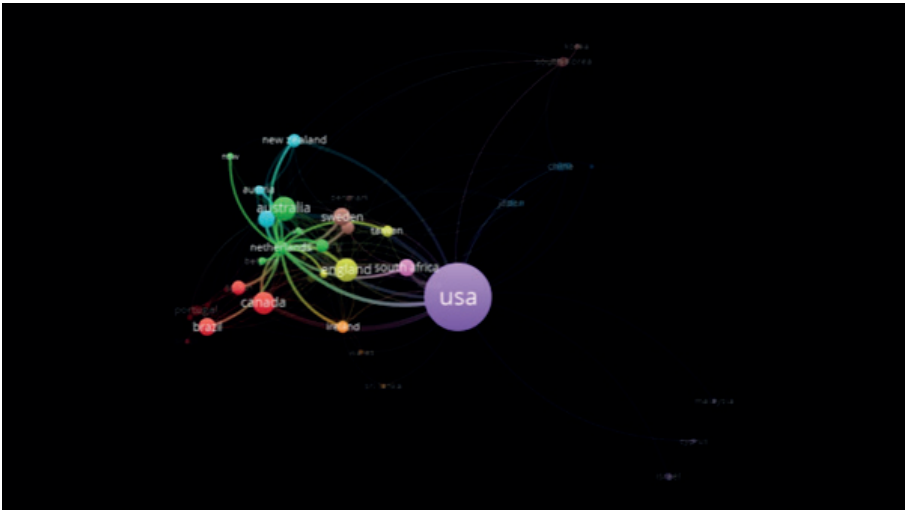


Figure 9. Collaboration between researchers in the AAC field.

## Intermediate goals

A related problem is that therapists in disability care do not always have formulated an explicit end goal for their treatment. Because an auditory or (multiple) communicative impairment is often permanent, symptom elimination is usually out of the question in assistance, and symptom reduction is sometimes only marginally feasible. Therapists tend to focus on small (intermediate) goals in training, education and assistance. Their long-term expectations often remain implicit. If there is then also no knowledge and understanding of the client's developmental niche and story, there is a risk that the assistance provided will be inappropriate, undesirable, suboptimal and thus ineffective. As a result, clients may not develop to their full potential and participate fully in society.

Knowing the client's developmental niche and story plays an essential role in assisting children and young people with multiple communicative disabilities. The form and content of language and all other forms of communication are an essential part of that niche and that story. Manuals on AAC consistently emphasise that setting intervention goals and priorities, and collaborating with the client and their communication partners, are essential for the intervention's success (van Balkom, 2018; Beukelman & Light, 2020; Loncke, 2021). Assistance should align with the concerns, priorities and *resources* of the client and their communication partners.

This is important for two reasons. First, this alignment is generally done to maintain high motivation among all involved. Communication requires at least two people: a client with MCD and a communication partner. Those partners are indispensable. Although not ideal, regular speech therapy can still partially suffice with treatment by a speech therapist, with minimal input from parents or caregivers. In AAC, treatment entirely outside the natural context of children or young people with MCD makes little sense. So, an AAC intervention places a significant demand on their communication partners. If the intervention does not align with their experience, they will find it difficult to sustain it. It may also be ineffective because the impact of such interventions is now measured by the success with which children and young people can participate in social groups relevant to them after the intervention (see the participation model in Beukelman & Light, 2020, p. 28). This means that people in those relevant groups should also become proficient in using communication supporting devices.

The second reason why assistance must align with the concerns, priorities and resources of clients and their communication partners relates to the content of AAC interventions. In addition to content and form, communication also has a purpose or function for a child. We need to recognise those functions and leverage them in the communication training. Light (1988) and Rowland & Fried-Okken (2010) described these functions as follows:

- 1) expressing wants and needs, regulating behaviour, communicating what you do and do not want (the refuse and obtain categories in Rowland's Communication Matrix);
- 2) information transfer, i.e. sharing information (the seek/provide information category in Rowland's Communication Matrix);
- 3) social proximity, engaging in and maintaining social interaction (the social interaction category in Rowland's Communication Matrix);

- 4) social etiquette, conforming to social conventions;
- 5) conducting an internal dialogue: the internal language we use to communicate with ourselves as part of thinking and (self-)reflection.

The first four communication goals are susceptible to cultural bias. If the therapist does not take the client's developmental niche and story into account, they miss the mark.

In a project with colleagues from Stichting Milo, Koninklijke Kentalis and the Centre of Expertise for Dutch Language Education, we are currently working on a guideline for culturally sensitive practices in AAC. We think guidelines are a good way to bridge the gap between science and practice because guidelines translate scientific knowledge into practical action in clinical practice (Newnham & Page, 2010). They prevent errors and biases and encourage practitioners to follow crucial and necessary treatment steps and prevent them from 'drifting away' from them (i.e. intervention drift). This guideline is expected to be completed in the autumn, and it will be quite a task. This is not primarily because the differences between cultures are not known, but because we want to try to also link a recommendation to an identified difference. An example: parents from some cultures note that the use of an AAC tool may be appropriate in a Dutch school but that it is not acceptable to them at home. They want their child to learn to speak, but that is not always feasible. And if we interpret the desire for their child to learn to speak in a very culturally sensitive way (i.e. respect that no communication supporting devices will be used at home), it means that the child will not learn to speak, at least not at home.

## Research lines within the chair

The guidelines project fits within the first of three lines of research (i.e. Participation) we have set up within Stichting Milo as a basis for the chair. The other two research lines concern Diagnostics and Clinical Reasoning to find the most appropriate treatment, and research on Educational and Developmental Opportunities through Literacy.

### Research line 1: Participation

This line aims to promote the participation of children with MCD in everyday life in a manner that suits their development and abilities. The challenge is not to convince people that children with disabilities have the right to inclusive education or should be able to participate in society. Almost everyone agrees on that. The challenge is related to what this looks like, whether it is always feasible and whether there is the money, knowledge and time to make it happen. Another challenge is convincing people that participation must involve more than just the presence of children with disabilities, as that is only physical inclusion. They must also feel involved in the situations in which they participate. And this involvement must come from both sides: from the child and from society. We ask people who can speak and communicate to consider children who cannot do so spontaneously. And arranging that is not easy.

You probably have noticed that there is a shortage of teachers in the Netherlands, which means that many school-age children are not attending school. This situation has worsened rather than improved since the introduction of tailored education. Between 5,000 and 15,000 children stay at home and do not go to school. Many children with multiple disabilities are exempt from educational requirements. Instead, they go to a day care centre or attend a day programme. And if they go to school at all, it is special education, not regular education. In our education system, children are expected to achieve the minimum learning outcomes for primary education. For many children with multiple disabilities, this is not achievable. Fortunately, experiments are now underway with education-care arrangements and 'going back to school together' classes. But this is happening on a small scale, and if children are in the same building but not in the same class, is there true social inclusion? Another factor is that many people in education are convinced that our special education system is not only extremely good, but also much better for children with multiple disabilities than inclusive regular education. I can endorse the first statement, but I have reservations about the second.

As far as I know, no primary school teacher training programme in the Netherlands includes teaching children with disabilities as a compulsory part of the curriculum. Perhaps it is part of a theoretical course, but not part of internships. If a student teacher does not come into contact with children with disabilities, how can you cultivate affinity with this target group and how can you equip these students with the necessary skills and knowledge? Let me make a second appeal here, and this time to my own colleagues: arrange for teaching children with disabilities to become a regular part of our academic primary school teacher training programmes. I am very pleased with the optional opportunities our students are offered to gain experience in special education and cluster education, but I believe it should be mandatory.

So the chair's first research line is about promoting the participation of children with disabilities. Incidentally, in my ideal world, that does not mean that I think every child should receive regular education, but I do value the idea that parents and children should have that choice. Although many parents struggle with sending their child to cluster education, I also know that many children with disabilities flourish once they are in that setting. For me, participation means above all that children receive an education close to home and at a school of their choice. This participation ideal reflects a choice, a vision, if you will. For now, it is a goal we are happy to pursue.

## **Research line 2: Diagnostics and treatment**

Investigating what works in diagnostics and treatment is a challenging task. At Milo, this is done using the Communication Competence Profile, which was developed based on social-neurocognitive development theories. Soon, we will proceed with validating this profile and further developing the principles of dynamic assessment. This approach to diagnostics involves alternating between learning and testing to map the skills and abilities of children. Stijn Deckers is the driving force behind this diagnostics-treatment research line.

This autumn, Myrthe Vermeiden will become a PhD candidate and start her research on the social-neurocognitive model under my supervision and that of Stijn and our colleagues Nienke Peters-Scheffer and Linda Visser.

Orthopedagogy is an action science, which is why we like to use interventions such as augmentative and alternative communication. The question is whether they work. Generally, the answer is yes. You can see that in the video of Tess, and the scientific literature is also full of examples. However, expectations must be realistic. Some children with disabilities learn to speak hundreds of words, while others can only learn to use a few dozen words expressed through a device.

By the way, significant individual variation is very characteristic of early language development. This variation manifests not only in the degree of language development but also in the timing of when specific skills become apparent. One reason for this significant individual variation is the language input a child receives, both in quantity and quality. The amount parents talk to their children varies greatly, but the content of that speech also differs significantly, and that strongly correlates with their children's language skills. The language input is also guided by the child's responses. Individual differences reflect not only the parents' talkativeness but also the child's language skills and the way in which they respond to the offered language. If a child does not respond and does not show that they understand a message, the language input from the conversation partner will gradually decrease. Unfortunately, we often see this with the use of communication supporting devices. A crucial task for trainers, therefore, is to keep therapists and parents engaged, motivating them to intuitively do the right thing and continue talking. This ensures communication becomes accessible to everyone.

## Interventions

I would like to briefly discuss some hot off the press interventions from Stichting Milo. Together with Stijn Deckers, I supervise two research master students, Romy Traas and Sophie Tesselhof, who are researching two interventions from Stichting Milo: KLIN© and IKOOC (Figure 10).

Both interventions are preceded by a diagnostic phase in which a communication competence profile is drawn up. KLIN© takes place at three sites, while IKOOC is applied in all daily contexts of a child with MCD: at home, in schools and in children's day centres. In her PhD thesis, Margje van der Schuit showed that the KLIN© method, which was initially offered at only one location, is effective. The children showed progress in language and communication. The KLIN© method has since been further developed, and new practitioners and locations have been added. In addition, IKOOC was introduced. This is an outpatient treatment in which the Milo staff member supports parents, family members, a group leader or teacher in carrying out language and communication interventions. This intervention is less intensive and less controlled than the KLIN© method. We now have data from about 50 children with whom the KLIN© method has been used and from over 160 children who have used IKOOC in recent years. The results are very promising. Language and communication

measurements indicate that both interventions lead to improved performance, regardless of the initial level at the start of the interventions. However, younger children seem to make more progress on some variables than older children. As expected, children who received the KLIN© intervention had made more progress than those in the IKOOC group. More intensive training leads to better performance. For the KLIN© group, we have now also been able to study children's individual trajectories. It appears that not only did the children as a group make significant progress, but most individual children also showed clear improvement on 80 to 95 per cent of the variables. Whether the results will hold in the long term is still being investigated.



Figure 10. Interventions by Stichting Milo.

### Research line 3: Education and literacy

Children's linguistic and communicative development proceeds through three transitions:

1. from interaction to communication;
2. from communication to language;
3. from language to literacy.

The first two transitions are included in the interventions offered by Stichting Milo. You might not expect (the research on) the third transition, from language to literacy, to apply to children with multiple disabilities and communication needs, because it may seem strange that children who do not speak can understand written language. Yet this is often the case. Thus, in addition to the first two research lines (Participation and Diagnostics & Treatment), we have a third line of research. In it, we examine how language and literacy can contribute to children's development and make education more accessible to them.

If you look at the example of a playground sign from ISAAC-NF (Figure 11), you will see that the icons are accompanied by the matching words. This is useful for the adults who wish to communicate with the child, as the meaning is clearly indicated alongside the drawing.



But the same convenience also applies to the children. Once they can read, written text becomes an AAC tool as well. In the Netherlands, in particular, Loes Theunissen from the Sint Maartenskliniek is training teachers from cluster 3 education to use her LOeS working method<sup>3</sup> to teach children with MCD to read. Together with Jan van der Burg, remedial educationalist at the Sint Maartenskliniek and lecturer in Pedagogical Sciences at Radboud University, Loes is enthusiastically promoting her method. We are also very pleased that she is willing to share her knowledge and experience with us.



Figure 11. Playground sign from ISAAC-NF.

## Emergent literacy development and teaching of children with complex communication needs



Figure 12. PhD research by Lilianne Janssen-Duim.

<sup>3</sup> <https://loeswerkwijze.nl/>

Within the chair group, we also started researching early literacy a year ago. This research is being conducted by Lillianne Janssen-Duim. This morning, in the absence of Lillianne due to maternity leave, Judith Stoep told us about this research. Via literature study and an observational study, we hope it will culminate in an effective intervention for early literacy (see Figure 12 for an overview of the sub-studies). It is exciting and incredibly enjoyable research, not least because I get to conduct it with a true expert in the field, Judith Stoep. She is also the driving force behind our third research line, Education and Literacy.

## Language theories and augmentative and alternative communication

I have been an endowed professor since September 2023. Given my training as a remedial educationalist and my PhD in developmental psychology, it seemed prudent to delve not only into the world of AAC but also into linguistics and psycholinguistics. I had the notion that understanding how spontaneous spoken language development occurs would directly inform my approach to cases where this development is not self-evident, such as with children with multiple disabilities who have a language or speech problem. This proved to be somewhat naive. Nonetheless, I can assert that linguists, language psychologists and pathologists, speech therapists and language philosophers view language development in incredibly interesting ways. I have read with admiration the experiments set up to prove or disprove one theory or another.

At present, however, there is no generally accepted theory that can explain how children learn words and language. Figure 13 shows an overview of some leading theories, summarised in key concepts.

Leren van woorden en taal					
Nativisme, Generatieve grammatica	Connectionisme	Constructivisme	Behaviorisme	Emergentie coalitie model	Complexe (dynamische) systeemtheorie
Taalleren is genetisch bepaald	Taal product van een neurale netwerk	Geen aangeboren rol van een taalsysteem, wel van intenties lezen en herkennen van patronen	Taal is niet aangeboren, maar ontstaat uit imitatie van gedrag	Kinderen zijn gevoelig voor meerdere aanwijzingen om taal te leren. De manier waarop verschilt gedurende de loop van de ontwikkeling	Taal ontwikkelt als een zelforganiserend non-lineair systeem

Figure 13. Learning words and language.

All these theories explain parts of word and language learning, but not everything. The question is whether it is necessary to have a single theory to be able to explain everything. From an evolutionary perspective, this is rather impractical. If a skill can only be learned in one way and the conditions for that learning are violated, you are very vulnerable. Moreover, if you want to help children who do not learn spoken or sign language spontaneously, it would be detrimental if language could only develop in one way. So, from this perspective, the emergentist coalition model shown in Figure 13 is the most likely theory. This model posits the following:

1. Children are sensitive to multiple cues to learn words and language.
2. The way they weigh situations varies over the course of word learning. When determining what the best cue for the meaning of a word is, they consider the situation in their assessment.

## Redundancy

The advantage of the emergentist coalition model is that children can use multiple strategies to learn words. If word learning is a specific application of learning in general and various learning processes may share common features, this strongly reminds me of an important learning principle: children benefit from and need redundant information when learning something. In this context, the synonym 'abundant' better captures the meaning of redundancy than 'superfluous'. In the past, I conducted a lot of research on children with visual impairments. During our research into the language and tactile development of children and adults who are blind, we encountered this phenomenon of redundancy. Susanna Millar (1997) also described that redundant information helps the child. Studies on tactile development conducted by Ans Withagen (2013) found that children who are blind were just as accurate as adults in matching objects by touch. The redundancy manifested in two areas: they were often slower and touched the objects longer, and they used more exploratory procedures to feel the properties of objects. While an adult, blind or sighted, mainly follows the outline of an object with a finger to match objects by shape, children will also use other exploratory methods, like grasping and rubbing an object with their whole hand, which primarily provides information about the texture. So adults are not better at the task, just more efficient. When it comes to familiar objects, they can also rely on their memory, which is naturally better filled through experience than that of children.

In the field of language, we see something else. Some children who are blind repeat words or phrases in a stereotypical way without the situation necessarily calling for it. This may appear peculiar and is often labelled as echolalia and considered abnormal. However, developmental psychologist Miguel Pérez-Pereira and linguist Gina Conti-Ramsden (2020) have shown that echolalia also has an adaptive function for the child. Not only is it a way of checking whether a conversation partner you cannot see – the child is blind, after all – is still present, but it is also a way of practising with words and language, grasping the meaning of words that refer to events, people and objects in a world that can only be heard and felt, not seen. These children thus create their own redundancy for learning. This is essentially what Tess's parents demonstrated in the aforementioned video clip. They used different forms

of communication to convey the message more clearly, thereby creating redundancy. This is also what teachers and therapists do. Information is offered and repeated over and over again with slight variations and additions.

An important diagnostic question for the therapist then is whether redundant information should be offered simultaneously or sequentially. In the social-neurocognitive model used at Milo to identify critical developmental areas for language, this is certainly part of the diagnostics. While sensory perception and information processing in children without disabilities often proceed almost automatically, and thus without attention, i.e. effort and energy, this is not always the case for children with MCD. Their senses will have to be engaged one after the other rather than simultaneously. Dynamic assessment is a suitable form to properly map out this aspect of the learning process in a child with MCD. In such an assessment, the child is provided with information both simultaneously and sequentially in a learning situation. By closely observing the child's reactions, it can become clear how this child learns best.

So the emergentist coalition model is attractive when working with children with MCD. However, Rowland rightly notes in her book *Understanding Child Language Acquisition* (2014) that the disadvantage of an integrative theory is that it is almost unfalsifiable because there are always data that explain something, but never everything.

### Usage-based theory

Now, as a remedial educationalist I do not need to prove language acquisition theories, but it would certainly be nice if our research into children whose language development diverges entirely from those without disabilities could contribute to the formation of such theories. I will attempt to do so.

Constructivist theories, such as Tomasello's usage-based theory, are very applicable to children with multiple disabilities. Tomasello (2005) argues that children do not have an innate ability to learn grammar, but that to learn words and language you need to be able to do two things: read other people's intentions and recognise patterns. In many of his publications, he busily contrasts his usage-based theory with generative grammar and connectionism. What is unique about the usage-based approach is that it considers the function of communication. He writes about this: "The current model is thoroughly functionalist-based explicitly in the expression and comprehension of communicative intentions (intention-reading)."

For children without disabilities, the form and nature of their understanding and expressions are far less influenced by the communication partner's intention. However, this certainly appears to matter for children with multiple disabilities. In situations that are very important to them (like wanting or not wanting something), they may sometimes use a more abstract form of communication, speaking or gesturing than they use for less important things (like exchanging information). If a child does not want something, the quickest and most efficient method is to make a dismissive gesture, yet they might sometimes say 'no'. Exchanging information or sustaining social interaction is more efficient when using words, but in those situations such children often use unconventional or conventional gestures.

Naturally, these situations are more complex and require more language to express oneself. The point remains that children with multiple disabilities demonstrate the importance of the function of the communicative message that they should be able to read. Besides having to read the other person's intention, you also need to know how to direct their attention to be able to convey your own message.

### Joint attention

The process of reading, following and directing another person's intention poses a significant challenge for our research. That is because there is a practical difficulty inherent in discerning someone's intention. To read another person's intention, one must first focus on them and, in addition, pay attention to the context (e.g. another individual, objects or events) to understand where their attention is directed. We call this phenomenon joint attention. Both communication partners must have this awareness.

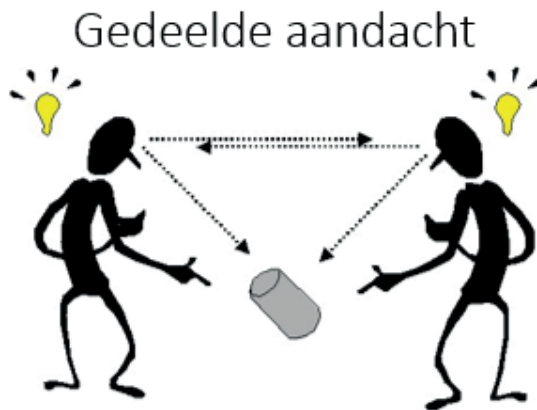


Figure 14. Joint attention.

We measure joint attention by looking at gaze direction. Why do we do that? Because gaze direction is usually a good indication of someone's attention as well as their intentions. I can easily illustrate this using Figure 15, which asks the question: What does Charlie want?

Most of you will say Charlie wants a banana. However, there is a group of people who sometimes, but not always, struggle with this, namely people with autism. Some members of this group are relatively blind to the information they can glean from someone's gaze direction, even if they are quite capable of answering this explicit question: What is Charlie looking at?



Figure 15. Intention reading, what does Charlie want?

That also applies to interpreting facial expressions: individuals with autism do not automatically make the connection with the most likely underlying emotion. The fact that individuals with autism cannot quickly or accurately read others' intentions is one reason they may struggle with language, even with a normal level of intelligence. This difficulty is not necessarily with word comprehension or grammar but rather with pragmatics: using language appropriately in social situations. However, if someone with an autism spectrum disorder also has an intellectual disability, other language areas may also be affected. It then appears that even people with autism can benefit from augmentative and alternative communication.

### Attention and Theory of Mind

So we use gaze direction to measure someone's attention. But what do we do if someone is completely blind? How do we measure shared attention then? And what if someone has only limited vision or squints? Are these improbable scenarios? Not at all. Research by Heleen Evenhuis, a physician for the mentally handicapped (Evenhuis et al., 2009; van Splunder et al., 2003), found that the severity of intellectual disability correlates highly with the occurrence of visual impairment in children and adults. This is not because these individuals have inherently poor eyesight; no, the problem lies in the brain. When the brain is affected and cognitive abilities are consequently diminished, we see that the functions controlled by a large part of the brain are also very vulnerable. Vision is one such function. Therefore, among children with multiple disabilities, we frequently observe visual perception problems due to brain damage, referred to as cerebral visual disorders. This could mean functions such as visual acuity or colour vision are impaired, but more often there are problems with interpreting what one sees or the ability to focus visual attention on details or the entire picture. Examples of this can be seen in Figure 16.

## Point Light Display / biological motion



Figure 16. Point light displays.

These are examples of biological motion detection, an evolutionarily significant function. When motion occurs at the periphery of our visual field, we instinctively direct our attention to this by turning our head and eyes to ascertain whether the movement poses a threat or not. It could very well be a predator, such as a lion, intending to eat you. Thus, in addition to the orientation response, you also have to interpret what you see. Humans excel in this regard. In fact, we do it so well that we can clearly see that the figure on the left is a woman. We also see someone throwing a ball, skating and using sign language. However, there are children with multiple disabilities who are incapable of these interpretations. The major issue is that we often do not know this.

Measuring gaze direction is thus problematic for two reasons. First, it is not always successful (e.g. because a child is blind). And second, it remains uncertain whether gaze direction is a reliable measure for reading attention and intentions. Gaze direction is a good indicator of attention in most situations, but people who close their eyes during a lecture are still paying attention to the speaker. Gaze direction is just one indication that attention is present, but attention can also exist without looking, although looking does aid perception. We know this because children who are blind can also participate in joint attention, provided the situation can be perceived through hearing and touch.

However, these children find it challenging to take the next step in cognitive and language development, which is developing a theory of mind. This is the ability to attribute mental states to oneself and others (i.e. to empathise with the thoughts and feelings of others) and, on that basis, to understand and predict the behaviour of others. Brown, Hobson, Lee and Stevenson (1997) described the prerequisites of this ability. First, there must be a communication pattern between parent and child in order to be able to communicate about thoughts and feelings. This generally proceeds well for children who are blind but less so for children who are deaf, resulting in delays in theory of mind development among that group. This delay occurs because

parents are less inclined to communicate about thoughts and feelings when spoken language is inaccessible. This is because it is inherently more challenging to do this without words than to communicate about objects, individuals or actions. Second, you need to see the direction of a person’s attention relative to a shared world. That’s where things go wrong for children who are blind. That leads to about a two-year delay in theory of mind development among such children. Finally, you must have a propensity to identify with that shared world. This is where things sometimes go wrong for children on the autism spectrum. Thus, the same problem – an incomplete or delayed theory of mind – arises from three distinct causes. Children with multiple disabilities can present with all sorts of combinations of autism spectrum disorders and vision and hearing impairments in all possible degrees. You can see why it becomes exceedingly difficult to develop joint attention, theory of mind and, ultimately, the ability to read intentions. This is also why it is crucial to examine young children with developmental delays for vision and hearing problems and symptoms of autism spectrum disorders. And importantly, one must consider that similar symptoms may stem from different causes. Gitta de Vaan (2018) addressed this in her PhD thesis.

### Tests for hearing and vision problems

Conducting these tests is challenging because children with multiple disabilities often have communication problems and they are usually unable to articulate what they can or cannot see, hear or think. There are now many objective tests we can use for research that measures hearing and vision problems. These are often electrophysiological in nature, especially for hearing (also see Figure 17).



Figure 17. Objective tests: eye tracking, EEG and VEP.

For vision, the group led by Hans van der Steen and Johan Pel from the Department of Neuroscience at Erasmus Medical Centre in Rotterdam has done some fine work. They use



eye trackers to determine the visual acuity of children with severe multiple disabilities, as well as their ability to perceive colours and contrasts. For some time, it has been possible to use an EEG technique, Visual Evoked Potentials (VEP), to determine whether a child sees details and if so, how many, and whether this vision is fully continuous or intermittent, with jerks or delays. Thanks to improvements in the recording of EEG patterns, these measurements can now be performed more and more easily without the need to attach multiple electrodes and require the child to remain still for extended periods.

We recently observed a demonstration from the company MindAffect, which includes colleagues from this university. They use this technique to objectively determine vision and hearing in young children. Although their current focus is on children without disabilities, the developments in this field are promising, and we hope to eventually apply this technique to children with multiple disabilities as well to obtain accurate and valid sensory assessments. However, there is a limitation: we can only determine if a visual or auditory stimulus is received and can be distinguished from other stimuli. We still do not know how children process, interpret and use those stimuli to take action. This requires further research. I was happy to read, therefore, that the group led by Saskia Damen in Groningen will be researching cerebral vision disorders and auditory neuropathies in children with deafblindness. Since some of those children exhibit behaviours and needs that are very similar to those of children with MCD, I anticipate that the insights gained from this research will also benefit the latter group of children.

## Pattern recognition

The usage-based theory also states that recognising patterns, especially those offered auditorily, is necessary for language learning. Pattern recognition is essential to be able to understand that verbs are conjugated in singular or plural, that an 'apostrophe + s' at the end of a word indicates possession, and that the word order in the sentence 'Jan hits Piet' results in a different victim than in the sentence 'Piet hits Jan'. Pattern recognition is necessary for developing grammar. Everyone who has tried learning a foreign spoken language or sign language knows how difficult this is. Languages have the unfortunate tendency to not be logically designed but to have emerged spontaneously and organically, sometimes containing as many exceptions as rules.

Measuring pattern recognition in children with multiple disabilities is extremely difficult, although brain scans can sometimes help here too. However, measuring whether a child hears sounds and can distinguish them from each other is still different from measuring rhythm, tempo, prosody and melody. Music is often used in clinical practice because it can help in investigating melody and rhythm, among other things. Even without an EEG, a child's emotions, mobility and breathing can often show whether they notice the changes in rhythm or melody. Thanks to EEG recordings in infants, there is now evidence that observed patterns in music – such as changes in sound frequency and differences in rhythm between speech and non-speech sounds – can be made visual in the EEG pattern and also correlate with later language development (Ní Choisdealbha et al., 2023). Among 10-month-old infants from families in which autism is prevalent, neural tracking (the synchronisation of brain activity

and incoming speech) was found to be a good predictor of vocabulary at 24 months, but not of autism spectrum disorders themselves (Menn et al., 2022). This type of research has not been conducted on children with communicative disabilities. It may not be technically and ethically possible at all, but it does make one curious. Motor movements can now be recorded by mapping them in parent-child or child-child pairs via video and automatically scoring these movements based on approach or distancing and synchronicity. Harmonious interactions tend to possess a certain degree of synchronicity. This is not visible to the naked eye but can be detected with video or motion recordings. The idea is that these may be reflections of discourse qualities of a communicative interaction, such as turn-taking and leading and following a conversation.

The tools for analysing such patterns largely come from researchers who study complex systems. Such systems do not behave linearly but do follow patterns, and interactions between system elements and changes over time can lead to new behaviour. This form of emergence, the origin of behaviour, has been described for various complex systems. My PhD supervisor Paul van Geert was at the forefront of thinking about complex systems. He has published on this topic, for example on the development of language and vocabulary, as in 2023 with Marijn van Dijk in the *International Encyclopedia of Education*. What gives me hope for the target group I am now advocating for, children with multiple disabilities, is that Paul and Marijn demonstrate in their article (Van Dijk & Van Geert, 2023) that language development is idiosyncratic and thus differs from person to person. As a result, analyses must be conducted at the level of individuals: individual learners, individual pairs, individual classes and so on. If, like me, you study heterogeneously composed groups with a lot of individual variation, it is encouraging to hear that individual variability is a central feature of a complex system like language learning. That requires completely different analysis techniques, and for that we need to move away from studying group averages. And if I have correctly understood one of Fred Hasselman's latest publications, it is possible to achieve coordinated systems by recognising and producing redundancies, and systems that do so produce meaningful information. If the form of redundancy discussed above satisfies this criterion, I am curious to see what techniques from the complex systems field can bring us next.

### **Applied behaviour analysis**

In addition to the emergentist coalition model, usage-based theory and complex systems theory, there is another language theory that has had considerable influence in the field of augmentative and alternative communication: behaviourism. However, that influence is valued to varying degrees. In a chapter on language development, Stephen von Tetzchner (2023) expresses his amazement that instruction in the teaching of language to children with autism, intellectual disabilities and developmental disabilities is still often based on Skinner's ideas on applied behaviour analysis. This despite the fundamental criticism of the behaviourist explanation of language learning: namely that language development occurs through learning processes such as classical and operant conditioning, reinforcement and imitation. My explanation for this is that we resort to it because it works, at least to a

certain extent. The disadvantages are well-known. The focus is on the form of the language rather than on conveying information. Children can become prompt-dependent, meaning they only start responding when given a cue, and both child and trainer can perceive the training to be mechanical, impersonal and directive. This makes language learning a task with little room for personal initiative instead of an activity that is spontaneously carried out throughout life. But with extensive and prolonged training, it is possible to link objects or images to a meaning and teach a child to express choices, wishes and desires or answer a question in this way. It may remain at the level of single-word sentences, but that is already a significant achievement for some children.

Leaving aside the assertion that language learning only or mainly occurs through conditioning (which is practically impossible according to many linguists), studies show that when language learning does not happen naturally or spontaneously, applied behaviour analysis as a remedial method can offer an alternative. Applied behaviour analysis also includes elements from other instructional methods, such as repetition (because memory requires repetition) and consistency in linking object, action or event with a communicative symbol (because this leads to faster and better learning).

It strikes me that theories on language development seem to seek one or a few rules to capture the phenomenon of language learning. Yet the variation in early childhood development and in children with severe single or multiple disabilities shows that children take different paths to learn the same thing and, more importantly, to achieve a goal. In the case of language, that goal is conveying a message. Learning is more effective when unambiguous and redundant information is provided; that is, information that is supplementary and partially overlapping. The same information is presented in different ways and supplemented with supporting information, such as pointing, gestures, pictures, photos, clear speech and a higher volume to improve audibility. As argued earlier, there seems to be a general learning principle that learning starts broadly and becomes increasingly specific and therefore more efficient over time. Children need this redundant information.

Another reason why applied behaviour analysis works might be that learning a language that is not acquired spontaneously partly resembles the way we learn a second language: rote learning, exercises and practice, with reinforcement in the form of praise from the teacher.

The fact that words or language can be learned does not necessarily mean that this is the only way language learning occurs. An intervention for behaviour that works and does not occur spontaneously does not necessarily prove that the behaviour would have to be learned spontaneously through the same principles in the first place. In this sense, intervention studies do not provide evidence that learning principles have a causal relationship with outcomes.

## Opportunities and challenges in our research

So far, I have talked about various aspects of augmentative and alternative communication, children with multiple communicative disabilities, and the research lines and plans within Milo and our chair group. I would now like to address the opportunities and challenges that lie ahead.

### Research on children with multiple disabilities

Theories of language development now seem to apply mostly to children who develop without disabilities. However, research on children with single and multiple disabilities can provide valuable insights. The function of language and the power of redundancy are examples. What research on children with disabilities has also taught me is the adaptive capacity of the children themselves and of their parents. If it is a guiding developmental principle that we humans adapt to the environment as best we can to survive physically, socially and emotionally, then it is crucial to also examine the spontaneous adaptations of children and their caregivers. These adaptations can, incidentally, also result in undesirable and disruptive behaviours because, after all, 'language that does not arrive in speech always finds its way out in communication'.

A first challenge is dealing with problematic behaviour. It is no easy task to ascertain what a child is trying to convey when they display anger, sadness or aggression. Ideally, a remedial educationalist should be able to analyse such situations, ascertain a probable cause or reason, and devise strategies to make the situation manageable. In essence, this situation is no different from that of children with language development disorders, as they also frequently exhibit socio-emotional and behavioural issues when they cannot express themselves or do not understand others. However, the nature, form and intention of the problematic behaviour can vary significantly. For example, self-injury is relatively common among children with multiple disabilities but not among children with language development disorders. If a child primarily receives attention when they exhibit problematic behaviour, then teaching communication, alongside ignoring or unlearning the problematic behaviour, can be a successful strategy. This often works very well with the help of applied behaviour analysis, which is therefore a crucial reason why this method is still used.

### Spontaneous adaptations

To return to spontaneous adaptations by parents and children, I would like to draw a comparison to the situation where we interact with a foreign tourist. We seem to think that people who do not speak our language are deaf, lack any spatial awareness and have a short memory. So when a foreigner asks for directions and a simple 'Turn right in 300 metres and then it's the second house on the right' does not work, we start talking louder, gesticulating excessively and repeating the explanation at least twice, often with increasing volume. Why do we do that? Because it works. Speaking words more loudly makes it a bit easier to distinguish sounds, pointing and making gestures support the spoken words that are probably not understood, and repetition – especially with subtle changes and additions (known as recasting and extension in linguistics)

– aids comprehension. We do something similar when we talk to babies and young children: we spontaneously use motherese, parentese or infant-directed speech. Why? Because it works. It captures the child's attention and facilitates language learning. We speak more slowly, articulate better, raise the pitch, accentuate the pronunciation of vowels, repeat what we say and add exaggerated facial expressions while staying well within the child's field of vision and rewarding any form of response from the child with a hug, smile or touch. Research shows that when parents use more parentese, babies later talk back more and learn more words.

Gradually, as a toddler becomes more proficient in language, this is no longer necessary. However, for children with multiple disabilities, it can be extremely helpful if we continue with this spontaneous technique a bit longer, even if you get little in return from the child. This might feel awkward. You have to overcome some embarrassment because it can feel like overacting.

Actors who perform for children are very good at this. They use a form of overacting to convey all the information as clearly as possible. If you watch online videos of Milo staff members, you will see great examples of this. Sometimes they also use face paint to make their facial expressions even clearer. This is particularly beneficial for children who have problems with facial sharpness and contrast perception or children who have difficulty selectively directing their attention within a visual scene or switching between relevant parts of a scene. If you watch those videos, however, you will notice another thing: the speed of communication is much slower and there is much more repetition than you are used to.

In some children with multiple disabilities, the nervous system does not operate at normal speed and continuously. As a result, these children perceive normal, everyday events on fast forward and with interruptions. By slowing down tremendously and repeating a lot, you can help them follow events better. The speed of actions is then closer to what the child can handle. Repetition fills the gaps that arise because perception and processing of events and reactions to them occur with stops and starts.

The pedagogical and didactic difficulty lies in the fact that not every parent, therapist or teacher does this automatically or, if they do, can maintain it for long periods. They need coaching to do this. But then it becomes apparent that not everyone can do this, simply because it does not match everyone's natural disposition or personality. You can expect professional therapists or teachers to have a professional attitude and some commitment, so training and coaching will often help. They have the advantage over parents that they only have to supervise the child for a few hours a day, but even then, it is very exhausting to maintain this approach. Parents are parents 24 hours a day, including weekends and holidays. For them, it is much more difficult to consistently apply the correct approach to their child for long periods, especially if this differs from their instinctive way of doing things. And finally, there must be a match between a parent's personality and the child's behaviour and personality. If this is not present, you have a double pedagogical problem.

## Parenting resources

So far, we have mostly talked about secondary parenting problems. These are problems that arise because parents do not understand their child's behaviour. When a child has one or more disabilities, parents do not always know what to expect and how to deal with them. Of

the resources that parents usually have at their disposal – tradition, intuition and common sense – tradition (falling back on how you were raised, on what is customary in your family or culture) and intuition (doing what feels right or comes naturally) often become irrelevant. And when parents do act intuitively, they often doubt whether they are doing the right thing. That leaves only common sense. Common sense involves reflecting on one's own behaviour and that of the child and adjusting situations to prevent issues or resolve them. The difficulty with common sense is that not everyone has enough of it, and that the behaviour of a child with disabilities can greatly exacerbate parental doubts.

But there are also situations where having a child with a disability does not disrupt traditions. Parents who share the same disability as their child can very often use this constructively. The clearest example of this is the use of sign language by parents who are deaf and have a child who is also deaf. These parents know exactly how to do this. They only encounter problems if their child needs to learn a spoken language.

In general, it can be stated that parents of children with multiple disabilities are overwhelmed by the situation, lack any experience with such disabilities and thus doubt their actions and hesitate to trust their intuition. This situation can be exacerbated if having a child with a disability leads to intense and prolonged negative emotions. Having a child with congenital disorders can result in feelings of loss, specifically the implicit and explicit expectations and dreams that every parent has when a child is born. When a child becomes severely multiply disabled due to illness or an accident, it can lead to feelings of losing the child you once had and so desperately want back. Those feelings of loss typically fade over time and, in my experience, that usually occurs a bit faster with congenital disorders than with an acquired disability. At each new phase of life, or indeed the absence of that new phase, these feelings of loss can reoccur. If these feelings are intense and/or disruptive for a parent or sibling, we refer to this as living loss. When a child has disabilities and the underlying disease or condition is progressive and may lead to premature death, parents and family members often experience very intense and recurrent emotions. In situations where there is a stable condition, the therapist can still work to ensure that parents learn to trust their intuition as quickly as possible by providing knowledge, teaching skills and building new traditions together with them. But that task is more difficult when children have a progressive condition. The problems keep recurring and it often feels as though one is constantly taking a step backwards.

### **Measuring attention**

This topic was also touched upon in the passage on the theory of mind. But what exactly is attention? Broadly speaking, there are two types, distinguished by William James in 1890 as active and passive forms of attention. Attention is active when an individual consciously and internally directs goals or expectations. Attention is passive when it is externally driven by external stimuli. Krauzlis et al. (2021) define attention as a set of unfolding brain processes that lead to environmentally adaptive and effective behavioural choices. Attention is a process in the brain, and as such it cannot be measured. Attention is only measurable when it directs our behaviour: for example, through the choices we make, the

answers we give, the way we focus our eyes on something or turn our ear to something. It is precisely those behaviours that children with multiple disabilities are not always capable of, and when they do show those behaviours, they sometimes mean something different than in children with a typical development. This represents a major challenge: how can you measure attention when the characteristic expressions of it (e.g. eye movements, reaction times or motor responses) are not reliable and valid?

## Interventions

Another challenge I wish to discuss is the implementation of interventions. Do they make sense? Do they actually teach children to communicate? The therapist in me says a resounding 'yes' to this, while the scientist says 'perhaps'. Children with communicative disabilities can learn to communicate both with and without the aid of augmentative and alternative communication. But we should not expect these children to reach the same language level as children who have no disabilities.

To give you an idea, Stephen Von Tetzchner (2023) references a study in which a typically developing one-and-a-half-year-old child, one without any impairment, used 1,860 different word forms and spoke 13,800 words in a single day. The most talkative child in that study used 37,700 word forms. When it comes to word learning, English-speaking children learn between 3,000 and 5,400 words a year at school. Over 12 school years, this adds up to between 36,000 and 64,800 words.

That significant individual variation is quite characteristic of early language development. It is not only about the variability in volume but also in the age at which skills are demonstrated. For example, many children speak their first word around their first birthday, but the paediatrician only starts to worry if this has not happened by 20 months. Apart from potential factors within the child, one reason for this significant individual variation is the language input a child receives, both in terms of quantity and quality. The amount that parents talk to their children varies greatly. Von Tetzchner (2023) references a study in which the number of linguistic statements directed towards children aged 1 to 3 years ranged from 34 to 793 per hour. If a child is awake 14 hours a day, this is a range of 476 to 11,102 statements per day, and between 175,000 and 4 million statements in a year. The quality of that input depends, among other things, on the parents' language skills. It is therefore unsurprising that many studies find a strong correlation between the educational level and social background of parents and their children's language skills (Rowland & Fried-Okken, 2010).

However, it is essential to understand that the amount of language input is also guided by the child's responses. Individual differences reflect not only the parents' talkativeness but also the children's language skills and their reactions to the language directed at them. This mechanism often falters in children with multiple disabilities. If a child does not respond, gives no indication that they understand a message or shows no emotional reaction, parents, teachers, and caregivers may gradually reduce their language input. It is particularly frustrating for parents if their child does not show emotional responses and does not indicate that they enjoy something or find it pleasant. In the aforementioned

video of Tess on the Deelkracht website, Tess's mother explicitly states how important it is to receive emotional responses from her daughter. A crucial task for therapists is thus to keep parents engaged, motivating them to intuitively do the right thing. This means that therapists sometimes need to coach and motivate parents rather than provide direct treatment. Because if a professional succeeds, perhaps more than the parents who lack the required expertise, it might demotivate the parents, reduce their involvement and deprive the child of valuable practice opportunities.

I hope that my story about the function of language and the power of redundancy can persuade language researchers to study children with multiple disabilities more frequently. These children often disprove the notion of sensitive periods in development, as they frequently learn to speak or sign at ages well beyond those periods. I am committed to embedding this understanding in practice, ensuring that older children and young adults also continue to be stimulated to develop their language and communication skills.

### Smart toys

One way to enable redundancy is through smart toys. Figure 18 shows a few examples. Our own technical support group created these for the research of a former PhD candidate of mine, Suzanne Verver (2020). Children play, hear sounds when play figures are placed on an electronic reader, and are allowed to repeat this endlessly. They learn to associate sounds with figures, hear short sentences, and thus, implicitly, learn language and acquire knowledge in a playful way. Meanwhile, a farm is also in the works. Let's see if this form of implicit learning also works for children with MCD.



Figure 18. Smart toys.

### Complex systems approach

It seems worthwhile to me to explore whether we could better view language development as a complex system. That is a system that as a whole exhibits certain properties that cannot be derived from the properties of its individual components. Complex systems are characterised



by elements such as self-organisation, non-linear relationships between the parts, and emergence. An emergent phenomenon occurs as a result of components interacting with each other under favourable conditions. A key feature of this phenomenon is that it possesses different properties than the components from which it is composed. Emergent systems also exhibit path dependence: the behaviour of complex systems at any given moment is also and mainly determined by their entire history. This requires us to collect extensive data on one individual child rather than extensive data on a group of children.

## Challenges for augmentative and alternative communication

Below, I will discuss several themes that Filip Loncke touches upon in his book *Augmentative and Alternative Communication: Models and Applications* (2021).

### Technology

Loncke (2021) first discusses that many of the technologies for augmentative and alternative communication have now become mainstream, particularly smartphones and tablets, to which I would add eye trackers. Hopefully, there will come a time when technology can bridge the gap in access, speed and participation opportunities between users of AAC and others. This could also blur the distinction between communication supporting devices and other communication tools. There are great opportunities for tech suppliers and the device industry to collaborate on this. Loncke also raises the important question of what we need to know first about a child's language capabilities, so that we can predict where they would end up without assistance and subsequently decide whether intervention is necessary.

### Receptive language

For children with multiple communicative disabilities (MCD), we must find ways to accurately measure their receptive language, that is, the understanding of language. Sevcik and Ronski (2016) note that researchers measured expressive language as a dependent research variable in 81 per cent of cases. This is logical in itself since it is simpler and more straightforward to measure, but it is also problematic because understanding language often precedes expressing language. If you only measure language expression, you get an incomplete picture of language development and thus an underestimation of the children's capabilities to understand language.

### Mechanisms of action and predictive factors

In addition, there are often two methodological problems. First, it is difficult to determine why a child does not use or understand spoken language, i.e. the mechanisms behind it. And second, evidence-based research does not always enable one to identify the basis on which to predict outcomes of language development. Indeed, how generalisable are the results of interventions if, methodologically, the correct comparison group cannot be formed or alternative explanations for the observed effects cannot be ruled out? These uncertainties are likely to persist for some time.

For now, I want to promote 'better safe than sorry reasoning'. If you want to learn a skill, you better start practising early. After all, you do not want to miss anything that might work. But of course, you also do not want to do something that in all fairness has no positive effects. In this context, Loncke suggests working with decision flowcharts – freely translated as decision or reasoning diagrams – in clinical practice. Stichting Milo's social-neurocognitive model is a nice starting point in that regard, but it still requires extensive research. Another suggestion from Loncke is to use big data because he reasons that if a pattern emerges from a large data set, it provides a direction for your clinical decisions. I am not in favour of this because group averages would then be equated with an individual's developmental trajectory. Although generally speaking this is a practical assumption, it is also a debatable one. I think it is better not to use group data about children's language development because that development is idiosyncratic, meaning it is typical and characteristic of one person. Pieter van Strien already understood this when he described his regulative cycle for conducting action-oriented diagnostics in orthopedagogy (Van Strien, 1986). When forming an integrative picture, you formulate an idiosyncratic theory about how problems or atypical behaviour in this child, in this situation, might all be interconnected. You then test this iteratively, again and again; if your hypothesis works, you stay on the same path, and if it does not, you try something else. This is dynamic testing in its finest form.

### **Core vocabulary**

It is good practice to compile a core vocabulary for children. Besides the question of how to plan, compile and maintain a good vocabulary for a user of AAC, we also face what I will briefly call the spontaneity dilemma. The key words children learn arise spontaneously during natural interactions. They are taught by people with no linguistic training, in a rather arbitrary order, usually with no preconceived and logically thought-out plan. The question then is whether, in ACC, we are not reversing the situation by turning keywords into preselected targets. In doing so, you run the risk of imposing words on the child that belong to the dominant culture or language in a community, as discussed when we talked about WEIRD research. WEIRD research is a problem and so is WEIRD assistance.

### **Learning to communicate or learning language**

Another thing recognised in practice is the question of what a language intervention for users of AAC should consist of: is it about learning to communicate or learning language? For many users of AAC, that question is not at all difficult to answer. If the child has only a limited number of words in their repertoire, learning to communicate is much more important than language learning. For children with a more extensive vocabulary and the ability to connect words through grammar, the question of developing language becomes more urgent. For these children, important questions then arise about the effect of the AAC tool on the language structures the child learns. For example, do these children feel compelled to express themselves in short sentences? And if a child grows up with AAC, is their language development comparable to that of children who grow up with spoken language?

## **Literacy**

The final question posed by Loncke is whether literacy contributes to good language development and if, therefore, we should incorporate literacy into our approach to AAC. I cannot answer this question at present. But we might have an answer in four years, after Lilianne Janssen-Duim has finished her project.

## **Communication for everyone**

I have talked about diagnostics, treatment, a social-neurocognitive explanatory model, culturally sensitive parenting and education and literacy wrapped up in three research lines. Are they going to enable communication for everyone? Perhaps not overnight, but since I have the privilege of working with a fantastic team of people from Stichting Milo, Pedagogical Sciences and the Behavioural Science Institute at this university, I am confident that we will make significant strides towards achieving communication for everyone.

## Acknowledgements

Esteemed Rector, I have now reached my acknowledgements and words of thanks.

### Desondankswoord



But in Milo's world, that thanks is two-sided. Because, had you not loved me but simply ignored me, dear wife,  
 And had you celebrated your birthdays alone, dear brother, sisters and in-laws,  
 And had you not asked me to babysit, coach and listen to all sorts of toe-curling school performances, dear children,  
 And had you not gone sailing, cycling and *fierljeppen*, dear friends,  
 And had you kept all those lectures, meetings and conferences online, dear colleagues,  
 Then, dear everyone, I might have stood here much earlier.  
 But then again, I obviously wanted this all for myself, so that's why this is a thank you in spite of all that.

Dear Hans van Balkom, I initially interpreted your phone call in May 2021 as a request for advice on who should succeed you. I have only just recovered from the shock that you had me in mind. Since then, we have been in frequent contact, and I have come to appreciate your incredible knowledge of language, neuropsychology and augmentative and alternative communication. That Stichting Milo has been recognised by ZonMw as a centre of expertise is, in large part, to your credit. I look forward to the joint challenges that lie ahead.

Wim Prins, together with Hans the founding father of Stichting Milo, your love for your daughter drove you to set up Milo. 'But as a business', you never fail to mention. And what a business you, Hans and Arjen Beekman have set up. It runs like clockwork, and I hope you and Arjen will continue to contribute to it for a long time.

Paul van Geert, my PhD supervisor, how wonderful that you are here today. You taught me that research, in addition to being challenging, should also be fun. At a conference a very long time ago, your PhD candidates joked that no one would recognise a quote from William James,<sup>4</sup> and the next day you casually dropped a quote from the man in your speech. And indeed, the statement was correct: no one noticed. Nowadays, that would be called plagiarism, but then it was humour.

I would like to thank Masha Legel, Judith Stoep, Lilianne Janssen-Duim, Johannes Dommers, Peia Prawiro-Atmodjo, Suzanne Meijnen, Bea Maes, Stijn Deckers and all the suppliers of devices for their contribution to the symposium this morning. You have made this day unforgettable for me. Wilma Vossen, Daphne Gerbecks, Ellen van Ophuizen, Christel Tielen and Lanneke Dreumel, I thank you for organising this symposium, for all the support in publicising the chair, and for the assistance this afternoon.

In my ongoing projects, Stijn and Judith are my partners alongside Hans. I greatly appreciate your support, knowledge and commitment, but above all your team spirit. Know that this is also your chair. At various moments, you have discreetly guided me through the etiquette and customs of the world of augmentative and alternative communication. And the fact that Judith shares a first name with my wife has led to some amusing autocomplete mishaps in Outlook. Fortunately, Ms Stoep was polite enough to classify my email that started with 'Hi dear' under the shopping list category that was meant for the other Judith. I still wonder about the times we had to dine out because neither of us had done the grocery shopping.

Harry Knoors, first of all, I want to thank you for being the best office mate I ever had. You were never there. On the days you were present, we had many a conversation about deafness, sign language and education, as well as about exhibitions and hiking holidays. You were also the PhD supervisor of two PhD candidates we co-supervised with Ludo Verhoeven. Both of you always knew the right questions to ask and the right suggestions to make to move the investigations forward. You were also instrumental at various points in my career. Thank you for that.

Ludo Verhoeven, Ron Scholte, Debby Beckers, Toon Cillessen, Mariska Kleemans, Evelyn Kroesbergen, Anna Bosman and Ard Lazonder have all, at different times, been my supervisors, colleagues or subordinates, and often all three at the same time. However, above all, you are very valued colleagues with whom I can discuss anything and have, up to now, managed to resolve everything. I would like to keep it that way in the years to come.

Bert Steenbergen, our rector today, my real supervisor and also co-PhD supervisor of Suzanne Verver and Carlijn Veldhorst, always adorned with headphones, you provide pointed commentary and ensure the correct wording in articles. Personally, I most enjoyed our travels to Malaysia, Jordan and the West Bank in Israel. Apart from the lectures and training sessions we gave, it was a revelation to me to discover that

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<sup>4</sup> Na afloop van de oratie kwamen Paul en ik tot de conclusie dat de anekdote Gerard Heymans betrof en niet William James. Evengoed een leuke anekdote.

there are vegetarians who like non-plant-based bitterballs and with whom you can visit a McDonald's. And ladies and gentlemen, he did not eat salad there. Bert, thank you for this refreshing insight.

Sabina Kef and Saskia Damen have been my companions in various projects over the past few years. Your expertise and work ethic are unparalleled, and you embrace collaboration. I appreciate that very much.

To my current PhD candidates – Carlijn, Peia, Lilianne and, a little, Masha and Myrthe – and those of the past – Ans, Gitta and Suzanne – you made it possible for me to realise my research plans. You threw yourselves wholeheartedly into the research and completed it successfully (or will undoubtedly do so). It has been and continues to be a pleasure to work with you.

My dear siblings, the four of us epitomise the spirit of the Dutch education reform. My colleagues here in Educational Science find that very interesting. Largely sharing the same genes and upbringing, we pursued diverse educational paths, ranging from domestic science school to higher secondary education. In addition, we all ended up in the field of education. Our in-laws did not, but we can forgive them for that. Mark, as an IT specialist, authored a textbook, which counts as working in education. And Guanita works in disability care, so she is beyond reproach. It is wonderful to have you all here today.

Dear children, my own, my wife's and their partners, Judith and I married almost two years ago. Each of you played a special role in the wedding, from witness to master of ceremonies to videographer. Today, you only had to listen, and you have done so admirably. You are wonderful people; please stay that way. And know that the title 'esteemed father' is greatly appreciated.

Judith, you are the best thing that has ever happened to me. You brighten my day and continue to make me happy. Thank you for the advice to insert 'lassos' into a speech to capture attention. Therefore, as a token of gratitude, I dedicate the final, yet-to-be-addressed learning objective – mastering one AAC tool – to you. In fingerspelling, I send you: I Love You.



Figure 19. I Love You.

You also taught me that communicating involves talking and listening, and that it helps to ask a question now and then. So, as a final lasso addressed to the audience, which announced point have I not yet covered? Indeed, the door.

What does a door have to do with this story? Absolutely nothing. But yes, I made this one (Figure 20) myself and I am quite proud of it.



Figure 20. Door.

But now suppose the door is a metaphor. Such a thing can open and close; it closes and opens worlds. And when the door is open, you can go through it with Milo and enter Milo's world.

This world moved and inspired me immediately, thanks to the people who work there and the parents and children they help. It is the world of language and communication. It is also the world of Victor and his mother, who, with the help of a speech-generating device, will tell you exactly why augmentative and alternative communication – even if you can only utter one word – is so important and well worth the effort.

*I am finished.*

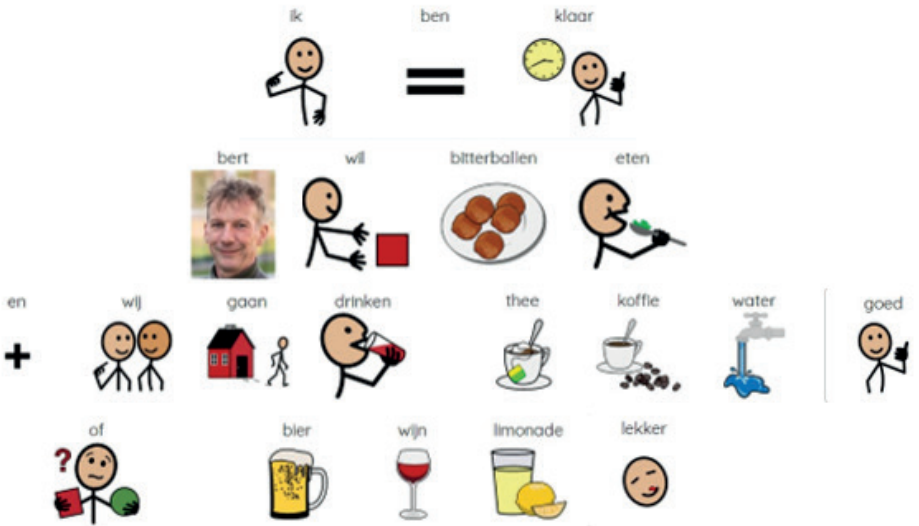


Figure 21. I am finished.



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#### Descriptions of figures

Title. Created in Mind Express 5

Figure 1, Language that does not arrive in speech, Mathijs Vervloed

Figure 2, The Phantom Tollbooth is a scan of that book, published by Epstein & Carroll, 1961

Figure 3, downloaded from the Utrecht University website: <https://profs.library.uu.nl/index.php/profrec/getprofdata/1147/18/36/0>

Figure 4, Forms of augmentative and alternative communication, downloaded from the Stichting Milo website <https://www.wijzijnmilo.nl/ondersteunde-communicatie>

Figure 5, AAC in VOSviewer, screen print from VOSviewer

Figure 6, Children with multiple communicative disabilities, downloaded from the Stichting Milo website <https://www.wijzijnmilo.nl/ondersteunde-communicatie>

Figure 7, Alternative terms for MCD, compiled by me

Figure 8, Interaction, communication and language, compiled by me

Figure 9, Collaboration between researchers in the AAC field, screen print from VOSviewer

Figure 10, Treatments by Stichting Milo, downloaded from the Stichting Milo website <https://www.wijzijnmilo.nl/behandeling/behandelprogrammas>

Figure 11, Playground sign from ISAAC-NF, downloaded from the ISAAC-NF website <https://www.isaac-nf.nl/communicatiekaarten/>

Figure 12, PhD research by Lilianne Janssen-Duim, compiled by Lilianne Janssen-Duim

Figure 13, Learning words and language, compiled by me

Figure 14, Joint attention, unknown artist

Figure 15, Intention reading, based on Baron-Cohen 1993

Figure 16, Point light displays, screenshots <https://www.biomotionlab.ca/html5-bml-walker/>

Figure 17, Objective tests: eye tracking, EEG and VEP. Free internet downloads

Figure 18, Smart toy, Suzanne Verver

Figure 19, I love you, [https://www.lingvano.com/asl/wp-content/uploads/sites/3/asl\\_content/content-pages/blog/ILY\\_combination-1024x359.jpg](https://www.lingvano.com/asl/wp-content/uploads/sites/3/asl_content/content-pages/blog/ILY_combination-1024x359.jpg)

Figure 20, Door, Judith van den Hul

Figure 21, I am finished, created with MindExpress 5

