Elephant paths point the way to augmentative and alternative communication

Exploiting natural compensation in the brains and behaviour of people with multiple communicative disabilities

VALEDICTORY LECTURE BY PROF. HANS VAN BALKOM

Radboud Universiteit

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In his valedictory lecture, Hans van Balkom discusses the power and robust functioning of neurogenesis and neuroplasticity in the formation of neural elephant paths to alternative forms of expression when talking does not work (or no longer works). These paths create new routes to main and secondary connections in the brain, which is particularly important for bypassing blockages. People live (or survive) by the grace of their ability to communicate. Because communication and language are vital to us, our central nervous system has a widespread network of connections with a powerful repair capacity. Barriers to communication can therefore be quickly repaired, compensated for or circumvented. Knowledge of the development and organisation of neural elephant paths is therefore important to developing the most suitable forms, methods and tools for assisted communication. Scientific research within the Chair in Augmentative and Alternative Communication (AAC) is focused on the search for the strongest predictors of and conditions for the construction of neural elephant paths to augmentative and alternative communication.

Hans van Balkom (1954) is a psycholinguist, and he studied general linguistics at the University of Amsterdam. He has specialised in assisted communication for people with disorders in perceiving, processing, understanding and expressing speech, text and language (including sign language). He completed a doctorate in 1991 with a thesis on developmental language disorders. In 2010, he received a special appointment at Radboud University as a professor of Augmentative and Alternative Communication for People with Multiple Disabilities, and he then established 'Stichting Milo: Wegbereiders in communicatie' (Pioneers in Communication). The chair was an initiative of what was at that time known as BOSK (association of people with motor disabilities and their parents), with support from Royal Kentalis and Stichting Milo. Van Balkom stepped down as professor at the Behavioural Science Institute (BSI) of the Faculty of Social Sciences on 2 June 2022, but he remains at the university as a professor emeritus.

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Exploiting natural compensation in the brains and behaviour of people with multiple communicative disabilities

Lecture delivered upon leaving as Professor by special appointment of Augmentative and Alternative Communication for People with Multiple Disabilities at the Radboud University Faculty of Social Sciences on Thursday, 2 June 2022

by Prof. Hans van Balkom

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The Chair in Augmentative and Alternative Communication for People with Multiple Disabilities was established in cooperation with

- BOSK, association of people with motor disabilities
- HandicapNL (formerly the Rehabilitation Fund) and Stichting 'De Drie Triangels'
- Stichting Milo: Wegbereiders in communicatie [Pioneers in Communication]
- Royal Kentalis
- Radboud University Behavioural Science Institute (BSI)

Esteemed Rector Magnificus, honoured guests

It is fine to meet and address you here in Nijmegen and by livestream. It was almost 12 years ago that I stood here to deliver my inaugural address. It was entitled 'Express yourself! Language that does not arrive in speech always finds its way out in communication'. But how? The answer to this question is in the title of my valedictory address: by elephant paths. More specifically, by neural elephant paths.

The proposition that 'communication always finds a way out' was inspired by the scientific and clinically applicable knowledge on neural plasticity, or the brain's natural capacity to adapt to changing internal or external circumstances. I use the term 'natural', because such neural adaptation is genetically anchored in the DNA of brain cells. The genetic coding of nerve cells regulates cell reproduction and determines the function and localisation of new and split-off brain cells in the brain. Once they have arrived at the desired location, brain cells 'naturally' continue to divide and seek connection with both proximal and more distant nerve cells. At a rapid pace, a cluster of like-minded and cooperating brain cells develops, which together form a specialised brain function area or core domain, such as consciousness and attention regulation, vision, hearing and motor skills. The progression to specialised core domains does not actually begin until birth, partly due to the rapidly changing environment and an increasing flow of stimuli and signals at that time. On their own, brain cells and core domains cannot do much. Working together, however, they construct a magical supercomputer. An extensive, deeply branched neural infrastructure emerges, in which specialised core domains perform complex composite functions and tasks in cooperation with each other. These include motor-visual pattern recognition, executive functions—including reasoning and problem-solving—a generic working learning ability and music perception.

Above all, a super-ordered infrastructure for communication and language is developing, building on-ramps to and exits from that super-ordered position, along with emergency lanes, bridges, overpasses, traffic plazas and signage to, from and between all underlying functional areas. In terms of network structure, communication and language span the entire brain, and they are therefore involved in almost all of our behaviour and actions, development and learning. This is also true of growth towards self-reliance, personality development: our cultural and social drive. This is the cumu-

lative result of a genetic development process that, in terms of evolution, enables humans to survive and to shape their environments to their liking, both consciously and rationally. The layered neural network structure has ingenious interconnectivity that allows our brain to adapt to changes quickly and appropriately. When blockages occur, there is always a truncation or detour, shortcut or crossing. This applies both to the normally developing brain and to the brain in which not all areas of brain functioning develop/mature, due to congenital or acquired conditions.

In one way or another, every brain seeks either (a) the shortest way to function as efficiently as possible or (b) a detour, if the shortest or most logical way has become obstructed. This involves an automatically controlled neural process embedded within the DNA of brain cells, referred to as 'neurogenesis'. As a result, new neural elephant paths to other brain cells and core domains in the brain keep rolling off the assembly line. The density of neural connections (connectivity) increases rapidly immediately after birth and especially in the first years of life. This makes the brain highly flexible and adaptive.

Knowledge of the manner in which communication and language organise and develop in the brain and behaviour under normal and atypical conditions provide insight into the systematics of elephant paths to circumvent language speech disorders and barriers to communication. This potentially compensatory, bridging role of neural elephant paths prompted research on its predictors and conditions. My chair's research programme started with the creation of a topographic map of neural elephant paths most suitable for (in this case, accessible to) communication enhancement. This led to a socio-neurocognitive model that allows a reasoned choice of assistive communication that best matches core domains with the most effective form of natural adaptation or compensation. Its assessment starts with an analysis of weaknesses and strengths. Weakness is measured by the severity of disabilities (arising from disorders) and the degree of resulting barriers (perceived limitations in daily life). Strength is assessed by the power and robustness in perceived skills that create potential opportunities and chances to bypass obstructions by deploying effective forms of Augmentative and Alternative Communication (AAC).

This leads to an informed, reasoned recommendation for assistive communication, documented in a communication competence profile (CCP). This profile describes the search for the most appropriate solution and easily accessible elephant paths available for effective AAC applications.

In this valedictory address, I discuss how the conditions and predictors of neural elephant paths can serve as an on-ramp, emergency lane, shortcut or highway for communication (including augmentative and alternative communication) and language. Much of the knowledge about this is derived from the various studies within the research programme of the Chair in AAC.

I start by discussing the concept of elephant paths and its various applications. I then define several key concepts that are important when discussing the development and functioning of neural elephant pathways for AAC. This development takes place in stages. I briefly describe each developmental stage. This phased classification served as the organising principle for the studies planned and conducted within the chair (including doctoral research): from interaction to communication, from communication to language and from language to literacy.

Finally, I discuss explanatory and reasoning models for communicative competence (culminating in the CCP), which I explain according to a case study from both theory and practice. I conclude with acknowledgements and the complimentary speeches of four dear friends and colleagues.

1. Elephant paths?

Elephants are famous for always choosing the shortest possible route, regardless of any obstacles they might encounter in the process. They quickly find a way around them.

Figure 1. Elephants seek their own paths.

Humans are also very adept at this. Where elephants work by instinct, humans create and choose their elephant path in a conscious and reasoned manner.

Elephant paths are self-paved paths created as a result of our tendency to choose the most practical and passable route, regardless of the presence of official roads, footpaths or cycling tracks. Elephant paths arise in the immediately proximal, freely available physical environment. They gradually become ingrained in the adjacent landscape as the alternative route is used more often and by more people. The more often the same side path is taken, the more recognisable it becomes. An elephant path is never longer than the official route.

Figure 2. Elephant paths.

In addition to elephant paths, the term 'goat paths' is also commonly heard. Although the two terms are used interchangeably as to their figurative meaning, there is a slight difference. A goat path is a trail that is inaccessible to humans and along which goats usually wander. Metaphorically, it refers to a difficult route with many challenges to reaching the goal: a winding, unreliable path that is often impassable for humans (somewhere out back).

The term 'elephant path' refers to an unofficial path: a shorter alternative route (a cut-off). It may also indicate a more accessible detour in the event the preferred or primary route is obstructed. In the figurative sense, it indicates a quick, substitute solution when encountering limitations and obstacles.

In humans, elephant paths emerge in a casual manner because we want to get somewhere fast (or faster). Delays and irritating congestion must be avoided or bypassed as efficiently as possible.

The term 'elephant path' is also used as a metaphor for pragmatic solutions for circumventing impairments or perceived obstacles that suddenly emerge. For example, consider mnemonic devices and looking for loopholes in the law. Another example is the hashtag (#) preceding a keyword in a Tweet, which is used to categorise tweets about a specific subject, thereby making them easier to find. More and more people started using it as an elephant path and, over time, the hashtag was integrated as an official application.

1.1. Linguistic and artistic elephant paths

We also come up with creative elephant paths in our everyday language, as with word associations, euphemisms, proverbs, sayings, emoticons and social media icons (such as the hashtag). These are linguistic elephant paths by which we soften or bypass the sharp edges, seriousness or harshness of our communications and reactions. In some cases, emoticons allow us to communicate mood and irony more efficiently in text messages or email than we could with fully written-out sentences (see Figure 3).

In communication, humans always find a creative way out or a self-constructed elephant path. Consider the example of Braille, with its tactile characters, or Morse codes consisting of dot-dash combinations. Both serve as iconic representations of letter characters, punctuation marks and numbers.

Particularly where speech or text is not the appropriate medium or where freedom of expression is under pressure, encrypted messages or elephant paths emerge to circumvent those imposed restrictions. For example, in situations with disturbing ambient noise (in noisy factory halls and traffic) or underwater, where speaking is no longer possible (divers), we almost naturally use instructive hand signals and gestures. This also applies to situations where we need to be able to recognise and process directions quickly to avoid accidents, as in the case of busy traffic situations. Traffic rules, road signs and hand signals from traffic officers can be helpful (Figure 3).

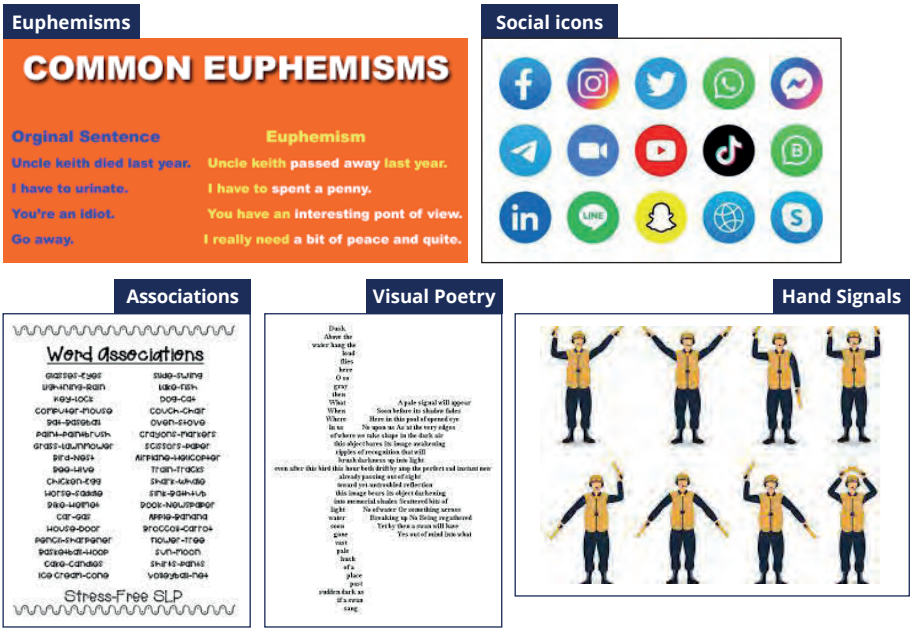

Figure 3. Elephant paths constructed from creative linguistic ability.

In paintings, dance forms and modern artistic expressions, ideas, opinions and critiques are also depicted in alternative and, at times, cryptic ways that could be termed artistic elephant paths. For example, in *Guernica*, Picasso protests the bombing of the town of Guernica during the Spanish Civil War. It is a form of 'Protest Art' against fascism and the warfare of the Hitler-Mussolini-Franco coalition (1937), see Figure 4.

Figure 4. Guernica, protest art by Pablo Picasso, 1937.

1.2. Elephant paths from musical experience

Marta Gonzalez has been confined to a wheelchair because her body is no longer cooperating. She has Alzheimer's disease and remembers hardly anything at all. Her emotional experience has flattened and is therefore no longer recognisable. She no longer speaks, nor does she use gestures, body signals or other functional movements. Communication between her and those around her has largely stopped. When staff at her residential care home played Tchaikovsky's Swan Lake, however, everything changed.

Figure 5. Music as trigger for emotional contact, increased alertness and movement patterns (see also: https://www.youtube.com/watch?v=hsLLXY_wZYI).

Here (Figure 5) we see how upon hearing the very first musical tones and after a loving touch, the memory of the associated libretto along with choreography springs to mind in Marta. This memory manifests itself in an expressive dance pattern, based

on a ballerina's lived experience, after being intensely rehearsed and trained. Music and direct touch (affection) arouse in her a deep emotion accompanied by heightened alertness. This prompts memories of hand, arm and dance movements stored within her memory. The recognition of the music instantly leads to increased awareness and activation of the corresponding emotional state, involving facial expressions, locomotor patterns and the manner in which contact is made with the environment—in this case, eye contact. Music and affection offered Marta access to neural elephant paths to procedural and long-term memory that was hidden and that had perhaps become overgrown. Rich memory coupled with a series of meaningful movement and dance patterns brought to life a sequence of memories fuelled by the emotional recognition of music (melody and cadence/rhythm) reinforced by familiar, loving touch. In this case, we could say that neural elephant paths go hand in hand with elephant memory. Here, the trick is to gain access to these robust stored memory pathways.

1.3. Elephant paths to augmentative and alternative communication

For example, neural elephant paths to alternative forms of expression arise in people for whom speech does not develop or becomes blocked due to acquired or traumatic brain injury (TBI). Examples include body signals and hand gestures in people with aphasia or eye blinking, to indicate yes and no, in people with locked-in syndrome (LIS). In both examples, severe impairments in speech and language production occur. In the case of aphasia, this may be combined with language comprehension disorders. The internal urge to express oneself in some way and indicate what one does and does not want drives the search to find suitable elephant paths—whether already present or yet to be created—that provide access to alternative forms of expression.

In most cases, LIS is caused by an infarct or haemorrhage in the brain stem, but it may also occur as a result of a traumatic brain injury (such as in a traffic accident) or due to brain cancer. Often, patients with LIS can only move their eyes and blink their eyelids. In a few cases, they can move a finger. They are both immobile and speechless, though fully conscious, being locked in their bodies . Intentional prompting, control of eye movements (sometimes only one eye or eyelid is functionally controllable) and eyelid blinking enable the formation of remarkable elephant paths, which allow these patients to control a speech computer ('speech- generating device', SGD), see Figure 6.

Sometimes, however, even eye control fails. Where possible, a brain-computer interface (BCI) can be used (Peters et al., 2022; Oken et al., 2014). A BCI is a set-up in which brain activity sensors are connected to a computer. Recording, displaying and transforming the measured brain signals are achieved by techniques such as fMRI and EEG (see Figure 7). These neural projection techniques provide insight into patterns of activity of

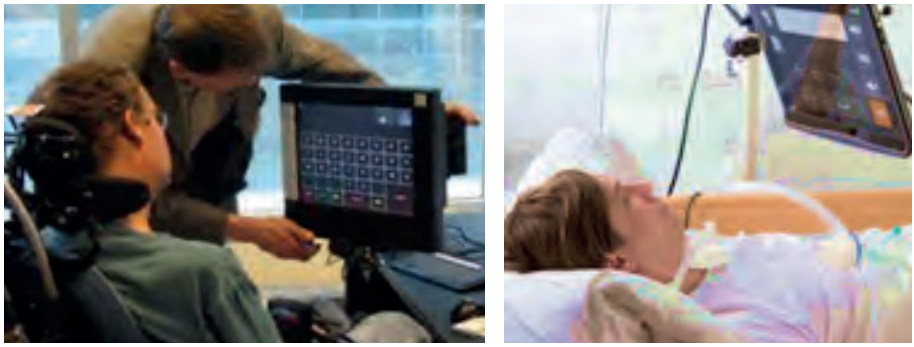

Figure 6. Eye control as an elephant path for augmentative and alternative communication in people with LIS. (Source: http://www.locked-in.nl and https://rdgkompagne.nl/expertisecentrum-oogbesturing/diensten/instellingen-scholen-ziekenhuizen/ consulted on 1 June 2022).

neurons (brain cells). The measured electrical brain activity is recorded accurately and then converted to an impulse which activates the cursor of a digital keyboard. Brain activity must be powerful enough to exceed the average background noise intensity of brain activity; otherwise, the recording fails and no conversion to activation of a switch, cursor or key occurs. Completely paralyzed people who (at least in part because of this) can no longer speak need to visualise and articulate in their minds a forceful locomotor action or movement (inner speech or inner signing). The resultant brain activity should then be able to use fMRI or EEG to generate a clearly identifiable measurement effect that generates an electrical impulse that can activate the cursor on a screen. Think of an internally formulated command, such as kicking a ball hard, running away quickly

Figure 7. Example of a BCI as access to augmentative and alternative communication.
Source: https://rerc-aac.psu.edu/research/11-investigating-use-of-a-bci-with-enhanced-language-modeling/ (consulted 29 May 2022).

or hitting a bunt ball hard. A link to a computerised spelling system allows characters or words to be selected from a list by scanning. By interfacing with a computerised speech generating device (SGD), the composed text can be voiced. If spelling fails or becomes unsuccessful, pre-programmed phrases or ready-made answers are potential alternatives. Icons or pictures can also be used as alternatives to letters and words (especially when spelling and reading skills are also compromised).

However, computerised speech- generating devices based on eye control or BCI are not appropriate for everyone. There are numerous other alternatives available within AAC, both with and without peripheral interface and control technology.

2. Basic definitions

In this section, I provide definitions of augmentative and alternative communication and describe the target group of studies within the chair: people with multiple communicative disabilities.

2.1. What is augmentative and alternative communication (AAC)?

Augmentative and Alternative Communication (AAC) is known in Dutch as ondersteunde communicatie (OC). *Augmentative and alternative communication* involves supporting the mutually aligned process of communication,[1] from the perspective of both the person with multiple communicative disabilities and the social network. Augmentative and alternative communication applies when all modes of communication and sensory functions can replace, support or complement each other in the case of disorders in perception, processing or comprehension, and when the expression of speech, writing or sign language is not or no longer possible (Van Balkom & Welle Donker-Gimbrère, 1989, 1994; Van Balkom, 2018). It always focuses on information exchange and maximising the efficiency of communication between people with complex communication needs. The descriptive wording 'people with complex communication needs' applies to both the individual with multiple communicative disabilities and those in the immediate environment; the communication disability is mutually experienced.

Augmentative and alternative communication is most effective when it connects to naturally existing, adopted or in-trained adaptive or compensatory strategies, denoted as neural and behavioural elephant pathways. These elephant paths provide a natural bypass for communication barriers. They are natural compensation strategies. In beha-

[1] Communication: the mutual conscious exchange of information and knowledge to influence each other's status and on which the feedback from each other is based.

vioural terms, this can lead to a variety of self-initiated expressions, ranging from mutism or withdrawn behaviours to rejection, repelling and ignition, social avoidance, runaway behaviour, overriding environmental noises or expressions of others, compulsive (obsessive) acts, self-injurious or physically aggressive behaviour toward others and the physical/material environment, gesticulations or self-determined, idiosyncratic ('self-conceived') expressions. Knowing, recognising and interpreting the specific characteristics of these person-specific elephant pathways is of key importance. Essentially, therefore, any behaviour or action should be understood as functional and purposefully communicative. To do otherwise would not work. For this reason, it is important to find out the how, what, when and why of all behaviours and created elephant paths. It is important to note that no one solution or one form should be chosen. In essence, augmentative and alternative communication is an all-encompassing basic attitude. It assumes that natural, embodied modes of communication (non-tech) can always be enhanced by a host of basic-tech, low-tech or high-tech (computerised) applications and tools, customised to the specific individual requirements of people with complex communication needs (see Figure 8).

Figure 8. Examples of augmentative and alternative communication.
Non-tech: Embodied forms of communication (e.g. body signals, gestures, facial expressions);
Basic tech: Easy self-made communication supports (e.g. a pointing book/board);
Low-tech: Single-button and multi-button communication devices (e.g. BigMack, GoTalk);
High-tech: Computer-based AAC devices (e.g. Speech Generating Devices (SGD's), eye-gaze and eye-tracking devices, Brain Computer Interface (BCI).

2.2. What are multiple communication disorders?

In the Netherlands, the term *multiple communication disorders* is used as an umbrella term for people with severe impairments and perceived barriers in communication and language development due to a combination of different disorders and/or impairments. In many cases, mental, sensory and motor impairments also play a role (see Figure 9).

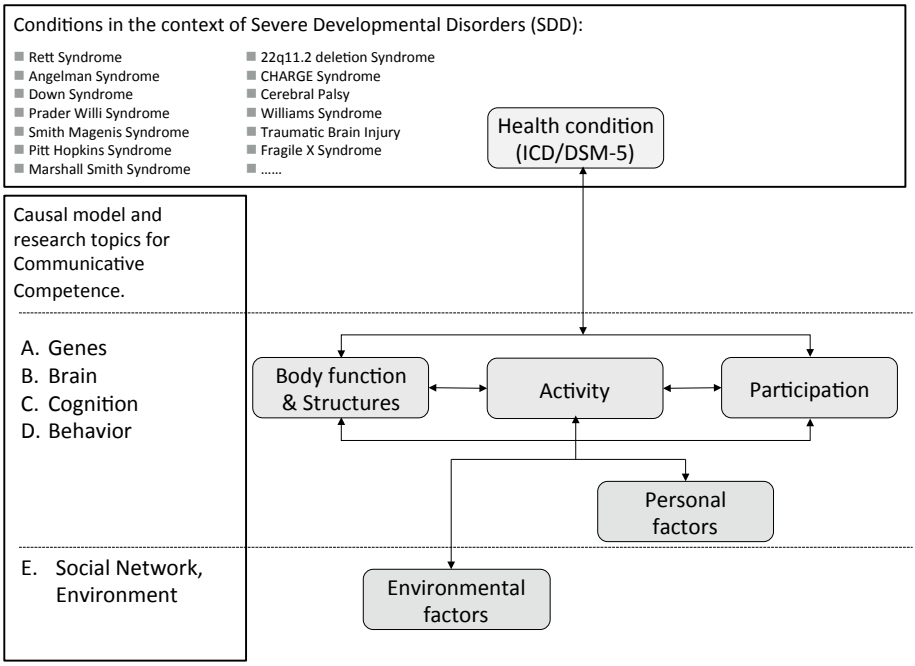

Figure 9. Target group of people with multiple communicative disabilities in relation to the ICF Model (Van Balkom, Deckers & Stoep, 2017)

Multiple communication disorders are a cluster of disorders and impairments that are difficult to disentangle. These difficulties may reinforce each other in different combinations, affecting the severity of the communication disorders. Personal characteristics and external influences often complicate the complex of disorders. People never face communication barriers in isolation. These barriers are always experienced together with those in the immediate environment. Social network or communication partners and settings are always part of the problem, but more importantly, part of the solution. In particular, AAC solutions are based on mutual acceptance and application. Communication barriers can be caused by congenital or acquired disorders (see Figure 9). In a congenital disorder, the condition occurs before or at birth (as in cerebral palsy) or is the result of hereditary defects (for example in children with Down's syndro-

me). Acquired disorders are the result of disruptions and consequences of disease that become apparent later in life. Examples include traumatic brain injury (TBI) due to accident or violence. Diseases may include brain tumours, stroke with aphasia or dysarthria, and neuromuscular disorders (such as ALS and MS). There may also be associated psychiatric problems, such as selective mutism, neglect, post-traumatic stress disorder (PTSD) or combinations with severe autistic spectrum disorders.

3. The emergence of neural elephant paths

The construction of neural bypasses or neural elephant paths is an important characteristic of brain development or neurogenesis (the brain's capacity to create new neurons and brain cells). The creation of new connections and the elimination of unused ones in the brain is an active process. It takes place continuously, and it is genetically prepared. This creation of neural pathways, new connections or elephant paths allows the brain to adapt to suddenly changing conditions right from birth. In children with relatively 'normal' brain development, these are mainly changes caused by external influences (including temperature, touch, sound and light) and the sudden independent start of primary bodily processes (including breathing, swallowing, drinking, eating, movement and the senses). Birth is therefore the key moment when the adaptive capacity of the human brain is triggered. This is important because, without this capacity to adapt, we would never be able to adapt. Hazards and threats are quickly recognised and converted into protective actions. This is accompanied by the rapid formation of neural connections. Even before birth, this predisposition is met by a series of survival and transitional reflexes (see Figure 10). Examples of survival reflexes include the breathing and sucking reflexes. Transitional reflexes occur after the initial period of adaptation from birth and include the postural reflexes that give rise to sitting and crawling. The transition from sitting to crawling introduces exploration of the immediate environment. Reflexes clear the first elephant paths, and they are partly responsible for initiating the process of neurogenesis and the growth of neural adaptive capacity.

3.1. Elephant paths as neural planners

More than 80% of all brain development takes place between birth and the age of three years. During the first year of life, the volume and weight of the brain triples almost daily. During this time, brain activity is at least twice that of an adult. Every day, about 700 new connections are made in the brain in response to interaction with the environment and communication with parents/caregivers. This is because nerve cells in the brain have the unique ability to make new connections in the adjacent free brain space, even outside their genetically defined areas of activity. As a result, the brain is able to perceive, connect, process and act on many signals and stimuli quickly and efficiently. This additional

Figure 10. Survival and transitional reflexes as the first neural elephant paths.

drive for recuperation, which is naturally present in nerve cells, creates space and ample opportunity to forge the necessary, convenient 'elephant paths' anywhere. This creates capacity for neural networks to grow and connect (Deacon, 1997; Karmilof-Smith, 2005; Newbury & Monaco, 2008).

The impetus for this arises in the embryonic development stage. From a predisposed blueprint, specialised areas of brain functioning (also known as core domains) arise for various purposes, including attention regulation, perception, memory function, motor skills and language. The localisation, organisation and specialisation of these core domains is determined by the DNA in nerve cells. The cells therefore possess and find their destination immediately upon division. The same applies to the manner and extent of mutual influence, coordination and cooperation. The genetically determined control in neural development and the organisation of the brain ensures that a preconceived basic cerebral infrastructure emerges immediately upon birth and develops rapidly thereafter (see Figure 11).

3.2. Neuroplasticity

From their familiar location (core domain or hub) and under the influence of incoming stimuli and signals, neural elephant paths access an unexplored area of the brain in search of processing space and functional cooperation. Expeditions of exploration and discovery emerge, seeking cooperation with neurons and core domains to expand and enhance brain functionality. This is evident in the way young children explore their immediate environment through action and movement. Everything is geared towards processing new stimuli, experiences and perceptions as quickly and appropriately as possible. This is accompanied by the development of the necessary lateral neural connections. Many more neural connections than are needed for later stages of development are initially created during this journey of discovery.

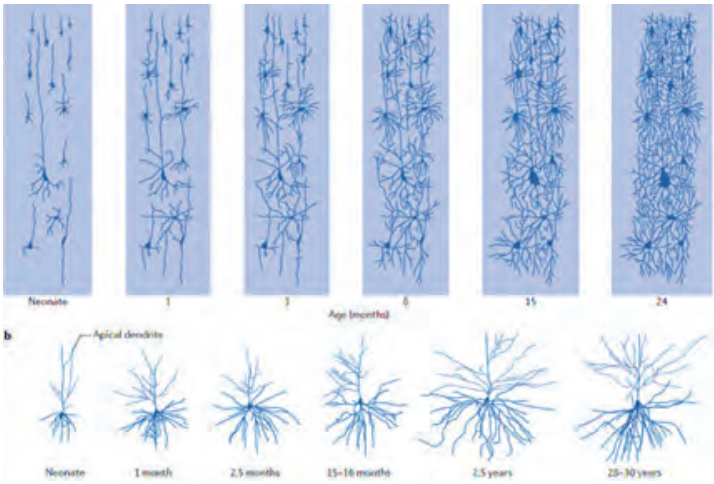

Figure 11. Growth and clearing of neuronal connections.
Source: Gilmore J.H., Knickmeyer R.C., & Gao W. (2018). 'Imaging structural and functional brain development in early childhood'. *Nature Reviews Neuroscience, (19), 123-137*.

The excess capacity of connections is needed to prepare the brain to process stimuli and information from the many unexpected, changing circumstances during this period. The extra neuronal capacity built up in this way acts as an in-breeder, where new and alternative connections or detours are prepared and scheduled. This promotes the efficient (or more efficient) transmission and efficacy of new information and knowledge provided by developmental and learning processes. In most cases, this also leads to the construction of new elephant paths and routes that can then be used in the event of possible blockages (Ellis & Young, 1988).

An example of a neuropsychological reasoning model for distinguishing different bypasses or elephant paths from a pre-constructed (acquired) neural network is shown in Figure 12. In later-acquired speech and language disorders, the previously used neural pathways for speech have become blocked. Alternatively, through the detour of vision ('concrete objects', text or 'written words'), an elephant path (newly paved or previously created and then reconstructed) can still be traced to other forms of expression, with or without the aid of augmentative and alternative communication (AAC).

The development of neural elephant paths is affected by personal factors, bodily processes and environmental influences. In this respect, favourable, experientially rich conditions and varied experiences offer more opportunities and chances for alternative pathways than do restrictive, obstructive conditions and a monotonous, low-stimulus environment. The environment in which a child grows up thus largely determines the utilisation of the available neural reserve capacity. In the case of under-utilisation, this

space will become surplus and the extra volume will lose its value. The brain space is adapted to the neural connections that are used regularly and frequently. What ultimately remains are frequently used neural connections: previously developed elephant paths now become the 'highway'. At later stages, the links continue to act as potential cut-offs, bypasses or alternative routes that can be used as detours in case of blockages on main routes. Gradually, a robust reorganising capacity or repair mechanism takes shape in the brain, consisting of a network of alternative connections that can be used as neural elephant paths.

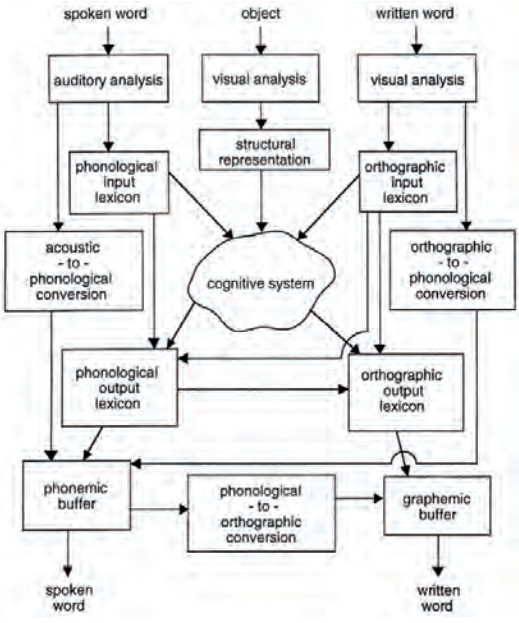

Figure 12. Neural compensation model based on Ellis and Young (1988).
Source: Luzzatti, C., Laiacona, M., Allamano, N., De Tanti, A., & Inzaghi, M.G. (1998). 'Writing disorders in Italian aphasic patients. A multiple single-case study of dysgraphia in a language with shallow orthography.' *Brain: A Journal of Neurology, 121(9)*, 1721-1734.

In the literature, the brain's ability to adapt quickly to changing (internal or external) conditions is also termed 'neuroplasticity' (Dennis et al., 2014; Zholudeva et al., 2021; Pasquini et al., 2022). Neuroplasticity is closely related to the genetically determined blueprint from which the human brain develops, which drives nerve cells (neurons) to create new brain cells and to use the free, nearby brain space to make new connections (neurogenesis), particularly to connect with other areas of the brain. This could be described as 'neural path-finding': a constant search for the most appropriate, efficient and effective neural connections and target pathways. In neurorehabilitation,

the natural compensatory capacity is used to create alternative neural pathways (e.g. after a stroke or traumatic brain injury) by using (or re-using) existing neural elephant paths wherever or whenever possible.

For people with acquired disorders, it is sometimes possible to regain all or part of the lost function by using previously established neural connections in the immediate region of the lesion and then using these connections as a detour. This often requires increased motivation and persistence within the context of highly intensive rehabilitation treatment. The result of an intensive neurorehabilitation programme is shown in Figure 13.

Figure 13. Neurorehabilitation: Construction of neural elephant paths.
Source: Kolb, B., Muhammad, A., & Gibb, R., (2010).

3.3. Neural elephant paths: Natural adaptation or compensation

During development, neurogenesis creates a dense and extensive neural network of connections that is readily accessible to create detours when blockages occur. The importance (in terms of functionality), density, state and intensive or non-intensive use of network connections determine the quality and readiness of the available reserve capacity for natural compensation. The effect of such a natural compensation network can be observed in different situations, such as in noisy environments, when speech is ineffective, and people automatically fall back on gesture and gesticulation. Similarly, in congenital deafness, children tend to develop sign language by means of visuomotor patterning, gesture and, under favourable conditions, sign language. This kind of predisposition also applies to persons with multiple communication disorders. Therefore, highly unique or idiosyncratic AAC pathways often emerge from survival and transitional reflexes that are gradually modified by interaction with the environment. In too many cases, these are still labelled as 'behavioural problems' and treated at the behavioural level, when in fact the behaviour resulting from natural compensation should always be considered as communicative. This is because 'communication always finds a loophole' when faced with disorders in perception, processing, understanding (comprehending) and expression of either spoken, written or signed language. The discovery of neural and behavioural pathways for AAC is therefore quite a daunting task.

4. Neural elephant paths: Stages of development

Neural bypasses or elephant paths are inherent to the growth and maturation of the brain. This is particularly true for the development of connections within and between areas of brain function. Communication and language span the most extensive and deeply branched neural network, involving several core domains, including attention, perception, memory, cognition, emotion and motor skills. Communication and language networks are also used frequently and very intensively. For this reason, there is ample opportunity for the creation of new routes that can be used as alternatives and detours in the event of disorders and obstacles. Most of the development and organisation of the neural network for communication and language takes place in the first five years of life. This period is perceived as a genetically controlled incubation period in which the underlying infrastructures of both the autonomic and central nervous systems become established. The result is a kind of ground-plan or circuit board based on an architectural blueprint, which indicates the localisation of the core domains with the main neural pathways and relay stations. The same applies to the connections from and to the sensory and organ systems. The main head connections and the ability to forge new neuronal connections are also predisposed to be ready in time.

The further unfolding, development and specialisation of this basic infrastructure begins at birth, in interaction with the environment. This developmental process involves three transitional phases:

(1) From interaction to communication
(2) From communication to language
(3) From language to literacy

I use these three stages to describe the development of communication, language and literacy, along with the role and function of neural elephant paths within them. The various research projects within the Chair in AAC can also be divided into these stages.

4.1. From interaction to communication

Immediately after birth, a number of pre-established neural elephant paths are already active. They trigger survival reflexes, which are the first steps towards adaptation and the search for security and affection, along with the creation of a developmental niche. Amongst other things, the group of innate survival reflexes causes the newborn to breathe independently. The sucking reflex points the way to breast or bottle feeding.

A mother is hormonally, almost instinctively, prepared to initiate a series of rituals to protect, nurture, comfort and bond with her newborn baby. These one-to-one contacts create an environment that is sealed off from the outside world. This filters out surrounding noises and other potential distractions. The attachment and

mutual trust create a 'developmental niche' (Narvaez et al., 2013; Stotz, 2010), within which newborns are raised by parents and caregivers in an embedded physical, social and cultural habitat. The emergence of this niche is in itself a 'favourable (elephant) path' for a child to embark on the first steps of learning and adaptation. It is a guided and protected development characterised by sustained and sequential eye-to-eye contact, mutual body and face orientation of the parent/carer and child, shared gestures and facial expressions, physical contact, being moved during feeding or diapering, comforting rocking accompanied by humming or singing, doing things together and experiencing them together. Within this developmental niche, other auxiliary pathways, or elephant paths, emerge as parents/carers and the child move from interaction to communication. The migration from interaction to communication is driven by the transition from:

- Reflexive (or instinctive) to responsive behaviour
- Responsive to shared attention to the initiation of joint attention
- Action-reaction to cause-effect and predictability (causality, object permanence)
- Experiencing daily recurring actions and events to understand regularity and structure in behavioural patterns in order to anticipate coming events, mainly through pattern recognition and ritualisation
- Body-centred, self-oriented behaviour to situation-oriented behaviour, focused on the environment and the other person's role in it (self-other relationship; mirroring and imitating behaviour; role patterns; turn-taking behaviour; Theory of Mind (ToM)
- Body awareness; learning to discover one's own body (physicality, corporeality) to embodied cognition (embodiment)
- Non-intentional behaviour to intentional behaviour (intention-reading)
- Non-referential behaviour to referential pointing and referencing behaviour.

See Tomassello and Carpenter (2007).

The recognition of fixed patterns of behaviour and the conscious experience of predictability through the fixed sequence of uses and accompanying expressions means that there is more overview and certainty. Greater visibility and understanding of what is happening and about to happen in the nearby environment further increases the sense of security. This allows the child more time for exploration and self-discovery.

4.2. From communication to language

The evolution from communication to language builds on the development from interaction to communication:

- Focused attention and perception develop into joint attention and intersubjectivity[2] (Trevarthen & Aitken, 2001).
- Through intersubjectivity, shared and divided attention are consciously used to follow something or someone (sustained attention) and observe it in order to find out its scope and meaning. The child makes a conscious effort to attract the other person's attention, with the intention of establishing reciprocal relationship and eliciting comments or explanations.
- Intersubjectivity generates a common focus and shared understanding or 'common ground' (Clark, 1996). This common orientation creates a joint sense of connectedness. It puts the parent/carer and the child on the same wavelength. This is an important prerequisite for converting exchanged information into shared knowledge.
- The development of a common ground is the most important requirement for mutual recognition and communication, which triggers language acquisition. This is reinforced by the interplay between parents/carers and children in ritualised daily routines. Symbolic play and role-playing, interactive reading aloud, moving and singing together, and many contact gestures are all part of this.
- Parents and carers have a dual role when interacting with their young children. As mentioned earlier, parents and carers comment on and interpret both their own roles and those of their children when they are involved in an activity or event together ('languaging'). In the process of 'languaging', parents and caregivers gradually use more self-staged monologue conversations. In the process of early language acquisition, parents and carers gradually use modelled question and answer templates in monologue format or 'proto-conversations' (Bateson, 1975, Snow & Ferguson, 1977).
- From these proto-conversations, children learn how to formulate intentional actions (such as asking, checking, instructing, claiming and promising) as they go along (Austen, 1980). Based on the cooperative principle (Davies, 2007), this generates an awareness of linguistic action. It is thus a powerful strategy for developing an understanding and direction of the (linguistic) conversation (co-creation).
- The range of linguistic speech on the part of parents and caregivers is highly simplified and situation-specific (child-directed register). These simplifications are characterised by omissions, abbreviations and contractions of words. In many cases, therefore, the sentences in the range of linguistic speech are also short (telegram style). These adaptations have the explicit function of guiding and modelling the child's speech and language development through

[2] The mutual and conscious sharing of each other's attention, emotions, experiences, perception and information.

communication. In this way, greater emphasis is often assigned to meaning-bearing and meaning-distinctive words or word parts within the range of speech, in order to propel and support the child's acquisition of meaning and vocabulary development. The use of diminutives and gestures to support or accompany speech also serves this function. The whole range of speech is further marked by overly expressive intonation and prosody, accompanied by mimicry and adjustment of the order of words in sentences (Snow, Perlmann & Nathan, 2021).

- The adapted range of linguistic speech attracts, sustains and directs the child's immediate attention to spoken language, making expressed intentions, purposes and meaning accessible and understandable. Such adaptations mediate and facilitate recognition and learning to distinguish speech sounds in ongoing speech, as well as phonological and phonemic awareness.
- Children mirror and imitate the parent's or caregiver's mouth and speech-supporting gestures, which provide a natural learning situation for practising speech sounds. This is manifested in gibberish and babbling (in the language of the surrounding, common community).

All these strategies are actually elephant paths along which children learn to find their own way from communication to language (Tomasello, 2008).

4.3. From language to literacy

In itself, the journey to literacy begins quickly with seeing text, signs and symbols on the street, in newspapers and magazines, with holding and handling books or orienting to books, with interactive (or passive) reading aloud, and with sharing, living and telling (or retelling) common experiences. The step to literacy thus does not begin only after the child has gone through the previous two transitional phases. Early literacy instruction builds on the aforementioned predictors of communication and language (Stoep, 2008). This applies to both typically developing children and children with multiple communication and language disorders (Van Balkom, 2018). Compared to communication development and language acquisition, literacy is certainly not automatic or self-evident. The actual technical ability to read (word decoding skills), as well as reading comprehension, does not come automatically. It requires an intensive process of teaching and learning to read. The National Reading Panel (USA) (2000, 2022) identifies a number of predictors for literacy learning. The 10 most important predictors are as follows:

- Attention: Auditory and visual attention, referring to hearing and seeing
- Pattern perception (hearing and vision): Sound patterns in running speech; the sequential organisation or ordering of sounds or phonemes in relation to graphemes or letters in a word (spelling), sentence and larger text files.

- Letter recognition: Recognition of and ability to name the shape and identity of characters in words.
- Phonological and phonemic consciousness: Articulatory arrangement, knowledge of and skill in the pronunciation of speech sounds or required expressive mouth and hand forms (hand alphabet), sign language, hand alphabet and sound gestures.
- Grapheme-phoneme coupling (letter-sound coupling) refers to word-decoding skills and the ability to use spelling rules to connect (synthesis) and differentiate phonemes and their corresponding letters.
- Reading speed and reading fluency in relation to the planning, processing and comprehension of sentences (i.e. pacing and rhythmic patterns in speech and sign production) and the temporal significance of prosody and intonation. From the beginning, the child learns to express sounds and sequences of phonemes (spoken language) by being read to.
- Working memory stores auditory and visual information, including the order of letters (graphemes) and syllables as representations of phonemes and words, word parts and their referential or attributive meaning.
- Vocabulary development: Transition to word comprehension and word production (receptive and productive language) through meaning allocation. Vocabulary involves long-term memory. The relationship between words is important: phonological and semantic networks are formed based on sound similarity (including rhyming words) and meaning relationships (synonyms, antonyms and word associations) respectively.
- Text comprehension arises from direct referential meaning (referring to something or someone in the immediate environment. Symbolic meaning occurs when the same reference is recognised in different environments. At this point there is a generalised meaning; the reference point need not be present in the immediate environment or textual context. Understanding text requires working and long-term memory.
- Motivation, interest and involvement: Children become motivated and interested from direct, physical and situational engagement, being together, acting together and experiencing together.

The transitional processes driving this development are examined and described from different theoretical perspectives. The main sources are listed above. The research programme of the Chair in AAC is based on a number of these studies. From this, a socio-neurocognitive model of reasoning and explanation has been deduced (Van Balkom, Deckers & Stoep, 2017). It is against the background of this model that research findings are interpreted and discussed. Therefore, I will give a brief explanation of this socio-neurocognitive model.

5. Reasoning and explanatory models

Reasoning and explanatory models of the development and functioning of communication and language have emerged from both psycholinguistics and neuroscience. Most of these models are hypothesis-testing diagrams, depicting processes such as information processing, communication, language acquisition, language and speech processing in light of knowledge about their neurocognitive development and brain infrastructure. They are usually block models with inscribed pathways indicating the hypothesised direction and course of processing.

Communication and language processing block diagrams provide a stepwise representation of concurrent processes. This makes the processing flow transparent and separable into interacting modules. These modules can be investigated and verified both individually and as they interact with one another. The models also help to design, structure, develop and validate test batteries in neuropsychology and speech-language pathology (see De Sonneville, 2005, 2012).

Figure 14a shows a widely used psycholinguistic model of the speaking process (Levelt, 1989) alongside a neurocognitive equivalent that is also widely quoted and applied (Hagoort, 2005 in Figure 14b). It also shows a more recent and differentiated elaboration of this neurocognitive representation of core domains (Hertrich, Dietrich & Ackermann, 2000 in Figure 14c).

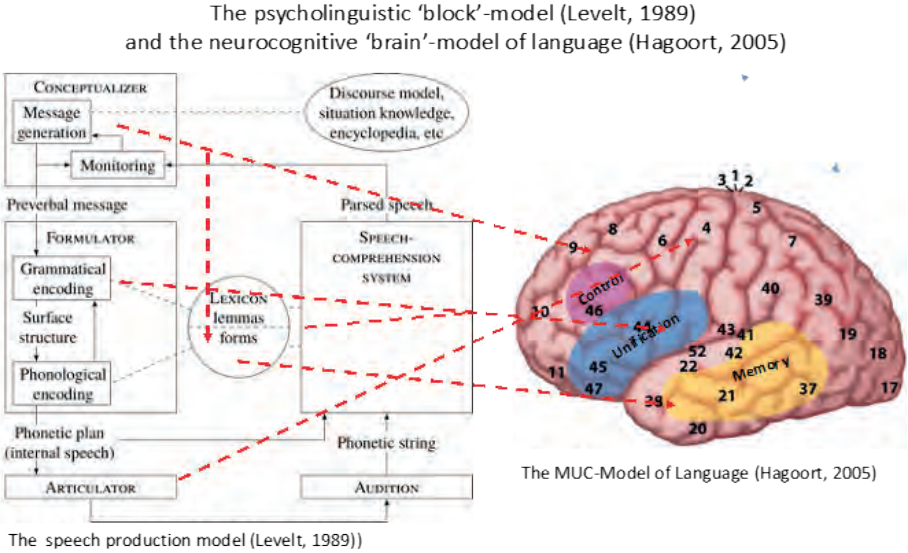

Figure 14. Speech Production Model (Levelt, 1989) related to the neuro-cognitive MUC-Model of Language (Hagoort,(2005).

What is interesting about these accounts is that hypothetically constructed block models from psycholinguistics (see Figure 14a) and neuropsychology (see also Figure 12, above) have found their way into neurocognitive research. They are increasingly contributing to the verification, validation and scientific substantiation of these block models. The same is true of the socio-neurocognitive models of thought and explanation that have been developed on the basis of clinical and scientific research. These models are now used on a daily basis in clinical practice at Stichting Milo.

Research within the Chair in AAC has focused on identifying key indicators of best-fit AAC. The notion of 'best fit' was conceptualised as 'matching (observable) behaviours that can be traced to neural elephant paths and associated core domains that circumvent communication barriers and correspond to the capabilities of the social network. The research projects within the chair of augmentative and alternative communication aim to answer this question: Which insights and knowledge derived from the various studies, compiled and interpreted from the basic model, potentially have sufficient reasoning and explanatory power to provide reasoned explanations for advice and decisions on the selection of the most appropriate augmentative and alternative communication and treatment goals?

Three further premises underpin this research question. First, the basic model visualises a possible organisation and assumed developmental sequence of communication, language and speech processes in the brain and behaviour. This is supported from within a rich tradition of scientific insights and knowledge. This is particularly true for the modular construction of the constituent core domains and neural network structure. Second, the basic model facilitates the operationalisation and interpretation of research questions that are relevant both for understanding the organisation of communication and language in brain and behaviour and to possible clinical applications in AAC treatment and counselling. Third, the basic model provides guidance for discussing neuroplasticity, the emergence and functioning of neural pathways and alternative routes or elephant paths (adaptation, compensation) for communication and language (and its acquisition).

5.1. Core domains as neural building blocks

The basic model for research within the Chair in AAC and for evidence-based clinical practice in AAC is based on knowledge of the development and organisation of communication and language in the brain and behaviour. Communication and language do not exist in isolation. They emerge in the brain under the influence of environmental factors (including an adapted language supply) and characteristic, personal traits. These ontogenetic processes involve different brain functional areas or core domains (Hagoort, 2005; Kolb et al., 2011; Houwen et al., 2016; Skeide, 2016, 2019; Gilmore et

al., 2018; Pasquini et al., 2022; Rolls et al., 2022). To and from these core domains, a broad and deeply branched network of neural connections (connectivity) gradually develops. Core domains become important traffic hubs in the neural connectivity for communication and language. The main nodes for communication and language arise in the core domains of arousal/attention, sensory perception and signal or stimulus processing, memory and working memory, cognition, orientation (social, bodily, spatial, temporal), socio-emotional regulation, adaptation and self-reliance and motor skills (see Figure 15). These core domains also play a central role in other developmental and learning pathways, such as reading, mathematics, logical and visual-spatial reasoning, and problem-solving skills (see Egorova et al., 2016; Friederici, 2017; Friederici et al., 2017, 2019; Malik-Moraleda et al., 2022).

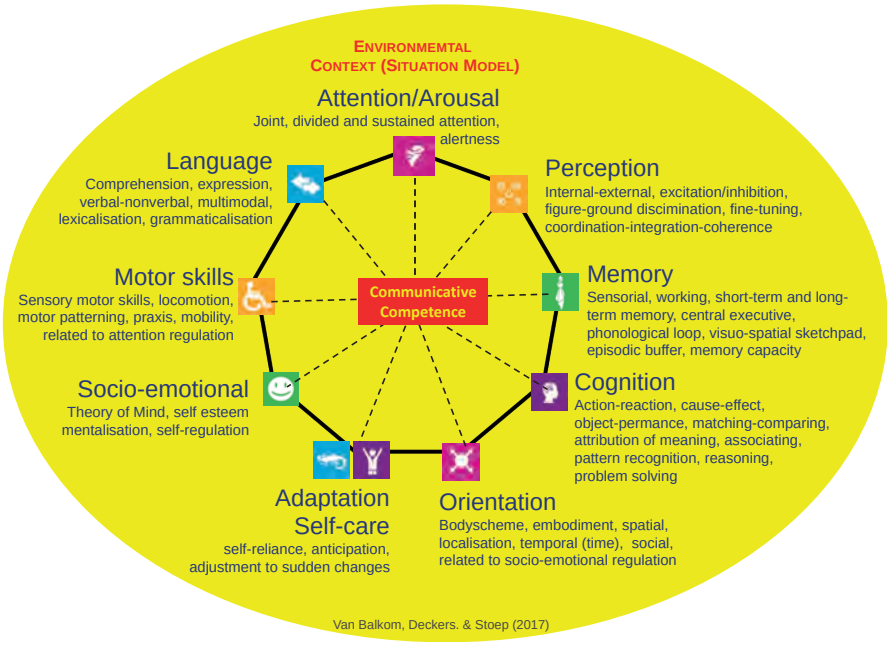

Figure 15. Core domains for communicative competence.
Source: Van Balkom, H. (2018). Kinderen Leren Initiatieven Nemen in Communicatie (KLIN©) [Children Learn to take the Initiatives in Communication). ACCO, The Hague/Leuven.

The networks are interconnected and reinforce each other during the first years of life. This means that a limitation in or to one domain has an inhibitory effect on other domains. Increased activity and ability in a core domain intensify connections in and with other domains. Such intensification can be facilitative or enhancing, but it can also be limiting and obstructive. These reciprocal influences create neural elephant paths (by-

passes) to or through other core domains. This can unblock emerging barriers, but also backfire, leading to more extreme, rejecting or withdrawn behaviour. In both cases, AAC can provide an appropriate solution, provided that the underlying triggers and target pathways have been identified and interpreted as fully as possible in context. This requires knowledge of the person and the context (environment) of both the brain and behaviour.

5.2. Socio-neurocognitive reasoning and explanatory model

The basic model (Figure 16) depicts the organisation and flow of communication and language processes. The functional components (as shown in Figure 16) are brain-functioning areas (core domains) that cooperate in neural processes that are involved in communicative competence and language processing. The model is an adaptation of similar information and language-processing models from psycholinguistics.

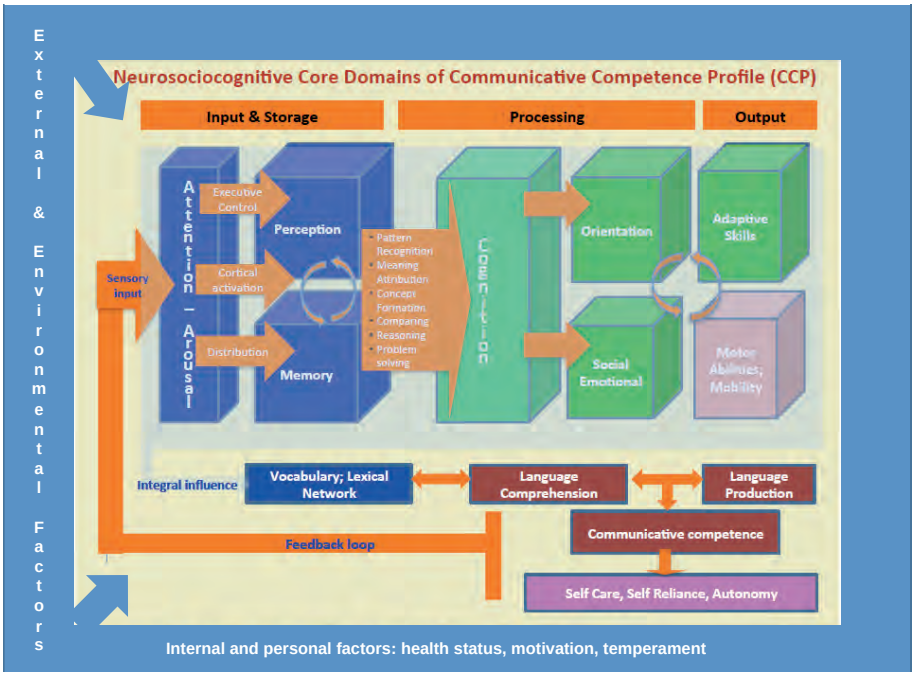

Figure 16: Figure 16. Information processing and communication and language.
Source: Van Balkom, H. (2018). Kinderen Leren Initiatieven Nemen in Communicatie (KLIN©) [Children Learn to take the Initiatives in Communication). ACCO The Hague/Leuven.

Note: **Attention:** Specific mental functions of focusing on an external stimulus or internal experience for the required period of time | **Arousal:** General mental functions of the state of awareness and alertness, including the clarity and continuity of the wakeful state (vigilance) | **Perception:** Specific mental functions of recognising, processing and interpreting sensory stimuli | **Memory:** Specific mental functions of

registering and storing information and retrieving it as needed (mainly working memory functions) | **Cognition:** General mental functions, required to understand and constructively integrate the various mental functions, including all cognitive functions and their development over the lifespan | **Orientation:** General mental functions of knowing and ascertaining one's relation to self, to others, to time and to one's surroundings (including embodiedness) | **Social emotional:** Specific mental functions related to the feeling and affective components of the processes of the mind (i.e. self-esteem and Theory of Mind) | **Adaptive skills:** Specific mental functions related to coping with sudden, unexpected changes in personal or environmental conditions | **Motor abilities:** Functions associated with control over and coordination of voluntary and intentional movements | **Mobility:** Moving by changing body position or location or by transferring from one place to another, by carrying, moving or manipulating objects, by walking, running or climbing, and by using various forms of transportation (e.g. wheelchair-bound mobility) | **Self-care:** Actions that people initiate and perform on their own behalf in maintaining life, health and well-being | **Self-reliance:** Having confidence in and exercising one's own powers, abilities or judgments (World Health Organization/ICF CY, 2007).

Communicative competence and language processing are shown statically in block diagrams in this model, but in reality, they are sequentially connected and interrelated areas of brain function or core domains. The 'spider-web model' in Figure 15 actually does a better job of capturing the interdependencies, but at the same time makes a clear line of reasoning more difficult. At the top of the diagram in Figure 16 are Input and Storage, Processing, and Output and Control. The process starts on the left with signals, where input refers to core domains, such as (1) attentional regulation (arousal, awareness) and perception. Memory refers to memory functions, followed by 'processing', which includes cognitive functions, 'social-emotional regulation' and 'orientation' (bodily, spatial, temporal, social). This ultimately leads to output through motor skills (practice, movement, behaviour regulation), non-linguistic forms of expression (body signals, gestures) and the integrated influence of all core domains on various expressive language functions, including vocabulary, language comprehension and language production. Together, these core areas determine communicative competence, self-care, independence and autonomy.

In the 'Control' (or feedback) mode, expressions and behaviours are reprocessed through perception to be assessed for correctness in terms of intention, form, content, use and effect on the communication partner. The overall process is influenced and partly determined by internal (personal) and external environmental factors (e.g. the physical environment, influences from the communication partner). Such control and its impact can lead to adjustments, iterations and revision.

5.3. Communication and language: Symbiotic partnership

This creates a symbiotic partnership that spans all major core domains in the brain (see Figure 17). The 'total brain', as it were, counts as a field of action in communication (Kolb et al., 2011; Friederici, 2017; Tirassa, 1999).

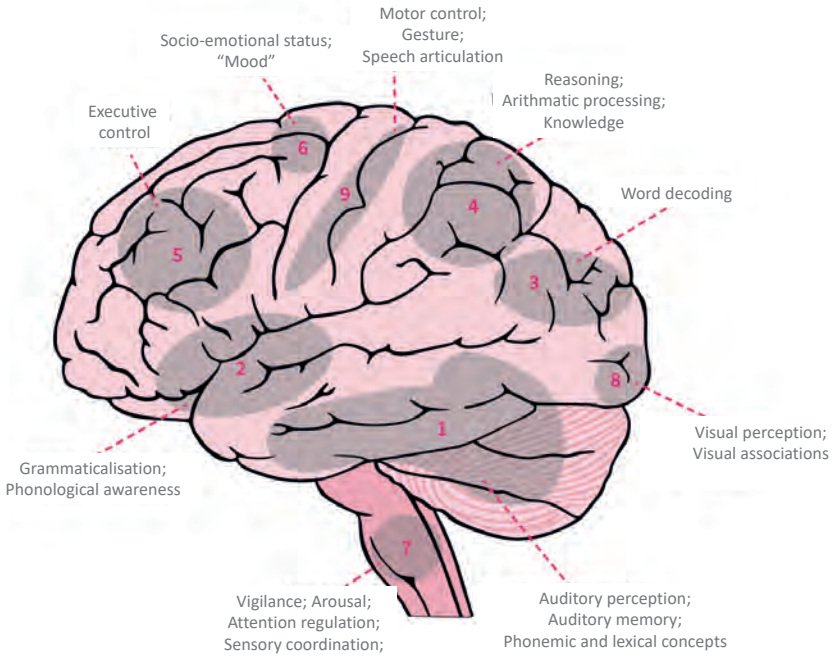

Figure 17. Neural network of core domains for communication and language in the brain.
Source: Van Balkom, H. (2018). Kinderen Leren Initiatieven Nemen in Communicatie (KLIN©) [Children Learn to take the Initiative in Communication). ACCO The Hague/Leuven.

Spanned by the core domains, each of the brain-function areas for communication has its own specialisation. These include neural networks that specialise in attention regulation, visual processing, auditory processing, memory functions, motor skills and emotion regulation. The neural network for communication and language is perhaps the most extensive, complex collaborative network involving virtually the entire brain and all major core domains. The order and degree of involvement of core domains depends on the communicative function and action to be performed, as well as on motivation and developmental status. For example, in the order of the core domains involved, the expression and regulation of an emotional state usually starts with the 'socio-emotional' core domain, with reasoning corresponding to 'cognition'. In cases of sensory overstimulation, motor skills are often activated by bodily impulses (orientation), such as walking or rocking, which has the corollary effect of heightening alertness and subsequently improves the perception and filtering of stimuli. The linked partnership of the core areas of communication and language gradually develops a large number of main and alternative routes (elephant paths). Together they form a complex web of main and secondary roads, shortcuts and detours. The way and extent

to which this happens varies from person to person, and from setting to setting. Either way, there is always potential for finding personal elephant paths somewhere in this neural network. Despite these interpersonal differences, the underlying innate driving mechanism (neurogenesis and neuroplasticity) is the same for everyone.

Building a densely wired neural infrastructure and behavioural connections within and between core domains also ensures that senses and modes of expression can substitute for each other when disrupted. For example, blind people learn to process text through tactile signs (i.e. Braille), and deaf people learn sign language if others in their immediate environment will use it. In this way, conversational partners develop and reinforce (through their natural predispositions) the most appropriate pathways for AAC. The same applies to the transformation of transient forms of expression, such as speech and gestures, into permanent forms, including pictograms, objects, writing or pictures. This kind of intermodal exchange makes it possible to capture, use, share, extend or modify knowledge gathered beyond the here and now and across time. Similarly, the discovery and recognition of graphic signs (including alphabetical characters) will further the process of learning to read, allowing us to reflect on and build upon previous knowledge and the knowledge of others even more effectively.

6. Elephant paths and AAC: The leitmotif of the research programme

The guiding principle for research within the Chair in AAC programme has been the search for predictors as antecedents from which neural and behavioural pathways for communication and language can be explained. These predictors can serve as a starting point for dynamic assessment, counselling and treatment of the most appropriate configuration of AAC. Rather than taking the disorder, impairment or barrier as the starting point for assessment, treatment and counselling, we explicitly look for opportunities and possibilities to use AAC to turn the compensatory skills (or neural pathways) into opportunities for development, learning and empowerment. At the heart of this approach is answering and understanding the 'why' of the behaviour that is shown and that needs to be modified. This process always begins by exploring the natural, initially strongly body-orientated, compensatory mechanisms of the person with complex communication needs. Getting to know this natural compensation strategies creates the preconditions and key success factors for augmentative and alternative AAC (Van Balkom, Deckers & Stoep, 2017).

6.1. Research results from the Chair in AAC

Through their PhD studies within the research programme of the Chair in AAC, the researchers have built up a body of validating and verifying knowledge that has led to significant improvements in the ability to diagnose (assess) and identify verifiable goals and

effects of treatments related to AAC. The outcomes from these studies pertain to critical predictors of the development of communication, language acquisition and literacy in children, adolescents and young adults with complex communicative disorders, as well as the role of the environment in this regard. The research programme follows the earlier outlined arrangement of developmental and transitional stages (see Figure 18).

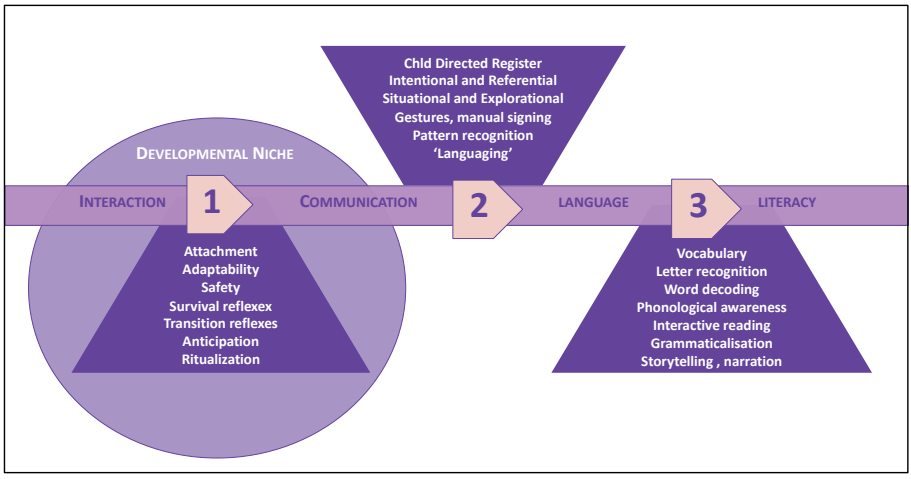

Figure 18. Developmental stages and transitional phases

6.1.1. From interaction to communication

In this first stage, as children move from interaction to communication, research focuses on describing and identifying the ways in which children make this transition together with their parents and others in their immediate environment. The following research questions apply within this context:

(1) To what extent can similarities and differences in adaptations and communication strategies be observed between typically developing children and children with multiple communication disorder?
(2) What predictors in the mutual involvement of the child and the immediate environment facilitate or block the transition from interaction to communication?

Study 1: Lexical development of children with Down syndrome: A communicative perspective[3]

It is important to consider the development of vocabulary in terms of communicative competence in order to understand the development of vocabulary in children with

[3] Stijn Deckers (2017) | PhD Thesis | Radboud University. https://repository.ubn.ru.nl/bitstream/handle/2066/173032/173032.pdf

multiple communication disorders; in this doctoral research, children with Down syndrome were the focus. This is because language learning occurs predominantly through communicative interaction with primary communication partners in a familiar setting. Previous research on the development of vocabulary in children with Down syndrome has shown several limitations in research design: (a) only spoken words were examined and other modalities were ignored; (b) very little or no functional use of vocabulary in communication situations was examined; and (c) most studies of children with Down syndrome examined functioning at one point in time. As a result, very little is known about the actual development and about the presence and stability of predictors of vocabulary development in children with Down syndrome. Therefore, the main focus of this PhD research was to gain more insight into these aspects of vocabulary development.

Stijn Deckers used the basic socio-neurocognitive model described above, starting from a neural infrastructure for communication and language consisting of nine core domains. This allows for a better understanding of the relationship between these core domains and the development of expressive and receptive vocabularies in a large group of children with Down syndrome (n = 123). The core domains are often assessed separately when diagnosing the nature and severity of the disorder or impairment. The relationship or interaction between these core domains and early language development—and more specifically, receptive (comprehension) and expressive (expression) vocabulary—has not previously been investigated simultaneously. Within this study, an inventory was made of limitations and barriers (weaknesses), as well as the abilities and opportunities (strengths) in the children's communicative competence and language development according to the criteria of the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY).[4] The classified characteristics were then arranged within one of the nine core domain. For children with Down syndrome (in fact all children with multiple communicative disorders), being of the same developmental age does not always mean that they have similar performance on communication and language tasks. The results are characterised by a wide range of limitations and obstacles (weaknesses), as well as abilities and opportunities (strengths). One possible explanation lies in the varying combination and severity of the disorders and impairments in Down syndrome and their influence on the relevant core domains that drive communicative competence and language acquisition through interaction.

A self-developed parent questionnaire was used in the study. The questionnaire underwent two rounds of expert review. It was compiled in dialogue with these expert review in 2014. This resulted in a large number (>300) of yes/no statements describing

[4] The ICF-CY is a World Health Organisation classification system that gives concrete form to the bio-psycho-social model of human functioning. The system provides a conceptual framework from three interconnected perspectives.

whether the child performed a particular action or behaviour. Examples include 'The child can roll over from the supine to the prone position' (core motor domain), which the parent could then indicate in the given case.

The questionnaire was eventually completed by parents of 123 children with Down's syndrome:— 74 boys (60.2%) and 49 girls. Several studies have shown that the development of communication and vocabulary is strongly influenced by the development of the above nine core areas and has an impact on the development of these areas. Even after adjusting for the influence of calendar age and for repeated measures, there remains a significant relationship between the core domains and receptive and expressive vocabulary development (see Figure 19).

	Receptive Vocabulary		**Expressive vocabulary**	
	Spearman's rho	Partial correlation	Spearman's rho	Partial correlation
Calendar Age	0.59**		0.74**	
Attention	0.51**	0.36**	0.55**	0.43**
Perception	-0.04	0.13	-0.06	0.13
Memory	0.17	0.07	0.14	0.13
Cognition	0.71**	0.48**	0.80**	0.65**
Adaptation+Orientation	0.57**	0.38**	0.63**	0.39**
Social-emotional	0.73**	0.49**	0.78**	0.54**
Motor skills+mobility	0.35**	0.13	0.48**	0.26*
Fine motor skills	0.61**	0.40**	0.70**	0.53**
Self-reliance/self-help	0.61**	0.38**	0.67**	0.51**

*p<0.01; **p<0.001

Figure 19. Correlation coefficients and partial correlations between core domains and vocabulary (expressive and receptive). Source: Deckers & Van Zaalen (2018).

The results of this study provide initial insight into the robust relationship between the various core domains of communicative competence as a basis for early language and lexical development in children with Down syndrome. The clear identification of information about functioning in all nine core areas is important to identify why and what kind of AAC is needed in or through a given core area. The results of the study also indicate how the intervention should be tailored accordingly.

6.2. From communication to language

The potential for communication and language acquisition is innate, but it needs to be 'nurtured' and facilitated by other developmental areas, as well as by an appropriate, responsive, caring and child-adjusted language input. In the daily, recurring interac-

tion between parent and child, fixed patterns of communication emerge. These are soon recognised and mastered by the child as rituals. Studies with the research programme on AAC in this area aims to answer the following questions:

- How do typically developing children and children with multiple communication disorders of similar calendar age differ in their development of communication skills and language acquisition?
- What are the main predictors of communicative development and progress in language acquisition for children with multiple communication disorders?
- What is the most appropriate developmental and learning environment for AAC in young children with multiple communication disorders and their family settings, taking into account the wide intra- and inter-individual differences in the skills and competencies of the children and their parents/caregivers?
- Which forms, methods and technical aids for AAC best suit the different developmental and communication levels of children with multiple communication disorders in relation to the capacities of their social networks?
- Which approach to AAC has the greatest potential to enhance communication and language acquisition given the adjacent developmental capacities of the child with multiple communication disorders, and taking into account the opportunities and possibilities that the environment may offer?

Study 2: Enhancing Early Language Development in Children with Intellectual Disabilities[5]

Children with multiple communication disorders experience many challenges in communication and language development. They depend heavily on the environment to develop good language skills. Stimulating the communication and language development of children with multiple communication disorders at an early stage increases their chances of becoming successful members of society. The evidence-based intervention programme KLIN© (Kinderen Leren Initiatieven Nemen in communicatie [Children Learn to Take the Initiative in Communication]) has been developed to create an experiential learning environment for children with multiple communication disorders that meets their needs and capabilities. The KLIN© programme creates a tailor-made play/learning environment for children with multiple communication disorders, where they learn in their own way through AAC.

This is done by using adapted forms of AAC (such as gestures, pictograms and/or voice computers). The KLIN© programme has used AAC-strategies and tools to facilitate the transition from communication to language in preschool children with multiple communication disorders.

[5] Margje van der Schuit (2011) | PhD Thesis | Radboud University.
https://repository.ubn.ru.nl/bitstream/handle/2066/173032/173032.pdf

The first study in Margje's dissertation reports on the longitudinal follow-up of a group of 58 five-year-old children with multiple communication disorders. This group is compared with two groups of typically developing children in terms of their communication and language development. The first group consisted of 42 typically developing children of the same calendar age (CA). The second group consisted of 42 children of the same developmental age (DA). The children were followed for two years in terms of their communication and language development. The study identified the impairments experienced by children with multiple communication disorders as a result of disorders in one or more of the core areas of communication and language. The children with multiple communication disorders were compared with the two groups of typically developing children on a range of pre-determined developmental measures. The results showed that the children with multiple communication disorders lagged behind the group of typically developing children of the same calendar age in all nine core areas. Of interest is the severe impairment in the development of working memory, cognitive skills and associative meaning (deep lexical knowledge determined in various ways, including meaning association and development of concept formation).

The results of an impact study carried out as part of this research indicated that all children made greater developmental gains during the intervention period than in

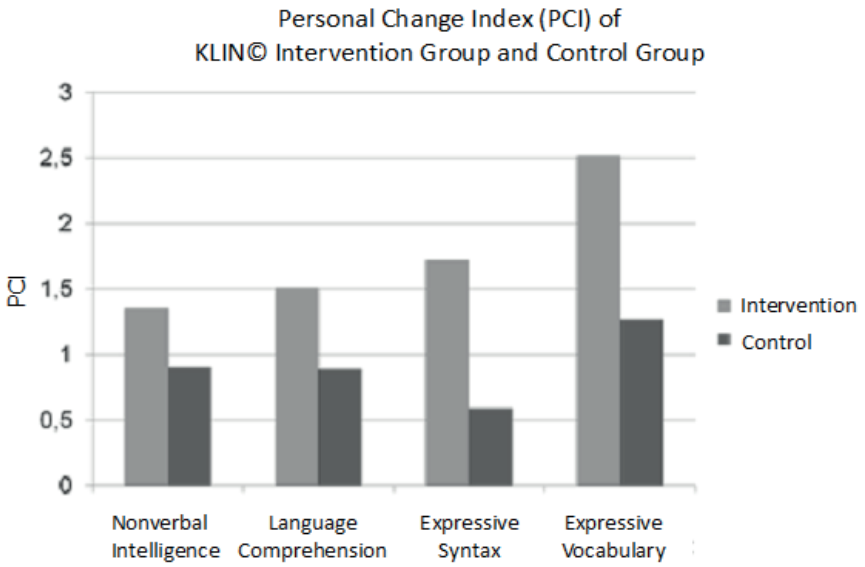

Figure 20. Effect study of the KLIN© early intervention programme.
Source: Van der Schuit, Stoep & Van Balkom (2012).

the pre-intervention period, particularly in the areas of language comprehension and productive vocabulary (see Figure 20). Furthermore, the results showed that the speaking children with multiple communicative disorders experienced more rapid developmental growth in language comprehension and productive syntax than the non-speaking children with multiple communicative disorders. This was observed even though the intervention did not directly target grammaticality. A comparative study showed that the children with multiple communicative disorders in the intervention group exhibited more growth in receptive and productive language skills and in non-verbal IQ than the children with multiple communicative disorders in the control group (without intervention). This increase in gains for the intervention group was determined mainly by the non-speaking children.

A retention study was carried out one year after the KLIN© intervention. The children with multiple communication disorders in the intervention group showed a significant decline one year after the end of the intervention. The developmental growth and use of AAC did not persist. In some cases, there was regression in comparison to the children's developmental level at the beginning of the KLIN© intervention (see Figure 21). The results of this retention measure suggest that early intervention can accelerate communicative competence and language development in children with multiple communication disorders. Unfortunately, however, the effect achieved declines rapidly if the intervention and the use of AAC are not continued.

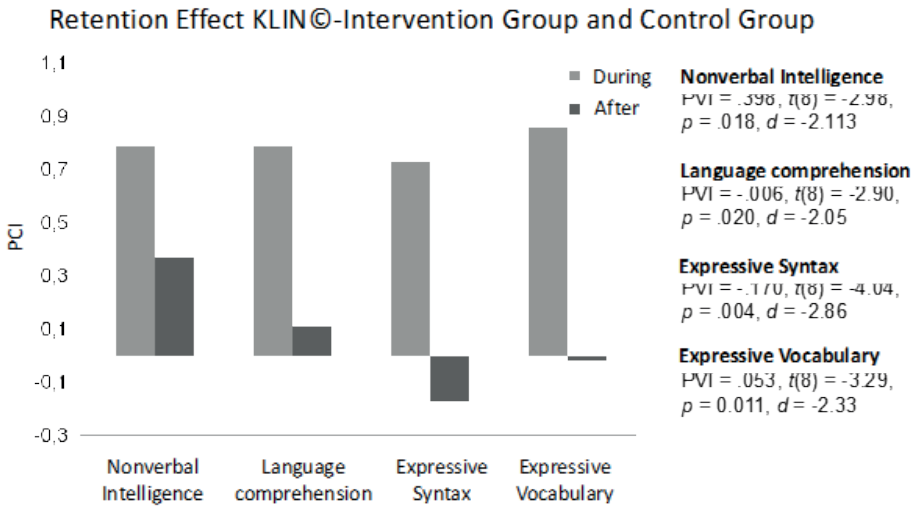

Figure 21. Retention study of the KLIN© early intervention programme.
Source: Van der Schuit, Stoep & Van Balkom (2012).

Based on the findings from Margje's studies, supplemented by similar studies, Stichting Milo developed the KLIN© early intervention programme, in collaboration with several day care centres for children (Van Balkom, 2018). Through this year-long intervention (four days a week), appropriate access to communication and language acquisition is created for each child (individually). It is aimed at toddlers and pre-schoolers with multiple communicative disorders and their parents. The parents are intensively involved in the treatment, and they receive regular specialised training in AAC, especially in sign language or sign-supported Dutch, in addition to learning how to use and maintain AAC devices at home. For this reason, the KLIN© programme instructs and supports the home situation through regular home visits. The intervention eliminates barriers in the development of communication into language acquisition and early literacy. To reduce the likelihood of relapse after the KLIN© intervention ends, the children are monitored for another six months in their follow-up school or care setting.

6.3. From language to literacy

The third area of focus concerns research on predictors of development from language to literacy in children with multiple communicative disorders. Knowledge of these predictors (which ones they are and their catalytic effects) guides the design of intervention and support programmes aimed at the development towards learning to read in children with multiple communicative disabilities for whom appropriate AAC should be applied. In this case, we refer to 'assisted literacy'. The reading curriculum offered at the child treatment centre or at school plays an important role in this regard, as does home literacy, especially for children with multiple communicative disabilities. Literacy refers to both technical and reading comprehension, spelling and writing skills, and storytelling and narrative skills.

Through scientific research, we search for the best predictors or conditions needed in order to become literate. We also examine whether the conditions and predictors for typical development towards learning to read in regular primary education also apply to assisted literacy. The KLIN© treatment approach includes assisted literacy, because it is essential in providing an accessible pathway to education.

To date, little is known about the early learning process of reading in children with intellectual disabilities (ID). In addition, reading and learning methods are often not adequately adapted to the needs of this group of children. Alternatively, they might continue to use materials that have not been proven effective. In a longitudinal study, Arjan van Tilborg examined a group of children with ID with regard to a variety of underlying factors (predictors and conditions) related to learning to read. In parallel, Evelien van Wingerden studied a group of older children with ID to determine how they understand written text (reading comprehension). The core question that guided her research was: 'What are the factors that influence reading and text comprehension (both stimulating and inhibiting factors)? Answers to such questions are important for

designing appropriate AAC and literacy interventions for children with ID. This is particularly true for the question of whether children with ID learn to read in a similar way to typically developing children. What is needed, then, is some basic knowledge about early reading and textual understanding, and the extent to which that knowledge is applicable to the practice of learning to read with children who use AAC.

Both reading projects started with a preliminary study on the status of literacy and its conditions in children with intellectual disabilities. In the project on technical reading, the children were five years old at the first measurement and eight years old at the last measurement. In the reading comprehension project, the children were eight years old at the start of the study and 12–13 years old at the last measurement. The studies compared children with multiple communicative disorders to a control group consisting of typically developing children in similar age groups. The results from both studies were intended as the starting point for the development of an assisted literacy programme for children with multiple communicative disorders in the primary-school age group. Because of the great diversity in typology of multiple communicative disorders and the limited numbers of children in each diagnostic group, two large longitudinal cohort studies were set up: one for technical reading and one for reading comprehension. Three measures of development in a number of theoretically motivated core areas and related conditions and predictors of literacy, derived from published research on normal reading development in mainstream primary education, were carried out over two years.

Study 3 (technical reading): Early literacy development in children with intellectual disabilities[6]

A group of 53 children with multiple communication disorders (aged between 5.5 and 6.5 years; IQ 50–75) and a group of 74 typically developing children of similar age participated in a longitudinal cohort study aimed at identifying predictors of early reading acquisition (technical reading or word decoding skills). One striking finding was that letter knowledge was also identified as an important predictor of phonological awareness, as in typically developing children. Children with intellectual disabilities appear to use their knowledge of letters to learn to distinguish sounds. They can then use these skills to learn to read. In addition, background factors such as speed in naming symbols and words (rapid naming; speed and automation in naming objects) and phonological short-term memory were found to be predictive of key early literacy skills.

Overall, the results support the conclusion that children with ID use the same predictors and conditions in their reading development as typically developing children. They share the same developmental learning course, albeit greatly delayed and so-

[6] Arjan van Tilborg (2018) | PhD Thesis | Radboud University.
https://repository.ubn.ru.nl/bitstream/handle/2066/198059/198059.pdf

metimes more erratic. The deployment of appropriate strategies for AAC should therefore focus on customised access to developmental core domains for attention regulation, phonological awareness and working memory in order to facilitate motor-visual pattern recognition and letter recognition. Experiential learning and the use of AAC is needed to support interactive story-telling and contextually mediated meaning attribution as an impetus for lexical and language development.

Study 4 (reading comprehension): Reading comprehension in children with intellectual disabilities[7]

To address the lack of knowledge about reading in school-aged children with multiple communication disorders, a large-scale longitudinal cohort study on the development of reading comprehension in children with ID was initiated. In this study, children with ID (IQ between 50–85; ages 9, 10 and 11 years) were compared with typically developing peers. The study looked at language and reading comprehension and its underlying capacities, such as auditory and visual discrimination, listening skills, phonological awareness, lexical development, word decoding, executive functions (i.e. arousal, memory, pattern recognition, meaning attribution, cognition). It started with the selection of key predictors of language and reading comprehension in children with typical development in terms of decoding skills, working memory, reading comprehension, vocabulary and non-verbal reasoning, amongst other aspects. The study showed that children with ID who had a basic reading level (corresponding to the third year of primary school) exhibited the same degree of explicit text comprehension as typically developing children with the same age and decoding skills. At the same time, however, these children with ID were weaker on reasoning skills and implicit text comprehension. Explicit text comprehension was related to both word decoding and listening comprehension, as in typically developing children. This pattern is consistent with one of the main theories of reading comprehension, the *Simple View of Reading* (Hoover & Gough, 1990). Word decoding was an important predictor of implicit text comprehension, but not of listening comprehension or other skills (see also Arjan van Tilborg's study involving the younger target group of children with intellectual disabilities). In this context, cognitive skills other than those included in this study may have an influential role.

In the subsequent longitudinal study, more attention was paid to executive functions (including the regulation of attention and working memory), partly for this reason. Eighty-one students with ID (11.5-12.5 years old) and 86 typically developing students (10.5-11.5 years old) participated in the longitudinal study. The aim was to identify the pattern of reading development in children with ID and compare it with

[7] Evelien van Wingerden-Fontein (2017) | PhD Thesis | Radboud University. https://repository.ubn.ru.nl/bitstream/handle/2066/167031/167031.pdf

that of typically developing children. Reading comprehension, for example, seems to be strongly predicted by vocabulary. Sub-optimal development and functioning of working memory leads to abnormalities and delays in vocabulary development (and, consequently, language comprehension). Vocabulary, in turn, is dependent on the speed of word naming (rapid naming) and basic early literacy skills, including alphabetic knowledge, phonological and phonemic sound awareness and, to a lesser extent, listening comprehension, vocabulary/word comprehension and grammatical comprehension. Suboptimal development and dysfunction of working memory lead to severe abnormalities and delays in vocabulary development and (consequently) language comprehension. A significant correlation was also found with rhythm (or temporal processing problems) and non-linguistic reasoning skills. These findings suggest that reading comprehension problems involve information and language processing problems.

From these two studies, we learn that the reading development of children with multiple communicative disorders does not differ substantially from that of typically developing children. This applies to both technical reading and reading comprehension, as well as in terms of predictors and developmental conditions. There are nevertheless serious delays, and the explicit initiation of reading development requires customised AAC solutions. Without these augmentative and alternative communication systems (AAC), used in an approach to assisted literacy (especially for skills related to the aforementioned predictors and conditions for literacy), children with multiple communi-

Figure 22. Film as augmentative and alternative communication (FAAC).
Source: https://cominbeeld.nl/onderzoek/ (consulted 30 May 2022).

cation disorders will not be able to make the step towards functional and linguistically controlled literacy and will not be able to arouse their interest in it. Nor will they be able to do so unless their parents are directly involved in the process at home (i.e. home literacy).

In another, still ongoing PhD project (Film as Augmentative and Alternative Communication or FAAC), Mascha Legel is developing and validating a film-based methodology of storytelling. Within the 'My Film, My Story' project, children and adolescents with multiple communication disorders make their own personalised films from their own perceptions and experiential perspectives. They then edit these self-made films and use them to assist their communication (see Figure 22). It thus allows them to share their experiences through storytelling with others in their own unique ways. This is usually much more efficient, explicit and lively than typing in textual or picto-narratives letter by letter, word by word.

This method has since led to the 'My Film, My Story' teaching method, which was designed to improve the narration and storytelling skills of students with complex communication needs (CCN).[8] It offers alternatives to composition assignments, oral presentations and participation in discussions on prepared topics. Its scientific foundation is the subject of a number of validation studies. These studies have now been completed and described and are under review for publication.

7. Practical relevance

The research programme of the Chair in AAC has contributed to the expansion and improvement of the available understanding of how to identify key conditions and predictors for the development of communicative competence, language and literacy in children with multiple communication disorders. The research was designed with the intention of applying this knowledge to AAC assessment and treatment in ways that match the neural pathways or natural adaptive and compensatory strategies of children with multiple communication disorder and significant others in their social networks.

The studies contributed to the development and implementation of evidence-based intervention programmes, such as the KLIN© programme, emergent literacy programs with AAC and a socio-neurocognitive assessment, the results of which are displayed in a custom-designed communication competence profile (CCP). Conditions, prerequisites and predicates from the above studies underpin the results from which these clinical AAC-applications have been developed. Figure 23 displays a causal

[8] See also: https://www.ookoc.nl/projecten/mijn-film-mijn-verhaal/ and http://www.etnosfilm.nl/web/contact.

arrangement of these underlying factors based on the results of SEM analyses[9] in the PhD studies. The predictive power of these factors cumulates in meaning making, concept formation, lexical growth and vocabulary development. This is also the ideal feeding ground for the acquisition of language (phonological and phonemic awareness, pragmatics) and the development of learning to read.

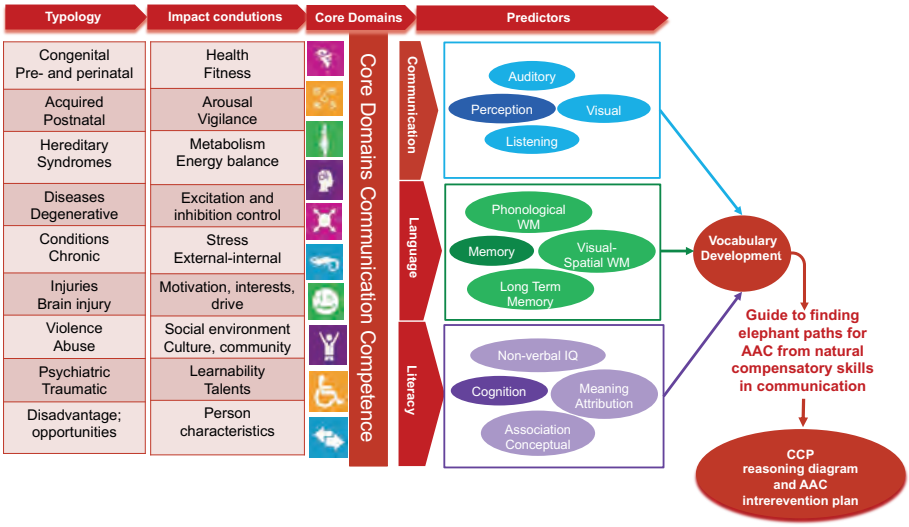

Figure 23. Impact of results from PhD studies on practical applications.

However, due to barriers in the underlying predictors and conditions, lexical or vocabulary development in children with multiple communication disorders is difficult to address separately by intervention and AAC. Available neural pathways and potential neural 'elephant pathways' (bypasses) within and between the core domains for communication and language development will be identified by using the CCP. This profile then helps to outline a reasoned treatment plan along appropriate neural pathways, bypasses or 'elephant paths' with appropriate AAC.

[9] Structural equation modelling (SEM) is a set of statistical techniques used to measure and analyse the relationships of observed and latent variables. Similar but more powerful than regression analyses, it examines linear causal relationships among variables, while simultaneously accounting for measurement error (Beran & Violato, 2010).

8. CCP: Exploring the most suitable elephant paths

There is a need for knowledge and understanding of the organisation and development of communication and language in the brain and in behaviour in order to find the most appropriate adaptation or compensation in communication for severe barriers in communication due to multiple complex disorders. The CCP is very useful in searching for accessible neural pathways or bypasses ('elephant paths') as alternative routes to other or adapted forms of expression. It assists in analysing communication limitations and barriers (weaknesses) that evoke compensatory pathways and opportunities (strengths), both within and across core domains for communication and language.

This is done through participant observations, interviews, file research and dynamic assessment, supplemented by trying out a variety of possible forms and methods of AAC. Special attention is also paid to what the social network is already doing, followed by what could be done differently and better (Granlund et al., 2008; Van Balkom, 2018). The collected data are recorded in a mind map and then arranged in a summary table for each core domain, including a brief description of limitations/barriers and skills/possibilities. In addition, an assessment is made of the degree of limitations/disabilities and the strength of abilities (compensations). The strongest core area from which the observed behaviour can be explained from natural compensations (the neural elephant paths) is then identified through a strength-weakness analysis. The most important question in this analysis is: Why is the individual exhibiting this behaviour? Based on the results, the compensatory route (the elephant path) is drawn out with the follow-up path, which consists of the intervention steps with the core domains involved. At the same time, each step and core domain is accompanied by an explanation and description of the corresponding approach to AAC.

This subsequently provides a line of reasoning path or schema for the design and application of AAC. The CCP format describes the how, what, when and why of AAC and outlines the steps of intervention that need to be modified as a result of observed compensatory behaviour. These adaptations may include, for example, assistive technology or partner-related strategies to prevent, reinforce, adapt, model, transform or redirect the compensatory behaviour. Guidance for intervention approaches and the use of appropriate AAC advice is derived from the overall heuristic process leading to key predictors and conditions of the compensatory behaviour identified. This knowledge provides insight into how compensatory behaviours for communication and language can be leveraged for AAC.

The CCP is based on the basic socio-neurocognitive model and proceeds from 10 premises according to which (1) communication and language do not stand alone, but are the result of an extensive, deeply branched neural network between and within nine core domains; (2) the development and neural organisation of communication and

language in humans are driven by an innate predisposition; (3) communication and language develop a symbiotic relationship; (4) from their predispositional structure, humans always end up communicating, no matter what; (5) all behaviour is basically communicative; (6) the neural infrastructure of the brain is the result of neurogenesis, and that neural elephant paths are always part of it as a source of neuroplasticity; (7) neural elephant pathways or bypasses for communication and language are an ideal starting point for establishing detours to different forms of expression in AAC; (8) the environment and the social network always play a role in impeding communication, but especially in finding and implementing solutions to these barriers; (9) there are never any preconditions for augmentative and alternative communication; and (10) all senses and modes of expression can be substituted in AAC.

9. Example of a CCP

Before starting treatment, the most appropriate neural circuitry with functionally adequate working neural pathways and idiosyncratic sideways, bypasses (or neural and behavioural elephant paths) should be traced through the dynamic assessment and described in the CCP. The most appropriate AAC system and intervention approach is then determined from this knowledge. The CCP begins with an integrative picture of the person with multiple communication disorders and the most significant persons in the direct environment (social network). This description is based on several resources, such as information from indirect, direct, participatory observation, interviews, medical and other clinical or educational records about neural and behavioural (compensatory) skills, competencies and experienced limitations/barriers. To illustrate how this is done and what comes out, I now want to look very briefly at an example of the CCP. The personal data are anonymous. The parents have given their permission for the use of the data from the CCP.

9.1. Personal and environmental sketch

AZ is a five-year-old boy who lives at home with his parents and younger sister.[10] He attends a child day-care centre nearly every day. AZ has a rare congenital disorder, termed Skraban-Deardorff syndrome (Cheng et al., 2022), also known as 1q42 microdeletion syndrome. This syndrome is caused by an abnormality in the WDR26 gene and characterised by a combination of several disorders that reinforce each other in severity, including intellectual disability, difficulty walking, energy imbalance, epilepsy, disrupted attention regulation, distinctive face, non-speaking and sensory over-

[10] AZ: fictitious name. The parents have given permission to share the information (anonymously) for the purpose of this valedictory speech.

stimulation. Learning and development (personal and otherwise) stagnate. There is an insufficient capacity to process incoming sensory stimuli (inhibition weakness).

WDR26 is a regulatory protein that directly controls the division and localisation of neurons and brain cells, as well as the connections amongst neurons and functional areas of the brain, immediately after conception. Abnormal brain development (mainly white matter connectivity) leading to a less efficient brain network is associated with a defective WDR26 gene. Skraban-Deardorff syndrome causes a disruption in the formation of network connections and neuroplasticity (or the capacity to find and create neural bypasses or elephant pathways in the brain). Incoming stimuli are not passed on to the brain quickly or accurately enough. This leads to overstimulation and causes stress, accompanied by feelings of uncertainty and insecurity. AZ expresses himself mainly non-verbally through behaviour and body movements. He is either over-stimulated or under-stimulated (inhibition weakness). This leads to atypical forms of stimulus-seeking behaviour. The aim is to avoid the number and severity of disrupting, disturbing influences and stimuli as much as possible. From the outside, this looks like compulsive rocking and swaying. AZ is able to focus his attention (for example on choosing an object) by (over)stretching his arms, hands and fingers or by rubbing and pushing on a hard surface. This gives him just enough energy to maintain eye contact and follow the other person, without being distracted by other environmental stimuli.

Key features	Severity Rating			Communication Competence Core Domains	Capability Rating			Key features
Disorders or ilmpairments	3	2	1		1	2	3	Skills or Abilities
Disabilities								Competencies
Hyper arousal, disturbed inhibition	3			Arousal/ Attention		2		1-to-1, co-regulation, no distractors
Regulation (selective, divided)	3						3	Co-creation, attachment, co-movement (tactile signing)
Hypersensitive, sensorial integration	3			Perception			3	Vision (R), auditory-visual
Fine-tuning, figure-ground (visual and auditory)		2					3	Vestibular, deep pressure, walking
Sensorial memory, executive WM	3			Memory	1			Situational smell, sounds, daily used objects
Sequence, serial, associative order, LTM (lexical)	3					2		Episodic buffer, tangibles, rhythm, rituals, daily activity planning
Signal processing, intentionality, and referencing		2		Cognition		2		Action-reaction, object permanence, matching, intentional
Meaning-attribution, associations, cause-effect	3					2		Cause-effect, comparison, association, pattern recognition
Over-excited, automutilation, stress	3			Socio-Emotional			3	Situational, defensive, self-oriented, survival-reflexes
Control, get an overview - and insight, ToM	3				1			Feeling safe, mirroring and imitating, ToM, turn-taking rituals
Spatial, time, social,	3			Orientation			3	Physical security, situational control, bodily
Embodiment, body scheme, localisation		2				2		Co-regulation, getting an overview, embodiment, situational
Situational overview, activity planning,		2		Adaptation			3	Action-reaction, co-regulation 1-to-1, rituals, daily routines
Transitions, 'in control', anticipation	3				1			In contact co-activity, ritualization, anticipation, temporal
Sensorimotor skills, stagnant transition reflexes		2		Motor skills		2		DA: 1 year.; crawling; walking, physically active movements
Coordination, praxis, motor plan	3						3	Grasping, taking, massage, motor-visual patterning
Speaking, signing, story-telling	3			Language		2		Understands 1-2 word-combinations (known setting) in speech
Lexicalisation, grammaticalisation	3				1			Lexicon: Situational objects (tangibles, pictures, 'languaging'
1: Light 2: Moderate 3: Severe								1: Doubtful 2. Emerging 3. Strong

Figure 24. CCP Quick-scan of constraints and barriers, in addition to skills and abilities for the purpose of strength-weakness analysis.

9.2. Strength-weakness analysis

The collected data on disabilities, experienced limitations, potential abilities and opportunities (what a child can do with the help and support of others or when using

AAC) have been arranged in a mind map (organised by the neural core domains for communication and language). They were then described in a table in which these written data can be compared to strengths and weaknesses (see Figure 24), with limitations and barriers on one side and abilities and opportunities on the other. This makes it possible to analyse strengths and weaknesses. The results lead to reordering and prioritising the core areas, starting with the core area from which compensatory abilities are most strongly drawn.

9.3. Reasoning and explanatory scheme

The data collected should be interpreted in the light of the natural compensatory behaviours that occur in the Skraban-Deardorff syndrome, as described in Figure 24.

In AZ, we see that incoming sensory stimuli from the outside (sight, hearing, smell), but also incoming somatic stimuli from the inside (proprioception, musculoskeletal system, vestibular system, energy management or basic metabolism, consciousness (vigilance), signals from the respiratory and digestive organs) are not sufficiently and quickly relayed and recognised. The sparse network of neuronal supply and connectivity pathways in the brain becomes quickly congested. This creates a rapid 'over-pressure' of overstimulation with a rapidly building pattern of stress. It makes you feel physically unsafe and insecure. The body-related survival reflexes therefore remain largely in operation as concomitant behaviours, including grasping, grasping, oral targeting, visual and auditory tracking of what is happening in the immediate environment, motor-visual targeting, action-reaction patterns, strong reliance on rituals, withdrawal, rejection, seeking attachments. All this is organised as autonomous bodily compulsive behaviour, characterised by rocking behaviour, overstretching of arms, hands and fingers seeking for deep pressure sensations. The fingers of both hands are vigorously pressed against each other and against the table in an alternating sequence. Humming loudly is part of that calibrated compensatory pattern. Thus, V exerts the greatest possible 'counter-pressure' on the constant supply of stimuli that are not or barely inhibited or filtered out at the neuronal/neuronal level (also known as the inhibitory weakness syndrome). These compulsive and body-oriented behaviours enable him to pay close attention to his immediate environment (as a form of self-maintenance). Perception, working memory and cognition, however, are not given enough opportunity to develop. Their functioning and development stagnate. This also applies to social-emotional development, communication, and language acquisition. A disturbed energy balance (basic metabolism or mitochondrial problems) exacerbates the consequences of the disturbed disposition of the nerve cells. The regulation of vigilance and attention is further impaired by this energetic deficit. The data from the strengths and weaknesses analysis (Figure 24) lead to a characterisation of the compensatory behaviour, shown in the first three steps of the 'CCP Reasoning Diagram' (shown in Figure 25), which starts with bodily sensory

orientation, motion, and vestibular activation, and leads to increased alertness and attentiveness, which supplies sufficient energy for auditory and visual monitoring of what is happening in the direct environment.

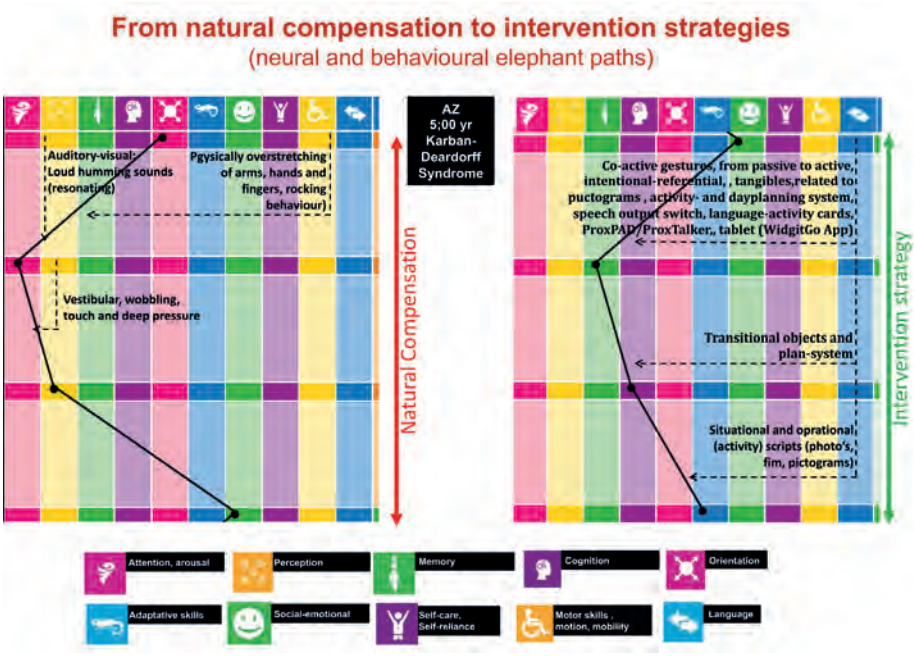

Figure 25. Reasoning diagram for the best explanatory routing of neural elephant paths.
On the left, the compensation route and, on the right, the subsequent intervention route and deployment of AAC.

In an intervention, AAC should be used and further guided from these core areas to enable access to development and learning. This reasoning is outlined in the CCP Reasoning Diagram (see Figure 25). It distinguishes the following steps:

Reasoning steps for identifying natural compensatory strategies

Step 1 Moving from body-oriented to attention-oriented

Sensory overload and stimulus-seeking behaviour lead to a prolonged relapse towards reflexive, compulsive and body-orientated, self-centred behaviour. The unconscious, automatic (reflexive) return to body orientation causes strong sensations of movement, such as rocking and swaying, which activate the vestibular system (sense of balance, perception of gravity) and thus arousal and attention, even if only for a short time. This increased urge to move is also seen in the atypical overstretching of the arms, hands and fingers. In terms of its reinforcing effect

on arousal and attention, the resonant effect of loud humming (mouth-nose-cheeks and forehead) also enhances alertness.

Step 2: From attention to perception
The only way to break through AZ's inward-looking, shielding behaviour is to physically touch him and call him by name. Then, especially in one-on-one activities and without much distraction from the environment, he can direct his perception and attentiveness towards the environment briefly. Other support is provided through tactile contact, co-operative movement, rhythmic experiences and the use of concrete objects that he can manipulate.

Step 3: From perception to social-emotional regulation
In the often-brief moments of focused attention, AZ enjoys social contact. He learns associatively and can make connections between what he does and what he experiences together. However, this focused attention and information processing consumes attention and energy. He can release this energy only temporarily (due to the disturbed energy balance). Social contact and doing things together improve attention regulation and gives him a sense of fulfilment. By gesturing together in direct bodily or other contact and by physically modelling facilitation by pointing, grasping and holding something together (objects as referents), AZ's strong body orientation is anticipated in its developmental power. This power is derived from perception, the experience of direct body contact and doing things together. In the absence of such contact, the body orientation falls back into survival mode, seeking to escape the uncomfortable socio-emotional sensations brought about by sensory overstimulation and feelings of detachment and insecurity. Using AAC should prevent this. In order to bring about this change in AAC, the strong regulatory or corrective effect of body orientation needs to be transformed into a driving force for development through the use of appropriate AAC. The term 'most appropriate' means using AAC to harness momentum (a turning point, a choice to change) and move towards development and learning. AZ and the people around him will be able to do, experience and make sense of things together, without the risk of over-stimulation that could lead AZ to revert back to compulsive action and introspective behaviour, involving stress and panic.

Reasoning steps for the planning of intervention strategies

Step 4: From social-emotional status to working memory
In moments of physical (or other) contact and doing and moving together, AZ can better regulate his attention and store incoming information in his working memory. One-on-one situations and proximity can then be used to build routines

and rituals. The strength lies in starting with body-centred communication strategies and support (in direct bodily contact, by gesturing together and modelling concrete reference points). This body-centred AAC should be applied in familiar, similarly body-centred experiences (at home and at the child day care centre in one-to-one movement games, interactive reading aloud from shared experiential and experiential activities, moving to music and singing).

Step 5: From working memory to cognition
Cognitively, his good intermediate performance demonstrates that he is able to pick up objects, to navigate, to stack (from large to small), to puzzle and to match (shape size, drinking and eating) in the environment together with another person. At this stage, however, these skills are not yet strong.

Step 6: From cognition to adaptation and language
Language must gradually take form and meaning from the steps and domains outlined above. From all these activities, concepts or vocabulary should grow purposefully through concrete referential skills involving meaning attributions, labelling and naming (language and gestures, pictorial or graphic symbols and other representations), corresponding to activities, and everyday situations.

9.4. Elephant path to the most suitable AAC

These six steps are used to develop an intervention programme. The most appropriate AAC strategy is chosen. In particular, the AAC approach consists of body-centred forms of expression such as reaching, grasping and touching concrete (situation-specific) objects linked to graphic representations and related pictograms. From a daily schedule (cabinet) concrete referential objects or pictograms are chosen. AZ should then be encouraged to pick them up and bring them to the setting or activity to which the objects refer. On site, these referential objects and symbols are connected to voice-output switches or buttons (where needed). This is done both in the planning system (i.e. cabinet) and in the situation (see Figure 25). The AAC system consists of referential (concrete) objects, graphic symbols, the planning system (cabinet), voice output switches or buttons, drawings or pictures and AAC devices (ProxPAD and ProxTalker), iPad with Widgit Go App.[11] The ProxTalker provides enough memory capacity for the first 100 to 150 lexical items or concepts. It is also important for attention, perception, working memory and socio-emotional regulation to choose activities based on movement and rhythm, body contact and touch. One way of doing this is to combine Sherborne Movement Therapy with tactile signing or gesturing, the AAC devices mentioned above

[11] https://www.google.nl/search?q=Widgit+Go+app&client=safari&channel=mac_bm&source=lnms&tbm=isch&sa=X&ved=2ahUKEwitjN_1p-D9AhV5_rsIHW8fB-cQ_AUoAXoECAEQAw&biw=1600&bih=730

(speech-output switches or buttons, ProxPAD and ProxTalker) and active music experience (as well as making music together, ideally with resonating music instrument).

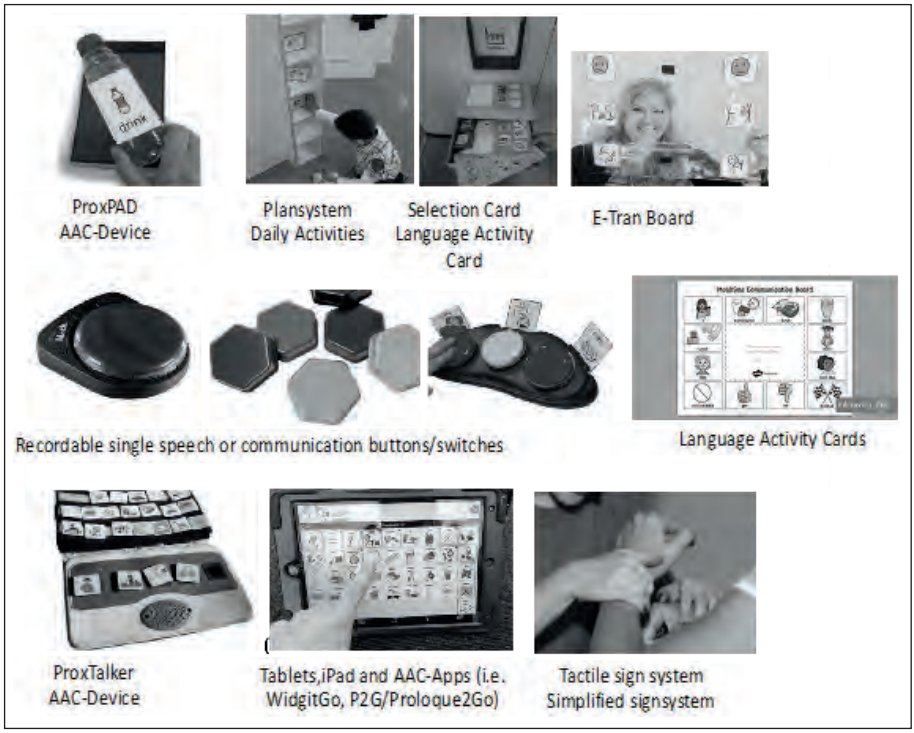

Figure 26. AAC recommendations that make neural elephant paths accessible based on the advice given.

10. Acknowledgements

At the end of this valedictory address, a word of gratitude is in order. This is always a precarious and risky undertaking. It is always a precarious and risky thing to do. For every person who is mentioned, there are many more who are not mentioned, even though it would certainly have been appropriate. The more people mentioned, however, the less interesting it becomes for you, dear listeners.

Agnes. I completely forgot to include my dearest Agnes, my children and my family in the litany of acknowledgements following my inaugural address. In 2011. This was obviously inexcusable. Although such things cannot be corrected in retrospect, fortunately everything turned out all right. Not wanting this to happen to me again, I developed a very deep elephant path to Agnes. Without her, I would have lost my way many times. So first and foremost, I owe Agnes my most heartfelt thanks—a gratitude that extends to Rachel, Judith and Tim, and both my treasured grandsons, Sam and Mees.

The Faculty. This farewell speech gives me the opportunity to thank the management of the University. I would also like to thank the Faculty Board, the Dean—Prof. Michiel Kompier—and the Director of the Behavioural Science Institute (BSI)—Prof. Toon Cillesen—as well as the Director of the Educational Science Department—Prof. Anna Bosman—for their pleasant cooperation in the realisation of the academic programme of the Chair in AAC and its continuation following my retirement.

Kentalis. My appreciation and gratitude also go to the current directors of Royal Kentalis - Oscar Dekker and Sandra Beuving—for their substantive, strategic and financial support of the research programme and part of my time as Chair of Augmentative and Alternative Communication. I would also like to acknowledge the previous Executive Directors: Bas van den Dungen and Henk Bakker. From my chair, under the leadership of my colleague Prof. Ludo Verhoeven, I participated in the development of the Reading Masterplan within Kentalis. My main focus was on providing guidelines for the reading and writing of students with complex communication disorders. It is with great pleasure that I reflect on working with the members of the Kentalis core team for people with complex communication disorders. This cooperation will continue throu-

gh my involvement in the ZonMw-Deelkracht programme, via Stichting Milo and by the supervision of the PhD research currently conducted by Peia Prawiro-Atmodjo-Puts within this programme.

Stichting Milo. The content and strategy of the Chair in AC and my professorship were immediately adopted and, since the first renewal in 2013, co-financed by Stichting Milo: Wegbereiders in communicatie ('Pathfinders in communication'). Together with Wim Prins, I founded Stichting Milo in 2010 after years of counselling and planning. Milo started as soon as I was appointed professor. Since then, it has served as a clinical centre for assessment and intervention, specialising in augmentative and alternative communication for people with complex communication needs—a centre where my research programme was immediately put into practice. Soon after the formal establishment of Milo, Arjen Beekman started as its Executive Director in 2011. This was on the recommendation of Wim Prins. For the first three years, we have been doing this together. Arjen and Wim have a typically straightforward Rotterdam business and management style. To combine this with my somewhat softer Limburg hill country style took a while. This led to a lot of cracking and creaking in the early years. I nevertheless admire and thank them both for having pulled my Milo-AAC dream out of the mud and turned it into a solid organisation. Stichting Milo built and co-funded the programme of the Chair in Augmentative and Alternative Communication (AAC) at Radboud University from the beginning, and it is now continuing the follow-up financing and strategic support of the Chair following my retirement, in close collaboration with Radboud University.

It is at this point that I would like to address a special word to **Wim Prins**. About two decades ago (2002), we had regular discussions about my plans to establish @on centres for AAC as a business concept for specialised assessment, intervention and related services. At that time, the Milo Resource or Knowledge Centre was to be established in Kentalis, from which the regional @on centres would be supported. For a time, it seemed that this plan would go ahead at Kentalis, but unfortunately it did not. The alternative plan of an independent Milo foundation with its own treatment capacity, completely separate from Kentalis, had already been in the pipeline as a business concept, and it was revived. Wim, it was you who gave me the courage. It was necessary to ensure that Milo and the chair were a dual entity, so that there would be evidence-based assessment and treatment programmes as well as professional training capacity in AAC. Many thanks for all the support and close friendship. Most of all, thank you for your creative thinking and your now 12 years of involvement in shaping and driving the successful combination of the Chair in AAC and Milo's AAC.

Stijn Deckers. I would like to devote a very special word of thanks and appreciation to Stijn Deckers. Your passion for AAC existed before you had even heard about it and well before you included AAC in your PhD research. You didn't know what you already knew. You organised summer holidays and communication weeks with and for

children with complex communication support needs, along with their parents. It is fantastic to see how you did and how quickly you found your own way in the complex, multidisciplinary world of research and development, sign language and sign systems, communication-assistance devices, ISAAC and assessment and treatment methods for AAC. You provide passionate leadership for the substantive quality, service delivery and scientific foundation of augmentative and alternative communication within Stichting Milo. It is nice to see how you have made my rather complex socio-neurocognitive view of AAC our own and soon managed to find your own way within it. I hope we will continue to discover and walk numerous creative elephant paths together for some time to come. Thank you for all your support in organising this day, and especially this morning's farewell symposium. I am obviously especially grateful for your trust, your thinking, your positive-critical comments, your collegiality, your pertinent humour and your friendship.

Judith Stoep. You have been involved in the establishment of the Chair of AAC from the outset, and even before that, when you were the project leader for the KLIN© study and, subsequently, when you provided support to various PhD students within the Chair. Working together, we have given AAC a scientific flavour and made sure that research findings were translated into clinical and educational practice. In many ways, you acted as a support and anchor, bringing structure and overview to my highly associative way of thinking. I thank you for your friendship and collaboration, which still remains very pleasant. It is nice to know that you will remain actively involved with the Chair in AAC.

Ludo Verhoeven. The Chair in AAC would not have existed without your support and cooperation. We had already worked together in the field of speech and developmental language disorders in the ambulatory care centre of Saint Marie (in 1995). At that time, I was still working at TNO within the Institute for Rehabilitation in Hoensbroek. When I moved to the Institute for the Deaf (now Kentalis) in February 1997, we started to work together more closely. Together with Eliane Segers, we supervised many PhD students in the field of developmental language disorders and complex multiple communication disorders. In 2001, we founded the University Expertise Centre for Atypical Communication (Development) Foundation together with Harry Knoors. In this enterprise, all the deaf institutes ventured to work together on research for the first time. We have had challenging discussions about content, which have always had constructive and concrete results. You are at least as intense in the creation of elephant paths as I am. Thank you for all these years of very pleasant collaboration and mutual thinking.

I am also grateful to **Eliane Segers** for the many years of dedicated effort and sharing of ideas on designing and carrying out the PhD studies with a very challenging target group of children with complex multiple communication disorders. It took a lot of brainpower, discussion and time to determine the most suitable scientifically valid research methodology for this population. Once the research was in place, however, we

hit the ground running. I have very fond memories of working with Ludo, you and the PhD students involved.

Colleagues and students of pedagogy. I hope you now know what I have been working on all these years and how important augmentative and alternative communication is for a heterogeneous target group of children with complex communication needs, as well as for those in their surroundings. I have enjoyed working with you for many years, and I will stay with you for a while longer.

Harry Knoors. We have been friends since secondary school. We studied Dutch language and literature and psycholinguistics together at the University of Amsterdam. You did your PhD in sign language. I did mine in Specific Language Impairments (SLI). Our paths have not always been parallel, but they have somehow crossed for more than 50 years now. That is quite special. Another special thing was that, without knowing it, we both started in management positions at the Institute for the Deaf in 1997 (you in January and I in February). We were the first to be appointed after a period of about 40 years in managerial positions from outside the Institute for the Deaf. Almost immediately we were faced with a budget crisis, in the midst of a turbulent, quite revolutionary transition from an oral, inward-looking Institute for the Deaf to an organisation that also began to focus on sign language and bilingual education for the deaf, and that became more focused on the education and care of the target group of children, adolescents and the young people with developmental language and speech disorders as well as people with multiple communicative disorders, including deafblindness. Thank you for your friendship, your constructive critiques and the always interesting discussions that we shared.

I would like to thank my **colleagues and the staff members of Kentalis** for the many years of collaboration. Although my persuasion and missionary drive in relation to AAC and CCP may at times have been a little too dramatic, it has always been with the good cause in mind. However, I sincerely hope that I have inspired you and that we have shared sufficient clinical evidence and expertise to continue the quest for the best possible AAC-system to support children, adolescents and young adults with multiple communication disorders and their social network.

The colleagues, parents and children at Stichting Milo have managed to inspire me every day for the past 12 years. Every shared journey we took towards a solution and in which AAC successfully opened the way to self-reliance, development and learning strengthened my belief in possibilities. Each time is a euphoric experience, with an energetic impulse to keep going. We are all doing this quite nicely together, aren't we? I thank you for the trust and support from the very first moment that we set out together within Milo. It could be said that Milo is the chair's finest ancillary gift in AAC, and it has since created numerous successful elephant paths for AAC.

Filip Loncke. Far away, but close. You are still passionate about shaping and informing AAC education and research at the University of Virginia and beyond. Theoretical conceptions of AAC regularly inform our thinking and approach. We share a psy-

cholinguistic approach to theorising about AAC. For years, your students came to Radboud University before their summer holidays to experience researching AAC here as well, guided by Judith Stoep, Stijn Deckers and myself. You, Marguerite Welle Donker and I have worked together since 1985. In 1988 the three of us founded the still thriving ISAAC-NF Foundation and in 1994 we organised the biennial ISAAC International Conference in Maastricht. And there was more. Thank you for your always willing, substantive thinking, valued friendship and cooperation. My thanks go to Lee as well. It is heart-warming to have both of you here today. Much appreciated.

Marguerite Welle Donker-Gimbrère. Marguerite, we have known each other since 1982. We met through the BOSK, the national association for people with motor and multiple disabilities. Together we coined and defined the Dutch equivalent—Ondersteunde Communicatie (OC)—for the term 'Augmentative and Alternative Communication (AAC)'. In 1988, we published the first Dutch handbook on AAC, entitled 'Kiezen voor Communicatie' [Choosing for Communication]. You single-handedly ensured the viability of the Chair in AAC. With the financial support of 'Stichting De Drie Triangels' [The Three Triangles Foundation] and the Rehabilitation Fund (now HandicapNL), an AAC chair was to be set up in the name of BOSK. The Chair was given substance and form at Radboud University in collaboration with Ludo Verhoeven. Through you, I would also like to thank the board of Stichting 'De Drie Triangels' and HandicapNL for their generous support during the first three years of the chair. I would also like to thank Metie and Jos Dirks from Stichting Kwecoo in Landgraaf. We have worked together for many years and continue to do so. Without you, the world of augmentative and alternative communication would have looked very different and the chair would not have existed. You are the quiet force behind the success of AAC internationally, as well as in the Netherlands and Flanders, and you have been and remain an inspiration to many in the field and beyond.

Thijs Soede, former executive director of the Institute for Rehabilitation Studies (IRV) in Hoensbroek, the Netherlands. My early career as a researcher began in Hoensbroek in 1982. I had the opportunity to do my doctoral research in the field of developmental language disorders, which led to the development of a computer-based method for 'Interaction Analysis of Communicative Abilities (IACV)'. The PhD followed in 1991 at the University of Amsterdam. Together, we started the research group 'Communication and Handicap' within the clinical rehabilitation research programme of the institute. This was a relatively successful venture, with many large grants for the development of AAC tools. I was given the space, time and funding to work with Marguerite on the publication of the aforementioned handbook on AAC and the production of two introductory films on AAC in cooperation with the Stichting Film & Wetenschap (Film & Science Foundation). You introduced me to ISAAC, the international organisation for AAC, and in 1990 I joined the International Board of ISAAC. Together we were the organisers of the international ISAAC conference in Maastricht in 1994. In short, it was

through IRV that I found my way to specialising in AAC. It has been a very enjoyable period of work. I thank you for your trust and all the years of support and contact, even now as chair of our supervisory board for our research foundation, set up and commissioned by Stichting Milo to advance research in AAC.

Dear **PhD students**. First of all, thanks for your contribution to this morning's symposium. How wonderful it is to see all of you shining together once again. We have shared an intense, inspiring research period. Luckily, it was not all doomsday. Hanging out together and laughing together was great fun. Margje, Stijn, Arjan, Evelien, Mascha and Peia, thank you for your trust and, above all, thank you for all the good results of the studies you conducted and some still are conducting. Many publications have appeared in peer-reviewed journals. In almost all cases, these reports have been incorporated into new and improved assessment and treatment methods for AAC at Stichting Milo and Royal Kentalis, and into the teaching of students in pedagogical science at Radboud University. You may not be aware of it, but you have left many elephant trails that we now follow in our clinical AAC practice.

I am sincerely grateful to **the AAC providers and developers** for their cooperation in the development of AAC devices. Their support and joint efforts have made it possible to put AAC on the agenda in the Netherlands and abroad. It is through highly trained and expert consultants that almost all modern AAC devices are available in the Netherlands. Without them, AAC would never have grown into a specialised field.

Finally, I would like to mention **the many parents and children**, as well as the passionate **practitioners, teachers and caretakers** that I have had the pleasure of meeting and getting to know over the years. It is through you that I have experienced and learned to appreciate the relevance of all that I know. With and through you I have seen and felt the true power of our collective expertise in AAC. It gives an enormous boost, every time. Thank you for your trust. Together we can turn perceived adversity into prosperity.

This farewell speech does not sound like a farewell to me. I have a feeling that I am just at the beginning of a fascinating journey and that there is still a need for more basic and practical scientific research into the field of AAC. Fortunately, the chair is being continued. I will be able to stay involved in it for a while as emeritus professor. In fact, this farewell lecture is a response to my inaugural address. As I say this, I realise that there are even more and different elephant trails ahead of us, worthy of exploration and pursuit. Most importantly, I want to do this together with my family, relatives and friends.

I would like to conclude by quoting the Swiss philosopher Ludwig Hohl: 'Man lives according to his ability to communicate'. Or, in Dutch: 'De mens leeft en overleeft bij de gratie van z'n communicatievermogen'. Make sure that this is always considered!

I have spoken.

Speech 1: Sandra Beuving

Member of the Board of Directors for Royal Kentalis

Dear Hans, honoured guests,

What an honour it is to speak to Hans today. I do so partly on behalf of my colleague on the Kentalis Board, Oscar Dekker. Hans has dedicated more than 40 years to advancing knowledge and expertise in the field of communication aids for people with disorders in the perception, processing, comprehension and expression of language. You will appreciate that I cannot possibly do justice to Hans' extensive track record in this short speech.

Of course, we should reflect briefly on his track record. Hans joined the former Institute for the Deaf as Director of Research, Development and Support (RDS) on 1 February 1997. It has always struck Hans that communication can be so difficult for people with multiple communication disorders that they become locked up in themselves. He views augmentative and alternative communication (AAC) and communication devices to create (or re-create) more opportunities and autonomy. For him, it is not just about using high-tech tools, but about finding the most appropriate means of support. For him, it is not just about the person, but also about the person's social network. Independence and participation are important to Hans, which is why he is not and has never been in favour of institutionalising clients.

Hans believes in putting people first, no matter how hard it is. He combines a passion for substance with an entrepreneurial spirit and drive. He was instrumental in setting up Stichting Kwecoo in Landgraaf in co-operation with Viataal, as the institute for the Deaf (IvD) was called after a previous name change into Viataal (from 2003 to 2009, since then changed into Kentalis). Augmentative and alternative communication (AAC) is still the basis of Kwecoo's concept. Hans continues to seek solutions to help people who cannot speak, write or sign/gesture. This passion led him, together with Wim Prins, to establish Stichting Milo in 2010 to offer specialised services to children, adolescents and young adults with multiple communication disorders and

their families. Prior to founding Milo, Hans made several attempts to establish AAC centres within and outside of Kentalis. In these centres, Hans wanted to combine treatment and diagnostic knowledge in the form of centres of expertise that could assist groups of clients in diverse organisations. The establishment of these centres was not possible within Kentalis.

Hans was also a developer and innovator. He developed innovative assessment and intervention programmes in which parents had a crucial role, including dynamic assessment and a wide range of resources and assistive communication systems. Hans hoped that these initiatives would provide examples of good practice. He has been a source of inspiration and reflection for many people.

Hans is obviously more than an advocate of AAC. Colleagues remember Hans as a golden co-worker, a gentle man, a manager who loved to make house calls and give his interpretation of what might happen. Hans is also known as a talker, so knowledgeable that subtitles were sometimes needed to get the message. He also had a reputation for being in meetings all day long. Hans always puts the customer in the first place. He represents people who cannot speak and have no voice. Hans remained committed to doing this, even when the legacy systems did not work together. Quite the contrary, it has made him very creative and sometimes a rather rebellious person. Hans is serious in his work, but also a true Burgundian Limburger. He is always ready for a laugh and a joke.

In 2010, Hans received a special appointment as professor of AAC at Radboud University. Today we say goodbye to Hans as a professor and look back on more than a decade of the Chair of Augmentative and Alternative Communication for Persons with Multiple Disorders. We can honestly say that Hans is an icon in his field. On an international level he is an important personality in the field of AAC. Everybody seems to know him. Hans is one of the pioneers of the field of AAC. He was therefore fully justified in being made an Officer in the Order of Orange-Nassau.

Thank you, on behalf of the many colleagues and clients who have benefited from your knowledge and expertise, and for your commitment to this field. Today we will enjoy all the knowledge and expertise that you and your colleagues have accumulated. Thank you, Hans!

Sandra Beuving,
Board of directors member
Royal Kentalis,
Sint-Michielsgestel, the Netherlands.
www.kentalis.nl

Speech 2: Arjen Beekman

Executive Director of Stichting Milo

Esteemed Rector, dear Hans, honoured guests,

Elephant paths. The elephant's path to augmentative and alternative communication? What does it take? Paths and elephants: the word itself says it all. I have seen both in the last 10 or 11 years as managing director of Stichting Milo. Let me explain, starting with a few paths.

The paths

- **The Chair.**

The Chair in AAC refers to the establishment of a professorship and academic research programme in AAC at Radboud University Nijmegen. This was originally called 'The BOSK Chair in AAC'. BOSK wanted the chair to be independent of any institutional organisation. It was therefore initially funded externally by the Rehabilitation Fund and Stichting 'De Drie Triangels', mainly to ensure an independent focus on research into AAC for people with complex communication needs. When the chair was renewed after three years, Kentalis and Milo became equal sponsors of the chair and of a number of specific research projects. The Chair provides the scientific foundation for the clinical and educational AAC practice of Stichting Milo.

- **Stichting Milo.**

The idea of a 'Milo-centre' was conceived as a kind of German-style 'An-Institut'. This is a practice organisation that co-operates with the university without being a part of the university organisation in a formal, financial and personnel sense. Legally, it is an independent working institute. It offers the possibility of converting the scientific results from the Chair of AAC into clinical practice, without a vested interest and without a profit orientation.

The continuous exchange of knowledge between science and practice and vice versa is unique and, in my opinion, necessary to be able to help people with severe communication challenges in the best possible way. These are the people for whom we do the things we do! This link with the university allows Stichting Milo to truly live up to its claim to be the treatment and expertise centre for AAC, which is why Milo has decided to continue funding the chair independently, in cooperation with the Behavioural Science Institute of the Faculty of Social Sciences at Radboud University.

- **The health insurance companies.**

The insurance companies and, before them, the health authorities, quickly recognised the uniqueness of Milo's services and the importance of the link between Milo and the Chair in the person of Hans van Balkom. For them, the evidence-based or evidence-informed nature of our programmes is an important condition for the funding of these clinical assessment and intervention programmes. This has made it possible for us to guide and support more than 1,000 families and children with multiple communication disorders in the use of AAC.

Now I would like to move on to a couple of elephants; elephants who have made sure that the trails have been made and followed.

<u>The elephants</u>

- **Hans van Balkom**

In the first place, our greatest elephant: Hans van Balkom himself, because of his weight, which I do not necessarily mean in the physical sense. When I met Hans 12 years ago, his knowledge, vision, passion, emotion, and perseverance took hold of me, and that has not changed to this day.

Hans is also an elephant, as an authority on AAC for people with complex communication needs, he will walk through fire, taking a shortcut, an elephant's path where necessary. Obstacles? Not at all. Hans always sees 'possibilities and opportunities'. I experienced this myself when, at the start of Milo, we discussed how to fund a visit by Hans with about four colleagues to a client. Hans found this completely irrelevant. The client had to be seen and assisted, so of course we would just drive straight from Nijmegen to Groningen with five people, right? The funding would come later, or not. Finding an elephant path or, as he often calls it, an emergency communication Band-Aid, was the most important thing for Hans. Fortunately, Hans also joined me on my way—the business way—every now and then. Otherwise, we might not be sitting here. Since then, our paths have converged.

- **Wim Prins, another elephant**

With his strategic insight and wealth of experience in the business world, Wim played an important role in guiding Hans in the most appropriate direction. An important path in this context was: first become a professor in AAC, then start Milo. Science is a guide to evidence-informed practice, and practice guides and verifies science, in constant interaction.

- **The other Milo elephants**

This includes all current and former Milo staff members. All of us have constantly been looking to find the right paths for our clients and lead them along the way. There are currently more than 100 elephants on the road to AAC in the Netherlands, including specialised AAC clinicians (freelance), AAC intervention supervisors and coordinators (clinical and educational psychology/orthopaedics), outpatient treatment practitioners (as freelance professionals; i.e. speech and language pathologists (SLPs), occupational therapists, physiotherapists, music therapists) and KLIN© therapists specialised in early childhood care and AAC. Without them, we could not have come so far and put AAC on the map as we have done.

- **The elephant researchers**

Today, all of the aforementioned Master's and PhD-students have demonstrated the impressive ways in which they have contributed to the applicable knowledge and development of the field of AAC in collaboration with Hans.

And finally

Dear Hans, it is great to know that, despite the farewell here at the university, you will remain available to Milo, and thus to our clients. Your broad outlook, inspiration and personal wisdom continue to be an inspiration, every day. The paths are there, and we have become increasingly able to find and create our own elephant paths. This is your achievement.

Many thanks to you, Hans, on behalf of all the Milo elephants.

Arjen Beekman,
Executive director of Stichting Milo: Wegbereiders in communicatie [Pioneers in Communication]
Schijndel, the Netherlands.
www.stichtingmilo.nl

Speech 3: Marguerite Welle Donker-Gimbrère,

Parent of a son with complex communication needs, experienced AAC expert, Anglicist, sparring partner, co-author.

Highly esteemed and distinguished guests,

Dear Hans, our history goes back a long way. I will try to summarise those more than three decades in a few minutes, while also mentioning your main achievements.

For me, the starting point was the birth of my eldest son. His birth was not without complications. In addition to possible congenital features, birth defects were found. His motor skills were wobbly, his balance was terrible and his mouth and tongue were difficult to control.

In 1968, when he was three years old, he was diagnosed at the UMC in Utrecht with a severe speech disorder. He was the youngest of a trio of non-speaking children, aged 3, 5 and 8, who had been discovered in the province of Utrecht and who were to undergo an experimental treatment programme. Apparently, this did not work.

We continued to wait. What were the circumstances? The parents still had to accept that their children were simply disabled and would never walk, talk or learn: He will never learn, walk or talk normally. It is time for you to learn to accept that you should take such a child out of the home so that your husband and other children are not being disadvantaged. Parents began to organise. The BOSK was the home for these children with a possible neurological basis for their problems. Departments for children with speech disorders were attached to schools for the hearing impaired.

As a parents' group we discovered an international meeting in Sweden about people with communication problems. There we heard about a certain ISAAC (which turned out not to be a person but an organisation in the process of being formed) and we met the director of the then IRV (Institute for Rehabilitation Issues), Thijs Soede. He invited us. At the IRV, a young researcher (a psycholinguist) was working on text prediction, assistive communication technology and methods. You guessed it: Hans van Balkom. The parents and Hans clicked. For the first time, there were no reservations or

polite refusals. Together, we wanted to improve the quality of life for our children. This is characteristic of Hans. He found funding for parents to attend international conferences and we learned and discussed a lot. The Dutch synonym 'Ondersteunde Communicatie (OC)' for 'augmentative and alternative communication (AAC)' was coined there. I enjoyed discussing 'compensation' with him. What is there to compensate for if you don't know what you are missing? I prefer to talk about maximising opportunities. Better insights emerged from these discussions and it was decided to write a handbook (Kiezen voor Communicatie [Choices for Communication]) and to start a Dutch branch of ISAAC (ISAACnf). Finally, the IRV was persuaded to organise the biennial ISAAC International Conference in Maastricht.

Nothing was too much for Hans. However, he has a difficulty with saying 'no'. When it becomes too much, it would be easier to say 'no'. In the end, we achieved a lot. We found funds for a professorship by special appointment, which you were able to fill in a special way. You have carried out interesting research. You also managed to find the people who came together to set up Stichting Kwecoo, where everything centres on helping people with complex communication need to communicate.

Thank you for all this. You have made all the difference.

Marguerite Welle Donker-Gimbrère

Speech 4: Stijn Deckers,

Lecturer in Pedagogical Sciences and senior-researcher within the Chair in AAC, manager 'Quality and Innovation' at Stichting Milo.
On behalf of students and PhD -students at Radboud University

Dear guests and, obviously, Hans in particular,

In 2012, I began a doctoral research project on the language and communication development of children with Down syndrome. I entered a world of AAC that was relatively new to me. With Hans as my supervisor, I was fascinated by the endless possibilities of the many children with multiple communication disorders who, unfortunately, too often remain invisible. I became intrigued by what was possible for them when AAC was used in the most appropriate way. After completing my PhD, only one job was possible: Milo, Hans' baby. I have been working with Hans for about a decade now, and I still learn from him daily.

A few months ago, Hans and I were sitting together brainstorming about his farewell speech. We talked about the possible title 'Communicatie op eigen wijze [Communication in its own way]', one of the books Hans has published. The final idea was to use this as the title for his speech. But Hans changed his mind and came up with a surprisingly new title. The following day I received the email with the new, official title: 'Elephant Paths in Augmentative and Alternative Communication…'. That's Hans: creative, contemplative, constantly playing with language and wordplay. Hans is known for his elephant paths, associations, using theories to look at the organisation and development of communication and language. In conversation, Hans will often take you down his elephant paths. You will often wonder if you have arrived where you thought you were going with a question. Sometimes you get lost, but he always manages to show you where to go next. His ingenious and unique mind is an inspiration. Hans is a walking encyclopaedia, and he can connect theories from a variety of fields. His ideas and elaborations have broadened and strengthened my thinking, my knowledge and my view on children and their families. This is not only true for my own purposes, but also

for those of many special needs teachers, speech and language therapists and other professionals, both here in the Pedagogical Sciences, within Milo, Kentalis and beyond. Hans is also praised internationally; his name opened doors for me as a doctoral student that would otherwise have remained closed. Hans was my guiding elephant to reach out the international world of AAC and to learn about AAC.

Hans always puts the child and the family first. It is touching to see how Hans, sometimes like an elephant, goes up to the child, sits and rolls on the floor to make contact.

It was great to learn from you and thankfully this will continue in the years to come. Going to conferences with you was a pleasure. As well as many substantive conversations, we also had a lot of good laughs. You are the embodiment of the sprightly professor. Or as some of your former PhD students like to call you: the archetypal 'primal mother' of augmentative and alternative communication, who has given birth to many children who use AAC during the decade that you have held your chair.

Hans, on behalf of me, on behalf of the graduate and undergraduate students you supervised, on behalf of the Milo staff and professionals you enriched, but especially on behalf of the thousands of children and families you directly or indirectly empowered, thank you.

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