



Education and Culture

Socrates
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Learning and **LAPH**asia

A European Learning Partnership



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Preface

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Preface

Learning and Aphasia was a two year project funded by the Grundtvig 2 EU programme 2006-2008. It attracted representatives from Estonia, Finland, Italy, Ireland, Sweden and The Netherlands.

The broad aim of the project was to share ideas and expertise as well as to establish European links in the field of learning and aphasia.

The representatives had diverse experience working with adults with aphasia, most coming from specialised centres for adults with aphasia.

This report is a culmination of two years of discussion, learning and sharing of information. It details what aphasia is and gives an introduction into lifelong learning. It also encompasses services provided in each country and the environmental factors involved.

Most importantly it portrays personal accounts from people living with aphasia.

Whilst it has been impossible to capture all of the valuable shared information and experience in this report, it is our hope that it will serve to stimulate further interest, discussion and research into this area. We would like this report to lead to the facilitation of lifelong learning for people living with aphasia.



Chapter 1
Lifelong learning and aphasia

Aphasia, A (=non) Phasia (=speaking) is a neurological disorder that affects a persons ability to communicate. It is a very common problem, in fact it is estimated that about 5 million people worldwide suffer from this acquired language disorder¹. Aphasia occurs when established language abilities are corrupted by a brain damage, usually due to a stroke, traumatic brain injury, brain tumour or infection (Tesak 2001). Problems can occur in speech production, comprehension, reading or writing. (Crystal & Varley, 1999) and each person has a unique pattern of symptoms at various levels and with different modalities (Tesak 2001).

... your life, family, everything changes. After three years of adapting and fighting for myself, in a world that has changed so much to me, I reach a level on which I can function quite good... (Nelly, 42 years)

Communication difficulties often cause psycho-social consequences, i.e. social isolation, inability to work and study, and often people with brain damage have also minor and major depression (Herrmann, 1993).

Along with aphasia, hemipareisis can occur and/ or problems with regard to conscious acting, observing the surroundings, concentrating, taking initiatives and memory. However, usually aphasia doesn't directly affect an individual's intellectual functions. People with aphasia usually get support and information in the acute phase, post stroke or post injury, but when they are "well enough" to return to daily life some problems may occur. A person with aphasia might need assistance in taking care of daily affairs, might have problems talking on the telephone or writing e-mails and usually participation in life activities becomes challenging (the person might have problems in taking part in his/her

¹ It has been estimated that annually 15 million people worldwide suffer from a stroke and that about a third of the people who experience strokes are affected by aphasia (A. Tinti, Education, Identity and People with Aphasia, 2007)

former social activities or continuing studying). And another important issue has to do with disability identity (Shadden, 2005).

... Yes, I have changed, my whole body has changed, but my heart is still in place. But just give us space, which to us is so necessary (Nelly)

Many of the problems could be solved/ helped if surrounding people knew how to support people with aphasia. In fact the social isolation can also be seen as a product of the society we live in, and not so much as a consequence of the aphasia. It's well known that people generally know very little of aphasia and its symptoms, and therefore don't understand that aphasia usually is not solely a cognitive handicap. The person suffering from aphasia is still a capable thinking person with feelings, ambition and ideas for the future. Psycho-social intervention is also becoming an important factor since the psycho-social sequelae are enormous for people with aphasia (Tesak, 2001).

We know that a person with linguistic difficulties finds it challenging to engage in a mutually satisfying conversation because aphasia masks competencies usually revealed through conversation (Kagan & Gailey, 1993). Most likely it "masks" also the ability to learn in a formal educational setting (Tinti, 2007).

How the aphasia impacts a persons ability to take part in an educational setting and to learn, depends on the persons aphasia symptoms but as well on the educational societies ability to support and give accurate tools to the person. Therefore it is very important that we provide information about aphasia and how to support people with aphasia so that we can support them to fulfil their right to lifelong learning.

Learners with aphasia are first of all adult learners. When focusing on adult students, it is crucial to consider two substantial theories in learning: the Andragogy of Malcom Knowles and the constructivist approach derived from a theory of cognitive growth and learning that

centers on the individual and creates learning experiences and tools (Tinti, 2007). The most important statements are that adults maintain the ability to learn in a wide variety of physical/ sensory environments. They must be life-centred in their orientation to learning and are motivated to learn to the extent that it will help them perform tasks they confront in their life situations.

In relation to the concept of learning within the rehabilitation context, and according to the WHO's new ICF classification framework, one of the main goals is to enable the client to live an active life and to participate in all life situations. In the rehabilitation of communication impaired people this aim has created a shift from the medical model towards a social model of rehabilitation. In this model the communication barriers caused by the surrounding environment as well as the functional communication abilities of the client are considered (Rautakoski 2005).

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Chapter 2

Learning Environment

Environmental factors that influence learning and participation of adults with aphasia in educative programs

Environmental factors are defined by the WHO-based International Classification of Functioning, Disability and Health (ICF) as: The physical, social, and attitudinal environment in which the individual lives and acts.

Environmental factors can facilitate the participation of adults with aphasia in programmes of education. However, they can also create barriers. When looking at environmental factors, it is important to consider the following:

To what extent is the factor facilitating?

To what extent it is reliable and consistent?

How often is the factor considered as being a barrier?

What is the magnitude of the barrier?

Is it possible to remove or avoid that barrier?

Below, environmental factors which influence learning and participation of adults with aphasia in education programs – as well as in society at large - will be explored. The presentation of factors uses the ICF framework as a guide.

Technical- and Non-Technical Equipment and Methods

Products and technical equipment that facilitate communication in an educative setting are described by the ICF framework: Adapted and specially designed equipment, products, processes, methods, and technology used for acquisition of knowledge, expertise or skill, such as specialized computer technology. (ICF - e1301)

In an educative setting, technical equipment specially designed for persons with aphasia, can be facilitating for learning. It is important to recognise that one type of technical equipment can be helpful by one person but constitute a frustration for another. Every technical aid can be experienced as a barrier if the person has not made the decision to use it. It is important that the technical tools given are person specific which can only be assigned by a trained professional. Ongoing consultation is required with the person and their significant others to ensure all tools are environmentally appropriate for that person. More recently due to modernisation and development, tools are becoming more portable and user friendly. However, some designs are not always appropriate for example because of physical limitations. Examples of technical equipment specially designed to be used by persons with aphasia are: different computer software programs e.g. word prediction, speech recognition, different pre-recorded books, newspapers e.g. DAISY, symbol or text based communication aids with speech output, as well as equipment with speech synthesisers.

General everyday technical equipment that maybe facilitating for conversation and communication, are the use of television, video, DVD, programs with subtitles, camera, telephone or mobile, e-mail, internet, hearing aid, as well as glasses.

An educative setting does not rely on technical equipment alone. Non-technical products and methods are used to great extent to facilitate learning and training of speech and language abilities in people with aphasia. Products used for this purpose are: communication books and person specific books based on the individual needs and interests of the person with aphasia. General “easy-to read-books and easy-to-read-newspapers” are aimed at adult readers the language is simplified the text is enlarged and spaciouly organised (The Centre for Easy to Read, Sweden). Also, specially designed pens, magnifying glasses and “reading-supports” may help to facilitate reading and writing.

Pedagogical methods chosen and used within an educative program are vital in facilitating participation and learning in persons with aphasia. Methods being emphasised are for example the Supported Conversation of Adults with Aphasia (SCA™), introduced by Aura Kagan (Kagan, 1998) and the London based method of Total Communication (Green, 1982; Fawcus et al, 1990; Lawson and Fawcus, 1999). Chapter 1 of this report also discusses pedagogical methods that are evident in an educative settings.

Accessibility

Accessibility to environment

The person with aphasia may experience environmental difficulties. Therefore, one must regard the accessibility to the environment where the structured education and training takes place, as a factor influencing learning. For example,

Is the building and/or the room equipped with portable or stationary ramps, lifts, power-assisted doors and level door thresholds?

Are lavatories designed for easy access by a disabled person?

Is the room in which the educative process and training occurs, facilitative to learning? That is, is it well lit and quiet? Is it equipped with furniture adequate for good sitting? Is it comfortable and appealing to people for optimal learning?

Is it possible to get to the aphasia centre with public transport? Are services provided such as specially adapted taxis?

Accessibility to information

Accessibility to public information may be difficult for people with aphasia. It is important that all public information is as clear and simple as possible in order to be understood. The Plain English Campaign <http://www.plainenglish.co.uk/> is a resource to adapt documents into simple English. Elizabeth Mc Millian states during a seminar in Australia (1990): People with learning related disabilities (for instance, brain damage) need materials relevant to their interests, age and information needs, written in a clear, simple and easily understood language.

Bror Ingemar Tronbacke (date??), representing the Easy-to-Read Foundation in Sweden claims that: “Being able to take part in information, literature, etc, is normally considered a fundamental democratic right, as it is necessary to be well-informed, in order to participate in social life, discussions at work, and to be able to influence one’s own situation”.

It has to be remembered however, that people with aphasia are not a homogenous group, and differences in reading ability also exist among people with aphasia. They therefore need a range of different easy-to-read materials.

Currently, it is relatively uncommon that public authorities provide aphasia friendly documents. Often it becomes a task for the Aphasia Centres to develop aphasia friendly documents and websites, e.g. www.aphasiahelp.org. At present, the person with aphasia must rely on others in order to have more complicated texts (for example on a website or an application form) orally explained, translated into simple writing or depicted in a simple drawing.

Accessibility to information includes websites that are made accessible to functionally disabled persons. This means that persons with aphasia should be able to recognize, understand, navigate and be able to contribute information to the website. Today, most websites are impossible to use by persons with aphasia. This is despite their great potential for relating information by technologically overcoming the existing barriers. Web Accessibility Initiative (WAI), is an international guideline for the standard of accessibility. Association ALIAS has developed its own website based on the results from the Rehabilitation Engineering Research Centre on Universal Telecommunications Access of World Institute on Disability (WID) and on the project by Linda Worrall and Jennifer Egan “The web access for people with aphasia”.

Accessibility to environments influenced by geographical conditions

An environmental factor such as geographical conditions that may additionally influence accessibility to a place, (and therefore learning) in a person with aphasia, is the population density. This will affect the ratio of specially trained personnel to the number of persons with aphasia within a specified geographical area. This influences the extent to which a

special program can be offered, and/or the intensity of that program. Access to a learning centre may also be influenced by the geographical distance that a person has to travel to a centre or a school. This factor is likely to depend on whether the person lives in a rural or an urban area.

The accessibility to internet connections may also vary due to geographical conditions and where in the country a person lives. This may influence learning, and participation in society and political issues.

Support from External Persons

The amount of physical and emotional support a family member, friend or colleague provides is also an environmental factor influencing learning and participation in educational programs. These external persons are often of utmost importance as they not only give practical support to the aphasic person, but also, in some cases, provide the person with intellectual, psychological, and mental encouragement throughout the different stages of the re-development of communication skills.

However, family members and friends can also constitute real and significant barriers in the communicative process for the person with aphasia. This may be the case when, for example, an important external person takes on complete responsibility for the communication to occur between the aphasic person and others. This is often the case when the external person has not observed (or is not able or trained to do so) the communicative competence the person with aphasia does indeed possess. This inability among the general population is often the reason why a person who has aphasia becomes isolated from friends or why her/his formal social life becomes restricted. Friends may avoid a perceived difficult communicative situation.

Having no close family members or close friends may create a barrier to the communicative process of an aphasic person, as she/he becomes socially isolated. However, in some cases, the lack of immediate family or close friends may push persons, despite their aphasia, forward in the communicative process, as they find themselves forced to develop strategies for social survival.

Support from Persons within the Educative Programs

The Participants:

Within a setting of an aphasia centre or a school (folk high school or college offering special programs directed towards persons with acquired brain injury), the participants themselves constitute environmental factors which most often are conducive to learning as they give each other support and encouragement while sharing similar experiences. This creates a secure and calm environment where optimal teaching and optimal learning can take place. This in turn increases the self confidence within the individual, which enhances communication.

The Person in Charge of an Aphasia Program:

It is crucial that the person in charge of the aphasia program facilitates the communicative process of the person with aphasia, be it at a centre or at a school. They must possess skills and knowledge as well as an understanding of how the communication process evolves and develops in a person with an acquired brain injury.

The person must convey flexibility and possess an understanding of the “hidden disabilities” a person with an acquired brain injury experiences. The staff and other people who work in an aphasia program in the chronic phase have to be able to create an atmosphere in which people with aphasia and their families feel at ease, acknowledged and valued. A few important factors hereby are to create a non-clinical atmosphere, in which the people with aphasia are ‘participants’ and not ‘patients’ and where the participants are partners in the goal- and activity planning. The person in charge must convey a sense of naturalness also when adopting a communication style of a reduced speaking rate, of a slightly overemphasised articulation, of using pauses and repetitions, and of using writing, drawing and gestures concomitant with talking.

The person in charge of an aphasia program must also have the knowledge and ability to educate external people involved with the person with aphasia – people such as assistants, staff, other teachers, and public employees.

Attitudes

The attitudes of external people that a person with aphasia may encounter are also environmental factors that might be facilitating or a barrier. These attitudes stem from, and are consequences of customs, practices, ideologies, values, norms, factual beliefs and religious beliefs, as well as from the degree of knowledge of aphasia the external people possess.

An external person who encounters a person with aphasia without prior experience and/or knowledge of this specific language disability, is very likely not able to observe and appreciate the aphasic person's inherent communicative abilities. Instead, the person with aphasia will be regarded as a person possessing limited, or very rudimentary skills in communication and conversation as these acts of human interaction are often associated with verbal language abilities only and not with a total system of communication where body language, mime, gestures and pointing are parts of the communication. The perceived communicative difficulties between the aphasic person and an external other are environmental factors causing barriers. So is a patronizing attitude and an overindulgent caring for the person with a language disability. It deprives the person with aphasia of both independence and integrity constituting a hindering factor in the evolvement of the communication process. Non-experienced external people can be found in all areas of society. It can be people within the medical field such as physicians, nurses and paramedics, as well as politicians, social workers, public employees, etc. This common ignorance constitutes barriers in the communication act between the person with aphasia and the external "other".

Services, systems and political policies

Services, systems and political policies constitute environmental factors which influence learning and the participation of people with aphasia in various specialized programs. Such a system, or service, is the Aphasia Association of a country. It operates at different levels: Locally, regionally, nationally as well as internationally. The aim of such an association is to improve the communicative conditions for people with aphasia and their family

members. Often, one of the main aims of this type of association is to provide opportunities for people with aphasia to participate in education and training programmes. Ireland doesn't have an aphasia association. The supply of these programs is highly dependent on political policies at the local, regional national levels. Systems and rules, shaped by political decisions, regulate the existence and supply as well as the access to the various specialized programs.

These programs are offered within different settings:

Estonia

In Estonia aphasia became an issue only in the 1970's. Before this time very few speech therapists were working with people with aphasia. Some hospital neurology departments had a service where only individual speech and language therapy was offered.

In the 1980's the first conversation groups for people with aphasia and their families was launched in Tallinn Central Hospital. This was also the first attempt to support learning activities for people with aphasia.

Estonian Aphasia Association (EAA) established in 1992 they identified one of its main objectives as enlarging the circle of people involved in activities for people with aphasia, informing society about aphasia and problems caused by aphasia as well as possibilities to avoid discrimination of people with aphasia in social life.

For the Association it has been its focus to work on teaching methods for people after brain injury. In 1995–1996 Aphasia Association together with Speech and Language and Hearing Institute in the Danish Odense University carried out a PHARE program project “Establishing a NGO co-operative structure related to aphasia rehabilitation”. In this project 15 speech therapists from all over Estonia were trained to run aphasia groups in different counties in Estonia.

An independent aphasia centre was opened by Aphasia Association in 2000. It became possible thanks to a donation from Evald Pesari, a successful inventor and businessman who had family members that suffered from aphasia and had aphasia himself at 58 years.

These personal experiences made him want to help other people in similar situations. He donated buildings and equipment to run a rehabilitation and activity centre for people with aphasia.

In 2002–2003 to design a method of programs to teach people with aphasia Estonian the Aphasia Association together with Odense University Speech- Language and Hearing institute continued their involvement with a project “Establishing a Social Rehabilitation and Resource Centre for Persons with communication handicap due to brain injury” This project was financed by Danish Foreign Ministry.

Until now in Estonia all activities for people with aphasia and their significant others, such as conversation and education groups, self help group guidance, social adaptation groups, family members education groups, recreational activity groups etc (except individual aphasia therapy) are financed by projects. The Aphasia Association from 2005 has been involved with the Estonian Health Development Institute ESF project PITRA to change governmental policy and reorganise the social services system in Estonia, along with the attitudes and the environment that influences the quality of life of people with aphasia.

Finland

The Speech Interpretation Service for Speech Impaired in Finland

Since 1994 Finland has -in accordance to the Finnish law- a speech interpretation service for people with speech impairment.

The Aim of the Speech Interpreter Services, is

to enable people with speech impairment to take part in everyday life in their community

to increase their autonomy

to give them the opportunity to live an equal life in society

Each municipality has a duty to provide these services. A person with a severe speech impairment has a right to use the service at least 180 hour per year . Municipalities are responsible for the payments to the interpreters; the service is free of charge for the users

The speech interpreter assists the client to interact with other people in everyday communication situation. They can interpret the non-intelligible speech into intelligible speech. With aphasic clients, the interpreter mostly interprets the messages from single words, symbols, gestures etc into spoken language. The interpretation service also includes assistance in writing and reading and (the interpretation service) can include taking care of and updating communication aids and giving guidance for communication partners on how best to communicate with the client.

In Finland there is specialized education for speech interpreters (competence-based qualification). In this education, which normally takes 1-2 years, students learn about communication disorders and AAC.

The service is applied for via social services . The implementation of the service is followed-up by the social security office.

Most of the aphasic clients use the service for getting assistance in daily affairs (going shopping, library, pharmacy) which involves communication and for reading the paper and post.

Case: Client E. started to use the service after his divorce. He uses the service for taking care of the daily affairs (going shopping, going to the association for people with stroke etc) and for reading the post. The interpreter assists him with making reservations through telephone. The interpreter updates his Imagetalk –device and his Arnit- e-mail programme and helps him to get to know new people.

The Finnish Stroke and Dysphasia association work within other areas:

controlling rights

local activities

information services looking at changing attitudes towards stroke, material production and prevention of the stroke

educative services including therapy, education, communication centre and youth house development.

Ireland

In Ireland The Education for Persons with Special Educational Needs Act 2004, in reference to adult higher education, states that a National Council for Special Education will be established and its functions will include:

General review of the provision made for adults with disabilities to avail of higher education and adult and continuing education, rehabilitation and training and to publish reports on the results of such reviews (which reviews may include recommendations as to the manner in which such provision could be improved)

Provision of advice to all educational institutions concerning best practice in respect of the education of adults who have disabilities

Further to this, The Education Act 1998 states that the function of the Act is to “promote opportunities for adults....to avail of educational opportunities through adult and continuing education.”

The Department of Social and Family Affairs (DSFA) has a Back to Education Allowance that can be used by people on a disability allowance whilst the Department of Education and Science (DES) also has a Financial Support Scheme for third-level students with disabilities.

Some education/training organisations’ like the Association for Higher Education Access and Disability (AHEAD) and the National Learning Network provide learning opportunities for adults with disability, including communication disability.

AHEAD, the Association for Higher Education Access and Disability is an independent non-profit organisation working to promote full access to and participation in third level education for students with disabilities in Ireland.

National Learning Network is Ireland's largest non-Government training organisation with more than 50 purpose built training and employment units nationwide catering for over 4,500 students each year.

Its objective is to assist people at a disadvantage in the labour market to learn the skills they need to build lasting careers in jobs that reflect their interests and abilities.

This is achieved through a brand of training, education, employment access and enterprise development that is respected and often replicated across Europe.

The organisation offers over 40 different vocational programmes which carry nationally and internationally recognised certification and are designed to lead either directly to jobs or progression to further education.

However, whilst Speech and Language Therapists in hospital and community settings do provide individual and group communication training programmes and support and links to relevant organisations and education resources, no streamlined education services exist specifically for adults with aphasia in Ireland nor are there any specialised aphasia centres.

In Italy aphasia is an almost unknown problem for the community although it is estimated that there are approximately 150,000 aphasic people with an annual increase of 10,000 new cases. It is very difficult to spread knowledge about this condition from a social point of view because we are still influenced by an old medical model.

Italy

In Italy people with aphasia generally benefit (with differences bound to the geographic localization) from rehabilitation sessions provided by the National Health Service (NHS). In the NHS, professionals use mostly traditional approaches (from behaviorism or the clinical linguistics up to the cognitivist neuropsychology). In many ambulatory services impairment-based therapies associated with rare therapies based on a functional focus still prevail.

However in a few Italian Regions, located prevalently in the North, there are some little and big associations which distinguish themselves for the adhesion to different service models. In ALIAS we chose in particular to address activities focusing on psychosocial issues,

personal relationship & interaction

using supported conversations

promoting maximum autonomy and choice in people with aphasia

conducting self-focused activities around acceptance, adjustment, re-framing and identity

counseling for people with aphasia and partners/families

We work

with significant others generally in groups focusing on social issues,

establishing new social networks and facilitating the

process for building self-identity.

We work in a perspective based on projects, choosing fundings which allow us to act in the community, where we perform a cultural sensitization action, and within the social context of the people with aphasia that takes part in therapeutic education paths.

Our objective is to create a social and cultural dimension in which the communicative disability is not a barrier or an obstacle, a society respectful of the differences where each can find a space inhabitable, besides any labels.

The activity of education/formation at community level, diversified according to the demands, is one of our main interests, since it is a fundamental tool to obtain a real cultural change with respect to the communicative disability and to address the social resources correctly.

The experience we acquired pointed out the necessity of extending the educational offer to the people with aphasia and to their families, in order to activate empowerment paths functional to the improvement of their quality of life.

The people with aphasia are indispensable to develop awareness about their own competence and degree of autonomy, which can give the person the responsibility of the fundamental choices along their path toward autonomy.

As regards significant other's, it is necessary that they - with the experts' help - discover their role as an ally of the person with aphasia in his/her path toward autonomy more than of full time "assistant".

For this purpose ALIAS organises meetings opened to the people with aphasia, their relatives but also the whole community to develop a constructive debate on the theme of the communicative disability in adulthood.

In fact while the medical and linguistic aspects of aphasia are of interest in several publications and public initiatives, themes related to the autonomy loss and to the communication impairment impact on the various aspects of the daily life are never addressed carefully or in the social-health world or elsewhere.

ALIAS wants to address these problems, respecting the first and real necessity of the person with aphasia and of her/his relatives: be able to have at the most useful information not only about the impairment from a medical point of view, or the differences among the various rehabilitation methods, but also for example the strategies useful for preserving the social relations and/or how to manage and help the person, in short how to live with the aphasia.

Netherlands

Services that provide benefits in The Netherlands

In the chronic phase the following organisations provide direct services for people with aphasia.

Aphasia Association AVN

In the Netherlands an important role is played by the “AVN”. AVN (Afasie Vereniging Nederland) is the Dutch aphasia association. It was founded in 1977 and its main aim is, to improve the well being of people with aphasia and their relatives. The AVN attempts to achieve this aim by:

Promoting and establishing contacts with and between people with aphasia and their family members.

Providing information to members and other people who are interested.

Increasing the public’s awareness about aphasia and its consequences for people with aphasia and their families.

Encourage the foundation of Aphasia centres and supporting the existing Aphasia centres.

Support regional activities like organising self-help groups, partner groups, groups for young people with aphasia, choirs, art-groups and many more activities.

Publishing a magazine 4 times a year for members with aphasia and their families, it includes information, personal experiences, an aphasia friendly part, puzzles and information about new brochures and books etc.

Structured programmes for people with aphasia

Aphasia centres

It is recognised after rehabilitation that some people with aphasia who attempt to return to an everyday life are often disappointed. Life has changed and the impact on daily life is immense. Many of the hobby’s people used to have can no longer be done because of the language impairment and social activities and social contacts most often reduce enormously. Besides this most people with aphasia have a hard time to actually practice strategies and techniques they learned during therapy in daily life.

Experience has taught us, that people with acquired brain injuries are life-long learners: often they need some more therapy or professional help after a couple of years – it is then that they set new goals for themselves and most of the times are able to reach these new

goals and learn new techniques. The current rehabilitation resources in the Netherlands do not provide possibilities for life-long learning. The activities offered by the Dutch Aphasia Association such as self-help groups and computer training only answer the question for life-long learning partly. In 1998 an Aphasia Centre was established in Rotterdam: a centre that provides professional help to meet the needs of people with aphasia, their family members and caretakers in the chronic phase. The AVN was one of the co-founders of this centre and it is convinced that such centres are a necessity for people with aphasia. Therefore, the AVN, together with the Aphasia Centre Rotterdam started a national project in 2002: 'The support of founding Aphasia Centres in The Netherlands'. The main goal of the project is to start Aphasia Centres in all regions in The Netherlands.

At the moment (January 2008) 9 Aphasia Centres have been founded in different regions in The Netherlands. An Aphasia centre supports and activates people who ask for help with communication and re-socialisation after they have been confronted with aphasia or other communication disorders caused by adult brain damage. An Aphasia centre is an expert centre for information and professional care, based on the needs as expressed by the clients, their carers and /or professional caretakers. It gives people with aphasia the opportunity to help others and is a connection to welfare activities. The aphasia centres are comfortable, safe and easy accessible.

The Aphasia centres are based on the believe that people learn most from other people who are in the same situation, that people can learn life-long and that people with communication disorders caused by adult brain damage need professional help with that.

People work with professional guidance on their own goals, focusing on improving and maintaining communicative skills and re-socialisation. Group work is an important base of the success of an Aphasia centre. Everybody in the Aphasia centre is responsible for making coherent groups, based on the gravity of their aphasia, the needs of the client, social background and interests of the clients. The active participation of the clients, the

participation of qualified staff and volunteers and a flexible small organisation in society are all important.

The AVN officially registered the name Aphasia Centre and supervises all centres in terms of quality. A speech and language pathologist that is specialized in aphasia treatment and has several years of working experience is the head of each Aphasia Centre.

The AVN attempts:

to fund a professional Aphasia Centre in each region of the country.

to inform members about new developments considering care and cure in the chronic phase.

to guarantee close cooperation between the Aphasia Centres and the regional departments of AVN.

to support and assist regions and organisations that are planning to fund an Aphasia Centre.

to support Aphasia centres that are already started by providing courses and trainings for the professionals and offer them the possibility to maintain contact with their colleagues from other centres.

Day care and welfare services

Many welfare activities are organised throughout The Netherlands. Sometimes these activities are specifically for people with aphasia, other times the target group is people with acquired brain damage in general. This includes over 100 local and regional initiatives, which we will not mention here, because of their number and the fact these are not national projects.

Sweden

In Sweden, in the 1830's, the concept of a liberal adult (folk) education entered the national discussion of culture and society. This developed especially during the 1900's and still has a vital influence on the Swedish culture. This liberal folk education is considered a life long learning process and is a matter of defending, vitalizing, and developing democracy...The survival and vitality of democracy must build on a culture of democracy with

dialogue, discussions, and participation as important elements. [...] Liberal adult [folk] education has a key role in this process. It can help create meeting-places for change and bridge the gaps between groups of people and between humans and technology. (The Swedish National Council of Adult Education).

Outside of the hospital setting, meeting-places, at which special communication programs are provided which enhance communication for people with aphasia, can be found in Sweden within different constellations. They are as follows: a) Aphasia centres located in three (?) different cities; b) Specially run computer training rooms (at 50 to 60 locations throughout the country) in cooperation with the local government and the Aphasia Association; c) Study-groups organized by one of the study-associations (Studieförbundet Vuxenskolan) affiliated with different workers' and professionals' unions and in cooperation with the Aphasia Association and; d) Folk high schools offering specialized programs for adults suffering acquired brain injury. Throughout the country, there are twelve such schools offering these programs.

The UN Standard Rules

It is of interest to note that issue number six of the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities identifies that the most important outcome of the International Year of Disabled Persons, 1981, was the World Programme of Action concerning Disabled Persons, adopted by the General Assembly by its resolution 37/52 of 3 December 1982 – and that the Year and the World Programme of Action [...] both emphasised the right of persons with disabilities to the same opportunities as other citizens and to an equal share in the improvements in living conditions resulting from economic and social development. There also, for the first time, handicap was defined as a function of the relationship between persons with disabilities and their environment. (Adopted by the UN General Assembly resolution 48/96 of 20 December 1993)

If you like to read more about UN Standard Rules or if you need it when working with people with aphasia, go to <http://www.lattlast.se/pub/3128/UNstandeng.pdf> .

Economy

Economy of the Individual

The personal finances of a person with aphasia are a factor that may influence access to settings and situations where communicative learning can take place in some countries. Private funds may facilitate access to privately hired assistants, facilitate purchasing specialized equipment, facilitate encouraging and stimulating journeys, etc.

Economy of the Local and Regional Governments.

The economy of the local and regional governments is an additional factor that influences the public services of specialized programs for persons with aphasia. Access to a program might depend on the extent at which a person with acquired aphasia receives financial aid from public and private funds.

To what extent does the person with acquired aphasia receive financial aid regarding travel to and from the aphasia setting?

Does the welfare system provide for health services, cost of living, personal care and assistance, aid for acquiring necessary specialized equipment for specific communication difficulties?

The availability of funds and financial support from the local governments affects people applying to, and attending folk high schools. These offer courses with specialized programs intended for persons suffering acquired brain injury and aphasia.

Medication and Diet

The medication a person is prescribed can influence participation in a program as well as the ability to learn. The chemical substance of a medicine can either be facilitating or constitute as a barrier to learning and participation depended on the persons reaction to the medication. For example, depression can occur at the first onset of stroke but can reoccur at different intervals and at different intensity levels throughout the life cycle. This often influences learning as it often has a negative influence on physical and cognitive abilities. Depression must be treated pharmacologically as it maybe connected with dangers

for the depressed person. The medical treatment consists often of selective serotonin reuptake inhibitor, SSRI- substances (Socialstyrelsen. Nationella riktlinjer för strokesjukvård 2005)

One can speculate that this type of medication – in case of depression – will facilitate learning. “One could think that language abilities of a person with aphasia would improve from centrally stimulating substances and from substances prescribed for dementia. One can in some people observe a worsening of the aphasic condition from substances that influence the level of alertness in a person such as sedatives and tranquillizers in cases of insomnia. These effects are non-specific [...] other medical substances – such as those prescribed at conditions of epilepsy and mental illnesses – may have specific worsening effects on the language abilities” (Personal correspondence with Dr Eva Helene Ahnlide, specialist, rehabilitative medicine).

The type of diet a person adheres to may influence learning – a well balanced diet provides for adequate nutrition which is necessary for the brain to work optimally and is a prerequisite for optimal learning.

Absence of treatment/education in it self, can hinder a persons ability to learn and develop.

Summary

The above is an account and summary of environmental factors influencing learning, accessibility and participation at various settings, offering specialized programs, for persons who have aphasia – as well as environmental factors influencing participation in the society at large. The settings described are situated in six of the EU-countries. The policies connected with the settings vary and so does the outline of the various educative programs as it depends on the system of the individual country as well as on the individuals involved in the programs. However, the influencing environmental factors remain mainly the same in the different cultures and can be concepts around which programs, although different, can be developed – programs that focus on enhancing and encourage the use of inherent communicative skills of the person who has aphasia.

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Other sources

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UN General Assembly resolution 48/96 of 20 December 1993

WHO, International Classification of Functioning, Disability and Health . WHO 2001

Links

<http://www.plainenglish.co.uk/>

<http://www.lattlast.se/pub/3133/fightillit.pdf>

<http://www.lattlast.se/?page=162>

www.aphasiahelp.org.

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<http://www.w3.org/WAI/Policy/#EU>

[http:// www.aphasiaforum.com](http://www.aphasiaforum.com)



Chapter 3

Pedagogical Approaches

Introduction

Nelly's story

Paragraph 1

Professional intervention based on demands.

(demands should be changed to needs)

Paragraph 2

Setting goals

Paragraph 3

I want to...talk

Paragraph 3

I want to...read

Paragraph 4

I want to...write

Paragraph 5

I want to participate in society...

Paragraph 6

The significant others

Introduction: Nelly's story

Nelly, 42 years, married with Ron and four children living at home, tells her story:

Aphasia means to me...

At the age of 15 I started my education to become a nurse. I had to work with people who suffered from stroke. Not knowing that one day the same would happen to me and certainly not at the age of 36: your life, family, everything changes. After three years of adapting and fighting for myself, in a world that has changed so much to me, I reach a level on which I can function quite good.

Then something I never thought of happens: I have another stroke. This time more severe than the previous one. My complete right-hand side is paralysed, and I can't speak anymore. Fortunately I can understand everything anyone says. That was different the previous time. I think it will work out just fine, but at the hospital everything I have to read is like a foreign language to me. This is terrible. I don't even mind the reading that much, but that I'm not able to say what I think...

To me it feels like I can say what I think, but it just comes out the wrong way. It sounds nothing like what I've made up in my mind. I can no longer pronounce the names of my children, I can't write them down either. And what seems so strange to me, the way to do certain things, is lost. The order in which I have to bath or dress myself is gone, I just do something. Brushing my teeth, I don't succeed in that, what do I have to do with that brush...? Every small thing they can teach me to improve this, is fine with me.

After a while I can read words consisting of three or four characters, but the pronunciation is still wrong. In my head it's fine but it all comes out differently. Fortunately the characters no longer look like strange figures. There's no speech therapist at the hospital, but once a day my physical therapist comes to work with me. Walking is still very difficult but not being able to say anything the way you would like to say it is the hardest.

The general practitioner organises a visit by a speech therapist, she will take a closer look at my case. The 'Gespreksboek' and communication through gestures helps me enormously.

The rehabilitation centre

After three weeks of hospitalisation I'm transferred to the rehabilitation centre. At the hospital I was allowed to try to do some things on my own. I could come out of bed and reach the chair. With good support it was possible to go to the bathroom. But at the rehabilitation centre I was put in a wheelchair with the comment: "Keep in mind that you cannot do anything yourself, at the rehabilitation centre we're going to do it

our way". I had to call a nurse for everything, two nurses got assigned to me – they had to watch me very closely to make sure everything I did would fit in their rehabilitation program. I was a nurse myself! Even when I got in to bed, I got a lesson in how I had to lie down. They all meant well but oh, they made me feel just like a young child.

They asked me what I thought was most important for me to learn. I indicated that for me talking came on the first place, walking at the second. So my schedule was made in that order. All speech therapists are put to the job. They will record my speech.

The battle has started. Every morning after my breakfast I go to the silence area, there I start writing down the names of my children, pages full, until I can write them from my memory. It's very difficult to write with my left hand, but using my right hand is even harder.

Every day there's some progress, my problems are taken seriously and my family is kept well informed. The children are even taught how they can improve communication with me.

I need to learn everything all over again...If therapy came to an end for someone at the rehabilitation centre it always was a strange feeling. We were glad for that person, but we also knew that when you come home again and leave the safe surroundings of the rehabilitation centre that's when the real rehabilitation starts.

My period as an inpatient at the rehabilitation centre comes to an end, I also get to go home. I will receive therapy, three days a week for a period of five months.

At home

I underestimated coming home again.

I felt left out of everything. Everybody had their own things. And everything went fast, so very fast. I thought that me being here was of no use, just a burden. It took a long while for that feeling to go away. A social worker at the rehabilitation centre has meant a great deal in this process. The children could come to her for help and ask her everything they wanted. With her help we searched for a way in which we could function as a family again. In real life it's always different, that became clear but it was something I hadn't thought of. My life has slowed down. As an outsider it's very hard to understand. Nothing can be done in a hurry.

For example: Someone says to me: "..Hey, how are you? I can't really talk to you right now, I'm in a hurry but Monday I can come and visit. We'll have a chat and a cup of coffee. But only if it's alright with you, if it's more convenient you could come to me, or we can make an other appointment, all right? Bye!"

Situations like these are a real nightmare to me. First of all I'm in a store, there's music, which already disturbs my concentration. There are people everywhere, that's also very distracting. Someone asks me how I am doing, I'm preparing an answer. But before I can even answer, the person starts talking again. I try to understand but

so much is said in one sentence that I'm not able to put things together anymore. Then I panic, because I wouldn't want anyone to think I'm stupid. After this incident the shopping that is left to be done has become more difficult. I keep wondering "what exactly did she say? Do we have an appointment? Was there something important to remember?"

I can't handle fast people anymore and that's difficult in this fast world.

It sometimes seems as if people with a disability, in the eyes of their family and friends, have changed. And perhaps that's the way it is, but maybe besides that the change of character has to do with the fact that every day is a battle. We need to speak up. It can look like we're bold, but in general, and especially for people with aphasia, it's difficult to find the right words and sometimes you didn't mean to say something the way you did. You don't notice the difference yourself because you had it right in your mind.

I know that for outsiders it's very hard to understand. I can see the confusion I bring to my family with every slip of the tongue. Together we can often laugh about it, and that's o.k.

I would like to continue about what people say <especially to each other, not to the person whom it's about> that we've changed. I think they mean your character. The people who are close to you can all see that you try to live a normal life. They can all see that there has been a great change and how much effort, time and patience it all takes.

And yes, I have changed, my whole body has changed, but my heart is still in place. But just give us space, which to us is so necessary

What's also very annoying, when they tell you that you've been lucky. You could have died. Or be severe disabled. People don't know what to say, and I understand it's just to make conversation. But really, there were many times that I thought, I wish I had died. Because, how lucky you've been is really the last thing you think of. Of course people want to cheer you up, but sometimes it's better to say nothing at all. We're not pathetic, simple or sad people, we just haven't been so lucky. We only want to feel accepted, that it's o.k. to be who you are, despite of the disability. And this feeling, acceptance, is what I experience at the Aphasia centre."

Nelly's experiences are recognised by almost everyone with aphasia. After a period of hospitalisation and rehabilitation, people end up in a vacuum. The 'optimum result' has been reached and the impairment-specific therapy¹ comes to an end.

An approach based on demands

Being at home again, trying to go on with every day life: it can be so disappointing. It becomes clear how much life has changed. It takes some time for someone to realise he would like to learn.

The approach of an Aphasia centre is based on specific needs. People can come here with different kinds of language, communication or leisure activity goals which are focussed on a better participation in society. At an Aphasia centre all activities are accompanied by professional staff.

A domestic and open atmosphere ensures that it's a social environment in which it's easy to work with each other. It's obvious that people can practise their goals best at a place that feels comfortable and safe.

An Aphasia centre can offer:

- Support for people with aphasia.
- Professional care or education based on needs.
- Centre of expertise through which knowledge and information is shared with everyone who has to deal with aphasia.

Support for people with aphasia.

It's important to get in touch with people who are facing the same problems. People can learn most from people who are in or have gone through the same situation. For they know what it's like to live with aphasia. The group in which a person will participate at an Aphasia centre is based upon the individual goal one wants to reach. The main aim is to form a group that caters for these personal goals. The contact with others with aphasia together with the activities that are offered, stimulate and reinforce what one has learnt in therapy.

As an example, the working vision of an Aphasia centre in the Netherlands is mentioned below:

Contact with others who find themselves in the same situation enables people to discover their own possibilities. Supported by experts and together with others who share the same difficulties one learns to develop capabilities and regain confidence. The Aphasia centre fulfils a special role in the chronic phase of aphasia by offering a specific program for people with aphasia. It focus's on different levels of communication and can be adapted to various social networks based upon individual needs.

Professional intervention based on needs.

All activities at an Aphasia centre are centred around active participation. People with aphasia and their significant others can optimise communication and develop skills for social reintegration. Vital factors are 1) working in groups and 2) recognition.

Wanting it yourself

At an Aphasia centre the severity of the aphasia is investigated. The admission interview highlights the person's personal history, communication abilities and a clear view of their goals. It is important to identify what the participant wants himself. Activities can then be tailored to this need.

Dirk remembers what a great step it was to first visit the Aphasia centre:

“ Stroke. Age 64. Teacher 40 years and retired 3 years. 4 weeks unaware of surrounding. Paralysed right side, severe aphasia, lots of grief and depression, dependent. 3 months hospital, never come home again, but nursing home.

After 6 weeks sudden improvement and ‘happy’.

10 months rehabilitation and 7 months clinical treatment. Going home.

Hobbies were reading (English and Dutch literature), difficult cryptograms. Holidays walking in England, cycling, photography and listening to music. All no longer possible.

To be in wheelchair, being looked at, need help with everything. Powerless and angry. Previously 150%, now feel like 0%, worthless. After rehabilitation referred to Aphasia centre, never heard off.

Hesitate, meeting others with same difficulties... What's in it for me? What do I have to offer? I'm nothing anymore. They ask, what do you want to learn? ...I want to read like before... If that's not possible then for me it's over...

Always persist, went to the centre. Don't give up, strong will-power.

See others handle their situation; through social contacts, continue practice and support learn handle situation more and appreciate life.

At Aphasia centre, try new things, working with computer, practice reading in group. Participate, feeling to belong to...

Now I read, small parts. Aloud, slow. No longer angry when one prompts. Bring finger to lips and, sshh...

Long road ahead, learned to accept and sense of humour comes back. Been some time since stroke but Aphasia centre important. Always, and happy to go.

To formulate personal goals

The real need for help arises from daily experience. Questions and needs become clear when a person returns to the home environment. This isn't as easy as it seems. Additional examination can be necessary to determine if intervention can be provided.

Reading, for example is a **very complex skill**. It can be that someone can understand headlines and subjects of interest. Traditional assessment often lacks contextual background.

Almost everyone with aphasia indicates that he wants to learn to talk better.

- Sometimes one already has come to terms with a very serious or global aphasia and isn't able to speak. Can it be justified to agree with this goal? Is learning to speak again a real possibility?
- What's the advice to be given to a young woman who can tell, fluently, what has happened to her? For the past 10 years she was working, now she's been fired. She indicates that she wants to improve her conversational skills. For two years she has received speech therapy and she thinks she isn't improving enough. Her request is reasonable because she's convinced that she has been fired because of her aphasia. *"I don't speak fluently enough. I sometimes need to think hard to find a word and I say eh.. a lot..."*
Hardly anyone can tell she's aphasic but she does suffer from it.

So it's important to acknowledge her needs and find an approach to make her more confident.

Setting goals

Choices have to be made: Try to fix what's broken – that's the impairment specific approach² – or focus on the remaining capabilities and take advantage of what the patient can still do. The second option means that compensatory strategies are pursued to get around the disorder to approach the goal (e.g. reading or talking). This approach is used at an Aphasia centre, and we call this training at the level of *activities and participation* (WHO model, 2001).

The speech therapist (or 'speech- language pathologist') will put a great deal of time and effort in to identifying the impairments together with the client. Remaining capabilities will become clear. The client's capabilities and desired activities are the focus of attention. Therefore it's not: "I can't read any more and I would like to read again". Rather, it is: What's your level of reading at this moment. How can it be improved? What would you like to read? (words, headlines, texts, books, complicated documents and work related reports....?) In which situation would you like to read and what do you want to achieve by reading?

Nelly tells:

² We need to point out that an impairment specific approach is useful and necessary during the first period of time that one has acquired aphasia. First of all **MUST** be tried to reduce or dissolve impairments. This type of therapy usually takes place in at the hospital, rehabilitation centre or nursing home during the period of rehabilitation.

I had the fear of talking to ordinary people. Me, I never had problems speaking up, and was now afraid to speak in public. I had the hope that they could teach me. And yes, did it work! Even more than I could have wished for. They renewed my confidence. I've made new friends. The people at the centre became like relatives. I go there two half days a week. You're allowed to practice what's difficult: that can be maths, language, computer skills. Did I improve the last couple of months?

I really notice the difference. And besides that it might be nice to know that we are really stimulated to work hard and try and reach our goals. It's not just for fun.

Our perception is that clients learn best from others in the same situation and by peer support. Goals are formulated individually, through working as a group one will notice that others face the same difficulties.

The speech and language therapist needs to explain the 'scientific knowledge' for the client and caregivers. Detailed mapping and understanding of the language processes improves insight and makes it possible to come to an appropriate diagnosis. This will help to prevent the client from setting unrealistic goals. If for example the goal is to improve reading, this client's reading process will be mapped in detail. The language model (Ellis and Young, 1988) is used to visualise the language problems the client faces, after which strategies to improve the reading process are identified. Hypotheses are formulated and a therapy plan is defined. The same will happen with questions which refer to talking, finding words, formulating sentences, improving reading and writing, etc.

It is always important to introduce participants to the latest developments in supportive communication devices. Programs are being developed which can be adjusted to personal needs and can be trialled. One can practice and evaluate programs before deciding to purchase a supporting communication device.

Communication groups are present at different levels. Groups are formed based upon goals and level of linguistic impairment. The combining of people who are in different stages of the adaptation process is a great advantage as they can help each other. Group continuity is guaranteed by the participation of peer supporters.

Training at an Aphasia centre is often referred to as courses or conversation groups. This is done intentionally to make it a smaller step to join ordinary courses. A training programme is based upon a main goal. Other goals can be supportive of the main goal. For example, grocery shopping can be a supportive goal to fit in to the 'cooking' activity.

Computers are available. Courses for 'computer skills' and 'e-mail and internet' are provided. It's possible to work with specially developed computer programs for aphasia, language, maths and entertainment. Besides that, leisure activities as creative

workshops are organised. People can cook or enjoy games to support language activities. With leisure activities, clients are encouraged to make an active contribution to the organisation or the promotion of it for a newsletter or website.

The experience of success

If people go through enough successful experiences, (in which they can feel and discover success without being told so by a therapist), they develop their own initiatives, an active social participation and eventually are able to leave the Aphasia centre. It's most important that clients can decide for themselves when a goal is achieved, with no time pressure.

Some clients can become volunteers at the Aphasia centre as a peer supporter. People with aphasia may need support with verbal tasks. That's why they need extra help to formulate goals, enter new relations and fully apply their remaining (communication) abilities

New challenges

Besides being successful it's important to experience new challenges. Contact with others who face the same difficulties can stimulate initiatives and encourage people not to give up.

Most people with aphasia learn how to adjust their communication, because talking cannot be taken for granted anymore. It's necessary to keep applying and practising new skills. Group therapy in particular makes it possible to practise, maintain, and if possible use remaining language functions.

Aphasia expertise

People who need or want to know more about aphasia can come to the Aphasia centre for information, advice or education.

There's the possibility of an internship for students. The speech- language pathologist/speech therapist can provide courses for employees, volunteers and professionals from other organisations. Some Aphasia centres cooperate with educational institutes in providing practical courses about aphasia in which even a number of clients are sometimes involved.

2. I want to...talk

Frank tells:

One of the most important ways to understand the extent of the language area is to talk! Aphasia groups started for that reason. Through talking, the brain is trained to be used in a special way (if it can still be used for this purpose, because in some cases the brain isn't able to learn to talk again). If the disability can be taken away – and that's the dream of every aphasic person – he will be liberated.

Talking, and just the purpose of it, is important. Your voice is heard when you talk. This means that talking, communication, is something that's significant when people come together. For people who haven't been able to express themselves in this way, it's different. They won't listen to anyone anymore... Their absence of talking touched a sensitive chord.

Talking: in the social sense, you need others, like the air you breath. Talking is like you control the words. As a teacher that strikes me. Actually it's startling if you pay attention to what happens. Until you speak you don't control the words. But you speak and the miracle happens! Talking is fantastic! You can speak to everyone, everyone who will listen. With this sense you can be social and that's why you need it so much: for all humans are social creatures. People with aphasia sometimes dream about it at night...

Frank is married has three children and taught maths, science and history. Besides that he's an artist and previously contributed to philosophical and theological books. Now, two years after his stroke he works as a voluntary art teacher.

Talking at the Aphasia centre

People practice (sometimes with help or adjustments) to express what they think, and it keeps them busy. People listen to each other, prompt, laugh and discuss. When you have aphasia, talking can't be taken for granted anymore. Sometimes others don't notice, but still...talking remains difficult. Constantly thinking about the right words, easily distracted- it's terribly tiring to have a good conversation. Others may notice the search for words and often will adapt their rate of speech. When someone is mute because of a severe (global) aphasia and uses repetitive vocalization or stereotype words or sentences, listeners often don't know how to react. How to communicate with someone who 'does talk, but can't speak?' How to reach an equal communicative situation, or did it become impossible? How come that some people with aphasia can talk and others can't?

A lot of questions and only a few standard answers. A lot depends on the nature, the location and the size of the brain injury. As a rule, this usually means, the larger the brain injury, the more severe the aphasia. For most people, language skills are

controlled by the dominant side of the brain (with right handed people that's the left hemisphere, and aphasia is caused by damage to this dominant hemisphere). The language skill situated at this hemisphere is the language we need to think about before we speak. A part of language is used unconsciously. For example when we swear, count, sing childhood songs or recite a prayer. Repeating proverbs and completing sentences are tasks we don't really have to think about. This unconscious language is situated at the non-dominant side of the brain (with right handed people that's the right hemisphere). This explains why people with a severe aphasia, and are mute, can still sing, swear or count. This means the unconscious (or 'automatic'), right hemisphere language functions are undamaged and can still be used.

The left side of our body is "wired" to the right side of our brain, and vice versa. Left hemisphere damage can cause paralysis of the right hand side of the body. It's a misunderstanding to think that learning to speak is the same as learning words. For speaking you need to use language. The language process is very complicated. It consists of different phases.

On the basis of the language model the process of speaking will be explained. This model is based on the language model of Ellis and Young (1988)

Language model 'talking'

Talking: what happens inside our head

First of all we need to **know** what to talk about. We picture the message and think of the meaning. At this stage we don't use or think words. We think in images, sounds, smells or patterns of movement

When we have a thought which we want to express verbally, we **STRUCTURE** this in our mind. We shape the **STRUCTURE OF THE SENTENCE**. The word order is different in a question than in a notification:

For example:

*Thought: I see a wrinkled blouse and I don't know if I turned off the iron.
I want to call home...*

Question: Can I make a call? Did I forget the iron?: WHAT – WHO – DOES

Notification: I call. I forgot the iron. I see the iron: WHO – DOES - WHAT

In our head 'dictionary' we then search for the right **words**. We connect words to the images. With a severe aphasia connecting words to images fails.

This can manifest itself in two ways:

- *Global aphasia: one is mute, can only use repetitive vocalization or stereotype words or sentences.*
- *Severe Wernicke aphasia: language content is incorrect with an outpouring of jargon. It's like one speaks a foreign language.*

In our dictionary in our head (or 'lexicon') information about words is stored.

- **Word meaning.** Some words have multiple meanings, e.g.: bat (*the mammal and the tool*)
- Which words can be **combined**, e.g.: *ride horse, feed horse, big horse* but *to refuel horse, oval horse* etc...
- **Grammar:** verbs, nouns...
- Is there a different word with a similar or identical meaning (**synonym**)
- Word **consistence**: short or long, number of syllables, pronunciation.

Everyone with aphasia has difficulties finding the right word. Some have more difficulties than others.

Automatic language and repeating: This can be done by almost everyone with aphasia. We don't need to think about it.

When the right words have been found and put in the right order, we look for the **sounds**. It's like we 'talk' in our head.

People with aphasia often know the words in their head, but when they speak out loud it sounds completely different from what they had in mind.

When the articulation is added, the word is pronounced.

Supportive communication

In the case of severe aphasia it's not possible to redirect information to the dictionary in your head. It's like a short-cut occurs between word-image and dictionary. The information is still there but can't be reached.

This becomes evident in **repeating, automatic language, proverbs or reciting songs**. It's no use practising repetition or completion of sentences if someone has been aphasic for some time. People may keep depending on the first letter or on the words that are prompted.

It's much more important that people with a severe aphasia can express themselves independently and by using whatever means necessary.

Expressing ideas in images and gestures

At the Aphasia centre people with global aphasia are encouraged to draw in order to support talking. It's shown that talking can sometimes be provoked by drawing. Not being fixated on finding the right word and focussing on the meaning of the word activates the word characteristics. Information is redirected to the dictionary and this makes spontaneous pronunciation (naming) sometimes possible while drawing.

The use of gestures can also provoke speech. Sometimes a communication aid can be useful. Examples of communication aids are:

Life book

The history, hobbies, family and friends are portrayed with the use of multiple choice questions, pictures and drawings. The result is a book which can be used to show a part of the persons life without the need to talk much.

Touchspeak

Touchspeak is a program for alternative communication which can be used on an ordinary PDA. The program allows the user to express his needs and communicate through a hierarchic chain of words (spoken, symbolized, pictures etc). Together with the speech therapist a personal vocabulary is composed in a number of sessions. The PDA contains information such as name, address, phone number, things that the person often wants to ask or tell, lines to order a taxi etc...

When a drawing, picture or word on the PDA is touched the PDA will pronounce the message. Every Touchspeak is designed to personal needs and demands. Every device will be programmed with a personalized vocabulary. The program also comes with the option of drawing or typing. This makes it possible, for example, to prepare a note.

Tilly tells:

Hank uses the Life book as well as Touchspeak. A few years ago the Aphasia centre participated in a study about criteria for the use of Touchspeak with people with a

severe aphasia. Hank has a severe aphasia. He can only use a few words as: hi, great, beautiful, delicious and good night. Everything else is “con, con”. He participated in the research and learned to use the PDA.

The program Touchspeak made it possible for Hank to for the first time really participate in a conversation we had about planning our holiday. A lady came by and wanted to know a number of things about Hank’s situation. Formerly I (Tilly) had to be around with this kind of conversation to provide all the information. Hank isn’t fond of showing his life book to everyone, it contains a lot of personal information. Now with Touchspeak he could answer most questions independently again. Hank got a great kick out of it. He really participated in the conversion.

His life book he takes along when, for example, he goes on holiday or during a stay in the hospital. It helps him to have a conversation that reaches further than talking about the weather. He shows the book to people he likes and trusts. It gives them the opportunity to get to know the real Hank.

Gespreksboek (conversation book)

The Gespreksboek is a communication aid from the Netherlands. It is a kind of dictionary that contains words and drawing that are divided into five question words. These words: “who or what”, “where” (at home or not at home), “when” and “how” form the basis for mapping and sentence formation. They are mentioned in the “who, what, where...schedule” at the first page of the book. The colors of this schedule correspond with the tabs in the book.

Every first page of a section is like an index for the pages further along the section and contains the headings of different pages. The information is arranged from general to detailed information. This makes a conversation about events and feelings possible.

“Good morning Audrey, that’s been a while” Bridget (employee at the Aphasia centre) greets Audrey who has had a large stroke at the left hemisphere and became aphasic. *“Da wa. Da, da dawa”* Audrey speaks emotionally.

“Just try and calm down a bit. I can’t really understand what your trying to tell me. Did you bring your book?” “da, dawa”

Audrey takes her book. Luckily Bridget doesn’t ask her: *“can you look it up”*. No, she takes the Conversation book and opens it at the first page.

The first page contains the question words. Bridget takes a pen and paper and asks: *“Am I right that your angry? “Dawa”* Audrey nods.

“Are you mad at me?” Audrey neither denies or confirms.

Using the Conversation book Bridget helps to try and find out what’s going on.

“Do you want to tell or ask something,.... or should I do something?”

Audrey reacts to: Tell an do something.

Illustratie ingangsschema

Audrey points out:

I
Others
happened
home
car

Briget: *"Who are the others?"*

At the page of 'family members' Audrey points out Pete (her husband) and Connie (her sister). Brigitet is starting to see the problem.....*"Two weeks ago I called your sister because , you weren't here for two times. You didn't notify us. I couldn't reach your husband. Your sister said you were planning to come and she didn't know why you weren't here"*

"Dawa, dawa, dawa".

"Does it have to do with your sister?", "But what do you mean by car?"

Bridget writes down *"car, Connie, Pete and taxi"*. *"You mean taxi? Did the taxi forget to pick you up?"*. Audrey points one, two times with her fingers.

"The taxi forgot you two times! When it happens again, you must call us, we can call the taxi company. Then we can still arrange for you be picked-up."

"let's see, is it in your computer?" It does say: *"I won't come one Wednesday"* *"I'm sick, I won't come"* but *"the taxi didn't show up"* isn't in there. Shall we add that to Touchspeak? We can practice together this afternoon. *"Da!"*

It's not that easy to express yourself when you are not able to speak anymore.

People become dependent on the patience, questions and creativity of the listener. The person with aphasia as well as his significant others and caregivers become discouraged when there's a misunderstanding. How do you figure out what someone means when he only uses recurring utterances like kere, ke, ke, kere, te, te, te or do, doddoddo and finds it hard to understand language. A conversation like this can have many similarities with charades.

Someone with a global aphasia will never be able to 'just talk'. Word finding has been severely damaged. The connection between the **idea or meaning in images** to **the meaning of words** has been disturbed.

We know that the dictionary in our head is not gone. The information and the words are still there but a short-cut occurred and the words can't be reached anymore.

It's most important to learn strategies that enable reaching the information again. This can be done by using capabilities that are undamaged.

To be able to use for example the Gespreksboek book, a person needs to recognize and understand words. It's not necessary to read them out loud . When words can be recognized a personal dictionary (like for example the Gespreksboek) can be used to describe words and clarify what you mean. The example above illustrates that you still need a good listener to put the words in to context.

Primarily, a Gespreksboek is a communication aid. It has also proven to be useful in improving word finding. Some people experienced that improvement even two years after stroke so it can still be possible.

At first Hanna wasn't able to speak at all. When she came to the Aphasia centre two and a half years ago she could only say: "the what, that the what". Now she's able to write down words using the Gespreksboek and she can speak in one-word sentences. She hardly uses the recurring utterance anymore. If it doesn't succeed she tries to gesture or point out what she means. Hanna practiced a lot in improving word finding with the use of the Gespreksboek., but she still dislikes using the Gespreksboek during a conversation.

Hanna didn't learn words. She practiced expression through describing strategies. She practiced by copying words in an exercise and thinking of one or more associations. She could draw the associations or search in the Gespreksboek. During the search for the right word descriptions she almost automatically spoke some words. Three times a week she practiced to improve word finding. This wasn't easy and involved hard work.

From words to sentences

Rick practiced word finding through associating. Together with Carl he looks back at the previous time at the Aphasia centre. As regular visitors at the Aphasia centre they speak frankly about their expectations, goals and progress.

"That's astounding, my wife!" Rick speaks up enthusiastically when he has been asked how he got to go to the Aphasia centre. Both men were notified about the existence of the centre and were inspired to visit by their spouses. They can't remember a lot from the first period. When they were done rehabilitating they did feel like they weren't done learning.

After some time Rick can describe how his language was at that time. *"short words, no writing, reading very short parts"*

Carl adds to this that at the beginning he could only say 'yes' and 'no'. When they came to the Aphasia centre they had obvious goals. Rick: *"talking, talking, taking. That's my wish, may that be clear"*

Their activities at the Aphasia centre consisted and still consist of writing, reading and calculating. They both noticed progress, even when they had just started to visit the centre, but they differ in the opinion about the origin of the progress. Rick is convinced that practicing with a special language program on the computer led to the improvement. Carl says he has learned a lot by reading together at the Aphasia centre: *"I learnt more than at home, together we have more knowledge."* Rick practiced a lot using the computer. *"at different levels"* Two years ago he started by

practicing with the Conversation book, but he doesn't use it anymore. *Two years ago word finding, now using sentences. First covering a word, writing from memory, make something up with it or draw. One, two, three words. Then writing by memory, associate to think of the word. First writing than typing. Now sentences. It's difficult, but I can do it.*

At home Rick still practices on the computer. At the Aphasia centre he tries different exercises.

Rick found that at home he wasn't stimulated to speak anymore. Everyone at the centre now keeps an eye on Rick's talking and makes sure he uses sentences. When he uses keywords instead of complete sentences he is told so. Rick now also participates in the group that practises in role play.

Carl tells: *"one side of the table and at the other side of the table. I had to completely not... what was it? I had to completely disagree with her. She had to agree with her. For example at the restaurant and you get, disgusting. Not good. Than practising one says this and the other the opposite.*

They have a clear vision of what they want to accomplish "Now 30%, I want 70%. Learn everything, as much as possible. Two times a week Aphasia centre, reading, talking, writing, computer.

Receiving enough time

Bettie, Jack, Lisa, Tony and Andre report that it's important to receive enough time during conversation. Tony: *"When I want to say something, I need more time than others. Listeners don't have that much time. While I'm thinking they talk and they complete the story for me"* Jack: *"It's like speaking a foreign language. You have to search for the right words and talking is less fluent"*

The other group members confirm. They recognise this feeling.

Talking improves when you have enough time and others give you the time. There also has to be a minimum of background noises.

At the Aphasia centre, texts form the basis for discussion. The subject leads to a conversation. The conversation chairman asks questions and tries to formulate a statement. The group will come up with arguments and try to express themselves.

3. I want to...read

The magic of words. Those who really enjoy reading should understand the frustration to not be able to wander away in a fascinating book . How difficult it must be not to be able to read anymore.

Most people with aphasia have difficulties reading. Something that was taken for granted has since become a great challenge.

We read in different ways. We sometimes read fast and sometimes slow, because we really want to understand the text. Words that we use a lot can be read more easily and with less effort. People can usually recognise their own name out of a thousand.

Long, complex sentences and professional language are more difficult to read. Reading out loud isn't the same as recognising words. When a person reads out loud the meaning of the text or story has to be expressed through intonation. If a long text is read comprehensively, typing errors aren't really noticed and the focus lies at the outline of the text.

A diverse range of reading difficulties are encountered by many people with aphasia. It is important that we investigate 'how does the reading process actually work' and try to understand the multifaceted problems which arise from aphasia

The reading process consists of small consecutive steps (levels). Each of these steps or the cooperation between these steps can be disturbed when someone has aphasia. If someone declares: "*I can't read anymore*" The challenge lies in finding out which aspects of reading are intact. Strategies for activation or support of the reading process can be developed by using remaining abilities.

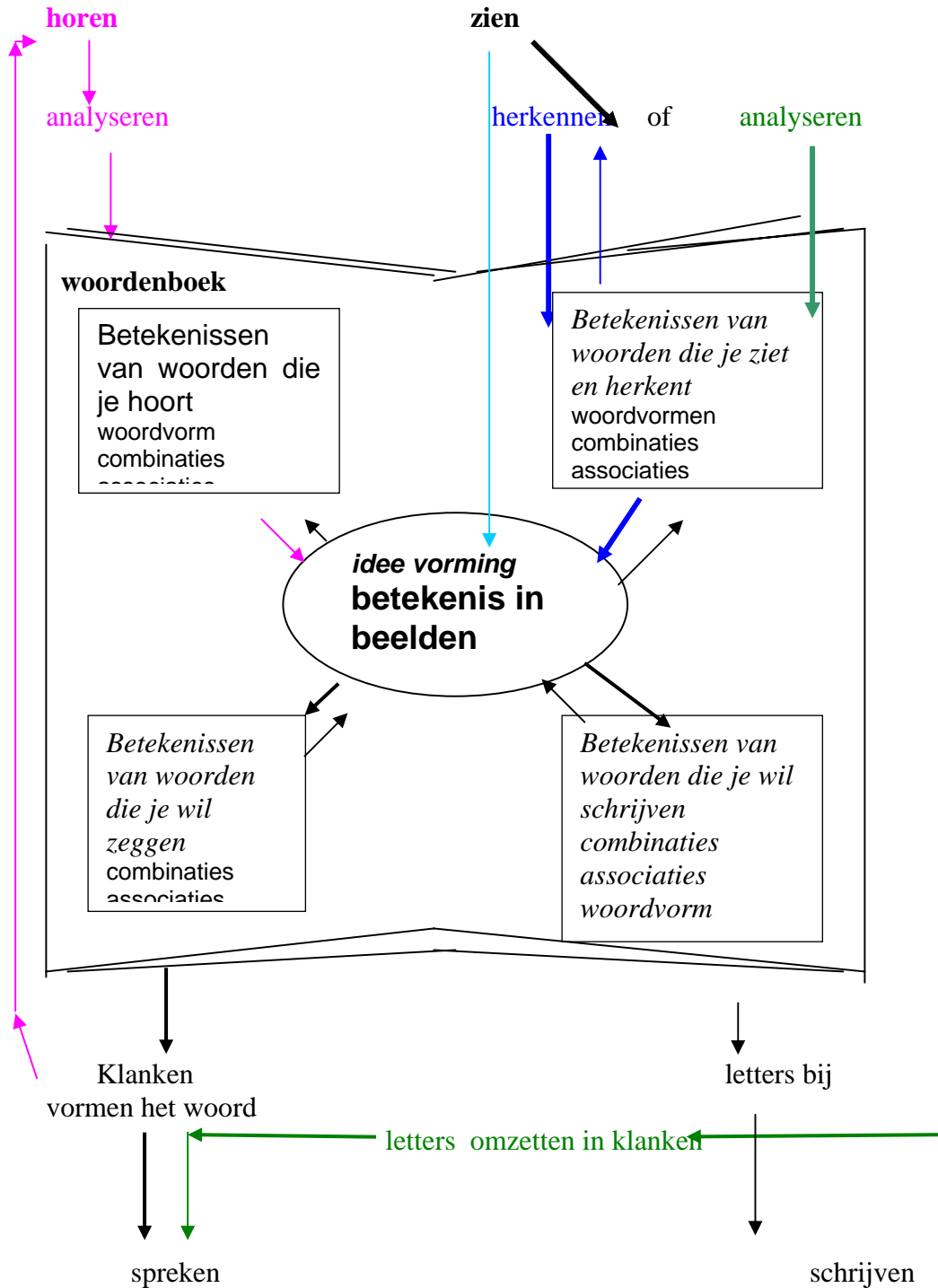
John tells:

"The reading came back one step at the time. In the beginning I couldn't recognise a single word. I could see the symbols, but didn't recognise them as characters. I started practising. First small words, than longer ones. I had to practice with the meaning of words. For example: four words in a row, one didn't fit in. I had to draw the meaning of the words. At the beginning that was strange (and difficult), but it did work. When I drew a word correctly no one had to prompt. I could say it myself. After some time there was no need to draw any more, I knew what the words meant, but If I couldn't read it out loud it helped to write down the words. As I wrote I automatically spoke the word. And still, If I sometimes talk too fast I still trip over words. If I have trouble finding the right word, It helps to write it down in my mind. My reading is all right now, but long texts are tiring. I need to be focused constantly. This makes reading less joyful. I'm glad I can practice in a group.

Together we decide which article shall be read. Every week another group member acts as chairperson. The chairperson will pick an article. We have a week to prepare this piece. In the group we first practice reading aloud. Everyone reads a part, together we summarise. That's how we make sure everyone understood the text. Subsequently we discuss or talk about the text. Reading together is o.k. If I had to do it all by myself I don't think I would read anymore. I still notice the progress I make. Every time It takes me less time to read and prepare the texts. With longer texts I write down the most important words. This helps me understand and remember. I otherwise instantly forget what I've read. I learned this writing down of important words at the Aphasia centre. It gives me a lot of support."

Reading: the process inside our head

Om te kunnen lezen moeten we verschillende stadia doorlopen



First of all we must be able to **see** what's written.

Reading can be done in two different ways. We can use the fast route or route of **comprehensive reading** or we can **read technically**, where we convert the letters into sounds.

We try to **recognise** what's written. We attach a meaning to it. Some words are **immediately recognised**. Think of words like exit, toilet and stop.

Most of the people with aphasia can read by using this route. They can read high frequency words and for example news headlines. This means that they know and understand what is written, but it doesn't mean that they can pronounce the words.

Longer words are first divided and sent to our dictionary piece by piece. All known words that start with that piece, are activated in the dictionary. For example words that start with pro.

This will activate words like: product, pronounce, program, process ...

This list will shorten while we read along and see *profess*, a word like *profession* will pop up. As we take another look we read professional.

People with aphasia sometimes read profession instead of professional, because that word might be more frequent or is recognised more easily.

Technical reading

With technical reading the characters or word parts are converted to sounds one after another. The word is first analysed (divided into pieces) as if it's **pronounced and read simultaneously**. The meaning of the words which are read, do not get through yet. Only when the words are **heard (in our head) they can be understood**. This is how we can read new words or foreign languages aloud, without understanding even the smallest bit of it.

With some people with aphasia this technical reading route has been damaged. It's impossible for them to read words which do not exist. For example they can't read: dorep but they read **door or drop**. This means that for reading they use the blue or comprehension route. People with Broca's aphasia (a non fluent aphasia) have trouble reading function words (the small words which have little to no meaning. e.g. if, it, with, then, well, etc...)

Remembering what's read

Sometimes reading itself can take so much effort and energy that what's been read isn't stored. This can happen to all of us sometimes, when we're tired or distracted. Afterwards we can't recall what we have read.

People with aphasia can often be bothered by this problem. In noisy surroundings they cannot concentrate and can't record what they read. A statement that can often

be heard is: "I can read, but at the end of the sentence I no longer remember what I have read."

People who have difficulties in remembering what they've read benefit from written keywords. Every three to six read sentences, some keywords are written down. The most important things from the text become clear this way.

Improving understanding of what's read

If a person can hear what he reads, the understanding of what's read will improve. At the reading group, everyone reads aloud, one after another.

The group members describe: Yes, I read, difficult. When I read while I hear the text, I understand it more."

Therefore in the group there is someone reading aloud. People with aphasia benefit a lot from spoken versions of sites on the world wide web.

4. I want to...write

“Just put it on paper”, in other words write it down... If you’ve written down something it will still be there in an hour, next week, next year and even after fifty years. What you say, eventually will be forgotten. What has been written down will continue to exist.

That’s why writing can be used to improve the use of words or the construction of sentences. Writing offers more time to find the correct words. It gives the opportunity to check for errors and correct words afterwards. If a person wants to tell a lengthy story it’s useful to write down the keywords in advance. At an Aphasia centre writing is used a lot, sometimes just quick drafts, in other occasions a large piece of paper is used. Also exercises are filled in, or people type at the computer.

Different purposes of writing

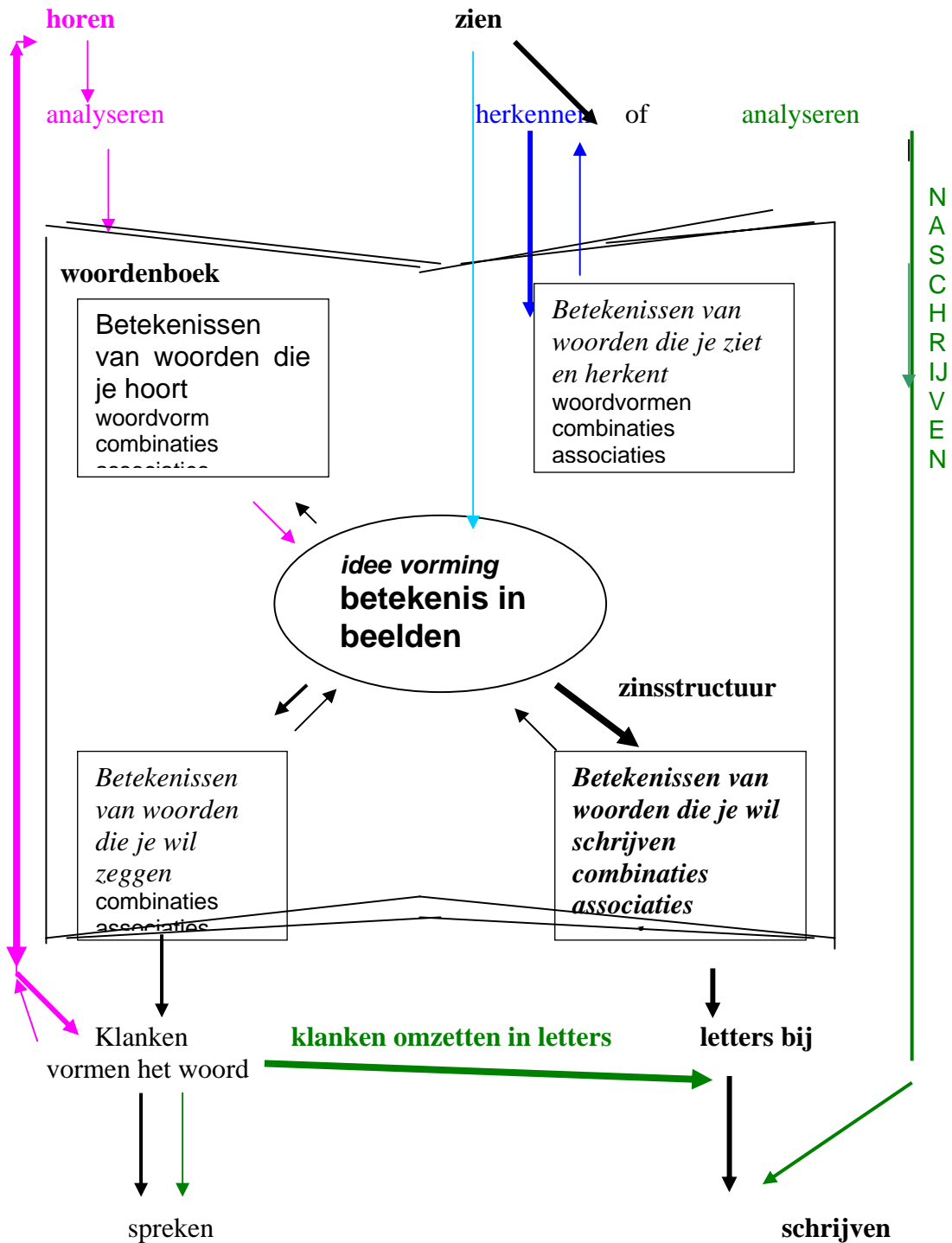
The amount of writing that’s done differs from person to person. Some write in a diary or agenda, others won’t even write down a shopping list. If someone has family or friends abroad, he will tend to write or send an e-mail.

When a persons occupation involves writing reports or business letters, he will most likely have improving his writing as an important goal. Even for people without a job and little help from family, writing is important. Because how can you otherwise for example, cancel a subscription?

Different ways of writing

With this we don’t mean the different handwritings or fonts. The different ways of writing consist of: copying, being dictated to, comprehensive writing or writing from memory. Different functions must be activated in our brain for three ways of writing. The language model below will illustrate the writing routes.

Schrijven: hoe verloopt het in ons hoofd



Copying

Before we can copy characters we first of all need to **see** what we want to copy. It's not necessary to understand the meaning of the written text, words or letters.

People with severe aphasia will copy the letters exactly. Printed fonts are copied letter by letter. If a person has a paralysed right hand and has to write with the left hand, it usually will be done in block capitals because they are less difficult to form.

Writing is a more automatic action than typing or putting words together from characters.

Writing down thoughts

The writing process is largely influenced by word finding. We distinguish between naming and writing from memory. With naming, an object or picture is imagined. This activates word finding. Word form and the letters are subsequently activated.

If something is written from memory, the subject must firstly be thought of. There's no picture to activate word finding, the content has to be made up. *When someone has aphasia, it is difficult to think of what to write about. It can be easier to write a story about a sequence of pictures that are shown. On the other hand, there are people with aphasia that know exactly what they want to write, can find the words and even say them aloud but aren't able to write them down.*

Some words are stored in our mind as a word image. We can write them down automatically. Longer or less frequent words we divided into pieces. These pieces are written down one by one. This is done by using the route of writing by inner speech . We say the words in our head and write down what we hear.

Writing down from dictation is writing down **what you hear**.

During dictation the letters or word parts are converted to graphemes one by one. The meaning of the words isn't important. We can convert phonemes into graphemes without understanding the words. This is how new words or strange words can be written down.

*In aphasia this writing route usually has been damaged. It's difficult to write down non existing words. For example: **scrateur** become **crater** or **skater**. In other words, the comprehension route has to be used in writing.*

Recommendations

If writing is a problem the activity can be practised for a long time to try and fix what's damaged, or strategies can be taught for using remaining capabilities. It's useful to write a lot. During writing, we use our inner speech, this activates speaking. When people with aphasia are able to write the beginning of a word (first letters of a word) they can benefit from such technologies as letter and word prediction. Software to support typing in this way, is available for computer and PDA.

Writing also gives time to incorporate the words (the word image). Writing serves well as an exercise for people with difficulties in word finding. With extensive

problems, small words can be used. If talking is less problematic, long words consisting of more syllables or even sentences can be practised.

Support of word finding

Writing activates word finding and also supports the memory.

For example: Think of the shopping list. At home you write down everything you need, at the grocery store you might not even have to use the list.

Evelyn: "Sometimes when I write a shopping list all of a sudden I can't think of a certain word. I know what I need, but I can't recall it's name. In a cookbook I have to look for the ingredient. It can be tough."

Agenda and dairy

"I couldn't do without my written memory. When I don't write down my appointments I will forget them. Every day I try to write something about what I've done that day. I can't make correct sentences and complex words are difficult. It's good practise to write something everyday."

Nelly has an agenda in which she can write down special details from that day. Beside that she uses a notebook in which she writes down step by step how certain procedures are carried out.

Nelly:

"Because I couldn't always remember the order in which I had to do something, I made a notebook.

This notebook contains most domestic tasks, written down step by step."

For example: making coffee:

1 water in coffee pot

2 Pour into water reservoir

3 coffee filter in container

4 coffee in coffee filter

5. put coffee pot on plate and turn on.

Set out for coffee:

2 coffee cups, sugar, milk, spoons, biscuits

Writing sentences

If someone finds it hard to write sentences it's best to do it step by step. The initial focus is on the content "what do you want to say". Keywords are used to write down the content. At a later stage these words can be used to make sentences. For this the content must be put aside for a moment otherwise too much information might be put

into one sentence. It's best if short sentences are composed. This can be done by using an outline: WHO DOES WHAT.

WHO DOES WHAT can give structure to make a short note or message.

It can be helpful to facilitate the content of what's been written by question words. (see part of *Gespreksboek*)

With this it's always nice to have a couple of questions or subjects on a crib note. The answers to the question on the crib note can be used in the story or letter.

Will: "As a result of the stroke I ended up at the Aphasia centre; I could talk, but I sometimes had a lot of trouble finding the right words. I found writing to be very difficult. I practised writing sentences by using the WHO DOES WHAT scheme. And I also used the five question words to build up my story.

It's nice to talk to others with similar problem. I use the computer during practice. I can type well and occasionally send e-mails to friends and family. I enjoy the trips that are organised. Afterwards I write something for the newsletter."

It would be nice that peer supporters with more difficult could also be able to write. I saw some people with a severe aphasia use computer software with drawing and words/short sentences to facilitate writing. It's a pity it's not available in our language.

Reading aids

It is possible that the writing will not improve at all. No matter how hard someone practises, it's just impossible to write. George knows all about that:

George:

"I can talk well. But writing is a disaster. I can write a shopping list but sentences are impossible to write. Single words are alright, short words and words like table, chair, hello; those are fine. Long words and words that I only use occasionally and words like : just, when, also. Terrible.

I've practised writing down just those words that have no meaning: dictation of nonsense words. I practised for a couple of months. There was no sign of any progress on the test I made. After that I no longer practised writing for years.

On the computer I started practising with word prediction. When the beginning of a word was correct, the computer predicted a number of words. The problem was that I didn't always have the right beginning. Therefore it wasn't really practical. Finally I practised using speech recognition software. I talk to the computer and the computer program types what I tell. Great!

6. I want to... participate in society

At an Aphasia centre all activities focus on improving, optimising and maintaining speech, language and communication skills to help with re-integration into society.

For example: Clare found it to be very frustrating to notice that her children, who at school learn to calculate, think it's very easy. For her it's such a difficult task. She doesn't even try to do fractions. *"Multiplications I learned at primary school are all gone. I used to know them by heart, I can't stand it that I don't know it anymore. I practiced hard for a long time. Sometimes I can all of a sudden do a multiplication, but I usually need to count."*

It's not easy to accept that things that used to be taken for granted aren't possible anymore. Coping takes a lot of time and professional intervention. The way people cope with loss differs from person to person. There is a great difference between people, in the kind of support needed and what they actually receive.

Judy tells:

"At this moment, after six years, I finally came to a point where I realise that me and my partner can't do it all by ourselves anymore.... At the Aphasia centre we took part in the course and we still meet monthly.

Now, every year I go out on my own for a week. After six years after my stroke, I learn to take better care of myself. No one can tell how much time me and my partner have left together. But despite of everything, in spite of the handicaps, in spite of the 24 hour influence the consequences of my stroke has, in spite of unexpected setbacks. We can still enjoy life, go out and try to make something out of life.

I try to focus on positive things, even my use of words has changed: I avoid the words 'have to' and replace them with 'want to' or 'like to'. This has changed my attitude as well as my families attitude in life."

Activities focussed on daily life

What does, for example, cooking have to do with communication?

Cooking is often a difficult task for people with aphasia.

Not only reading the recipe causes problems. Some people with aphasia can read but have difficulties in accomplishing tasks. With the use of only one hand, cooking becomes quite difficult.

When the problem is not in the physical aspect, it can be that a person has lost the ability to execute or carry out learned purposeful movements.

This is called apraxia. Actions can be done automatically, but when the action is voluntary it cannot be preformed.

Besides this, the activity of cooking can take up so much energy that nothing else can be done. The focus has to be on the cooking, two things cannot be done at the same time for example; a conversation during cooking isn't possible anymore.

Connor loved to cook and bake. A birthday party? He always made it into something special:

"In former days I used to cook and bake everything myself, except for such as the small pastries. It's all not that easy anymore. I have a lack of confidence. It's much better when someone helps me. This week I was awake for a whole night just thinking about everything. I puzzle my head about what I can and need to do. I try and do everything the right way. Every Thursday morning I cook at the Aphasia centre. At home I pick a recipe. I often cook something for lunch. I get some assistance determining the right quantities. Sometimes I have to cook for up to 19 people. I help with shopping. Picking the right ingredients, carrying the groceries. I like to cook at the Aphasia centre. If I find something to be difficult there's always someone who can help me. I now even dare to do something on my own. Responses are almost always positive, so I think that what I cook tastes good. My wife also speaks well about me cooking again. Even at home I try to cook once in a while. I enjoy it again."

I want to do something useful in society

When someone can no longer work there is the need to find a new purpose in life. The same goes with people who are not able to carry out their hobbies anymore because of their disabilities.

Sometimes it's possible to return to work again as part of reintegration program, maybe a couple of hours a week or in a different role. Some people become a volunteer, follow courses, spend time babysitting their grandchildren or look for a new hobby. Others enjoy the outdoors or like to spend time at home. If a person is willing there are numerous options to consider.

Workshops

From time to time workshops are organised to introduce several arts and crafts. This can be painting, arranging flowers or another art. Attention is paid to the fact that someone with the use of only one hand can participate independently and the environment must be adjusted to help with concentration problems. This can mean different aids have to be used. A role of tape to attach a piece of paper to the table or an anti skip pad are indispensable.

Courses

Besides workshops, the Aphasia centre also frequently offers courses. The creative activities that are being offered can differ a lot and are determined by wishes and needs of clients.

Nelly, attended a painting course. Painting, drawing and sculpturing were not new to her. She has always been very creative. To her, painting and drawing is part of life...

"It used to be no problem to do three or four things at a time. I could paint while a neighbour came by for a chat during which three or four children were playing around. In the meantime I cooked dinner. Nowadays that has really become impossible. I can only do one thing at a time.

At home it became impossible to carry out my hobbies. All kinds of different matters require my attention and distract me.

I tried to attend a course at a local community centre. I did not succeed at that. People are talking to one another while something is explained, this makes it impossible for me to listen and understand.

I would like to improve some skills so I can enjoy my hobby again. First of all I would like to improve my concentration. The creative process is of no problem to me, but planning and preparing the materials I need is difficult.

I would also like to improve the understanding of descriptions and putting them into action. If I read a description, I sometimes understand but I don't know what to do with it.

At the aphasia centre I attended Frank's drawing- and painting course. He's Aphasic himself and he knows how important it is to work in a quite surrounding. Together we have fun and learn new techniques. It can sometimes be hard but also a lot of fun."

Frank, drawing teacher, practices in teaching again....

"One thing I learned after stroke was the meaning of the word aphasia: in Greek: a – not, phatos - to speak. This means that the loss of speech is found to be the greatest loss: I totally agree with this. Aphasia centres first of all focus one being heard again. This is a long-term, but very important process.

Communication is the most important social skill we have. Losing the ability to speak can be compared to solitary imprisonment. Humans are first of all social creatures.

That's why practising communication and language come in first place. With the group conversation being number one. This applies to all of us because of the social aspect. In education there's no doubt that language is of great importance. Children need to be spoken to in a way that stimulates and encourages their curiosity. You need to bring the matter alive. Instructions need to be compact in all it's varieties. A teacher needs to know and use language by heart."

Experience experts

Some of the volunteers at the Aphasia centre suffer from aphasia themselves. They know, like none other what it's like to fight to regain language.

Diane comes once a week to the Aphasia centre as a volunteer to help others with aphasia.

“Being aphasic I visited the speech therapist for quite some time. I had worked for all my life but because of a reorganisation I was left without a job. I attended courses at adult education and had speech therapy twice a week. Once a month I attended a evening group at the Aphasia centre. I got to know others with aphasia and felt recognised. After six months therapy was finished. What should I do? Was I able and ready to work again? Is it possible to do something when you have aphasia?”

Volunteer...helping other people with aphasia. It was a nice idea, but...I had no self-esteem. And that while I used to work as a reception manager at a large international company.

The proposal was to accompany the Tuesday morning discussion group and assist with the computers at Thursday morning. The idea was very appealing but I was so afraid, afraid I would not succeed!

Now I still accompany the Tuesday morning discussion group. As difficult as it was then, that easy has it become. Working at the Aphasia centre. It certainly helped building self-confidence again. I like the discussion group that much because I, an aphasic who had a stroke 15 years ago, can help others who haven't come this far yet.”

7. The significant others

It is not only the person with aphasia's life that has changed, the partner, the children and other family members will notice that their lives are being influenced by aphasia as well. Depending on the severity of the disabilities, the partner maybe responsible for daily care activities, housekeeping, the children, administration etc...Some partners need to almost think for both themselves as well as for their partner.

Life rhythm will change:

- Planning everything in advance, nothing can be done in a hurry.
- Structuring activities, only one thing can be done at a time it can become frustrating or misunderstood otherwise.
- Worrying about the well-being of one another. For example, when he/she has only a few daily activities or stays away longer than the partner anticipated.
- Acting as a buffer between the partner and the children who also need attention and care.
- Interpreting, when the partner isn't understood or if they need an explanation about what's been said.
- Fighting for your position as a partner when dealing with medical professionals. Medical staff don't always understand the language difficulties people with aphasia have, for example, understanding what's been said at one moment but forgetting what's been told the next moment.
- Immunity to other peoples comments. Others always think they know best.

Getting back to daily routine after stroke and a period of rehabilitation. People often do have friends but they notice that people think: "It now should be over with" But it isn't a flu or a broken leg. This will last, it will never be over!

Partner courses

The course exists of a number of meetings. Several aspects can be taken into consideration: receiving information about stroke: ischemic or hemorrhagic and the consequences, use of language, aphasia and communication disorders following stroke. Partners get to think about role patterns in their family, dividing responsibilities and tasks. They become aware of their role as a caregiver and learn to let go of this role where and when needed.

It is the view that partners/carers realise that they themselves are responsible for the choices they make and receive information about the possibilities of support.

How to keep on my feet

"My name is Tilly (55) and I've been married to Hank (61) for 31 years. After a stroke Hank became partially paralysed, severe (global) aphasic and epileptic.

During rehabilitation Hank was the centre of attention. There was hardly any attention for me as the partner. Of course I met and talked to doctors and therapists about Hank but there was only one young nurse that had attention for me as a person. She just followed her heart and we had a short, but good conversation. That helped me a lot. I figured out that you need persistence, creativity, humour and a lot of patience to cope with the situation.

Hank could only say con, con, con.

By practising in appropriate situations he can now say: “hi, great, no, exactly, goodnight, enjoy, cheers, Tilly and excellent.” For me it’s important, only if just for a moment, hear Hank simply say something. Those small words make it ‘ordinary’ for a moment.

All the planning leaves me no time for me to grieve you know. I still feel unable to really give in to it. I’m too afraid to lose track and that’s not possible. I NEED TO KEEP ON GOING. And just when you think the situation has become steady and you can come to your senses another thing happens.

Finally, the answer to the question, which I’ve asked myself: How to keep yourself, as a partner on your feet? Of course I can only speak for myself. The first year consisted of strength, organising, problem solving and making arrangements. After that, came a period of finding a new rhythm in life-what makes me (us) feel good. This means for example, that I make Hank’s sandwiches. He could do it himself but he only has limited energy and before I also used to make the sandwiches for both of us”

Sources:

Het Afsiecentrum: Woorden en daden

Ellis & Young

Participants to Laph

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