

Netherlands Organisation  
for Scientific Research

# Dyslexia

Research programme

Brochure





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## 1 PREFACE

The Dyslexia programme was developed within the framework of the policy plan 1997-2001 of the Netherlands Organisation for Scientific Research (NWO). In this document NWO implements its 1995 memorandum *Knowledge Enriches*. The four-year plan opts for a strong emphasis on innovative, multidisciplinary research that is inspired by problems arising in society. One of the themes mentioned in the plan is language pathology:

‘Language pathology is situated in the triangle between linguistics, medical science and the behavioural sciences. Particularly in the field of language development disorders (a recommendation on dyslexia was issued by the Health Council) a connection is assumed between possible neuropathology, learning and developmental disorders, and the mechanism of language processing by children. Diagnostic and therapeutic techniques have been developed on the basis of fundamental and applied clinical research. It is now possible to design joint research questions connected with these techniques for linguists, medical scientists and behavioural scientists.’ (1997-2001 policy plan: *Knowledge Enriches under implementation*, 1996: 16).

At the beginning of 1996 the NWO Councils for Medical Sciences, Social Sciences and the Humanities set up a six-person committee to prepare a research programme in the field of language pathology. This committee, chaired by Prof. F. Zwarts, consisted of researchers in

linguistics, (special) education, neurology, psychology, and child psychiatry.

At its first meeting the committee concluded that a broad field like language pathology can not be fitted into a coherent research programme. As the Health Council report on reading impairment (*Dyslexia: Identification and Treatment*, 1995) played an important role in the NWO decision to make resources available for research on language pathology and this disorder is a recognised social problem that is pre-eminently suitable for innovative, multidisciplinary research, the committee decided to spend its further discussions on setting up a programme on dyslexia. By the autumn of 1996 the preparatory committee had completed a framework programme entitled *Identifying the Core Features of Developmental Dyslexia: A Multidisciplinary Approach*. After evaluation by the relevant councils, the programme was approved in March 1997 by the NWO General Board.

This brochure offers a general introduction to the Dyslexia framework programme. It also describes important organisational aspects. The programme secretary will send the entire text of the programme on request.

## **2 THE DYSLEXIA PROGRAMME**

In our modern literate society, being able to read and write is regarded as one of the most important cognitive and communicative skills. A disorder in the acquisition of reading and writing often has a negative effect on children's cognitive and emotional development. Since the publication of a report on dyslexia by the Health Council (Dyslexia Committee, 1995), impaired reading and writing abilities have come more and more into the public eye. The report indicates that every school year some 6,000 children in a group of 200,000 children become dyslexic. This implies a total of 36,000 children between the ages of 6 and 12 years. By now it is known that dyslexia has negative effects on school performance, disturbs the acquisition of knowledge from written sources, and hinders people in the exercise of their profession. Reports by patient organisations estimate the percentage of dyslexics among the working population at around five per cent. Some of them make substantial and expensive demands on health insurance schemes and on facilities related to special working conditions.

In the light of the importance of a good diagnosis and treatment of dyslexia, many research projects have been carried out in the Netherlands and abroad in the last few decades to identify the causes of reading impairment. Although considerable progress has been made, it is still not clear what exactly happens and can go wrong in learning the complex routines that form the basis of the reading process. According to the Health Council, 'in the Netherlands there is a demand [...] and

there are possibilities [...] for sufficiently wide, well-organised and multidisciplinary research on treatment' (Health Council: Dyslexia Committee, 1995: 17/18). This is partly motivated by the fact that, on the basis of its clinical experience, the committee considers that intervention is successful in the case of almost three-quarters of the children under treatment.

Besides the treatment of dyslexia, research should also – and perhaps primarily – target the causes of dyslexia. Once we know which children run a greater risk of becoming dyslexic, preventive action can be taken beforehand or in the course of treatment.

Research on the causes of dyslexia and on the methods of treatment calls for co-operation between researchers in neurology, (special) education, linguistics, genetics and psychology because all of these fields deal with aspects of impaired reading. The primary objective of this multidisciplinary research programme is therefore to combine methods from these areas in order to investigate what the causes of dyslexia are (prospective research). This is done on the basis of a longitudinal study in which children are monitored over a longer period. To find the biological causes of dyslexia, children must be followed from birth (before they have learnt a language) until the age of 9 years, the earliest age at which the disorder can be diagnosed with certainty.

A second component of the research programme concerns the consequences of therapeutic intervention in the case of children with dyslexia or children who run the risk of becoming dyslexic. The

importance of intervention will be examined for three age groups. Research to see whether prevention is effective will be carried out among children between the ages of 4 and 6 years. The consequences of early intervention will be investigated among a group of children between the ages of 6 and 8 years. Finally, intervention among children between the ages of 9 and 12 years will also be evaluated.

A third part of the research concerns the genetic causes of dyslexia. This involves a more detailed study of the presence of dyslexia in the family and the genetic risk among sib pairs.

## 2.1 INTRODUCTION

Dyslexia, a disorder in the development of reading and writing, has attracted the interest of researchers from various fields for more than 100 years. As a low reading ability clearly affects school performance and hinders the acquisition of knowledge from written sources, thousands of studies have been carried out to identify the causes of the disorder. Although considerable progress has been made, success has not yet been attained.

The literature contains a variety of figures on the prevalence of dyslexia. Estimates of between 5 and 10% are mentioned, in which the ratio of male to female dyslexics is 3.5:1 (Pennington, 1990). The severe forms of dyslexia that are the focus of the research programme described in this brochure are estimated to occur among roughly 3% of the

population. The Health Council report indicates that 6,000 Dutch children (in a group of 200,000 children) develop severe reading impairment each school year (Health Council, Dyslexia Committee, 1995). This means that in national terms at least 36,000 children between the ages of 6 and 12 years are dyslexic. It also means that every year we can expect 6,000 final examination candidates who require special facilities because of their reading handicap.

Dyslexia must be regarded as a problem that affected persons carry with them all their life, also in the exercise of their profession (Kamhi and Catts, 1989). Stanovich (1986) has indicated that people who have difficulty reading are the victims of what he calls the 'Matthew effect'. The term is a reference to the Gospel according to St Matthew, chapter 25, verse 29: 'For unto every one that hath shall be given, and he shall have abundance: but from him that hath not shall be taken away even that which he hath'. Focussing on dyslexia, this means that an initial problem with reading will increase because the victims fall further behind when a growing demand is made on their reading skills, while practised readers improve more and more.

Reports by patient organisations that recently appeared in the media estimate the percentage of dyslexics among the working population at 5%. This leads to substantial and expensive demands on health insurance schemes and on facilities related to special working conditions. The Health Council report goes into this when it refers to the social importance of advice on the identification and treatment of dyslexia:

“The social relevance of advice lies partly in the demands that the care and treatment of people with dyslexia make on resources in health care and education, and the need to test the value of the methods that are used. At least as important is the fact that the present situation is unclear with regard to diagnosis, opportunities for a systematic approach, and criteria for referral, intervention and expertise. Children may become the victims of this, as well as adults.

In the context of our literate society, severe dyslexia is a threat to cognitive and emotional development, and is thus a health risk.

Moreover, it can have negative effects on social functioning. Problems at work have led on several occasions - though unsuccessfully - to an appeal to the General Disablement Act (AAW). Nevertheless, in her letter of 19 February 1990, the Minister of State for Social Affairs and Employment calls proper treatment of (adult) dyslexics ‘an essential condition for proper social functioning’ (Health Council: Dyslexia Committee, 1995: 34/35)’.

This shows that an intensive research programme on the causes and effects of dyslexia and on therapy is justified.

## 2.2 RESEARCH OBJECTIVES

The principal objective of the programme is to obtain a better insight into the neurobiological mechanisms that lie behind dyslexia. A number of specific objectives can also be distinguished. First of all, research will be conducted to determine whether early visual, auditory or linguistic clues can be found that predict later reading problems with sufficient

reliability and have therapeutic relevance for children who do not (yet) attend school. Research will also be conducted to see whether dyslexia is connected with a disorder in certain layers of the brain, the so-called magnocellular pathways. Deficits in these regions might affect the speed at which visual and auditory stimuli are processed and thus lead to attention disorders. Another objective of the programme is to develop a neurobiologically-based classification of different types of dyslexia. In addition, an attempt will be made to explain the considerable overlap (25 to 50%) between dyslexia and hyperactivity (ADHD: attention deficit hyperactivity disorder). A third objective is to carry out genetic research among a large number of families to identify and characterise those genes that are involved in dyslexia. A final, but nonetheless very important objective is to investigate whether intervention at the earliest age (between 4 and 6 years) provides better and more durable results than intervention at the intermediate (between 6 and 8 years) or later age (between 9 and 12 years). This part will also include research on the possibilities of preventing dyslexia.

### 2.3 PROGRAMME STRUCTURE

The programme will be carried out in a multidisciplinary environment that guarantees co-operation between researchers from various disciplines, including neurology, psychiatry, psychology, (special) education, genetics and linguistics. It consists of three components: prospective longitudinal research, intervention research, and genetic research.

### ***Prospective longitudinal research***

The first component concerns a prospective study on the early occurrence of dyslexia, in which the acquisition of speech and language will be followed longitudinally. For this reason a group of 225 children with a significant genetic risk of developing reading impairment will be followed for a period of 10 years. The same will be done with a control group of 120 children without known risk. On the basis of the results reported by Scarborough (1989, 1990, 1991), it is likely that half of the children with a genetic risk will develop reading problems. In order to obtain reliable and comparable data, the prospective study must commence as soon after birth as possible. It is important for the collection of data to continue up to the age of 10 years, because the earliest age at which dyslexia can be diagnosed with certainty is 9 years. The children taking part in this study will be tested eleven times during the first five years of their life, followed by an interim test at the age of 7 years. The final test to diagnose whether the child is dyslexic is carried out at the age of 9 years.

### ***Intervention research***

The second component of the programme targets the opportunities for intervention in the case of dyslexic children. This part involves 150 children at risk between the ages of 4 and 12 years. Various kinds of therapy will be evaluated for different age groups:

4-6 years: prevention

6-8 years: early intervention

9-12 years: late intervention

In view of the importance of early detection and treatment of dyslexia, special attention will be given to prevention research.

### ***Genetic research***

The third part of the programme concerns a genetic comparison among 300 sib pairs (brothers and/or sisters) with dyslexia. The aim of this study is to trace genetic factors that are involved in dyslexia. A number of recent family studies have shown that there is a considerable risk that the child of a parent with a reading disorder will develop dyslexia. If time and resources allow, the parents of these children at risk will be asked to participate in various neuro-imaging studies (MRI/PET) in order to discover more about the anatomical and physiological basis of dyslexia.

## **2.4 PROCEDURE**

### ***Methods and techniques***

As a consequence of the multidisciplinary nature of the research programme, methods and techniques from different fields will be applied. The longitudinal component will involve electrophysiological registration (EEG and ERP), as well as tests to measure eye movements, memory, language skills, reading, and IQ.

The intervention study will use some of the same methods and techniques, including the scores obtained in the language, memory, and IQ tests.

In the genetic component, blood samples will be taken from the sib pairs of children and their parents. They will be analysed with 30 polymorphic markers. Research among adults may include neuro-imaging by means of PET and MRI.

### ***Research locations***

With a view to the available expertise and the multidisciplinary environment, the first two components of the research programme will be carried out using a single protocol on three locations in the Netherlands: Nijmegen (Max Planck Institute for Psycholinguistics, University of Nijmegen (KUN), and Nijmegen University Hospital), Groningen (School of Behavioural and Cognitive Neurosciences, University of Groningen (RUG) and Groningen University Hospital) and Amsterdam (University of Amsterdam (UvA) and Slotervaart Hospital). The genetic part and the neuro-imaging studies will mainly be carried out in Nijmegen and Groningen.

## **2.5 RESEARCH EXPECTATIONS**

Dyslexia seems to involve microscopic anomalies in the brain (at the neuronal level), including the visual and auditory pathways. This is often related to deficits in the interpretation of short and fast-changing stimuli, such as a short and rapid succession of spoken sounds or written letters. Previous research has shown that the language problems of dyslexics may be caused by some abnormality in the ‘timing’, in other words the

(automatic) execution of certain processes at the right moment, in this case in the field of language processing.

One of the objectives of the programme is to determine whether this means that already from birth dyslexics build up a language system that is incapable of analysing stimuli that occur in rapid succession. If this is the case, therapy should make use, for example, of assignments in which reading or listening can be done in a decelerated or otherwise simplified manner.

Extra instructions and practice in reading at a young age are not sufficient for children at risk or those who already have developed dyslexia. The nature of the extra attention is also important. Therapy will mean the search for alternative reading methods in which an attempt is made to restore or compensate those elements that create problems in reading and writing. Children who have problems in distinguishing the separate letters in a word will not benefit from extra attention to reading, but from learning a method that enable them to distinguish the separate letters.

The genetic study investigates which genes may play a role in dyslexia, and thus which individuals run a greater risk of developing dyslexia. That knowledge can then in turn contribute to the timely diagnosis and treatment of (possible) problems in reading and writing.

## 2.6 SOCIAL RELEVANCE

As mentioned at the beginning of this chapter, reading and writing disorders can seriously impair the social functioning of both children and adults. Dyslexia can be seen as a handicap in our literate society.

The report by the Health Council states:

‘Dyslexia as described here can be regarded as an incapacity (or a disorder) as defined in the International Classification of Incapacities, Disorders and Handicaps (ICIDH). The committee considers this view justified because a dyslexic person occupies an extremely weak position in the continuum of individual capacities to develop and practise a certain cognitive skill. The extent to which this incapacity leads to problems in social functioning (handicap) depends on various factors, including the demands that are made on reading and spelling skills.’ (Health Council: Dyslexia Committee, 1995: 53)

A better understanding of the causes of dyslexia and intervention that is timely and adequate on the basis of that understanding are therefore of crucial importance for dyslexics, in particular for children who are at risk of becoming dyslexic.

In addition, timely and improved diagnosis will lead to reduced demands on health insurance schemes and on special facilities for dyslexics. As a result of a better understanding of the consequences of prevention and intervention, children at risk of becoming dyslexic or those who are already dyslexic will be able to be treated more rapidly. This entails a reduction in the costs of therapy. Moreover, individuals who are treated

for dyslexia at an early age will be affected less, if at all, by reading and writing disorders in later life in their professional and other activities. This will lead to better social functioning and therefore to a reduction in the demand for social facilities.

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### **3 THE ORGANISATION OF THE PROGRAMME**

#### **3.1 STEERING COMMITTEE**

The steering committee assumes general and scientific responsibility for the implementation of the programme. It is responsible for the organisation of the three components of the research plan. The steering committee also monitors the progress of the studies to be carried out. The multidisciplinary steering committee consists of eight members, who have been nominated by the Councils of Social Sciences, Medical Sciences, and the Humanities. At present, the steering committee consists of the following members:

- Prof. F. Zwarts (chair), School of Behavioural and Cognitive Neurosciences, University of Groningen
- Dr F.J. van Beijnum, Institute of Phonetic Sciences, University of Amsterdam
- Prof. D.A.V. van der Leij  
Department of Special Education, University of Amsterdam
- Prof. G.W.A.M. Padberg  
Department of Neurology, University of Nijmegen
- Dr B.A.M. Maassen  
Department of Child Neurology, University of Nijmegen
- Prof. J.A. Sergeant  
Department of Clinical Neurology, University of Amsterdam
- Dr F.N.K. Wijnen  
Utrecht Institute of Linguistics, University of Utrecht

The programme itself is in the hands of six research co-ordinators who are assisted by local advisory committees. At least one of the members of the steering committee is a member of these committees.

The team of research co-ordinators consists of the following members:

Dr P.H. Been / Ms E.M. Krikhaar (University of Groningen)

Dr M. ter Keurs / Dr C.T.L. Kuijpers (University of Nijmegen)

Dr T.H. van Leeuwen (University of Amsterdam)

Dr F.A. Hol (Nijmegen University Hospital)

### 3.2 DURATION AND BUDGET

The programme is planned for a period of ten years. The co-ordinators are responsible for the preparation and implementation of the research activities. This includes locating and registering dyslexic families, drawing up a standardised protocol for the registrations and tests and a detailed research agenda, developing a standardised reading test for Dutch speaking adults, and processing and publishing the research results. The work will be carried out by both senior and junior researchers.

The preparations for the longitudinal study and the genetic part commenced in 1998. The intervention component has commenced in the autumn of 2000. A total of three independent evaluations are planned: after two years, after five years, and at the end of the project.

NWO has provided a budget of NLG 8 million for the Dyslexia programme. A rough estimate indicates that extra funds will be required in addition to this budget for the implementation of the whole research programme. The funds made available by NWO will be used in the first instance for the prospective longitudinal part (7 million). The costs of the intervention component are estimated at NLG 3 million, and for the genetic study at NLG 1 million. NWO has made NLG 500,000 available for each of these components. If the neuro-imaging studies are carried out as well, this requires a further budget of NLG 3 million.

A contribution has been requested from the university institutions taking part to fund equipment and junior researchers. Further funding will have to be obtained from bodies like ministries and health insurance companies.

### 3.3 DISSEMINATION OF THE RESEARCH RESULTS

The steering committee is responsible for disseminating the results of the programme within the research world, government and politics. In the light of their social relevance, the steering committee will ensure that the results are also brought to the attention of the general public. A regular bulletin will be issued with practical information about the progress and development of the programme. This bulletin can be obtained from the programme bureau.

### 3.4 OPPORTUNITIES FOR PARTICIPATION

As mentioned above, the first two components of the research will be carried out on three locations. The prospective longitudinal part of the research will span ten years and will be based on a joint protocol.

There are opportunities for individual or local experimental initiatives in addition to the studies that fall within the protocol. Proposals of this kind will be assessed by the steering committee.

There are also opportunities for individual or local research within the intervention component and – to a certain extent – within the genetic component. When necessary, the steering committee will assess and select the research proposals, giving priority to the possibility of incorporating such research within the framework of the proposed programme.

Funding for these proposals is limited and depends, among other things, on the amount of extra funding that is obtained. It is advisable to submit proposals to the steering committee at an early stage so that they can be incorporated where possible in a request for extra funding.

Besides this form of participation, it is also possible to carry out research as an extension of the Dyslexia programme that makes use of the data that have been collected.

Requests for access to these research data should be made to the steering committee.

#### **4 FURTHER INFORMATION**

For further information about the Dyslexia research programme, please contact Ms A. Dijkstra or Dr M. van Donzel at:

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