Health Council of the Netherlands

Knowledge infrastructure for autism spectrum disorders

Gezondheidsraad
Health Council of the Netherlands

To the State Secretary of Health, Welfare and Sport

Subject : presentation of advisory report *Knowledge infrastructure for autism spectrum disorders*
Your reference : DJenG/SenS-3023773
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Dear State Secretary,

I hereby submit the advisory report entitled *Knowledge infrastructure for autism spectrum disorders*, which was drawn up in response to a request for advice from the Minister for Youth and Families, dated 12 October 2010. Because the advisory report also covers the domains of education and labour, I have also submitted it to the Minister of Education, Culture and Science and the Minister of Social Affairs and Employment.

In its 2009 advisory report entitled *Autism spectrum disorders: a lifetime of difference*, the Health Council drew attention to the fact that the knowledge infrastructure relating to autism spectrum disorders might not be functioning as well as it might. This advisory report explores this matter in greater detail. The Committee has conducted an extensive survey of current research in the field of autism. An analysis was also made of the data on knowledge infrastructure contained in past Advisory Council on Health Research advisory reports dealing with areas comparable to autism. Also included in this analysis were programmes by the Netherlands Organisation for Health Research and Development (ZonMw) that were based on these reports. The lessons learned there were useful in formulating the present advisory report.

The Committee notes that, in a society that increasingly relies on the flexibility and social skills of children, adolescents and adults, there is a present and continuing need to focus on people with autism spectrum disorders. The Committee believes that the creation of two academic collaborative centres can substantially enhance the knowledge infrastructure relating to autism. The impetus generated by these collaborative centres will bring research more into line with treatment and support in everyday practice, while providing a major

P.O.Box 16052
NL-2500 BB The Hague
Telephone +31 (70) 340 59 15
E-mail: v.ruiz@gr.nl

Parnassusplein 5
NL-2511 VX The Hague
The Netherlands
www.healthcouncil.nl

boost for innovation. The Committee also recommends the establishment of a community of practice that is capable of gearing supply (research) to demand.

Another recommendation is that the impending overhaul in the areas of youth care services, youth mental health care services, the Medical Research Involving Human Subjects Act (Ministry of Health, Welfare and Sport), Appropriate Education (Ministry of Education, Culture and Science) and the Employment Capacity Act (Ministry of Social Affairs and Employment) be used as a natural experiment and its effects monitored.

The advisory report has been reviewed by the Advisory Committee on Health Research and the Standing Committee on Public Health.

I endorse the Committee's recommendations.

Yours faithfully,
(signed)
Prof. H. Obertop
Acting President

P.O.Box 16052
NL-2500 BB The Hague
Telephone +31 (70) 340 59 15
E-mail: v.ruiz@gr.nl

Parnassusplein 5
NL-2511 VX The Hague
The Netherlands
www.healthcouncil.nl

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to:

the State Secretary of Health, Welfare and Sport

No. 2012/09E, The Hague, June 26, 2012

The Health Council of the Netherlands, established in 1902, is an independent scientific advisory body. Its remit is "to advise the government and Parliament on the current level of knowledge with respect to public health issues and health (services) research..." (Section 22, Health Act).

The Health Council receives most requests for advice from the Ministers of Health, Welfare & Sport, Infrastructure & the Environment, Social Affairs & Employment, Economic Affairs, Agriculture & Innovation, and Education, Culture & Science. The Council can publish advisory reports on its own initiative. It usually does this in order to ask attention for developments or trends that are thought to be relevant to government policy.

Most Health Council reports are prepared by multidisciplinary committees of Dutch or, sometimes, foreign experts, appointed in a personal capacity. The reports are available to the public.

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Executive summary

Background

In the Netherlands, between 100,000 and 160,000 individuals suffer from autism spectrum disorder (ASD). In recent years, there has been an increase in the number of individuals known to be suffering from disorders of this kind. This is partly a result of improved diagnosis, and partly because society is placing increasing demands on people's social skills (so anyone with limitations will be more likely to encounter problems in this area). The extent to which autism sufferers are affected by their limitations varies greatly from one individual to another.

In 2009, the Health Council of the Netherlands published an advisory report on the prevalence, diagnosis, and treatment of autism. The Council found evidence that the knowledge infrastructure relating to autism is inadequate. However, a detailed analysis of this problem was beyond the scope of that advisory report. In the autumn of 2010, the Minister for Youth and Families asked the Health Council to examine the knowledge infrastructure in question. In preparation for this advisory report, the Health Council appointed a committee. This advisory report explores the state of the knowledge infrastructure pertaining to autism, and any improvements that are needed. The Committee also sets out the current status of research into ASD, identifying gaps that need to be filled as a matter of priority.

The importance of an effective knowledge infrastructure

A knowledge infrastructure is an important prerequisite for effective and efficient, high quality care. Such care is not only based on practical experience, its effect has also been scientifically substantiated. An knowledge infrastructure that performs effectively generates the knowledge needed for the development of a given field of study. Such knowledge then finds its way into everyday practice. At the same time, a knowledge infrastructure provides a platform where stakeholders can exchange know-how and learn from one another.

The configuration of a knowledge infrastructure presupposes that research is taking place at both the academic level and at the level of everyday practice, and that both forms are interconnected. Universities contribute to the development of knowledge by conducting fundamental research and by helping to ensure that practice-based research employs validated research methods. The results of both types of research find their way into everyday practice, in the form of guidelines, for example. The application of these guidelines, in turn, gives rise to new research questions.

In recent years, experts in a range of different fields have contributed to the evolution of a knowledge infrastructure. The fields involved include the public health service, addiction treatment and care, rehabilitation, and the care of those with intellectual disabilities. As was the case with autism, this involved multidisciplinary care which was initially based mainly on practical experience, and which was lacking in robust scientific substantiation. In formulating its recommendations, the Committee has examined the lessons that can be learned from those experiences.

Knowledge infrastructure and research into autism

The treatment and counselling of people with autism involves practitioners from many different fields, such as the mental health care service, youth care services, education, labour, and social support services. As a result, the knowledge infrastructure itself is also fragmented. Each individual domain has its own area of expertise and distinct approach to professionalisation. Professional practitioners also vary in the extent to which they are used to working on the basis of scientifically substantiated facts. Accordingly, research results do not always bear fruit in everyday practice.

Only a limited amount of autism research is carried out in the Netherlands. Most of this takes place in university medical centres (UMCs) and other university faculties. This often involves fundamental, medically oriented research, supported by direct or indirect funding. It is much harder to find funding for practice-based research, as this is often dependent on smaller funds, each with their own objectives and formats. As a result, research into everyday practice is fragmented and small-scale in nature.

There is little coordination between academic research and practice-based research. The differences are not limited to the research topics involved, they also extend to the methods used and the quality of the research itself. Some initiatives have been launched in an attempt to rectify this situation. These include structural cooperation between the Yulius mental health care service and the Erasmus MC. Another example is the partnership between the Dr Leo Kanner House (a specialised care provider in the field of autism), the University of Amsterdam, and the HAN University of Applied Sciences. Ideally, there should be better linkage between academic research and research in everyday practice, right across the board.

Establishment of academic collaborative centres

The Committee recommends that two academic collaborative centres for autism be established. These long-term partnerships provide a framework for practice-based, policy-based, and science-based research. The partners include institutions involved in everyday practice that have a strong interest in innovation and research. Others are university research institutes who want stronger ties between their research activities and everyday practice. An academic collaborative centre should preferably include other knowledge institutes and umbrella organisations, and should maintain contacts with policymakers. The Committee recommends that two academic collaborative centres be established, to address the full breadth of the field, provide a degree of geographical distribution, and generate competition in terms of quality.

Establishment of a community of practice for autism

As yet, there is no context in which autism professionals and researchers might routinely encounter one another. University researchers do not get involved in practice-based meetings, nor do caregivers attend scientific conferences. In an

effort to improve this situation, the Committee advocates the establishment of a community of practice for autism. This would provide an arena in which the participants could present their research results and discuss ideas for new research projects. In addition to galvanising the coordination of supply and demand, this would encourage individuals to implement outcomes. The community of practice could also publish a compilation of ongoing and recently completed research, which would include space for studies with negative results. This community of practice could also maintain a research database, containing up-to-date details of all ongoing research in the Netherlands. Measures of this kind would complement the publication practices of mainstream scientific journals, which (as yet) tend not to feature practice-based research or studies with negative results.

Research priorities

The Committee has formulated a number of criteria which could be helpful in identifying specific areas of research that need to be given priority. These criteria include a study's anticipated impact, the opportunities it provides for cooperation between academics and practitioners, and whether there is a good chance that its results will be widely implemented.

The Committee recommends that the impending overhaul of the education system, of sheltered employment, and of the health service should be used as a natural experiment to highlight the beneficial and adverse effects of these changes on people with autism. The results of this experiment could then be used to adjust the process.

There is also a great need for robust research into effective interventions for the treatment and counselling of people with autism. If the results of this research indicate that a given intervention is ineffective, this could then be dropped from the range of available treatments.

Research into new identification and diagnostic tools is also very useful. However, the Committee emphasises that implementation of the available instruments has top priority.

Finally, the Committee notes that there is a need for research into action-oriented diagnosis, as well as into stages of life and transitions.

Chapter 1

Introduction

1.1 Background

In the Netherlands, between 100,000 and 160,000 individuals suffer from autism spectrum disorder (ASD).[1] In recent years, there has been an increase in the prevalence of autism. This is partly a result of improved diagnosis, and partly because society has changed and is now placing increasing demands on people's social skills (so anyone with limitations will be more likely to encounter problems in this area). The extent to which autism sufferers are affected by their limitations varies greatly from one individual to another. What they all have in common is "A lifetime of difference". As yet, there is no treatment that can eliminate the core symptoms.

In 2009, the Health Council of the Netherlands published an advisory report on ASD. It addressed the prevalence, diagnosis and treatment of autism, as well as topics such as family life, education and employment. In this advisory report, the Council pointed to evidence that the knowledge infrastructure relating to autism is inadequate. However, a detailed analysis of this problem was beyond the scope of that particular advisory report. In the autumn of 2010, the Minister for Youth and Families asked the Health Council to examine the knowledge infrastructure in question. This is the topic addressed in this advisory report.

1.2 Autism Spectrum Disorders: a lifetime of difference

In its 2009 advisory report entitled *Autism Spectrum Disorders: a lifetime of difference*, the Council noted that although autism is not curable, early detection and diagnosis are nevertheless important to prevent problems from worsening. There is still considerable scope for improvement, in terms of timely detection and diagnosis. On average, affected children are first suspected of being autistic shortly after their fifth year of life. However, again on average, a diagnosis is not made until the seventh year of life. In addition, diagnoses of autism are routinely made even after the seventh year of life, indeed – in some cases – this may not take place until after the 65th year of life. The late recognition of their disorder (and any comorbidity) means that, throughout their lives, many of these people will have encountered numerous unnecessary problems, as well as the associated social repercussions.

The first signs of suspected autism are usually detected by general practitioners or doctors in child health clinics, or by paediatricians, primary care psychologists, and teachers. It is their task to ensure that these children are referred for further testing.

A diagnosis of ASD can only be made by a multidisciplinary team led by a child and adolescent psychiatrist who is registered under the Individual Health Care Professions Act (BIG), a health care psychologist, a child and adolescent psychiatrist or an REG (remedial educationalist – generalist) specialised educationalist. An assessment on whether the individual in question requires treatment and/or support (and, if so, which type) can only be made after a sound and meticulous diagnosis.

The treatment and support offered to ASD sufferers are designed to help them cope as well as possible with the activities of everyday life. This mainly involves the treatment of comorbidity, psycho-education, family support, psychosocial interventions, and school-work interventions. The main thrust of all such treatment and support is to provide structure, predictability, repetition and a focus on the generalisation of acquired behaviour. The Health Council found that, while there is a professional consensus on exactly what kind of treatment and support ASD sufferers and their families should receive, this is almost entirely practice-based. It also noted that there is still very little scientific evidence to support the effectiveness of such measures.

The Council's recommendations mainly involved an integrated approach to autism and to the limitations encountered by autism sufferers. The Council called for a uniform approach to detection and diagnosis. The Council also

recommended that research be carried out into the course of the disorder and into effective treatment and support for autism sufferers, with a special focus on adults.

Since the publication of 2009 advisory report, work has been carried out on the development of two guidelines on autism:

- the "Multidisciplinary Guideline on Autism Spectrum Disorders in Adults" is the brainchild of the Dutch Psychiatric Association and the Netherlands Institute of Psychologists (NIP). This guideline is being developed in close cooperation with the UK's National Institute for Health and Clinical Excellence (NICE). Methodological and organisational support is being provided by the Trimbos Institute[2]
- the child healthcare guideline entitled "Autism and autism-related disorders" is intended for caregivers in child healthcare and for the parents of children and young people with ASD. This guideline will focus on early detection, screening and diagnosis, and the options for referral. The Trimbos Institute is the project manager and lead institution.[3]

Both guidelines are scheduled for publication in 2012.

A report entitled *Zicht op kennis* (View of current knowledge) by the Dutch Knowledge Centre for Child and Adolescent Psychiatry and the Effective Youth Interventions Database of the Netherlands Youth Institute shows that there has been little real change in the availability of evidence-supported interventions for young people with an ASD since the advisory report was published.[4,5] The literature review carried out when developing the multidisciplinary guideline for adults showed that the same applies to adults.[2]

1.3 Requests for advice

On 12 October 2010, the Health Council received the formal request to issue an advisory report on the knowledge infrastructure relating to autism. The background to this request was that a knowledge infrastructure is an important prerequisite for effective and efficient, high-quality care. An knowledge infrastructure that performs effectively generates the knowledge needed for the development of a given field of study. Such knowledge then finds its way into everyday practice. At the same time, a knowledge infrastructure provides a platform where stakeholders can exchange know-how and learn from one another.

The Minister's questions concerned the state of the knowledge infrastructure pertaining to autism, and any improvements that are needed. He also asked the Council for information on the current status of ASD research, and on the gaps that need to be filled as a matter of priority. This involves research into the development and validation of tools for the detection and diagnosis of ASD for different age groups. It also involves research into the development and evaluation of ASD interventions (the professional treatment and support of ASD sufferers and their families). Details of the entire request for advice are given in Annex A.

1.4 Procedure

In order to answer the Minister's questions, the Health Council's Advisory Committee on Health Research (RGO)* has appointed a committee (Annex B). The Committee has made use of scientific and grey literature. It also consulted a large number of experts (Annex C). In many cases, this took place in the context of a research survey (for details of the procedure used in this survey, see Annex D).

The Committee met on a total of six occasions. The Advisory Committee on Health Research (RGO) was involved in determining the approach to be used. It was also consulted halfway through the advisory report's preparatory stage. The advisory report was reviewed by the Advisory Committee on Health Research and the Standing Committee on Public Health.

1.5 Structure of this advisory report

The RGO has had previous experience in this area, having issued recommendations on the development of knowledge infrastructures in health service domains where there was a gap between science and everyday practice. What lessons can be learned from the experience gained in those areas? The Committee explores this question in detail in Chapter 2. The Committee then conducted a wide-ranging research survey to obtain an overview of autism research and the associated infrastructure. The results are described in Chapter 3. In Chapter 4, the Committee outlines the role and position of professional

* Until 2008, the Advisory Council on Health Research was an independent sector council. In 2008, the Advisory Council on Health Research merged with the Health Council. Its name was changed from the Advisory Council on Health Research to the Advisory Committee on Health Research. This committee no longer functions as an independent council. It is now a standing committee of the Health Council of the Netherlands.

practitioners in the knowledge infrastructure relating to autism. Research and knowledge do not exist in isolation. They impact the everyday practice of professional practitioners who need and use such knowledge when practising their profession (education, care, support, employment). Drawing on the details contained in Chapters 2, 3 and 4, the Committee has created a model for the development of a knowledge infrastructure. This widely applicable model is described in Chapter 5. Finally, the Committee's conclusions and recommendations are set out in Chapter 6.

Some of the Committee's more broad-based findings are not restricted to the field of autism. This applies both to the lessons to be learned from previous endeavours to develop knowledge infrastructures (Chapter 2) and to the model presented by the Committee in Chapter 5.

Chapter 2

Knowledge infrastructure: lessons from the past

In the past, the RGO regularly issued recommendations on how to develop a knowledge infrastructure in areas of the health service where there was a gap between scientific knowledge and everyday practice. The Committee has examined a number of examples to see what lessons can be learned. What are the preconditions for developing a fully functional knowledge infrastructure? This is the topic addressed in this chapter.

2.1 Experiences from similar areas of care

The knowledge infrastructure relating to autism is complex in nature. One reason is that a large number of professional groups are involved in the detection, diagnosis, treatment and support of autism sufferers. Another factor is the wide age range in this group of patients. The professional groups involved each have their own knowledge infrastructures, some of which are better developed than others. However complex it might be, this situation is certainly far from unique. In this chapter, the Committee analyses a number of incentive programmes that were established in the wake of advisory reports from the RGO and the Advisory Group for the Health Research Promotion Programme (SGO). It has also opted for programmes in socially relevant areas that involve multidisciplinary treatment or care which, prior to the programmes, had been primarily based on practical experience rather than robust scientific evidence. These are programmes based on RGO advisory reports on: rehabilitation research, mental

health care service and public mental health research, Public Health knowledge infrastructure, research for those with intellectual disabilities, and the SGO Advisory Group's advisory report on addiction research.[6-10] With the exception of the incentive programme for the public health service, these all involve individual care. The public health service programme was included in the analysis because the public health service and the care provided to ASD sufferers have something important in common. They are both linked to various other policy domains, such as youth care services, education, labour, and social support services.

Interim or final evaluations of the incentive programmes have now been completed. The Committee's analysis covers the advisory reports, the programmes, the evaluations, and – in some cases – comments about the programmes as well.[10-28]

The baseline situations when the programmes were launched, as well as details of their objectives and outcomes, are summarised in Table 1. Detailed descriptions of the programmes are given in Annex E.

Table 1 Summary of the programmes.

Programme	Baseline situation	Implementation of the programme	Outcomes of first programme	Follow-up
Addiction 1986 advisory report Terms of consecutive programmes by SGO and ZonMw up to 2012	• No academic embedding, lack of basic knowledge • Care spread across many different agencies, with no inter-agency coordination • Effectiveness of interventions not investigated • Research and funding very fragmented	• National (academic) focal point for research • Fundamental and applied research • Creating networks for research, education and training • Training researchers	• Cooperation between universities and institutions involved in everyday practice, as well as multidisciplinary partnerships • Close attention to scientific research, too little focus on applied research • Educational targets for researchers achieved • Inadequate "academisation" (= the introduction of academic rigour) of everyday practice	Two follow-up programmes aimed at: • Consolidation of infrastructure to facilitate more in-depth scientific research, • To establish a connection between research (both basic and applied) and everyday practice Efforts increase the academisation of everyday practice are slowly gaining ground. The same is true of training programmes for addiction counsellors or addiction specialists

Rehabilitation research 1997 advisory report Term of consecutive ZonMw programmes until 2012	• Insufficient basic knowledge • No academic infrastructure for patient-related research (academic collaborative centres) • Effectiveness of interventions not investigated • Research fragmented, no coordination	• Strengthen academic research infrastructure • The academisation of rehabilitation centres, partnerships with universities • Concentration of research on specific topics • Developing knowledge that creates the necessary conditions for the future • Implementation of knowledge • Training researchers	• Effective academic research infrastructure • Greater cooperation between university medical centres and institutions involved in everyday practice • Implementation of infrastructure is still inadequate • The academisation of everyday practice is still inadequate	Follow-up programmes aimed at: • Further strengthening multidisciplinary research • Continuation of the research infrastructure • Research into the effectiveness of interventions, and into their mechanisms of action • Innovation programme for rehabilitation. Objective: to boost the innovation capacity of rehabilitation centres and hospital rehabilitation wards by promoting the use of knowledge that has been shown to be effective. Also, to improve the availability and accessibility of knowledge
GeestKracht (MindPower) 1999 advisory report Term of programme by ZonMw until 2013	• Scientific research is lagging behind somatic research • Research fragmented • Gap between knowledge and everyday practice • Shortage of academic collaborative centres for public health • Shortage of scientifically trained researchers	• Improving the research and knowledge infrastructure by creating three consortia, each with a pre-determined theme of their own. The consortia in question would be enduring, multidisciplinary partnerships between universities, non-university research institutes, institutions involved in everyday practice, and knowledge centres • Practical care projects: promoting applied research, knowledge transfer and implementation in everyday practice by healthcare providers • Training researchers	• Knowledge backlog largely eliminated • The consortia have developed an infrastructure, as well as creating more enduring collaboration and boosting it to a higher level • The practical care projects have sparked an interest in research among major mental health care institutions, and have involved them in the process • Adequate numbers of researchers in training • A greater structural focus is needed on the interaction between research and everyday practice • A greater focus is needed on implementation	

Academic collaborative centres for public health (ACCPHs) 2003 advisory report Term of consecutive programmes until 2014	• Research distributed across a broad spectrum of topics • Insufficient academic embedding in PH • Gaps in the acquisition and application of knowledge in the public health service • Lack of knowledge about the effectiveness of measures and interventions • Insufficient compliance with policy	• Improving the academic infrastructure by creating departments of PH, with professors, at all university medical centres • Establishing academic collaborative centres for public health (ACCPHs) to foster links between everyday practice, policy, research, and education in PH, and to academise this sector	• Nine ACCs, involving cooperation between one or more municipal medical and health service and a university • Research in various domains, including child healthcare • On the right track, but not long enough for effective embedding. Policy (the local authority) still not sufficiently involved	Follow-up programme aimed at: • Anchoring and broadening. Once the promotional work has been done, the academic collaborative centres must be maintained by the partners (including the local authorities) involved. R&D, knowledge, and innovation must be embedded into the structure of the municipal medical and health service • Addition of new themes in the follow-up programme
Intellectual disabilities 2005 advisory report Term until 2012	• Scientific research sparse and fragmented • Insufficient embedding in the academic world • Lack of knowledge about the effectiveness of procedures • Physician for the mentally handicapped is a new specialty with (as yet) a very limited research background. • No postdoctoral programmes for other professional practitioners in this area	• Role for parent and client associations in identifying research questions • Promotion of the infrastructure by setting up consortia involving at least one healthcare institution, one university (with at least one professor in this specific area of interest), and one knowledge centre • Focus on communication (dissemination of knowledge) and implementation • Strengthening applied research in terms of the central “course of life” theme, and of a medical focus and a behavioural science focus • In-house financial contribution by collaborating care and research institutions	• Pilot project to identify themes from the client’s perspective • Five consortia involving a total of nine different university departments and thirty institutions • The final evaluation of the programme has yet to be completed	

2.2 Analysis

The common goal of incentive programmes is the academisation of everyday practice. The academisation of everyday practice means that the procedures and interventions used are based, as far as possible, on scientifically based knowledge, that there is a degree of scientific curiosity, and that people take every opportunity to reflect about the profession. Academisation is not an end in itself, rather it is a prerequisite for effective and efficient professional performance. From its analysis of the incentive programmes, the Committee has distilled a number of preconditions for the academisation of everyday practice.

2.2.1 Culture and support

Professional practitioners are dedicated to delivering service in everyday practice. In many cases, after a time spent in everyday practice, even those with a university education begin to lose touch with academic ways of thinking and working. This process can be reversed. However, this requires both the availability of scientifically based knowledge and a culture in which there is support for an academic approach. It is the joint responsibility of professional practitioners, professional organisations, and employers to shape these conditions.

2.2.2 A robust academic infrastructure

The academisation of everyday practice requires a fully functional infrastructure at university level. Universities develop fundamental knowledge. Even if such knowledge is not directly applicable in everyday practice, it nevertheless provides fertile ground for those working in that area. Universities not only generate knowledge as a product, but they also have the knowledge and manpower to provide those in everyday practice with the methodological support needed to develop well-founded knowledge.

The baseline situations for the Addiction and Intellectual Disabilities programmes involved a lack of both scientific knowledge and of the university centres in which to develop such knowledge.[6,29] Strictly speaking, neither the Rehabilitation Research programme nor the academic collaborative centres for public health (ACCPH) were lacking in terms of scientific research. However, the coordination and pooling of their research was fragmented, resulting in an

academic foundation that was insufficiently robust to give effective direction to the process.[7,9] With *GeestKracht* there was a backlog in scientific research, relative to somatic medicine.[8] These differences in terms of the baseline situations for university infrastructure have been major considerations in the RGO's advisory process (and that of the SGO) and in subsequent programming. With regard to building knowledge on addiction, for example, it was necessary to develop an academic core from scratch. In the case of rehabilitation medicine, this core did exist but had to be expanded. It was also necessary to focus research on specific topics, to obtain greater cohesion and a more in-depth understanding. In the case of the other programmes too, there are increasingly specific considerations, depending on the baseline situation.

2.2.3 *Enduring partnerships*

The academisation of everyday practice requires those operating in this area to engage in intensive cooperation with universities. One major consideration is the identity of the partners involved, another is the division of labour. By definition, these partners need not be limited to institutions involved in everyday practice. Depending on the subject in question, these could be umbrella organisations, knowledge centres, universities of applied sciences, client organisations, etc.

If the partners involved were already cooperating with one another prior to the start of the incentive programme, this greatly benefits the development of a partnership. This explains why the development stages of Rehabilitation Research and *GeestKracht* were relatively smooth, compared to those of the Addiction Treatment and Care, and ACCPH programmes.[12,13,15,17,26,27,30]

In the case of the Addiction and Rehabilitation Research programmes, the partners were mainly universities and institutions involved in everyday practice. In subsequent programmes, the partnerships were expanded to include non-university research centres (*GeestKracht*) and knowledge centres (*GeestKracht*, Intellectual Disabilities, and ACCPH). The main purpose of partnerships with research centres such as the Trimbos Institute, Movisie, and the Netherlands Centre for Youth Health, is to disseminate scientifically substantiated knowledge and to support its implementation.

The work of building an effective partnership is dependent on the human element and is very time-consuming. The future partners need to agree on the principles involved, to learn to speak each others' language, and to trust one another. In addition, the partnership must have added value for all concerned. Yet, however effective the partnership, there is no guarantee that it will stand the test of time.

With this in mind, the *GeestKracht* programme's Evaluation Committee wondered whether (despite this programme's long lifetime) the positive changes, in terms of bridging the gap between science and everyday practice, could really take root.[15]

2.2.4 *Interaction between science and everyday practice*

The way in which the connection between science and everyday practice is established is enormously important. None of the programmes is based on the assumption that this process will be either top-down or linear in nature. This is because scientific knowledge is not simply handed down from on high to those in everyday practice, to be implemented and acted upon. Those involved with the programmes found that scientific research into effective treatments (even if carried out for and by individuals working in everyday practice) does not automatically result in the academisation of that area of everyday practice.

The intended interaction between science and everyday practice differed from one programme to another. The initial focus of the Addiction programme, for example, was firmly centred on fundamental scientific research, at the expense of dialogue with those in everyday practice.[24] In other programmes, academising everyday practice was the partnership's express purpose, right from the start. This mainly involved doing scientific research in response to questions from those in everyday practice, and helping professional practitioners to qualify as scientific researchers. Separate budgets were reserved for the training of researchers in the Rehabilitation Research and *GeestKracht* programmes.

However, the evaluations showed that this too offered no guarantees in terms of the successful academisation of everyday practice. In the case of the Rehabilitation Research and *GeestKracht* programmes, scientific research was regularly over-emphasised and was more in keeping with a university research project than with the needs of professional practitioners. A number of institutions involved in everyday practice who took part in the ACCPH and Intellectual Disabilities programmes felt that their partnership with universities was still too biased towards science.[21,26] This applied not only to professional practitioners, but also to the institutions themselves and to their umbrella organisations. They felt that insufficient account was being taken of their interests. At the same time, a growing number of institutions want to set themselves apart by using well-researched treatments and care wherever possible.

The emancipation of practice-based organisations and an effective organisation of professional practitioners are both important conditions for the balanced academisation of everyday practice.

2.2.5 *The connection between science, everyday practice and policy*

In its advisory report on the knowledge infrastructure within the public health service, the Advisory Council on Health Research recommended that academic collaborative centres for public health be established. The aim was to create an enduring system capable of bridging the gap between everyday practice, policy, research, and education. Other programmes had already shown that policy at the level of institutions and umbrella organisations is of key importance to the successful academisation of everyday practice. In addition, the ACCPH was also the first such scheme in which local authorities became directly involved.

Given their specific characteristics, it is no easy matter to connect the domains of everyday practice, research and policy. In the surroundings of everyday practice, work in the care sector is far from straightforward, moreover the acquisition of new knowledge is simply not a top priority. Researchers tend to focus on developing theories, on new insights, and on publications in international scientific journals. Policymakers have to solve social problems, preferably as quickly as possible. The only way to bridge gaps between different cultures is if the representatives involved are acquainted with one another and if they have the opportunity to work together for an extended period of time.[31] The nine ACCPHs have already made major contributions, in various areas, to the partnership between everyday practice, policy and research, both at the institutional and individual level.

The increasing decentralisation of policy means that local authorities have an ever more important part to play. This decentralisation is partly related to the desire to connect different sectors to one another. This is because private individuals often have to deal with several sectors at the same time, such as the public health service, the curative health service, long-term care, social care, and youth care services. In such situations there is often a lack of clarity about individual roles and responsibilities. As a result, there is a risk that a great deal of money and energy will be wasted. Furthermore, there has also been a shift in terms of policy. Whereas individuals were previously entitled to a given service, it is now the case that local authorities are duty bound to compensate people for

the obstacles they face when participating in society.[32] This further underscores the need for connections between sectors.

The decentralisation of policy makes the experience gained by those involved in academic collaborative centres all the more valuable. Local managers need information to determine whether their policies are working and whether the care provided is truly effective. For this reason, boards attach great importance to the social relevance of scientific research. Accordingly, the Netherlands Organisation for Health Research and Development's follow-up programme for the academic collaborative centres for public health stated that it is imperative that local authorities be involved, both as a principal and a partner, in academisation and embedding, and that they take joint responsibility for this process.[26]

This approach has been implemented in the policy domain of the public mental health care service. The follow-up programme is broadened by connections, at local level, between primary care, schools, youth care services, and the business community, for example. Accordingly, the nature of the academic collaborative centres for public health is more that of a strategic alliance and of a regional infrastructure for quality and innovation.[28,33] In this regard, it is important to carefully separate themes that might be usefully grouped together in an academic collaborative centre (to take advantage of the economies of scale involved) from the rest. One of the risks involved in this grouping process is that it might cause certain themes to lose their specific character.

2.2.6 *Encouragement is a necessary prerequisite for the flowering of self-reliance*

The construction of a knowledge infrastructure and the development of research programmes both require substantial financial resources. Even if the partners involved contribute funds of their own, external funding is still needed to kick-start this process. The conditions attached to such funding steer the process in a given direction, while influencing the quality of the partnership and that of the research produced. Once the partnership and the research activities are up and running, it is often possible to acquire funding that was previously inaccessible.

To some extent, this is probably because the pooling of knowledge and experience boosts the quality of project proposals. Furthermore, over time, the partnership can build up a solid reputation. This is an attractive prospect, not only for the partners themselves but also for grant-awarding authorities and private funds.

2.3 Conclusion

The analysis shows that the success of an incentive programme is dependent on a number of conditions. These conditions can be placed along an imaginary line linking fundamental scientific knowledge and its implementation in everyday practice. It should be noted that this is not a linear process that begins with academic knowledge and ends with the application of knowledge. On the line between knowledge and adopting an academic approach in practice, a great many processes take place simultaneously, each with their own dynamics and patterns. Incentive programmes help to link the different processes together.

The academisation of everyday practice increasingly involves partnerships operating in the context of academic collaborative centres for public health.

The significance of this has undergone substantive changes over time. The term was initially used for patient-related research, both in university hospitals and elsewhere. Gradually, the term has increasingly been used to indicate the academisation of everyday practice itself. Contrary to what their name suggests, academic collaborative centres for public health are not about putting science at the centre of things. Instead, they adopt a collective approach to planning and conducting research, drawing on everyday practice, policy and science.[28,33]

In the interests of a balanced introduction of academisation, the research questions and, wherever possible, the initial moves to set up a collaborative research agreement should both originate from the field of everyday practice. Collaborative situations like these involve an increasing focus on fostering an awareness among scientists of the realities of everyday practice. Scientists can help clarify issues encountered in everyday practice by working with practitioners to tackle specific questions, such as “what exactly is the problem?”, “exactly what problem can a proposed intervention solve?” and “under what conditions can it do so?”. This approach is defined as practice-based research. In this context, it involves close links between academisation, professionalisation and implementation.

2.4 Lessons

In terms of building a knowledge infrastructure for autism, some useful lessons can be learned from the situation described above.

- Robust scientific results achieved within the context of partnerships do not, of themselves, guarantee the academisation of everyday practice. If everyday

practice too often serves as a workplace for academics, this can tip the balance in favour of science. This suggest that, wherever possible, the other parties in such partnerships should defer to those in everyday practice.

- The academisation of everyday practice is only useful if it is accompanied by the professionalisation of the professional groups involved. Practitioners and their professional associations should impose requirements on the scientific rigour of their methods, make demands concerning the quality of practice-based research, and take ownership of the challenge of implementing the results. If they are to succeed in this, then they will need support. This must come from the boards of the organisations in which they are employed, and from their umbrella organisations.
- Establishing an infrastructural partnership between the domains of science and everyday practice is a delicate process. The individuals and institutions involved must first get acquainted, and then learn to trust one another. This takes a great deal of time. Accordingly, it is important to seize every opportunity to involve existing initiatives and partnerships in the construction of this infrastructure.
- Given the present trend of connecting policy domains and of implementing policies at local and regional level, it is essential to make allowance for the interaction between policy and research. Policies should be geared to research and, just as importantly, the research carried out must address those issues that are relevant to policy. Local authorities, either inside or outside the context of regional partnerships, will have an important part to play here.
- When partnerships are being connected and expanded, there is an attendant risk that those involved will lose sight of relatively minor topics or issues. In other words, it is important to avoid a situation in which the biggest problems become the centre of attention and consume all of the available resources. If such a situation were allowed to develop, more minor topics (such as autism) would be totally eclipsed.
- Adequate funding is the only way to achieve high-quality partnerships and programming. Subject to the proper conditions, a start-up grant can boost the financial self-reliance of the partnership's members. It can also help to create a community of practice for autism research, spanning a range of domains.

Chapter 3

Research survey

The Committee has conducted a wide-ranging research survey to obtain a reliable overview of autism research and the associated knowledge infrastructure. In this chapter, the Committee gives details of the method used in conducting the survey. It goes on to present and analyse the results obtained.

3.1 Procedure

The Committee limited its survey to research projects with a sound scientific basis that are either already under way or that are due to commence in the near future. Other inclusion criteria were that the research projects should be based on a specific question, that this should be investigated in a systematic way, and that the results should be recorded and shared with others (and implemented). Research projects that had already been completed were excluded from the survey.

To this end, a large number of professional practitioners working in the field of autism research have been approached (Annex C). Their names were either put forward by members of the Committee or by professional practitioners, in the course of interviews. Others were traced through the literature or using the internet. They were given a questionnaire (Annex D) containing questions about their research topic, type of research, partnerships, funding arrangements, and the staffing level of the study (or studies) in question. They were also asked to identify any gaps in our knowledge and to indicate which areas of research

should be given priority. The completed questionnaires were then discussed in the course of personal interviews. The object of the exercise was to obtain a summary of research in this area. Accordingly, the decision was taken to phrase enquiries about research topics in general terms. There were no questions specifically pertaining to the tools or interventions set out in the request for advice.

While the Committee has endeavoured to draw up the best possible summary of autism research in the Netherlands, it does not claim that this summary is totally comprehensive.

3.2 Results

3.2.1 Research topics

Table 2 summarises current research topics, per institution. Table 3 shows the same research, categorised by domain. For details, see Annex F.

The summary tables show that fundamental research in the field of neuroimaging and genetics is being carried out at the university medical centres. Epidemiological studies and research into diagnostic tools is focused in the universities and university medical centres. It should be noted that current research into detection and diagnosis is primarily related to tools for use in adults. Intervention research is being conducted both at university medical centres and in non-university institutions. Applied research into the everyday lives of those with an autism spectrum disorder is being carried out at non-university institutions and at institutes of higher vocational education (HBO).

Something that stands out in the summary is the virtual absence of research into autism and intellectual disability. This is noteworthy because the care for those with intellectual disabilities involves residential and working provision for a great many autism sufferers. Some of them perform fairly well within the safe and structured context that this care can offer. Even here though, many problems arise for autism sufferers who require specific care provision. This can be seen, for instance, in the very high percentage of autism sufferers and those with an intellectual disability who are registered with a Centre for Consultation and Expertise or CCE (45% of all those registered at CCEs).

Table 2 Topics of current research.

Institution	Topics[a]
Dr. Leo Kanner House	Applied behavioural analysis (ABA), pivotal response training, psychiatric family treatment, treatment monitor, course of life, emotion regulation, self-reliance, empowerment, occupational reintegration
Kentalis PonTem St. Michielsgestel	Target group knowledge (numbers, characteristics), diagnosis, intervention research
HAN University of Applied Sciences, Nijmegen	The course of life, IT resources and transition
Fontys Tilburg	More effective education
CED-groep Rotterdam (Educational Services Centre)	IT intervention for social performance, indicators for education
University of Amsterdam (UvA)	Cognition throughout the course of life
VU University Medical Center Amsterdam (VUmc)	Epidemiology (register), socio-emotional development, intervention research
University Medical Center Groningen/ Accare	Diagnostic tools, pharmacotherapy, genetics, information processing
Radboud University Nijmegen Medical Centre/Karakter	Biology (genetics, morphology, phenotype), imaging, emotion, language, signal processing, imitation
Radboud University Nijmegen Medical Centre/Medical Psychology	Cognition, aggression and intellectual disabilities with and without autism
Radboud University Nijmegen	Effectiveness of applied behaviour analysis
University Medical Center Utrecht (UMCU)	Imaging, genetics, pharmacotherapy, signal processing
Utrecht University	Pupil-teacher interaction
Erasmus MC	Diagnosis, course, associated problems, physiology, eye-tracking, family traits, intervention
Leiden University	Play therapy, behavioural problems
University of Groningen (RUG)	Occupational reintegration[b]
Tilburg University	Occupational reintegration[b]
Wageningen University	Nutrition, immune system, and behaviour
TNO Work and Employment	Occupational reintegration[b]
Eindhoven mental health care service	Efficacy of treatment in adults
Lentis Groningen	Diagnosis, intervention research, relationships, Theory of Mind (ToM)
NHN Alkmaar mental health care service	Care avoidance, diagnosis
Dimence Deventer	Usefulness of diagnostic tool
Yulius Rotterdam (Yulius mental health care institution)	Behaviour management cluster 4 schooling, course, associated problems, family traits, intervention (puberty)

[a] Some of the topics mentioned are being investigated in the context of partnerships. This table, and the following one, list the names of the principal investigators involved. Annex F lists the names of the partners involved, by topic.

[b] Research into occupational reintegration focuses on groups that have difficulty finding work. A significant proportion of these individuals are young people with a disorder in the autistic spectrum. However, this is not the only group with employment mediation problems. As a result, such research is not always entirely specific to autism.

Table 3 Topics categorised by domain.

Domain	Institution	Topic
Mental health care service	Eindhoven mental health care service	Efficacy of treatment in adults
	Lentis Groningen	Diagnosis, intervention research, relationships, Theory of Mind (ToM)
	NHN Alkmaar mental health care service	Care avoidance, diagnosis
	Dimence Deventer	Usefulness of diagnostic tool
	University of Amsterdam (UvA)	Cognition throughout the course of life
	VU University Medical Center Amsterdam (VUmc)	Epidemiology (register), socio-emotional development, intervention research
	University Medical Center Groningen/ Accare	Diagnostic tools, pharmacotherapy, genetics, information processing
	Radboud University Nijmegen Medical Centre/Karakter	Biology (genetics, morphology, phenotype), imaging, emotion, language, signal processing, imitation
	Radboud University Nijmegen Medical Centre/Medical Psychology	Cognition, aggression and intellectual disabilities with and without autism
	Radboud University Nijmegen	Effectiveness of applied behaviour analysis
	University Medical Center Utrecht (UMCU)	Imaging, genetics, pharmacotherapy, signal processing
	Erasmus MC	Diagnosis, course, associated problems, physiology, eye-tracking, family traits, intervention
	Dr. Leo Kanner House	Psychiatric family treatment, treatment monitor
Participation	HAN University of Applied Sciences, Nijmegen	The course of life, IT resources and transition
	CED-groep Rotterdam (Educational Services Centre)	IT intervention for social performance
	Yulius Rotterdam (Yulius mental health care institution)	Social spectrum, intervention (puberty)
	Dr. Leo Kanner House	Self-reliance, course of life, empowerment
Education	Fontys Tilburg	More effective education
	CED-groep Rotterdam (Educational Services Centre)	IT intervention for social performance, indicators for education
	Yulius Rotterdam (Yulius mental health care institution)	Behaviour management cluster 4 schooling
	Kentalis PonTem St. Michielsgestel	Target group knowledge (numbers, characteristics), diagnosis, intervention research
	Utrecht University	Pupil-teacher interaction
Work	TNO Work and Employment	Occupational reintegration.
	Tilburg University	Occupational reintegration.
	University of Groningen (RUG)	Occupational reintegration.
	Dr. Leo Kanner House	Occupational integration (European collaborative project)
Other	Wageningen University	Nutrition, immune system, and behaviour

3.2.2 Scope and funding

The university medical centres lead the field in terms of funding their research into autism. Projects are mainly supported by direct and indirect funding*, resulting in the creation of a substantial number of FTEs. The budgets for each project or line of research range from tens of thousands of euros to hundreds of thousands of euros.

University departments in other faculties find it more difficult to fund autism research. Their research is often conducted in an educational context, and is primarily supported by direct funding. The number of FTEs involved is limited.

Mental health care institutions vary in the scope and funding of their research. Yulius Rotterdam has a large research programme, which involves close collaboration with Erasmus MC. This programme is supported by indirect government funding and by contract funding. At the other end of the spectrum there is the Dimence mental health care service, with a budget just a few tens of thousands of euros and research staffing of 0.2 FTE. The other mental health care institutes fall between these two extremes, although they all tend to be limited in terms of funding and FTEs. They are funded almost exclusively from their own limited resources, with occasional supplementary grants derived from contract funding. The mental health care service makes extensive use of research in the context of training and education. This involves PhD students, research internships for Basic Psychology students, and research assignments carried out in the context of Clinical Psychology programmes.

The Dr. Leo Kanner House mainly finances its research from its own resources, so here too such activities are quite limited in scope. However, the Dr. Leo Kanner House Netherlands franchise has recently taken the initiative to pool its research and innovation funds with a number of large mental health care institutions (Altrecht, SBWU, Lentis, the Noord Holland Noord mental health care service, Dr. Leo Kanner House Brabant and Dr. Leo Kanner House, the Mondriaangroep, and the Parnassia Bavo Groep).

It is difficult for institutes of higher professional education (HBO) and other institutions to attract funding and staff for autism research. The HAN University of Applied Sciences has a Life Coaching research group for autism, which makes

* Direct funding: non-earmarked public funding (Ministry of Education, Culture and Science).
Indirect funding: earmarked public funding (The Netherlands Organisation for Health Research and Development, the Netherlands Organisation for Scientific Research).
Contract funding: funds, private foundations.
Industrial funding: industry.

it possible to conduct a significant amount of research. Fontys has just a single project, but those involved constantly have to find new sources of funding. Kentalis PonTem funds research from its own resources, occasionally supplemented by contract funding. As a result, this research continues to be rather limited in scope. These institutions also regularly use students from institutes of higher vocational education and universities. Two major problems in this connection are that dissertations are not always archived, and that dissertation topics are often not embedded in an existing line of research.

In overall terms, the research budgets of institutions of higher vocational education amount to just 1% of the budgets allotted to university medical centres. The corresponding figure for mental health care institutions is 10%.

3.2.3 *Embedding research*

At university medical centres, the study of autism is not usually an independent line of research. Instead, it is generally well embedded in the ongoing studies of departments such as Child and Adolescent Psychiatry. There is also an increasing focus on autism in adults. Research is an integral part of their organisational culture.

In non-medical university departments, autism research is part (sometimes a very minor part) of a larger whole. In such cases, a study's progress depends on its ability to attract the interest of students. In very few cases are there dedicated, formal structures focused purely on autism.

The mental health care institutions seem to be at an intermediate stage in this regard. There are substantial differences between mental health care institutions in terms of how they conduct research and how they embed it in their working practices. While some mental health care institutions, such as Dimence, do have research ambitions, their activities in this area have tended to remain small in size and scope. Most professional practitioners currently employed by these institutions have little or no experience of, or affinity with, research.

Conversely, in 2007, the Yulius mental health care institution took a conscious decision to develop a strong research arm, or academy, as Yulius calls it. Yulius uses this framework to purposefully connect science with everyday practice. To this end, for example, it uses "science clubs" to channel questions from everyday practice and submit them to scientists. In addition, some of its staff also have dual appointments at the Yulius mental health care service and Erasmus MC. Finally, Yulius' applications for research grants are carefully targeted. The research proposals are written by experienced practitioners. There is also a grant coordinator who is well acquainted with the various funding

options. Furthermore, clear agreements are made with partners concerning support and authorship. The professional practitioners involved receive training in research methods, and in how to adopt a scientific approach towards procedures and treatments. Altrecht in Utrecht is engaged in a similar development, partly within the context of TOPGGz (the Foundation for Top Clinical Mental Health Care). However, this particular institute does not carry out any research into autism.

As a tertiary health care facility specialising in autism, the Dr. Leo Kanner House has a strong and time-honoured research tradition. The institution works with a range of different partners, rather than with just a single, specific academic partner. Here, too, some employees have dual appointments involving both academic settings and institutions involved in everyday practice. The Dr. Leo Kanner House has established a chair at the University of Amsterdam, in addition to initiating the autism research group at HAN University of Applied Sciences. There, too, a number of individuals have dual appointments.

Institutions of higher vocational education have only recently entered this research field, in some cases, by setting up research groups. The funds set aside for research cannot be spent on education. In the context of research policy, HAN University of Applied Sciences has even made extra funds available for research. In practice, however, it is difficult to establish and conduct research projects that are fully adequate in terms of their size and impact. Rome was not built in a day, and the same goes for research traditions. In addition, it can be difficult to acquire extra funding, as indirect funding is not yet geared to research proposals from institutions of higher vocational education. Moreover, the quality of such proposals can be rather suspect, due to a lack of experience both in conducting research and in committing ideas for projects to paper. All things considered, autism research at institutions of higher vocational education is very limited. The only research group of any size is the one at the HAN University of Applied Sciences.

At Ketalis PonTeM, autism research is embedded in studies of target groups for cluster 2 schooling. However, the resources for such research will probably be squeezed as part of the upcoming cuts in special needs education.

The Committee was unable to find any instances of research in mainstream education.

3.2.4 Partnerships

University medical centres tend to cooperate mainly with one another, they very seldom work with mental health care institutions. The same applies to the mental

health care institutions themselves. They tend to cooperate mainly with one another, and very seldom work with universities. Very few partnerships include staff with dual appointments, either among those working for the care partner or those employed by the research partner. Some examples of such partnerships (cited in Section 3.2.3) are Yulius/Erasmus MC, Dr. Leo Kanner House/HAN University of Applied Sciences, and Dr. Leo Kanner House/University of Amsterdam.

Non-academic researchers mainly seek partnerships in everyday practice, with mental health care institutions, educational institutions, or social institutions.

The Dr. Leo Kanner House (a national centre of expertise and treatment for autism) has a special status in the field of autism. The centre started life as an institution, at Doorwerth, for the treatment of adolescents with childhood autism. It has now become a national player in the field of complex autism spectrum disorders. The past ten years have been characterised by a strong emphasis on the development and dissemination of knowledge. Accordingly, it was the Dr. Leo Kanner House that launched the Netherlands Knowledge Center for Autism, and that founded the Dr. Leo Kanner House Netherlands franchise network. Consisting of six mental health care institutions, this network has national coverage.

The Dr. Leo Kanner House in Doorwerth has a large Research & Development department, which engages in training, innovation, and research. As previously stated, the Dr. Leo Kanner House has fostered research by founding a research group at the HAN University of Applied Sciences (higher professional education) and the Chair in Autism at the University of Amsterdam. It also has a strategic partnership with Radboud University Nijmegen and the Trimbos Institute, in the areas of research and innovation. In the field of education, it has formed a strategic partnership with the RINO-groep to address the autism curriculum (post higher vocational education). Finally, all treatment departments at the Dr. Leo Kanner House have been awarded the TOPGGz (the Foundation for Top Clinical Mental Health Care) quality mark.

3.2.5 *Identified gaps and priorities*

Numerous gaps have been reported. Research into effective interventions for autism sufferers is the issue that is cited most frequently in this connection. This is also considered to be one of the most urgent cases, along with research into effective diagnosis. Another gap that has been highlighted involves longitudinal cohort studies, which could give a better understanding of the diversity of autism

spectrum disorders. Within the cohort, research could be carried out into topics such as aetiology, endophenotypes, genetics, development, and the effectiveness of interventions.

Research that was cited as being particularly valuable included studies into the origins of autism and into living with autism (cohort studies). In this context, VU University Amsterdam and the Dutch Association for Autism (NVA) are working on a plan for a National Autism Registry.

Intervention research was cited as the most promising area, in terms of funding and reasonably short-term results.

3.2.6 Other findings from the interviews

Virtually all of the experts were aware that the research effort in this area is very fragmented, especially applied research in the field of autism. There is a widely-felt desire (both by university staff and by those working in institutions involved in everyday practice) for a better connection between academic research and practice-based research. The interviewees indicated that this will require commitment at all levels, from directors to group leaders, from physicians to socio-educational workers, and from professors to research assistants.

By extension, several experts expressed a desire for an open platform where all those involved in autism research could engage with one another to exchange ideas, seek research partners, present research results, etc. Another suggestion in this regard was that an open source, peer-reviewed journal for autism research be established. In addition to academic studies, this could also publish practice-based research as well studies that obtained negative results. It is currently very difficult to get exploratory, practice-based research published.

The mental health care institutions in particular frequently voice concerns about the impact that changes in the funding of the mental health care service will have on research. The fear is that, with the upcoming transfer of the bulk of the mental health care service to the Health Insurance Act, there will not be sufficient scope (in terms of funding) for the careful observation and recording of the DTCs (Diagnosis Treatment Combinations) in use at that time. These two elements are important prerequisites for good research. Unlike the university medical centres, the mental health care institutions cannot fall back on research funding from the Ministry of Education, Culture and Science (direct funding).

The mental health care service also indicated that there is no reliable mechanism for eliminating interventions that have not been proven effective (or at least those that have not been properly substantiated by theory) from care

provision. Conversely, it is difficult to get interventions that have been proven effective (or that have been properly substantiated by theory) widely implemented.

Finally, the information gleaned from these interviews has enabled the Committee to identify a number of success factors for effective academisation:

- the success of a move towards academisation hinges on the involvement of a group of passionate, enthusiastic individuals in everyday practice and in academia
- any such initiative needs the support of the board
- dual appointments at academic institutions and at institutions involved in everyday practice promote interactions between academic and practice-based research, and help these domains to become more closely interwoven
- the chances of successful academisation will be greatly enhanced if, from the very beginning, efforts are made to achieve high quality research (including exploratory research)
- if there is scope for dialogue and for multidisciplinary working practices, this will greatly benefit the process of academisation.

3.3 Analysis

The Committee notes that autism research in the Netherlands is a relatively small-scale undertaking. It is particularly difficult to attract funding and staff for practice-based research. The research being carried out at university medical centres, however, is reasonably large-scale, and its quality is internationally recognised. In general, mental health care institutions are interested in carrying out research, and are looking for opportunities to do so. The remaining institutions have not fared nearly so well, as their research is primarily driven by the efforts of a few highly motivated individuals.

The research topics being pursued by academic institutions are very different from those favoured by institutions involved in everyday practice. This is partly a result of the available sources of funding. Fundamental, medically oriented research can be supported by direct funding for the university medical centres, and by the Netherlands Organisation for Health Research and Development's indirectly funded projects.

However, practice-based research appears to be more difficult to fund. This kind of research is mainly supported by smaller-scale funds, each of which have their own objectives, formats and jargon. As a result, applying for grants for

practice-based research is a very labour-intensive process. As one professional practitioner pointed out in the course of an interview “To obtain funding for just one research project, I have to write eight separate proposals, each with a slightly different phrasing and layout”. Accordingly, practice-based research makes extensive use of “cheap” student labour, which is not conducive to the continuity and consistency of the research in question.

It seems that it is no easy matter to establish a connection between universities and everyday practice. In terms of research interests and methods, there is something of a language barrier, which makes it difficult to formulate good research questions. This requires the investment of considerable time and effort, as Yulius, Lentis, Altrecht, and the Dr. Leo Kanner House have all shown.

Educational research is entirely lacking, however, leaving a yawning gap in autism studies. The present round of cuts have made research into various forms of education, and their effectiveness, a thing of the past. Decisions concerning reform are based on purely theoretical considerations that have not been tested in everyday practice. In view of the impending changes to the health system, the Committee regards this as a major shortcoming.

Chapter 4

Knowledge for professional practitioners in everyday practice

In this chapter, the Committee focuses on the professionalisation and academisation of everyday practice throughout the various social domains in which autism sufferers spend their lives. How is the care structure organised, how do the professional practitioners working in these areas acquire knowledge about autism, and what academic competencies do they possess? The Committee goes on to give details of the extent to which everyday practice has already been academised.

4.1 Care structure

The infrastructure for the treatment, support, and care of ASD sufferers is highly complex. Treatment, support and care take place in different social domains offering a wide variety of facilities and employing a broad range of professional practitioners.* The main points of this issue are set out in Table 4, but this summary is not claimed to be totally comprehensive. In reality, the boundaries between domains and functions are often not sharply defined. Nor do autism sufferers participate to an equal extent in each of the various domains.

* In 1999, initial moves were made to set up the Autism Covenant. Its goal was to improve cooperation and to streamline the care provided to ASD sufferers. See also the 2009 Health Council advisory report. In the future, this Covenant may continue to be of great significance in terms of regional and local partnerships, as well as for coordination in this area.

In addition, the focus of current government policy is that, wherever possible, policy should be implemented at regional and local level. The purpose of this decentralisation is to make domains more interconnected, and to integrate them, as far as possible, into a single, unified control structure. This will also affect the detection, treatment and support of ASD sufferers. For this reason, the Committee addresses the broad sweep of the system overhaul in youth care services, employment and income, and education, that are now in preparation.

4.1.1 *No sharply defined boundaries*

Table 4 focuses on the core activities of the various domains and on the key competencies of organisations operating in these areas. In everyday practice, there is often greater flexibility in the way that activities are distributed across the domains. This certainly applies to the domains of education, labour, and the mental health care service, for example. Education focuses primarily on knowledge and general development. However, in practical education and secondary special needs education in particular, it also involves actively guiding and supporting pupils who are preparing to enter the labour market.* Some schools implement this programme largely independently, while others tackle it by collaborating closely with employment experts and reintegration agencies. In due course, the government aims to fine-tune special needs education, to sharpen its focus on the labour market still further. Mental health care service practitioners also help people with psychiatric disorders of varying severity (including ASD sufferers) to find work. Understandably, and quite naturally, the key competencies of various organisations and professional practitioners will sometimes overlap the boundaries of several different domains. Some problems are so complex that even the most effective cooperation and coordination cannot always resolve them. In situations such as this, professional practitioners are sometimes required to apply their specific knowledge and skills outside the boundaries of their own domain.

Approximately half of all ASD sufferers also have some form of intellectual disability. Many of these individuals live permanently in institutions or sheltered accommodation that is funded by the Exceptional Medical Expenses Act (AWBZ). They are especially dependent on care and support, and are only able to participate in society to a limited extent.

* In a letter to the House of Representatives of the Dutch Parliament (dated 9 February 2009), the State Secretary of Education, Culture and Science describe the latter role as “qualifying and socialising”.

Table 4 Summary of the domains and professional practitioners who play a part in the detection, diagnosis, treatment, and support of people with autism spectrum disorders.

Domain	Role	Institution/organisation	Professional practitioners (list not exhaustive).
Mental health care service	• Individual mental health care, outpatient care, day treatment, and inpatient care	• GP/Primary mental health care • Mental health care services (including youth mental health care services) • Mental health care institutions • University medical centres (adults/ children and young people) • Specialist institutions and ASD centres • Multifunctional centres	Primary health care • GP • Psychologist Secondary and tertiary health care • Psychiatrist (adult/child/adolescent) • Psychologist • Family psychologist • Nurse (including psychiatric nurses) • Social workers • Geriatricians
Education	• Primary education • Secondary education • Senior secondary vocational education (MBO) • Higher professional education (HBO) • University education	• Primary schools (mainstream and special needs) • Secondary schools (mainstream secondary education and secondary special needs education) • Senior secondary vocational education (MBO) • Higher professional education (HBO) • Universities	• Teacher education (teaching academy) • Teachers qualified to teach at higher secondary school level and those qualified to teach at lower secondary school level. Senior secondary vocational education (MBO) and higher professional education (HBO) programmes • Teachers qualified to teach at higher secondary school level. University teacher training programme • Teaching assistants • Remedial educationalist-generalist
Public health	• Child healthcare (detection and advice) • Public mental health care service • Forensic care	• Youth and Families Centre • Municipal medical and health service	• Youth health care physician, youth health care nurse • Professional practitioners in addiction treatment and care • Social workers
Youth care services and social support services	Youth care services: care that focuses on children and young people with psychosocial problems, up to the age of 23 • Local authority: • Detection, advising, support and moderate care provision • Provincial authorities: • Indication and referral to care indicated[a]	• Local authority: Youth and Families Centre • Provincial authorities: Youth Care Agency • Child Abuse Counselling and Reporting Centre • MEE (support organisation for people with disabilities)	• Youth health care physician, nurse • Psychologists • Educators (including remedial teachers) • Youth care services workers (senior secondary vocational education and higher professional education) • educational worker (including Educational Social Worker (senior secondary vocational education) • Social workers • Family guardians • Forensic psychiatry

Work	• Assistance in preparing for paid work, and support at work	• Departments of Occupational Health, Safety and Environment • The organisation for reintegration into the job market and temporary income (UWV) • Local authorities • Sheltered employment facilities • Employers	• Occupational Health Physicians • Insurance physicians • Employment experts • Human resource managers
Intellectual disabilities	• The care, support, and home life of those with an intellectual disability	• Institutions for those with intellectual disabilities (intramural) • Substitute family homes (semi-mural) • Day-care facilities • Local authorities • MEE (support organisation for people with disabilities)	• Physicians for the mentally handicapped • GPs • Educators (including remedial teachers) • Psychologists • Social workers

[a] The youth protection service, the probation service, and the Child Abuse Counselling and Reporting Centre (AMK) are not taken into consideration

Those who live with their parents, or who lead largely independent lives, will make more frequent use of social support services funded by the Social Support Act (WMO). Occasionally, they may also use the outpatient services provided by the mental health care service. There are others who, even though they lead largely independent lives, still need to make extensive use of the mental health care service. The table makes no allowance for this broad spectrum of support needs, which is a major factor in everyday practice.

4.1.2 System overhaul

Youth care services

During the next few years, there will be an overhaul of the current youth care system. The new system is expected to come into operation in 2015.[34-37] Local authorities are both financially and administratively responsible for the care and support of all affected children, adolescents and young adults up to the age of 23, and their parents. They will take on the bulk of duties involving youth care services, which are largely the responsibility of provincial authorities at the moment. Under the new legislation, the local authorities will also take on a general duty of care for young people with mental health problems. This includes primary health care and complex care, such as child and adolescent psychiatry. The funding of youth mental health care services will be transferred from the Health Insurance Act to the local authorities. The healthcare providers,

professional practitioners (and their professional bodies), the organisers of training programmes, and the knowledge institutions will continue to bear responsibility for care-related innovation and for the quality of care.

Income and employment

New legislation (the Employment Capacity Act) is currently being drafted to promote the employment rate of those with occupational disabilities.* (Wwnv).[38] This will replace the Work and Social Assistance Act (WWB). It also has important implications for the Sheltered Employment Act (WSW) and the Work and Employment Support (Young Disabled Persons) Act (Wajong). Local authorities will assume responsibility for implementing the Employment Capacity Act. They will also have to help individuals who have some capacity for employment to find work, as well as those who are currently covered by various schemes. The aim is to place as many of these individuals as possible with conventional employers. The local authorities will have access to a single, pooled reintegration budget, derived from various sources of funding. They are free to allocate this money as they see fit. In this way, local authorities themselves will be able to reintegrate people with occupational disabilities. Alternatively, they could outsource this work to third parties.

Education

The Appropriate Education bill will introduce a requirement for schools to provide additional educational support.[39,40] This means that all of the schools within a regional partnership will be required to collectively offer additional educational support to any pupil who needs it. Details of the relevant agreements will be set out in a support plan. This will be funded from a fixed budget, agreed by the partnership in question. Accordingly, the national Indication Procedures for assigning places, and additional funding (such as the special-needs education and/or pupil-specific funding known as 'backpack'), will be revoked. The schools will continue to be responsible for the quality of education given to those children who need extra support.

In the future, the link between Appropriate Education and care for young people will cause schools and local authorities to become more closely involved

* The government tendered its resignation shortly before the advisory report was due to be published. As a result, this topic has officially been designated as controversial until after the elections of September 2012. However, the conceptual legacy underpinning employment capacity has not been lost. Accordingly, this theme may well be revisited by a future government.

with one another than is presently the case. For this reason, the partnership support plan will be discussed with the local authority (or local authorities) in question. This may include agreements on cooperation with the Youth and Families Centre. Also, the additional educational support for such children will have to be geared to the requisite youth care services. After the system overhaul, the Care Advisory Teams (CATs) will continue to play an important part. CATs are multidisciplinary teams that include schools and professional practitioners from the youth care services. Their goal is to provide adequate and coherent support to any pupils who need more specialised assistance.

4.2 Practitioners, professionalisation and academisation

Professionalisation is a process by which practitioners enhance the position of their profession, giving clarity and structure to their expertise. Professionalised occupations are categorised by six individual characteristics.[41]

- the profession has its own "domain of expertise", a well-defined area within which the practitioners in question are all experts
- their area of expertise is socially recognised
- they have a professional association
- there is a professional ideology and a code of practice
- the profession controls access to the labour market by means of professional registration
- the profession controls the content of vocational training and access to such training programmes.

It should be noted that some professions comply more fully with these points than others. The Committee relies on professional practitioners and professional groups having a responsible attitude in this regard.

Academisation is just one aspect of professionalisation. It involves improving the quality of professional practice by basing it on scientific knowledge, combined with scientific curiosity about (and reflection upon) the profession itself.

4.2.1 Education and training

In the above sense of the term "professionalisation", the treatment, support, and care of ASD sufferers is not in the hands of a single professionalised occupational group. The treatment, support, and care of ASD sufferers falls

within the domains of a large number of occupations with varying degrees of professionalisation.

In everyday practice, various generalist practitioners are involved in the detection of (and/or providing support for) ASD sufferers. These generalists, who include GPs, occupational health physicians, and teachers, base their approach on what they learned in basic training, possibly supplemented by continuing education and the occasional refresher course. Those practitioners who are more involved in the treatment, support, and care of autism sufferers tend to expand their knowledge about autism in the course of their work. This results from experience gained while working in everyday practice and through private study, as well as from activities in the context of refresher courses and continuing education (such as courses and workshops).

Psychiatrists (child/adolescent/adult), remedial teachers/generalists, and independent psychologists working in the mental health care service (health service psychologists, clinical psychologists, and clinical neuropsychologists) acquire specialised knowledge about autism in the course of their training programmes. The extent to which this happens depends on the circumstances of their training programme, such as the specialisation of the department in which they did their internship. The training programmes of child psychiatrists and adolescent psychiatrists include a mandatory autism spectrum disorder component (which is described in the training requirements).

Many organisations offer courses and training programmes at various levels, for a wide range of target groups.[42] The RINO-groep offers a post-senior secondary vocational education (MBO) programme in autism, for positions at senior secondary vocational level, such as supervisors at crèches, teaching assistants, and job coaches. In partnership with the Dr. Leo Kanner House, the RINO-groep (Utrecht) offers higher vocational education graduates (of socio-pedagogical programmes, nursing programmes, or teacher training programmes) a post-higher professional education (HBO) programme for qualification as an autism specialist.* The training programme includes a practice-based research module, which will commence in 2014. In addition, Fontys School of Special Educational Needs offers a post-higher professional education (HBO) programme in special educational needs (SEN), which includes five modules on autism.[43]

* RINO: Regional Institutes for Continuing Education and Training (RINO) in the mental health care service. There are three RINOs: RINO Noord-Holland, RINO Zuid, and the RINO-groep.

4.2.2 *Practitioners and competencies*

Professional practitioners with a senior secondary vocational educational (MBO) background generally perform practical work, often in teams, or under the supervision of staff with a higher professional educational (HBO) background. They have no specific scientific competencies. This does not apply to staff with a higher professional educational (HBO) background. Their competency involves applying scientific knowledge, insights, and research results in the professional situation. It also includes working towards professionalisation and innovation within the profession.[44] Students in the post-higher professional education (HBO) programme for qualification as an autism specialist learn how to set up research projects in the context of their everyday practices. However, staff with a higher professional educational (HBO) background have had no training in how to conduct independent scientific research. Nevertheless, they do tend to get involved in the scientific research that is carried out at the institutions where they work. University educated practitioners (physicians, psychologists, remedial teachers, and university-trained teachers) have been trained to conduct scientific research. Some institutions, however, do not have a tradition built on research and on the implementation of scientific knowledge. Nonetheless, the Committee takes the view that this does not absolve practitioners of their professional obligations to continually reflect on their actions (why, what, and how) and to integrate new scientific knowledge into their professional practice.

4.3 Academisation and domains

The extent to which everyday practice associated with ASD is academised varies from one domain to another. The Committee provides an overview, based on the survey in Chapter 3, on the information obtained during the interviews, and on a survey of the extent to which current incentive programmes focus on ASD.

4.3.1 *Work*

In the area of employment participation for ASD sufferers, research projects with a formal academic dimension are still few and far between. The Department of Social Medicine at the University Medical Center Groningen (UMCG)/ University of Groningen is currently conducting two studies into employment participation among young people with an occupational disability. One of these involves predictive factors for employment participation among young people

with an autism spectrum disorder. The other study is broader in scope, so the group of ASD sufferers is just a subpopulation. The Department of Social Medicine at the University Medical Center Groningen is one of the initiators of the Dutch Research Center for Insurance Medicine.* One purpose of the knowledge centre is to conduct scientific research into the occupational integration of individuals with physical and/or mental limitations. The Dr. Leo Kanner House (LKH) is a partner in the European Skills Lab research project, whose goal is to boost job opportunities for adults with an ASD.[45]

University research into the occupational integration of individuals with psychiatric limitations of varying severity, in more general terms, is also carried out by the University of Tilburg's Scientific Center for Care and Welfare (Tranzo) and by TNO Work and Employment.

Employment experts play an important part in helping ASD sufferers to find work. Employment experts are generally individuals with a higher professional educational (HBO) background who have had supplementary training. Within this discipline, there have recently been moves to further professionalise the occupation of employment expert and to promote the academisation of everyday practice. To this end, the Employment Expert Knowledge Centre Foundation was founded in 2009. Scientific research in the field is conducted in cooperation with various universities. There is also a connection to the Dutch Research Center for Insurance Medicine (KCVG).

4.3.2 *Youth care services*

Youth care services are currently implementing major developments in the areas of academisation and professionalisation.

Since 2009, applied research in the youth care services has been promoted by nine academic collaborative centres in the youth care services, funded by the Netherlands Organisation for Health Research and Development.[46] A wide range of partners (depending on the theme involved) cooperate within the context of these academic collaborative centres. None of these currently have a special focus on the care of young people with ASD. In practice, some themes do have areas of commonality with ASD. For instance, the Nijmegen Inside-Out academic collaborative centre focuses on prevention and care for children with

* The Dutch Research Center for Insurance Medicine is a joint initiative by the Coronel Institute of Occupational Health (Academic Medical Centre, Amsterdam), the departments of Social Medicine at the University Medical Center Groningen and the VU University Medical Center, Amsterdam and the Social Medical Affairs division of the UWV (the organisation for reintegration into the job market and temporary income).

internalising psychological problems, such as anxiety and depression.[46,47] Nineteen partners collaborate within this framework, the Gelderland youth care agency, the Nijmegen Youth and Families Centre, mental health care institutions, the Trimbos Institute, and the HAN University of Applied Sciences.

The professionalisation of youth care services is largely being driven by the Plan of Action for the Professionalisation of Youth Care Services (2007-2010).[46,48] This includes proposals for an occupational structure made up of two profiles. One would be "youth care services worker" at higher professional education (HBO) level, the other would be "behavioural scientist in youth care services", for psychologists and remedial teachers. The goal is to obtain legal recognition for these professions. Details of the Action Plan's proposals are now being fleshed out in the Implementation Plan for the Professionalisation of Youth Care Services.[46,49] The topics to be raised include the establishment of professional registers and disciplinary boards, a registration requirement for all youth care services staff with a background in higher professional education (HBO) and for behavioural scientists working in the youth care services, as well as educational and training activities for registration and reregistration. The Netherlands Youth Institute (NJI) has been tasked with supporting the professionalisation of the youth care services, in the broadest sense.

4.3.3 *Public health*

The child healthcare system has the important task of detecting ASD in young people under the age of nineteen. Using fixed contact times, healthcare workers monitor the development of virtually every child in the Netherlands. At other times, doctors in child health clinics, school medical officers and paediatricians also perform detection and advisory roles in Care Advisory Teams and at Youth and Families Centres. Adults with an ASD may also have dealings with the public mental health care service, concerning issues such as severe psychiatric problems, addiction, and homelessness, as well as in the context of forensic medicine.

Together with the Netherlands Centre for Youth Health (NCJ), professional associations, sector organisations, the Netherlands Youth Institute (NJI), institutions involved in everyday practice, universities and universities of applied sciences, the Netherlands Organisation for Health Research and Development is running a number of programmes to professionalise and academise child healthcare. These include the Innovation in Child Healthcare Operational Practices programme and the Child Healthcare Guidelines programme.[50] These programmes' activities involve the development of detection tools and

guidelines for the use of professional practitioners in child healthcare. This work includes the development of a Multidisciplinary guideline for ASD by the Trimbos Institute.

The public mental health care service academic collaborative centre (G4-USER) has no specific objectives relating to ASD.[51]

4.3.4 *Education*

In its report, the National Plan for the Future of Educational Sciences Committee concluded that education research was fragmented, and that there was a large gap between knowledge production and knowledge utilisation.[52] According to that committee, the users have not yet reached a level of professionalism that would enable them to influence the demand for academic research on the basis of the needs that they have identified in everyday practice. The State Secretary is looking into the possibility of establishing an organisation to coordinate and direct the chain of research, exploitation, dissemination, and implementation.[53]

The Health Council Committee's survey shows that there are few research projects in the field of autism and education. A key player for practice-based research and innovation in education is the Research & Development department of the CED-groep (Educational Services Centre) in Rotterdam. This department has taken on the research tasks that were previously assigned to paedological institutes and professors of remedial education. The department has close ties to Erasmus University Rotterdam. In the field of autism, the CED-groep also works closely with the Erasmus MC and Yulius.

4.3.5 *Mental health care service*

In recent years, the academisation of the mental health care service has been successfully driven by the *GeestKracht* programme, particularly in the form of practical care projects.[15]

This was confirmed by the research survey and by the interviews. Various mental health care institutions have launched initiatives of their own to implement the academisation of everyday practice, in cooperation with a number of universities. The Dr. Leo Kanner House, for example, has established both a chair in autism and an autism research group at the HAN University of Applied Sciences. Four departments at various mental health care institutions have been certified (by the Foundation for Top Clinical Mental Health Care) to care for

autism patients.* This foundation promotes tertiary and top referent care in the mental health care service. One way in which this is done is by the certification of specialised departments that provide patient care in combination with scientific research, innovative treatments and the dissemination of knowledge. There are a number of other initiatives that are in keeping with the goal of academisation. These include CASS18+ (the consortium for autism spectrum disorders in adults), the Dutch Knowledge Centre for Child and Adolescent Psychiatry, and the Dr. Leo Kanner House Netherlands. CASS18+ is a network of professional mental health care service caregivers who are committed to improving the diagnosis and treatment of autism in adults in the Netherlands. The National Expertise Centre for Child and Adolescent Psychiatry is a national network of academic and non-academic institutions. Here, professional practitioners, experts, researchers, parents, and children pool their efforts to develop the scientific support for everyday work in child and adolescent psychiatry. Scientific knowledge of the major themes in child and adolescent psychiatry, including autism, is translated into practical protocols. Dr. Leo Kanner House Netherlands is a franchise partnership of six institutions (mental health care institutions) that offer specialised treatment to ASD sufferers. Research and innovation are part of this partnership.

4.4 Discussion and conclusion

There is a need for professional expertise about autism and for scientifically based knowledge of this disorder in all sectors of society. Previous findings have shown that there is insufficient scientifically based knowledge to provide effective support for those working in everyday practice. Accordingly, it is vital to identify the conditions needed for the development and deployment of such knowledge.

The survey shows that there are substantial differences between domains. In recent years, moves have been made to develop well-founded knowledge in the areas of treatment, support, education, and care. However, some of these projects have been more successful than others, reflecting the extent to which professional practitioners and organisations have made the change to science-based working procedures. The Committee urges that, during the system overhaul, care should be taken to safeguard the professional knowledge about

* Two of these departments are at the Dr. Leo Kanner House (outpatients clinic, and clinical treatment/ treatment carried out on a day-patient basis), the others are at the Lentis and Yulius mental health care institutions.

ASD that the various domains have accumulated over the years. This is not something that will happen by itself, however.

The mental health care service is currently in the vanguard, both in terms of professionalisation and academisation. It has the best prospects for the further development and implementation of scientifically based treatments.

Professional groups are primarily responsible for their own internal professionalisation. However, other professional groups can benefit from the mental health care service's leading position, by cooperating on research and implementation, for example. This is necessary for a number of reasons. For instance, problems with autism are not restricted to the mental health care service, they are increasingly encountered in the areas of support and guidance. For this reason, the same outcome indicators need to be defined in each of the various domains (mental health care service, education, welfare, labour). This would allow autism specialists to develop a common professional identity, while keeping the risk of autism becoming medicalised as small as possible.

Chapter 5

Synthesis – contours of the knowledge infrastructure for autism

Drawing on the descriptions of past academisation programmes (Chapter 2), the research survey (Chapter 3), and details concerning knowledge, practitioners, and everyday practice (Chapter 4), the Committee has distilled a model for the development of a knowledge infrastructure. The usefulness of this model is not confined to the field of autism.

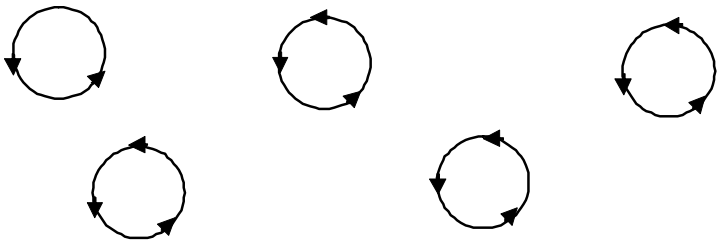
5.1 Model for knowledge infrastructure

Research can be subdivided into academic research and practice-based research. Academic research is carried out at universities or university medical centres. It is mainly driven by curiosity, and often involves fundamental or classical intervention research (Randomised Clinical Trials). It often takes longer for the knowledge generated in this way to be applied in practice. Accordingly, research of this kind is designated by a straight arrow.

Academic research (e.g. aetiology)

In its current form, practice-based research is primarily motivated by specific questions from everyday practice in the areas of support, care, education, and employment. Such research is mainly conducted in the workplace, is small-scale

in nature, and can usually be directly applied in the context of researchers' everyday practices. The Committee takes the view that practice-based research also includes innovation, such as developing concepts for new interventions or novel elements for existing interventions. In many cases, the methodology used in this research has room for improvement. Such researchers are not generally interested in tackling issues more widely, by cooperating with other institutions, professional groups or domains. For this reason, practice-based research is designated by small circles.



Practice-based research (e.g. the use of tools)

The Committee feels that these two forms of research should ideally be interlinked. This would result in different lines of practice-based research being grouped together, thus amplifying their impact. Such practice-based research would also make use of the research methodologies and statistical methodologies that have been developed and validated in universities. This requires those in everyday practice (mental health care service, youth care services, education, labour, care for the mentally disabled, etc.) to familiarise themselves with the requirements of academically based research. By the same token, the university world should also consider ways of applying its methods to practice-based research. Collectively, this is designated as "academisation".

The model can then be represented by the diagram below, with a connection between university research and practice-based research. However, this does not sound the death knell for university research or practice-based research in their present forms. In the Committee's view, the triad is an ideal situation (Figure 1).

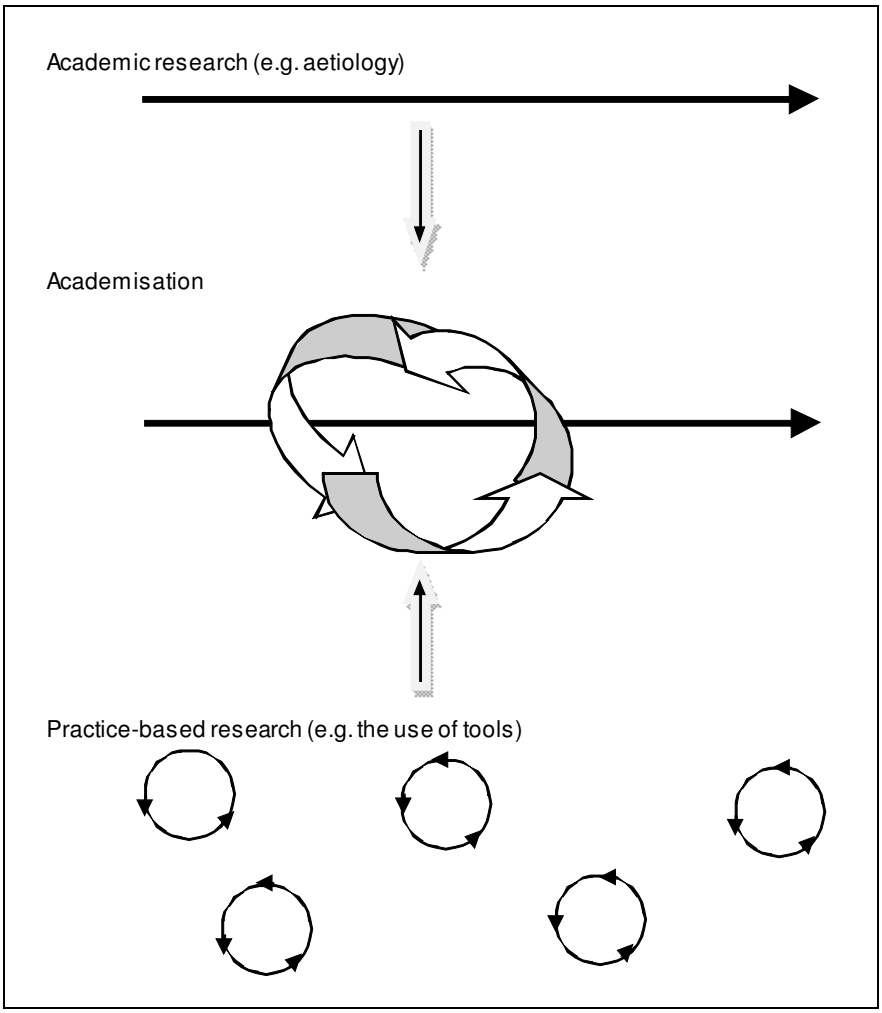
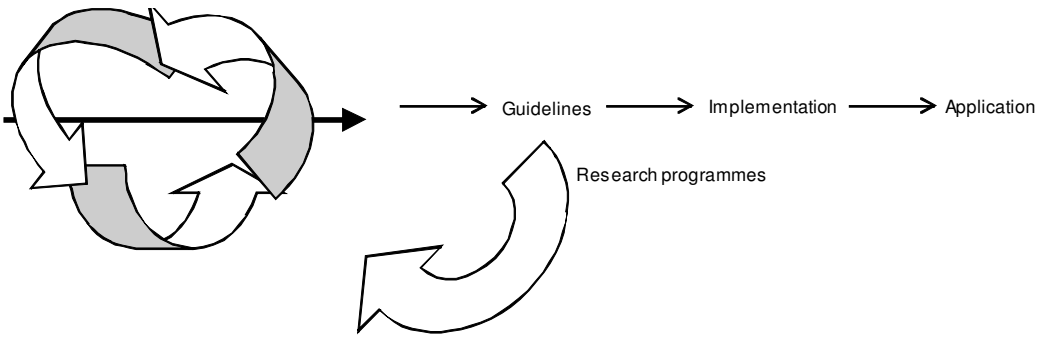


Figure 1 Triad of academisation.

The results of different types of research (fundamental, patient-based, and client-based) can be used as building blocks when knowledge is being accumulated. Ultimately, it can provide a basis for the establishment of guidelines for use in the context of professional practitioners' everyday practices (Figure 2). In this way, guidelines can support the application of new and existing knowledge in everyday practice. The use of guidelines, in turn, generates further research questions by highlighting gaps in knowledge or by bringing entirely new questions to light. For this reason, it is vital that basic training programmes focus



Application in everyday practice:
- Basic training programmes (medicine, higher professional education in nursing, socio-educational workerprogramme, teacher training programmes, etc.)
- Professional identity of autism
- Impact
  - Financial
  - Educational programmes (refresher courses and continuing education)
- Monitors impact of research on everyday practice (less demand for care, behavioral improvement, etc.)

Figure 2 Application of research results in everyday practice.

on research, on the process of guideline development, and on the use of guidelines in everyday practice.

In this way, research and everyday practice will become closely interlinked. As a result, research into (and reflection on) personal activities and procedures will become a permanent feature of professional practice.

The mono-disciplinary guidelines for each profession will be supplemented by multidisciplinary guidelines, which are currently development. Multidisciplinary guidelines in the field of autism spectrum disorders will help to make diagnosis and treatment more uniform. They will also provide an impetus to research within the various professional groups and to multidisciplinary research.

Guideline development is not an end in itself. Guidelines fall within the scope of professional standards. As such, their use in practice is subject to professional judgement and discretion. They also have implications in terms of keeping knowledge up-to-date. This is true not only of individual practitioners but also of the organisations in which they work. Accordingly, this can have an impact on funding (fees, research funds), on training courses (basic training, refresher courses and continuing education), and on an organisation's operating procedures.

Finally, guidelines can be used to monitor the effects of research programmes on the health or welfare of ASD sufferers (in this particular case). However, this

cuts both ways. If those in everyday practice operate according to professional standards (by using guidelines, etc.), then procedures will become more uniform, and effects can be better monitored. As part of the academic cycle, this in turn can provide input for further research.

5.2 Translating the model to the field of autism

The research survey described in Chapter 3 revealed that research into autism spectrum disorders takes place in two separate worlds, academia and everyday practice. The ideal situation, such as that depicted in the centre of Figure 1, is very seldom encountered.

Fundamental research into the aetiology of autism primarily takes place in university medical centres. The studies in question are embedded in lines of research, and are successfully financed by direct and indirect funding. While the results of fundamental research do eventually generate applications in everyday practice, this can be a rather lengthy process.

Institutions involved in everyday practice carry out numerous small-scale studies, however this is rarely embedded in longer-term lines of research. These may occasionally be linked to an academic centre, on an ad hoc basis.

The research carried out in various larger mental health care institutions tends to be closer to the centre of the figure. Lentis (Groningen), Yulius (Rotterdam), and the Dr. Leo Kanner House are just some examples of mental health care institutions that conduct autism research within the framework of long-term relationships with university partners. These examples also serve to illustrate the fact that research in everyday practice is not purely a matter for professional practitioners, it needs to be embedded in the organisation's policies. Clearly, however, the link between everyday practice and academia can and should be improved.

Chapter 6

Conclusions and recommendations

In this chapter, the Committee answers the questions contained in the requests for advice, and makes various recommendations. The Minister's questions concerned the state of research into ASD, and the knowledge infrastructure pertaining to autism.

6.1 State of research into ASD

The Minister's questions concerned the state of research into ASD, and what gaps need to be filled, as a matter of priority. This involves research into the development and validation of tools for the detection and diagnosis of ASD for different age groups. It also involves research into the development and evaluation of ASD interventions (the professional treatment and support of ASD sufferers and their families).

6.1.1 Development of tools for detection and diagnosis

In the context of this advisory report, the Committee has carried out a research survey. This survey did not find any studies into the development and validation of new detection tools* for autism spectrum disorders in children or adults.

* This advisory report will be completed before the publication of the new child healthcare multidisciplinary guideline for autism spectrum disorders in children and young people.

However, the topic of diagnosis is currently being investigated in a number of studies. Some are exploring the quality of observation tools and interview tools, while others are focusing on the further development of questionnaire tools. Such research is currently taking place in Groningen (UMC Groningen and Accare) and Rotterdam (Erasmus MC and Yulius).

Research into the validation of questionnaires is also being conducted by various parties, such as the Lentis Autism Team North Netherlands, in Groningen.

In the context of a broad mental health care service partnership, collaborative research is being conducted into the psychometric properties of a diagnostic tool for adults.

The shortfall in detection tools that was identified in 2009 has still not been completely resolved. Nevertheless, current research is sufficient to resolve the backlog in the diagnosis of adult ASD sufferers.

However, if the current tools are implemented and used systematically, the Committee feels that the development of new tools would not be an immediate priority.

In Section 6.3, the Committee puts forward a number of recommendations for further research and its prioritisation.

6.1.2 Development and evaluation of interventions for autism spectrum disorders

At various institutions throughout the Netherlands, studies are being carried out into interventions to promote the social performance of autism sufferers. This includes a wide range of psychiatric interventions, ranging from psychiatric family treatment to social skills training, from IT applications to play therapy, from research into medicinal products to relationship therapy and interventions in an educational setting. This type of research is mainly carried out by non-university institutions. Such research is generally limited in scope and difficult to fund.

The development of fundamental scientific knowledge about autism is in good hands, and is making promising progress. In the short term, however, this is not expected to generate any results that might help to resolve the personal and social challenges posed by autism.

The social effects of autism simultaneously impact a range of social domains. In each of these domains, a knowledge of everyday practice that is both disorder-specific and tied to the local context is an essential prerequisite for effective action. The changes required (concerning the effectiveness of actions) will be more easily achieved if all stakeholders* are involved in formulating the problem and helping to solve it (implementation).

In recent years, the various domains have evolved to favour knowledge development based on a familiarity with everyday practice combined with scientific scrutiny and reflection. Academic collaborative centres have had a galvanising effect in this regard. Knowledge centres have also played an important part, these include the Dutch Knowledge Centre for Child and Adolescent Psychiatry and the Trimbos Institute, as well as professional networks like CASS18+, and individual care institutions. This is exemplified by the two guidelines that are scheduled for completion in 2012.[2,3] Educational institutions should be more involved in these developments.

The further development of practice-based research can be galvanised by placing greater emphasis on the specific scientific value of this process. This could involve more scope for publishing and distributing research results, as well as greater cooperation between everyday practice and universities. Some other examples would be revised criteria for obtaining research funding, and changes to the DTCs to allow those involved to spend time (which, of course, also means money) on careful observation and recording, both of which are essential aspects of good research. Anyone "owning" specific expertise (professionalism) in autism would also tend to encourage these developments. Sadly, no such "owner" has yet appeared.

Last but not least, professional practitioners in various areas often lack common targets for interventions. They also operate within different organisational and financial constraints. These differences tend to impede both collective professionalisation and the uniform implementation of research findings. For this reason, outcome data in the various domains should be standardised and registered. Caregivers (and the organisations in which they work) can use outcome data collected from patients (or clients) as a benchmark for reflection and improvement. Standardisation can help to boost collective professionalism, while also bridging the spaces between domains.

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* This could involve caregivers, clients, institutional boards and supervisory boards, government bodies, employers, and various agencies.

In Section 6.3, the Committee puts forward a number of recommendations for further research and its prioritisation.

6.2 Status of knowledge infrastructure for professional development in autism

The knowledge infrastructure for professional development in autism is fragmented. There are a number of reasons for this.

Firstly, a wide range of professional practitioners in various domains are involved in the detection and diagnosis of autism spectrum disorders, and in the treatment and support of the children and adults in question. The basic training programmes for these professional practitioners generally make little or no mention of autism. The Dutch Association for Autism is currently cooperating with the Dutch Psychiatric Association to develop an autism module for training programmes in Adult Psychiatry.

Secondly, none of the professional groups or domains have structured systems of refresher courses and continuing education programmes for those professional practitioners who focus on this group of individuals. Many different organisations and institutions do provide programmes of this type, but there is no coordination of the courses on offer. This situation needs to be improved.

6.3 Recommendations

The Committee has based its recommendations on a number of general principles:

- the seeds of knowledge must be sown in fertile ground. This is subject to various constraints, such as the existence of professionalised groups of practitioners
- another constraint is that, in the interests of cross-domain, multi-disciplinary research (including practice-based research), both interventions and the associated outcome indicators must share common goals, to link the different worlds together
- research results should be implemented within a specific context. This requires detailed implementation projects, drawn up in accordance with the requirements of the everyday practice situation in which the intervention or tool is to be used
- once knowledge has been implemented and has conclusively proven its worth in practice, it should preferably be incorporated into formal guidelines.

6.3.1 *Academic collaborative centre*

Firstly, the Committee has formulated a recommendation on Figure 1 in Chapter 5.

The Committee recommends that two academic collaborative centres for autism be established, to deliver quantitative and qualitative benefits in terms of more practically oriented autism research. This would tend to shift it to the centre of Figure 1 from Chapter 5. Two collaborative centres would enable the full breadth of the field to be addressed, provide a degree of geographical distribution, and generate competition in terms of quality.* The Committee defines academic collaborative centres as long-term partnerships that jointly plan and implement practice-based, policy-based, and science-based research projects, with a strong emphasis on applications in everyday practice.

Academic collaborative centres include a range of different partners. Some are institutions involved in everyday practice, with an interest in innovation and research, and a desire to put these activities on a more robust academic footing. Others are universities and university medical centres that want stronger ties between their research activities and everyday practice. Such partnerships should preferably also include other knowledge institutes, umbrella organisations, and universities of applied sciences. They should also maintain contacts with policymakers at local, regional, and national level.

There are two main goals. The first is to bring everyday practice and academia closer together. This would make it easier to coordinate the research being carried out in each of these spheres. It would also enable the researchers involved to profit from one another's experience and expertise. The second goal is to streamline and improve the professionalism of practitioners at institutions involved in everyday practice.

In this connection, the Committee envisages a competitive programme for partnerships that aspire to the status of an academic collaborative centre.

The Committee suggests that registration be subject to the following conditions:

- all of the participants in partnerships registering for this scheme must be stable

* In these times of straightened research funding, the Committee believes that it would not be feasible to establish more than two academic collaborative centres.

- at least one participant in each partnership should have solid, long-standing, in-house expertise in the field of autism
- the party initiating the proposed academic collaborative centre should preferably be an institution involved in everyday practice
- any such academic collaborative centre must engage with existing care structures in each of the relevant domains
- given the specific and distinctive features of autism, the Committee recommends that these proposed academic collaborative centres should focus exclusively on this topic
- in principle, at least one of the prioritised topics listed in this advisory report should be tackled by researchers at the academic collaborative centres
- in addition to research, academic collaborative centres are charged with the professionalisation of autism caregivers. Certification of the autism domain of expertise might be useful in this regard
- it is recommended that pre-existing partnerships be incorporated into the academic collaborative centres

6.3.2 *Community of practice for autism*

Secondly, the Committee wants to make recommendations for strengthening the second part of the model described in Chapter 5 (Figure 2).

The requisite knowledge infrastructure would allow those in everyday practice and academia to work together effectively and to take full advantage of one another's input. Building such an infrastructure requires professional practitioners and researchers who are both motivated and enthusiastic. At present there is no obvious context in which these professional practitioners and researchers can encounter one another. Meetings held in the context of everyday practice are not attended by university researchers. By the same token, caregivers working in the field of everyday practice do not attend scientific conferences. Even autism researchers do not automatically encounter one another in existing contexts.

As an incentive to the interchange and coordination of supply and demand, the Committee recommends that a community of practice for autism be established along the lines of the former communities of practice set up by the Netherlands Organisation for Scientific Research.

This community of practice is for anyone working in the areas of autism support, treatment, or research. In this way, the community of practice could acquire virtual “ownership” (as previously mentioned) of specific expertise (professionalism) in autism. The community of practice would stage two-day

annual meetings, at which various ideas and research projects could be presented and discussed. In this way, ideas could be gleaned from those working in everyday practice and further refined into solid research proposals. The reverse is also true. Research results could be discussed in this setting, to facilitate their implementation in everyday practice.
The community of practice could also publish a compilation of ongoing and recently completed research, which would also cater to the publication of studies with negative results. This community of practice could also maintain a research database, containing up-to-date details of all ongoing research in the Netherlands. The HoorPlatform (Hearing Platform) has been using a database of this kind for several years now.[54] These facilities complement the publication options offered by mainstream scientific journals, which do not (as yet) focus on publishing practice-based research or studies with negative results.

Autism sufferers themselves, or their representatives (such as Balans or the Dutch Association for Autism) could also get involved in the community of practice by helping to identify key requirements. Research projects could then be tailored to these needs. Within the community of practice, patient organisations could then assess the reliability of this information on behalf of their members.

Improving the knowledge infrastructure for professional practitioners, while enhancing the quality of all aspects of autism research, could also improve the provision of information to autism sufferers and their families. The development of evidence-based treatment and support will ultimately cause details of ineffective or insufficiently substantiated interventions to be eliminated from the information provided.

The Committee sees this as a task for the therapists and carers of autism sufferers. More particularly, it is also a job for knowledge centres, for the information contact points of local, regional, and national governments, and for parent associations and patient associations (such as the Dutch Association for Autism and Balans). The parent associations and patient associations have a special responsibility with regard to selecting and providing information for their members, given their close relationship to these individuals.

An invitational conference was staged by the Dutch Association for Autism at the end of 2011, to coincide with a visit to the Netherlands by Autism Speaks. This conference, which was attended by researchers, policymakers, and patient representatives, could serve as an example for the community of practice.

6.3.3 *Prioritisation of research*

Finally, the Committee wants to influence the direction of autism research in the Netherlands by formulating various research prioritisation criteria, and by taking the first steps towards establishing a research agenda based on the research survey's findings. These criteria and the research agenda can be used by the proposed academic collaborative centres.

Prioritisation criteria:

- assessing the impact of research results
  - expected level of improvement in target group performance
  - size of target group
  - expectations regarding long-term effect
- opportunities for establishing partnerships between everyday practice and academia
- experience with type of research in question
- opportunities for widespread implementation.

Research agenda:

- Use of system overhaul as a natural experiment
  The impending system overhaul presents a unique opportunity for a natural experiment. The system overhaul will cause domains to converge, and will require them to cooperate closely with one another. In many areas, there is a debate about the impact of system changes on individuals with limitations, and thus on autism sufferers as well. A baseline study is needed among children, adolescents, young adults, and adults, with annual follow-ups. This would enable the effective monitoring of the negative and positive impacts of the system overhaul in education (Appropriate Education), sheltered work (the Employment Capacity Act), support (youth care services, Social Support Act) and treatment (youth mental health care services, Exceptional Medical Expenses Act). The results could then be used as an aid to any subsequent adjustments. People with autism spectrum disorders are ideally suited as research subjects for this experiment. This is because they are affected by each of the domains that are scheduled for a system overhaul, and because any effects on their performance will be immediately apparent.

- Effectiveness study
  The research survey revealed that there is a great need for research into effective interventions for the treatment and support of autism sufferers. Such research currently takes place on a limited scale, and is characterised by a lack of methodological validity. Accordingly, priority should be given to robust effectiveness research that is grounded in practice-based results. This is also a means of eliminating ineffective interventions from care provision once and for all. It will also greatly improve the cost effectiveness of treatment and support for this group.

- Implementation tools for detection, screening, and diagnosis
  There is already a wide variety of validated implementation tools for detection, screening and diagnosis. Such tools are not in universal use, however, nor are they always used correctly. It is recommended that steps be taken to promote the implementation of these tools. Research into new tools (see the details of deficiencies identified in 2009) would certainly be helpful, but this is not currently a top priority.

- Action-oriented diagnosis
  In anticipation of the upcoming publication of DSM 5 and the scheduled system overhaul, efforts should be made to promote (and to further develop) action-oriented diagnosis. Action-oriented diagnosis is an essential element of effectiveness studies, and is also needed for follow-up research over the longer term.

- Course of life and transitions
  Course of life and transitions are situations that ideally lend themselves to research involving action-oriented diagnosis, effectiveness studies, and cross-domain partnerships.

6.3.4 *Funding*

The Committee proposes that the above recommendations be funded as follows.

With regard to the establishment of academic collaborative centres, the Committee favours a procedure employed by the Netherlands Organisation for Health Research and Development, in which the latter organisation allocates Ministry of Health grants on the basis of competition. In terms of funding, the Committee considers that € 800,000 euros would be required over a period of four years. This equates to two PhD studentships at each academic collaborative

centre , each costing € 200,000. Fifty percent of the funding would have to come from the partnership's own resources.

The community of practice would also need support at national level, by means of an incentive grant.

The Committee appeals to various ministries to fund the natural experiment involving the impending system overhaul. The departments in question are the Ministry of Health Welfare and Sport (youth care services, youth mental health care services, Exceptional Medical Expenses Act), the Ministry of Education, Culture and Science (Appropriate Education) and the Ministry of Social Affairs and Employment (the Employment Capacity Act*). One option would be for these three ministries to each appoint a PhD student for that part of the system overhaul that affects them. This would involve a sum of € 200,000 for each ministry.

* See footnote on page 49.

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Annexes

Annex **A**

Request for advice

Letter dated 12 October 2010 (reference DJ enG/SenS-3023773) from the former Minister for Youth and Families to the President of the Health Council.

In a society that increasingly relies on flexibility, social skills, and communication skills, people with autism spectrum disorders (ASD) find it difficult to keep up. Sadly, there is currently no cure for ASD. Nevertheless, there treatments and types of support available that can help ASD sufferers to participate as fully as possible in family life, education, employment, and other social activities, in spite of their limitations. To this end, their ASD needs to be detected in time, and then diagnosed. As yet, however, few details are available concerning detection and diagnostic tools, and about potential interventions. Hence the need for research, and for the results obtained to be brought to the attention of professional practitioners in the care and education sectors.

In view of this state of affairs and given the generally perceived importance of promoting social participation for those who are too often involuntarily sidelined, I would like to take this opportunity to request an advisory report (as previously announced in my response to the Health Council's advisory report entitled Autism Spectrum Disorders: a lifetime of difference) on behalf of myself and my colleague at the Ministry of Health, Welfare and Sport.

I would like to submit the following questions to you:

- What is the nature of the knowledge infrastructure for the professional development of practitioners with regard to the detection, diagnosis, treatment, and support of ASD sufferers?

Does this knowledge infrastructure need to be improved and, if so, which specific improvements should take priority?

- Is there any ongoing research into the development and validation of tools for the detection of ASD in 2-4 year-olds, adolescents, and adults? Are there any topics in this area that are not currently the focus of research, but which deserve to be given priority? Is there any ongoing research into the development and validation of tools for the diagnosis of an ASD, particularly in adults? Are there any topics in this area that are not currently the focus of research, but which deserve to be given priority?
- Is there any ongoing research into the development and evaluation of interventions for ASD? In this context, by "interventions for ASD" I am referring to all forms of professional treatment and support that focus on ASD sufferers, their close friends and relatives, or others in their circle of acquaintances, and which are aimed at enhancing the social performance of ASD sufferers. Are there any topics in this area that are not currently the focus of research, but which deserve to be given priority?

Here, I am using the term "ASD sufferers" to specifically denote those who, in addition to an ASD, are suffering from disorders such as intellectual disability or some other psychiatric disorder.

When preparing your advisory report, please cooperate with organisations such as the Dutch Knowledge Centre for Child and Adolescent Psychiatry, the Netherlands Effective Youth Care Services Partnership (SEJN), the Netherlands Youth Institute, the Dr. Leo Kanner House, the Dutch Association for Autism, and the National Autism Network. Also, please give due consideration to ongoing research programmes being conducted by the Netherlands Organisation for Health Research and Development, the Netherlands Brain Foundation, and other organisations. In addition, when preparing your advisory report, I would ask you to involve appropriate organisations in the areas of education and employment.

I look forward receiving your advisory report in the autumn of 2011.

(signed)
The Minister for Youth and Families,
A. Rouvoet

Annex **B**

The Committee

- Prof. L.J. Gunning-Schepers, *chairperson*
  President of the Health Council (until 1 April 2012); President of the Board of Directors of the University of Amsterdam and Amsterdam University of Applied Sciences (as of 1 April 2012), Professor of Health and Society, University of Amsterdam
- Prof. R.W.B. Blonk
  Professor of Clinical Psychology, TNO Healthy Living, Hoofddorp
- A.A. van Dijk, M.Sc.
  Clustermanager Research and Development, Dr. Leo Kannerhuis, Doorwerth
- Dr. Y.M. Dijkxhoorn
  Educational and Family Psychologist, Lecturer of Educational and Family Psychology, Ambulatorium Faculty of Social Sciences, University of Leiden
- Dr. M. de Graaf
  Project leader Effective Youth Interventions Database, Expertise Centre for Youth & Education, Netherlands Youth Institute, Utrecht
- S. Hasper-Sitton, M.Sc.
  Project leader National Autism Network, Utrecht
- Dr. C.C. Kan
  Psychiatrist, Lecturer of Psychiatry, University Medical Centre St. Radboud, Nijmegen
- F. Stekelenburg
  Director, Netherlands Association for Autism, De Bilt

- Dr. J.P. Teunisse
  Clinical Neuropsychologist, Lecturer of Life Coaching, Arnhem and Nijmegen University of Applied Sciences
- Prof. M.J. Trappenburg
  Professor of Socio-political Aspects of the Welfare State, University of Amsterdam.
- Prof. F.C. Verhulst
  Professor of Child and Adolescent Psychiatry, Erasmus Medical Centre/ Sophia Children's Hospital, Rotterdam
- G. Ruis, M.Sc., *observer*
  Ministery of Health, Welfare and Sports, The Hague
- Dr. V.W.T. Ruiz van Haperen, *scientific secretary*
  Health Council of the Netherlands, The Hague
- F.M. Westerbos, physician, *scientific secretary*
  Health Council of the Netherlands, The Hague

The Health Council and interests

Members of Health Council Committees are appointed in a personal capacity because of their special expertise in the matters to be addressed. Nonetheless, it is precisely because of this expertise that they may also have interests. This in itself does not necessarily present an obstacle for membership of a Health Council Committee. Transparency regarding possible conflicts of interest is nonetheless important, both for the chairperson and members of a Committee and for the President of the Health Council. On being invited to join a Committee, members are asked to submit a form detailing the functions they hold and any other material and immaterial interests which could be relevant for the Committee's work. It is the responsibility of the President of the Health Council to assess whether the interests indicated constitute grounds for non-appointment. An advisorship will then sometimes make it possible to exploit the expertise of the specialist involved. During the inaugural meeting the declarations issued are discussed, so that all members of the Committee are aware of each other's possible interests.

Annex C

Experts consulted

- Dr. C. Aerts, Psychiatrist, Dr. Leo Kannerhuis, Doorwerth
- I. van Balkom, Director Treatment Affairs GGZ Lentis, Groningen
- Dr. S. Begeer, Psychologist, VU University Medical Centre, Amsterdam
- M. Beckers, Advisor, Netherlands Centre for Youth Healthcare, Utrecht
- H. Bijl, Staff Member Research and Development, CED-groep, Rotterdam
- S. Brands, Manager, Dr. Leo Kanner House Brabant, Goirle
- L. Broersen, Manager Centre for Autism, Centre for Mental Health Care Noord-Holland Noord, Alkmaar
- Dr. S. Brouwer, Assistant Professor of Occupational Medicine, Groningen University
- Prof. J. Buitelaar, Professor of Child and Adolescent Psychiatry, Karakter / University Medical Centre St. Radboud, Nijmegen
- B. Carmiggelt, Physician for Child Health, Netherlands Centre for Child Health, Utrecht
- Drs. A. Cuppen, Occupational Expert, UWV, Utrecht
- F. Dekker, Insurance Physician, UWV, Utrecht
- Prof. R. Didden, Professor of Intelectual Disabilities, Learning and Behaviour, St. Radboud University, Nijmegen
- Prof. I. Engelhard, Professor of Clinical Psychology, Altrecht, Utrecht University
- Dr. A.M. van Elburg, Child- and Adolescent Psychiatrist, Altrecht; director Netherlands Academy for Eating Disorders, Utrecht

- Prof. H. Geurts, Professor of Autism, University of Amsterdam on behalf of Dr. Leo Kannerhuis Foundation
- Dr. K. Greaves-Lord, Senior Researcher, Yulius / Child and Adolescent Psychiatry Erasmus University Medical Centre, Rotterdam
- N. Hofman, coordinator Regional Autism Network Zuid-Holland Zuid, Hendrik-Ido-Ambacht / Rotterdam
- Dr. J. Isarin, Senior Researcher, Kentalis / PonTem, Sint Michielsgestel
- E. Kalsbeek-Jasperse, president of the board, Altra, Amsterdam
- M. E. van Liere, Regional Insurance Physicians, UWV, Utrecht
- Dr. A. Maras, Psychiatrist, Director Yulius Academy, Rotterdam
- Prof. R.B. Minderaa, Emeritus Professor of Child and Adolescent Psychiatry, Accare / University Medical Centre Groningen
- B.H.F. de Mol, Director RINO group, Utrecht
- Prof. F.J.N. Nijhuis, Professor of Inclusive Labour Organisations, CAPHRI, Maastricht University
- D.A. Rodenburg, Lecturer RINO group, Utrecht
- P. Rodenburg, Occupational Physician, Chairman Netherlands Association for Occupational and Industrial Medicine, Utrecht
- Prof. H. Savelkoul, Professor of Cell Biology and Immunology, Wageningen University
- Dr. F. Scheepers, Psychiatrist, University Medical Centre, Utrecht
- M. Schipper, Policy Officer Netherlands Association for Autism, De Bilt.
- Dr. A. Sizoo, Psychiatrist, Dimence, Deventer
- Dr. A. Spek, Psychologist, Mental Health Care Eindhoven
- Dr. C. Struiksma, Senior Researcher, CED-groep, Rotterdam
- V. Verschoor, Secretary Academic Collaborative Centres for Youth, The Netherlands Organisation for Health Research and Development, The Hague
- F. Visser, Manager Philps Employability Center, Eindhoven
- Dr. L. de Vries, Director Netherlands Association of Community Health Services, Utrecht
- J. Wichers-Bots, Lecturer/Researcher Special Educational Needs, Teaching Centre Special Educational Care, University of Applied Sciences Fontys, Tilburg
- Prof. J. van Weeghel, Professor of Rehabilitation, Tranzo, Tilburg University
- Prof. H. Wubbels, Professor of Educational Science, Utrecht University
- Prof. T. van Yperen, Professor of Research and Development Effective Youth Care on behalf of the Netherlands Youth Institute Foundation, Utrecht

Annex **D**

Research survey procedure

Procedure

For the purposes of the research survey, the Committee approached a large number of researchers in the field of autism spectrum disorders (Annex C). The names of these individuals were put forward by the committee members' networks, by the Health Council itself, and by various researchers who had already been approached.

The researchers were first asked whether they were willing to assist the Committee with the survey. Those who indicated that they were prepared to do so were then sent a questionnaire (see below). All of those who completed the questionnaires were then given a personal interview, during which any ambiguities were discussed. The researchers were also asked for their views concerning the knowledge infrastructure, and for suggestions on how it might be improved.

The research survey was carried out between October 2011 and April 2012.

Questionnaire

Institution:

Project name or line of research:

Research question (or questions) addressed by the study:

Type of research:

Topic (tick box, it is possible to give more than one answer):

- ☐ aetiology (into the causes of autism)
- ☐ epidemiology (into prevalence, comorbidity, etc.)
- ☐ diagnosis
- ☐ prognosis
- ☐ intervention research
  - ☐ development of new interventions
  - ☐ effectiveness of current interventions
- ☐ implementation studies (rollout of interventions, methods)
- ☐ the significance of autism in terms of the patient's capabilities and limitations
- ☐ the significance of autism in terms of the patient's ability to take their place in society
- ☐ other, for instance …..

Methodology (tick box, it is possible to give more than one answer):

- ☐ basic (explain)
- ☐ epidemiological
- ☐ descriptive evaluation study
- ☐ quantitative evaluation study; randomised? Yes/No
- ☐ efficiency study
- ☐ qualitative study, for instance .....
- ☐ other, for instance ……..

Domains (tick box, it is possible to give more than one answer):

- ☐ clinical
- ☐ education
- ☐ labour
- ☐ other social domains (self-reliance, family life, etc.)

Funding:

Amount:

Source/type of funding*:

Duration of funding:

Staff

Total size (FTE):
Professional groups involved

Cooperation

Does the research involve cooperation with other institutes/institutions? Yes/No
If so, which ones?

Evaluation and implementation

Has a final report of the study been prepared? Yes/No
If so, what form did this take?
Are there any plans to publish the study's results? Yes/No
If so, what form will this take?
Can these findings be generalised, for those in the wider field of study?

Research gaps

Are you aware of any issues that are not currently being addressed by autism research?
Substantive:
Methodological:

Research priorities

In your view, which aspects of autism research should be given priority?
Most urgent:
Most valuable:
Most promising:

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* Direct government funding: non-earmarked public funding (Ministry of Education, Culture and Science).
Indirect government funding: earmarked public funding (The Netherlands Organisation for Health Research and Development, the Netherlands Organisation for Scientific Research).
Contract funding: funds, private foundations.
Industrial funding: industry.

Annex **E**

Analysis of knowledge infrastructures

Addiction

SGO analysis[29]

The SGO Health Research Promotion Programme advisory group concluded that the world of addiction research is very complex. It involves an extensive and poorly coordinated range of agencies and organisations, each with distinct concerns and/or interests of their own. The advisory group found that research and funding are both very fragmented. This is largely a result of the sheer complexity of the addiction issue. Its multifaceted nature had generated numerous research priorities in areas such as epidemiology, medicine, economics, law, and criminology. In terms of patient care, however, the lack of harmonisation, coordination, and concentration was a real problem.

1986 advisory report

One recommendation was that a national focal point of addiction research should be established. Another was that expertise in research and treatment should be pooled and strengthened. It was also pointed out that the training of researchers and clinicians needed to be improved. Finally, it was recommended that a network of addiction researchers and institutions be created. The Amsterdam Institute for Addiction Research (AIAR) was established for the provision of

patient-based research, education, and training. The Platform for Socio-Epidemiological Addiction Research (a Rotterdam-based partnership) was tasked with harmonising and coordinating the research activities of its affiliated institutions. It was also asked to generate proposals for studies in which the member institutions could cooperate, and to promote the exchange of knowledge and educational activities between the participants. The Addiction Research programme was launched in 1992.

Programme and evaluation (1996)[55,56]

The AIAR programme delivered good results, but it was strongly focused on fundamental research. The close partnership between the University of Amsterdam/Academic Medical Center, the Jellinek Clinic, and the AIAR was instrumental in establishing a broad multidisciplinary partnership, in completing numerous research projects, and in training researchers. The embedding of the AIAR study in two faculty (or inter-faculty) research groups also helped in this regard. Once again, there was too little emphasis on applied research. Having no research budget of its own, the Platform for Socio-Epidemiological Addiction Research was restricted to a limited role, coordinating and encouraging various activities. This not only rendered the Platform unnecessarily vulnerable and dependent, it also thwarted attempts to develop a clear, substantive, and strategic profile.

Follow-up

In collaboration with the Netherlands Organisation for Scientific Research, the Netherlands Organisation for Health Research and Development launched an Addiction programme (1997-2004). Its goal was to bridge the gap between fundamental research, applied research and the everyday practice of addiction treatment and care, and prevention.[25] Ninety-six projects were carried out in the context of this programme, boosting the level of cooperation between researchers in different disciplines, academic institutions, and practice-based organisations. In 1999, the Netherlands mental health care service launched its "*Resultaten scoren*" (Get results) programme.[57] The goal was to use science-based interventions to improve the quality, accessibility and effectiveness of prevention, treatment, and care. In 2005, the Evaluation Committee was very positive about the gains achieved by the Addiction programme. However, it also noted that academisation had not yet made significant inroads into the field of addiction treatment and care.[25] The Evaluation Committee ascribed this to the

fact that addiction research was neither a regular nor a substantial part of the scientific enterprise. At that time, there were still very few chairs in the field of addiction, there was a total lack of clinical academic addiction treatment and care, and there were no university-based or professional training programmes for addiction counsellors or addiction specialists. While mainstream universities and universities of applied sciences had started to offer modules in addiction treatment and care, these devoted scant attention to research methods and techniques. The Addiction programme was followed by the Netherlands Organisation for Health Research and Development's Risk Behaviour and Dependence Programme (2005-2012).[19,23] One goal was to acquire a knowledge of the mechanisms involved in the development and maintenance of addiction. Another was to harness such knowledge in everyday practice, through the use of effective interventions. A final objective was to further strengthen the existing infrastructure in addiction research and everyday practice. Despite a rapid growth in scientific knowledge about the causes of addiction and the risk factors involved, there is still a relatively poor understanding of how to achieve successful prevention and treatment.[14] The postgraduate Master's in Addiction Medicine programme was established in 2007 for physicians who wished to train as addiction specialists. An addiction treatment and care research group has also been set up.[58,59]

Rehabilitation

Advisory Council on Health Research Analysis[7]

In the mid-1970s, rehabilitation medicine was mainly concentrated in rehabilitation centres. Furthermore, there was virtually no academic infrastructure for patient-based research. As a result, rehabilitation medicine developed a strong focus on providing services to those in everyday practice, while research and education languished in the background. The effects of many interventions were not understood in any detail, nor were there any reliable measuring tools. At that time, too, recovery processes were poorly understood and reliable epidemiological data was in short supply. Rehabilitation research, in the broadest sense of the term, was carried out in many different places. These included medical schools, technical faculties, rehabilitation institutions, non-medical departments (Psychology) and non-university departments. Work was in progress on a range of uncoordinated themes. The implementation of knowledge was hampered by the gulf between the university world and rehabilitation institutions. The latter suffered from a poorly developed scientific attitude and

approach to work, while researchers were largely out of touch with the issues encountered in everyday practice.

1997 advisory report

The Advisory Council on Health Research recommended that the rehabilitation centres be academised. To this end, they could enter into regional partnerships with university centres at their core. As part of this process, they would reach clear-cut agreements about research, education, training and top-quality patient care. It was assumed that this structure would encourage those working in everyday practice to submit ideas for research, which would then be carried out in their own institutions. To ensure the continuity of such studies, it was necessary to train a body of individuals with the potential to become talented, senior rehabilitation researchers. The Advisory Council on Health Research also recommended that the available knowledge in a number of substantive themes be expanded, to facilitate the development of reliable measuring tools and to support the implementation of effectiveness studies.

Programme and evaluation

The 1998-2005 rehabilitation research programme was funded from sources such as the Association of Rehabilitation Institutions in the Netherlands and various funds. The programme was implemented by the Netherlands Organisation for Health Research and Development. The external Evaluation Committee concluded that a large number of the objectives had been achieved.[13] The infrastructure was greatly improved by increasing the number of chairs in Rehabilitation Medicine from three to ten. Also of great benefit in this regard were the cooperation agreements signed by universities/rehabilitation departments at university hospitals (11) and rehabilitation centres (21) and general hospitals (8). Rehabilitation research was clustered around eight themes. The programme had boosted multidisciplinary collaboration, and created a greater willingness to jointly fund follow-up programmes. The scientific gains were also substantial. Numerous scientific publications and dissertations were published, and these in turn gave rise to various protocols and guidelines, as well as to a couple of dozen measuring tools. The measuring tools were used in research and needs assessment, as well as for identifying and predicting subjects' performance. Some of the objectives were not met in full. For instance, no structure was created within which the research results could be implemented. The Evaluation Committee took the view that an essential prerequisite for this

was the coordinated training of competent researchers and caregivers. While the field of rehabilitation medicine had made up much of the backlog in 2006, it was concluded that this was still insufficient to make it fully competitive with other areas of research.

Follow-up

The second rehabilitation research programme was launched in 2006.[22] It was substantially expanded in 2008, with the aid of grants from private funds. Its term was also extended by moving the completion date forwards, from 2010 to 2012. The second programme's main objectives are the further strengthening of multidisciplinary rehabilitation research in the Netherlands, and continuation of the research infrastructure. Based on three individual themes, these objectives are being translated into studies of the effect of interventions in rehabilitation.

Mental health care service

Advisory Council on Health Research Analysis[8]

The Advisory Council on Health Research found that the mental health care service lagged far behind somatic care in terms of scientific research. Research in the mental health care service was fragmented and there was a shortage of scientifically trained researchers. It also identified a gap between research and everyday practice. As a result, new knowledge had too little impact on the quality of care. Correspondingly, questions being asked in everyday practice were not being adequately taken up by those involved in research.

1999 advisory report

The Advisory Council on Health Research recommended that knowledge should be enhanced, and that the research and knowledge infrastructures should be strengthened. This involved an ambitious programme focused on the incentivisation and scheduling of research into four specific disorders. These were common disorders, distressing to the patients concerned and to those around them, in addition to being associated with major healthcare and societal expense. The programme should focus on healthcare research, efficiency studies, and longitudinal multidisciplinary research, and should involve a balance of fundamental, strategic and applied research. The Advisory Council on Health Research also assigned high priority to the further development of a research

infrastructure. To this end, it recommended that university research capacity be further developed, and that the synergy between universities and national research institutes be strengthened. It also suggested that partnerships between universities and mental health care institutions should be encouraged, and that support should be given to developing training opportunities and career paths within the mental health care service. The Advisory Council on Health Research also recommended that a division of labour within the programme should be actively encouraged.

Programme and evaluation[9,15,17,60]

The *GeestKracht* programme started in 2001, with an initial completion date of 2010, and an extension until 2013. Its initial budget was € 24 million, however there was the option of increasing this several times over by awarding additional grants during the course of the programme. These funds were channelled into three sub-programmes.

INFRA (the sub-programme on infrastructure) addressed the objectives of enhancing knowledge, knowledge implementation, and augmenting the knowledge infrastructure. To this end, three consortia were selected, each with its own theme. These were psychosis (Group), child and adolescent psychiatry (CAP), and depression and anxiety (Netherlands Study of Depression and Anxiety – NESDA). The consortia in question would be enduring, multidisciplinary partnerships involving research groups from several different universities (and faculties), non-university research institutes, institutions involved in everyday practice, and knowledge centres.

At the heart of the practical care projects (PZP) are the promotion of applied research, knowledge transfer to everyday practice, and implementation. This involves demand-driven care from the client's perspective, drawing on evidence-based or consensus-based interventions wherever possible.

The sub-programme on research training (OOG) focuses on strengthening the infrastructure by boosting the potential of scientifically trained clinicians working in everyday practice.

In approving of the programme, the external Evaluation Committee identified a number of strengths. One was that the programme limited itself to just a few key issues, another was that it helped to strengthen the infrastructure. The Committee

also saw the link between research and practice as beneficial, as was the long-term nature of the programme itself. The consortia had boosted research cooperation to a higher level, made up much of the knowledge backlog, and had established an enduring partnership within the mental health care service. Practical care projects have proved to be an important vehicle for cultivating the interest and involvement of major peripheral mental health care institutions in high-level research. In addition, the target for the number of researchers (OOG) was met and significantly surpassed.

The Evaluation Committee also had a number of comments and points of criticism. For instance, there could have been more emphasis on translating the consortia's scientific results into everyday practice, and on the objectives of multidisciplinarity. One consideration when formulating the latter objective was the important part played by primary health care in the mental health care service, which was not fully addressed in the programme. The practice-care projects had indeed been an important factor in involving peripheral mental health care institutions in research work. However, there was still too little thematic cohesion between projects, client organisations were not sufficiently involved, and no adequate measures had been taken to safeguard the partnership's continuity. While targets were achieved, in terms of the number of researchers involved, much of the research they were doing was not prompted by issues encountered in everyday practice, instead it was part of the standard research "band-wagon". This has probably done nothing to improve the researchers' awkward position with regard to those in clinical practice.

Public Health knowledge infrastructure

Advisory Council on Health Research Analysis[9]

The request for advice was prompted by social and scientific developments that led to a shift in thinking, from disease-oriented to health-oriented, from cure to prevention. One of the related areas of knowledge was public health. In this area, the Advisory Council on Health Research identified gaps in both the acquisition and application of knowledge. Here too, the research carried out in universities and elsewhere was spread across a wide spectrum of subjects. Moreover, public health research was not effectively embedded in the university system. The largest gaps in the research effort were found in the field of intervention research. They involved the effectiveness of measures in the areas of health protection, health promotion, and disease prevention.

2003 advisory report

The Advisory Council on Health Research recommended that public health should be more effectively embedded in the academic world. All university medical centres should include departments headed by professors in this field. A body of talented public health researchers should also be created. In the short term, it was considered necessary to set up academic collaborative centres for social medicine/public health, to improve the connection between everyday practice and education. Infrastructures of this kind were intended to connect everyday practice, policy, research, and education. This, it was claimed, would lead to the academisation of the public health sector. In this case, "academisation" is intended to mean that agencies working in the area of public health (mostly municipal medical and health services) should adopt more evidence-based procedures, that research institutes carry out more demand-driven research, and that there should be an effective interaction between the two.

Programme and evaluation

The Netherlands Organisation for Health Research and Development's first Academic Collaborative Centres for Public Health programme (AWPG) was launched in 2005, and ran for a period of four years. Nine academic collaborative centres for public health have been established since 2006. An important aspect of this was the strengthening of contacts between the municipal medical and health services and the universities. The projects in question concerned infectious diseases, health promotion, child healthcare, and medical environmental science. The programme was given a positive evaluation. However, it was necessary to grant a four-year extension, as the initial period was too short for the requisite changes to take effect.[9,9,26,28,61]

Follow-up

One of the main objectives of the academic collaborative centres for public health's (AWPG) Follow-up Programme (2009-2012) is the structural embedding of the various infrastructures. Another is the safeguarding of results from studies and projects. The third prime objective is to expand and scale up the existing academic collaborative centres for public health.[62 20]A new academic collaborative centre for public health has been established for the mental health care service. The parties involved include the municipal medical and health

services in each of the Netherlands' four major cities – Amsterdam, The Hague, Rotterdam and Utrecht. An important point here was that the local authorities are involved, both as a principal and a partner, in academisation and embedding, and that they take joint responsibility for this process. It was also important that the "academised" municipal medical and health service should perform its advisory role assiduously and in close consultation with the local authority.

Individuals with intellectual disabilities

Advisory Council on Health Research Analysis[6]

In the Netherlands, there are more than one hundred thousand people with intellectual disabilities. To a greater or lesser extent, these individuals all need support in their daily lives. Carers from a wide range of disciplines provide this support for those with intellectual disabilities. These include physicians, paramedics, psychologists, remedial teachers, mainstream teachers, counsellors, parents, and informal carers. In 2005, the specialism of "physician for the mentally handicapped" (AVG) had only recently been recognised. It was still undergoing a process of emancipation, as had previously been the case with disciplines such as rehabilitation medicine. The Council also noted that only a few physicians for the mentally handicapped were actively involved in research work. The care system for the mentally handicapped had no specialist postgraduate training programmes for graduate remedial teachers and psychologists. Graduate behavioural experts working in everyday practice had no strong affinity for research. The scant amount of scientific research that did take place was scattered, and was conducted in faculties of Medicine and Behavioural Science, non-university research institutes, and various care institutions. The research groups involved tended to be small, and the studies in question embraced a wide range of themes that lacked any clear coherence. Furthermore, there was an almost total lack of structural cooperation and coordination between these researchers. However, a few care institutions did fund chairs. This was seen as a form of cooperation between the institutions and universities in question. Some of these institutions served as extramural workplaces for hospitals. There was a very poor connection between science and everyday practice. The limited financial resources available were a major barrier to research.

2005 advisory report

The Advisory Council on Health Research recommended that knowledge be developed by concentrating research within the overarching theme of Course of Life and Phases of Life. It also suggested that parent associations and client associations should play an important part in formulating research questions. It was recommended that two permanent chairs be established to further the process of academic embedding. The intention was that these chairs should serve as focal points for all kinds of research, preferably conducted in a multidisciplinary context. Finally, the Advisory Council on Health Research recommended that research training programmes be provided for practitioners working in everyday practice. The Advisory Council on Health Research recommended that a budget of seven to eight million euros be allotted for a programme lasting six to eight years. A substantial portion (40-50%) of the cost would be co-financed by institutions involved in everyday practice.

Programme and evaluation[21,63]

The Minister initially allotted a budget of two million euros to the Netherlands Organisation for Health Research and Development, for a period of four years. During the lifetime of the project, this amount was increased by a further 1.3 million euros. Given the limited time and financial resources available, the Netherlands Organisation for Health Research and Development focused on specific targets, such as building an infrastructure for scientific research. Its other targets were to strengthen applied research, promote and disseminate knowledge, and to implement results. The programme committee opted for consortia in the form of multi-disciplinary partnerships. These had to include at least one university or academic centre with a professor (specialising in intellectual disabilities), a care institution, and a knowledge centre. Here, the term "knowledge centre" referred to an organisation with the expertise to compile and disseminate knowledge. Five consortia participated in the programme. Great care was taken in defining the key elements of the project proposals. These were applied scientific research, building the infrastructure, implementation activities, and effective communication. In addition to applied research, each of the consortia will be tackling at least one practice-oriented or training-oriented sub-project.

Annex **F**

Research survey into topics and partnerships

Institution	Topic	In partnership with
Dr. Leo Kanner House, Doorwerth	1 Psychiatric family treatment at home (PGA)	1 Praktikon (phase 1)
	2 Treatment monitor	2 Franchise partners in Dr. Leo Kanner House
	3 Emotion regulation	
	4 Ageing ASD sufferers	
	5 AUGENDIA, autism genomic diagnosis	5 Erasmus MC
	6 ASD prevalence in forensic psychiatry	6 Dr S. van Mesdag Forensic Psychiatric Centre
	7 Pragmatics (social language use among young people aged from 10 to 16)	
	8 ABA training with pivotal response therapy elements	
	9 Cognition throughout the course of life	9 University of Amsterdam
	10 Couples	
	11 Wiki therapist	11 Eindhoven University of Technology
	12 Adaptive skills: effects of training “empty time becomes free time” / train the trainer	
	13 Adaptive skills	
	14 Effects of empowerment training in adolescents and young adults with ASD	14 Dr. Leo Kanner House, Brabant
	15 Transition planning for young people with ASD	15 HAN University of Applied Sciences, research group, Lucertis
	16 Cognitive strategies in autism	16 University of Oxford
	17 Effectiveness of digital coaching	
Dr. Leo Kanner House, Brabant	Treatment monitor	Dr. Leo Kanner House, Doorwerth, Dr. Leo Kanner House, The Netherlands

University medical centres		
Erasmus MC	1 Tackling the teenage years (puberty problems, effectiveness of the "*Ik Puber*" (I've Reached Puberty) programme).	1 Yulius
	2 Social Spectrum Study (validity of diagnostic tools; patterns of development problems, impact of ASD on individuals, family, society; role of family, vulnerability, genes, environmental factors in aetiology of ASD)	2 Yulius, Rijnmond Regional Institute for Outpatient Mental Health Care, Lucertis, Emergis, Noord-Brabant mental health care service
	3 Genetics ASD measuring endophenotypes (course of ASD, viewing behaviour)	3 Yulius
CAP UMCG University Center for Child and Adolescent Psychiatry (UCKJP), Accare	1 Tool development: VISK test and VISV test for adults	1 CAP and mental health care institutions in NL
	2 Research qualities of ADOS and ADI-R	2 CAP UMCU, Curium Leiden
	3 Genetic and behavioural overlap between ASD and ADHD (data IMAGE and TRIALS)	3 Radboud University Nijmegen Medical Centre
	4 Placebo-controlled study of atomoxetine in ADHD and ASD (RADAR)	4 CAP institutions, Karakter/Radboud University Nijmegen Medical Centre
	5 Effectiveness of social skills training in ASD (ESTIA)	5 Noord Nederland mental health care service
	6 Effect of oxytocin on perception of empathy in ASD	6 University of Groningen/ Biology
	7 Information processing in children with ASD (TRIALS)	7 UCP/UMCG and Erasmus CAP
	8 Feedback and reward: study of feedback and reward processing in children with ASD (in those with ADHD, and in healthy children)	8 University of Groningen/ Psychology
	9 Social language use in children with ASD and/or ADHD	9 University of Groningen/ Linguistics
	10 Serotonin and genetics in ASD	10 International networks (UK, US YaleCSC)
UMCG Social Medicine	Predictors for employment rate in autism spectrum disorder sufferers covered by the Work and Employment Support (Young Disabled Persons) Act	UWV (The organisation for reintegration into the job market and temporary income), knowledge centre with expertise in employment SME, PROREC schools
Cognitive Neuroscience and Department of Psychiatry, Radboud University Nijmegen Medical Centre and Karakter Child and Adolescent Psychiatry	Biological Origins of Autism (BOA)-genetics, endophenotypes, morphology, cognitive, glutamate ASD-ADHD controls, parenting styles of parents in ADHD/ASD	NL: University Medical Center Utrecht, University Medical Center Groningen Europe: Kings College, London; CIMH, Mannheim; Karolinkska, Stockholm
Radboud University Behavioural Science Institute / Special Education	Effectiveness of Applied Behaviour Analysis (ABA) in children and adults with autism spectrum disorder and/ or intellectual disabilities	National data collection, currently no joint responsibility with other institutions

University of Amsterdam	Cognition throughout the course of life • Strong/weak cognitive skills life stages • Subtyping of profile • Effect interventions based on cognitive theories of autism • Subtyping of effectiveness of interventions • Contributions of knowledge about ADHD etc to knowledge about autism • Brain Connectivity Theory explanation for development of cognition in autism?	Dr. Leo Kanner House, CASS18+, NVA, InGeest mental health care service, other mental health institutions
VU University Medical Center	1Social emotional development 2Epidemiology (Netherlands Autism Register) 3Efficacy of treatment	University of Sydney, Bascule, UvA, LKH, Berg en Bosch School, LKH/Trias youth care services, researchers at Universities in USA, UK, Canada, Australia
Leiden University	1 Effect of Berckelaer-Onnes play training programme on the play of children with ASD 2 Behavioural problems in ASD sufferers	1 Medical crèches and child day care centres in the Leiden region 2 Center for Consultation and Expertise
University Medical Center Utrecht (UMCU)	1 I see what you mean, the basics of social processing 2 Auditory attentional modulation in ASD 3 Effects of risperidone on cognitive rigidity in ASD 4 Detection of developmental abnormalities of the cortex resulting from mutations in ASD risk genes 5 Connectivity in child psychiatry 6 Connectivity in resting state EEG in children with ASD 7 Imaging genetics in ASD 8 Double hit in autism 9 Functional MRI of cognitive control in autism	1 UMCU/UU CAP 2 UMCU/UU 3 UMCU/UU 4 UMCU 5 UMCU/Leiden University Medical Center/UMCG/VUmc/University Hospital Maastricht 6 UMCU/UU 7 UMCU/Radboud University Nijmegen Medical Centre 8 UMCU 9 UMCU
Mental health care institutions		
Eindhoven mental health care service	Efficacy of treatment in adult autism sufferers	Tilburg University, Eindhoven University of Technology, OU, RINO-groep
Noord-Holland Noord mental health care service, autism centre	1 Care avoidance: diagnosis and treatment of suspected ASD 2 Translation and validation of the RAADS-R diagnostic tool	1 Dr. Leo Kanner House, Lentis Groningen 2 Five other mental health care institutions in the Netherlands
Dimence mental health care service	Assessment of psychometric properties of the RAADS-R (Dutch) in an adult outpatient population.	Centre for Developmental Disorders at Dimence (principal investigator), CASS18+, University Medical Center Groningen, Radboud University Nijmegen Medical Centre, Vincent van Gogh Venray, NHN mental health care service, Yale Child Study Center – USA

Yulius	4U study project • Effects of behaviour management programme in cluster 4 Special Needs Schools (primary) (*Taakspel* – a version of the American "Good Behavior Game"), factors impeding/supporting implementation, social relationships) • Effects of behaviour-oriented intervention on efficiency in cluster 4 Special Needs Secondary Schools (VSO; adolescents) (*Taakspel* – a version of the American "Good Behavior Game"), factors impeding/supporting implementation, social relationships)	Utrecht University (Educational Science), VU University Amsterdam (Psychology, Education), Erasmus MC (CAP), CED-groep
Lentis Autism Team Noord Nederland	1 Joint attention and symbolic play in children • Standardisation and validation of VSCG (Central Groningen Playground Association) questionnaire • Effect study early stimulation protocol C. Kasari	1 Noord-Nederland Autism Team (ATN)/ RUG
	2 The development of ToM in children	2 ATN
	3 BRIEF questionnaire: validation study in children and adults with ASD	3 ATN
	4 Cogmed Working Memory Training in adults (including young adults)	4 ATN, UCKJP, and UMCG, UCP
	5 ESTIA: Effect study of social skills training in young people	5 ATN, Accare, UCKJP
	6 Autism partnership training programme (adults)	6 ATN, MEE, Drenthe
	7 RelASS: partner relationship therapy (Adults)	7 ATN, Drenthe mental health care service, de Keerkring (special needs primary and secondary school for pupils with severe learning difficulty)
Universities of applied sciences		
Fontys Tilburg	More effective teaching in secondary education, thanks to pupils with ASD (PhD research)	Radboud University, departments of Special Education and CAP
HAN University of Applied Sciences	1 The use of IT resources in transition planning for autism sufferers	1 Dr. Leo Kanner House, Arnhem & Veluwe Vallei Regional Institution for Protected Living, De Brouwerij special needs secondary school
	2 "Life coaching in autism" research group	2 LKH, LKH-GB, MEE, VSO The Brewery, RIBW Arnhem, Berg en Bosch School, NVA, ROC Nijmegen, Arnhem, ROC

Other

Kentalis PonTeM, St. Michielsgestel	Research on autism • Familiarity with target group: how many clients have ASD? • Differential diagnosis (early detection; Early Screening of Autistic Traits usable for Kentalis target group, demarcation of target group) • Autism Communication Methods • Autism and deafness (including development of sign language in deaf autism sufferers) • Developmental study Autcome (serious game) • Intervention research (early treatment and Concept facilitated communication) • International Classification of Functioning, Disability and Health (ICF) classification of Kentalis clients with autism • ComFor-V (Forerunners in Communication) implementation study • Sexuality of normally gifted boys with autism • Modern media innovation project	Eindhoven mental health care service, Zuidzorg, Youth care services, Leiden University, Louvain, Groningen, NVA, autism support offices
CED-groep Rotterdam (Educational Services Centre)	1 Effectiveness, implementation of Education Guide (The folder entitled "*Wijzer Onderwijs Autisme*" (Autism Education Guide) gives teachers information about autism and makes specific recommendations on how they can adapt their teaching to meet the specific needs and abilities of students with autism)	1 School board with special needs schools
	2 *SociaalOpStap* (a website/app with social stories and action plans for young people with autism)	2 Erasmus University Rotterdam, KPN Finest Contact Foundation, National Autism Network
	3 Effectiveness of *SociaalOpStap*	3 Oberon, National Autism Network

Annex **G**

Abbreviations

ASD	Autism Spectrum Disorders
AW	Academic Collaborative Centre
AWBZ	Exceptional Medical Expenses Act
ACCPH	Academic Collaborative Centre for Public Health
CASS18+	Consortium for autism spectrum disorders in adults
CCE	Centre for Consultation and Expertise
CED	Educational Services Centre
DTC	Diagnosis Treatment Combination
GGZ	Mental health care service
HAN	HAN University of Applied Sciences
HBO	Higher professional education
JGZ	Child healthcare
KCVG	Dutch Research Center for Insurance Medicine
CAP	Child and Adolescent Psychiatry
LKH	Dr. Leo Kanner House
MBO	Senior secondary vocational education
NICE	National Institute for Health and Clinical Excellence
NIP	Netherlands Institute of Psychologists
NJi	Netherlands Youth Institute
NVA	Dutch Association for Autism

RGO	From 2008: Advisory Committee on Health Research (pre-2008: Advisory Council on Health Research)
RINO	Regional Institutes for Continuing Education and Training
SBWU	Utrecht Sheltered Accommodation Foundation
SGO	SGO Health Research Incentive Programme
ToM	Theory of Mind
UMC	University Medical Centre
Wajong	Work and Employment Support (Young Disabled Persons) Act
WO	University education
Wwb	Work and Social Assistance Act
Wwnv	Employment Capacity Act
ZAT	Care advisory team
ZonMw	The Netherlands Organisation for Health Research and Development