

## SUMMARY

On 29 October 2003 the Advisory Council on Health Research (Dutch acronym: RGO) received a request from the State Secretary of Health, Welfare and Sport for an advisory report on the current state of affairs with respect to medical and behavioural research on people with an intellectual disability and how to improve the level of cohesion in the research. She requested knowledge gaps to be identified and asked how research within the present research infrastructure could be further supported.

### DEFINITION

In the advisory report an intellectual disability is defined according to the model of the American Association on Mental Retardation (AAMR). The model describes the functioning of people with such a disability schematically as an interaction of factors in five dimensions: I intellectual abilities; II adaptive behaviour; III participation, interactions and social roles; IV health; V context. Disabilities in one dimension must not be viewed in isolation from other dimensions. In the model, 'support' is distinguished as a separate and key component, which refers to the individual policy targeted at furthering the development, health and functioning of a person in general. For a long time it was common practice to classify the severity of an intellectual disability as mild, moderate, severe or profound, solely on the basis of the IQ. However this failed to take into account the person's functioning in relation to the social environment. For this reason, the AAMR model has been adopted.

### DESCRIPTION OF THE POPULATION AND DEVELOPMENTS IN SOCIETY

In the Netherlands the prevalence of people with an intellectual disability is estimated to be 0.7% (111,750 people). Slightly less than half of these people make use of a form of residential accommodation. The other half live with their parents or independently.

The number of people with an intellectual disability has increased in recent years due to a higher life expectancy as a result of improvements in the care provided. In the report, the total group is divided into a number of partially overlapping subgroups, namely children, the elderly, persons with multiple severe disabilities, and persons with an intellectual disability and severe behavioural problems.

In recent years there has been a trend for an increasing number of people with an intellectual disability to move from institutes to small-scale residential facilities with the necessary support and guidance. This fits in with the government's

objective of community care, a policy targeted at full citizenship for everyone. These moves from institute to society are not problem-free.

#### SPECIAL CARE REQUIREMENTS AND PROFESSIONALS

As well as the requirements related to 'normal' illnesses, people with an intellectual disability also have care requirements of a highly specialised nature. There is a significantly higher risk for certain disorders and conditions and the problems associated with these. Geriatric conditions over and above the conditions already present lead to relatively serious limitations from the age of 50 years onwards. Furthermore diagnosis, treatment and supervision are hindered by the fact that people with intellectual disabilities have difficulties expressing themselves or cooperating due to anxiety or a lack of understanding. This means that care providers require good communication skills as well as a lot of patience and time. These problems also make it difficult to perform (clinical) research.

The care for people with an intellectual disability involves medics, paramedics, behavioural scientists, supervisors and group supervisors, parents, home carers, etc. People who remain in residential care, frequently with a serious intellectual disability, receive integrated total care across all dimensions of the AAMR model. As the severity of the disability decreases, the integration of the care provided across the different dimensions becomes less and the amount of coordination required increases. People with an intellectual disability who live with their parents or live independently consult the general practitioner with their everyday complaints. In the case of more specific questions the general practitioner can refer the patient to the paediatrician, clinical geneticist, mental healthcare specialist, etc. People with an intellectual disability experience problems with respect to the availability, accessibility, and continuity of the medical care and the transitions in this.

#### TRAINING

Medical research is mainly carried out within the disciplines of paediatrics, clinical genetics, primary care and mental health. Most of the behavioural research is carried out within the disciplines of special education and psychology. That is why this report considers the training of medical doctors and behavioural scientists, the possibilities to specialise in mental health care and the scientific training. As well as medical doctors and behavioural scientists, paramedics, nurses, care providers and social workers are involved in the care of persons with intellectual disabilities. Although they can be involved in research they rarely carry out research themselves. Therefore the training of these personnel is not further considered.

## RESEARCH POLICY

In 2003, medical researchers investigating people with an intellectual disability jointly compiled a list of priorities for future research. Behavioural scientists have yet to do this, but the Vereniging Gehandicaptenzorg Nederland (Netherlands Association for the Disabled) has recently indicated that it will clearly define its knowledge policy and with this it will limit itself to behavioural research for physical, sensory and intellectually disabled persons. The association was consulted during the preparation of this report.

## DESCRIPTION OF THE RESEARCH AREA

The basic premise in the report is that the research must focus on improving the health and functioning of people with an intellectual disability, according to the five dimensions of the AAMR model. This concerns problems in the daily provision of care, which can be answered by research and which are related to all dimensions of the model. In this manner the research will serve to support all types of care providers.

## CURRENT RESEARCH

The basis of the current medical and behavioural research could be laid with the research programmes? ‘Chronic diseases’ (NWO (Netherlands Organisation for Scientific Research)), ‘Innovation in the care for people with an intellectual disability’ and ‘Quality of care’ (ZonMw (The Netherlands Organisation for Health Research and Development)). These programmes have now been completed and with this the most important sources of research funding have been withdrawn.

From an inventory of the current research in 2004 it was concluded that university research groups mainly performed research in AAMR dimensions I, II and IV, and the non-university groups mainly in dimensions III, V and Support. On a limited scale the institutions carry out research into all dimensions with the exception of dimension I. At a number of places the research is integrated within other research. The university research is estimated to involve 56 full-time scientific personnel and the non-university research 12 full-time scientific personnel. It is estimated that a quarter of the personnel are financed by direct government funding but that does not mean that each of these persons has a tenured position. The university research is connected to 11 tenured and 6 endowed professorships. With a few exceptions, the research groups connected to these professorships are small to very small in size. In several cases there is a professorship with a critical mass of 3 to 4 full-time scientific personnel. There is just one professorship specifically for the medical care of these people, but this is an endowed professorship and therefore temporary. Research funded directly

by government is, with the exception of the basic research into dimension I, less well safeguarded within the medical sciences than within the behavioural sciences.

#### NEED FOR RESEARCH

Patients, their parents and care providers have indicated that there is a need for research into all of the AAMR dimensions. There are many urgent societal questions, also politically sensitive questions, to which research could provide an answer: questions that can be answered by both the medical and behavioural sciences, questions about the organisation of healthcare and questions about the care provided. Patients and their parents mainly need research on dimensions III, V and Support, and care providers mainly on III, IV and Support. This need is partly met by current research, with perhaps the exception of dimension IV. Patients and their parents have also expressed a wish to be involved in setting up research programmes.

#### PRIORITIES FOR RESEARCH

The Council notes that there is a need for research on all AAMR dimensions. There is a range of questions within which it is difficult to indicate priorities. From a societal perspective many questions are urgent.

The Council would like to introduce a greater degree of coherency between the questions and has therefore chosen one umbrella theme 'Levensloop en levensfasen' (Course of life and ageing). This will promote further coherence and multidisciplinary cooperation.

Various groups can be distinguished in the theme: children, adolescents, adults and the elderly. For people with an intellectual disability, a number of typical phases in human life can lead to a worsening of the disability or state of health, for example neglect, isolation or loneliness. This gives rise to many questions. Subject-specific questions are mainly found within AAMR dimensions II and IV: How do certain syndromes develop, how does the syndrome-specific ageing process progress, which limitations occur during the course of life, etc. Questions about the organisation of healthcare in dimensions V and Support are, for example: continuity and accessibility of care and support (in the case of an ongoing deinstitutionalisation), and the transition from medical care under a paediatrician to a specialist for adults.

However, the Council notes that there are several bottlenecks in the research infrastructure which need to be overcome if this theme is to be successfully investigated. The research is currently fragmented over many themes and there is a lack of coordination. There is scarcely any structured cooperation and har-

monisation. Moreover, research funding is a major problem. With the completion of the previously mentioned programmes, the most important source of funding has been withdrawn. Furthermore the scientific research scarcely relates to everyday practice and there are bottlenecks in the training. The supply of researchers cannot be taken for granted, especially in the case of behavioural scientists. The scientific research can only be further expanded if the support for research within the professional groups is increased and strengthened.

#### RECOMMENDATIONS

The Council has reached the following recommendations on the basis of the aforementioned information:

1. Parent and patient associations have an important role to play in highlighting research questions. The Council advises setting up a steering group within ZonMw to receive this information. This should be under the leadership of an independent chair who has no personal interest in this area. The steering group should consist of representatives from medical and behavioural research groups, care institutions, parent and patient associations, representatives from the various professional groups and the health inspectorate. However, the Council wishes to emphasize that converting a societal question into a scientific question is a complex process. The Council wishes to set aside about €100,000 for the duration of the research programme (see later) for this so-called broker and improvement function.
2. The Council is of the opinion that in order to strengthen the research infrastructure, the research needs to be more harmonised and concentrated on the theme 'Course of life and ageing'. The Council recommends that the aforementioned steering group appoints a programme committee, consisting of a small number of experts, to assume responsibility for setting up and implementing a research programme with a duration of 6 to 8 years. This should partly consist of Ph.D. projects (see later) and partly of bottom-up research proposals. About 3 Ph.D. students will have to participate each year. The total amount of funding needed for this is about €4.5 million.
3. The Council recommends appointing a working group to set up a systematic data collection system that will make long-term follow-up studies possible. The Council wishes to set aside about €300,000 to €400,000 for this purpose, with the proviso that the size of the budget is dependent on the possibilities for cooperating with existing projects.
4. In the Council's view there should be at least one tenured professorship which is completely devoted to the medical care of people with an intellectual disability and which has 3 to 4 fulltime scientific personnel. In addition

to this the Council considers it wise to appoint a second tenured professorship at a different university with sufficient scientific personnel. These professorships are specifically intended to act as a focal point for a wide range of research which should preferably be carried out within a multidisciplinary context. The Council wants to set aside a budget of at least €250,000 to €500,000 per year for this purpose, which totals up at least €2 to 4 million during the course of the programme. These professorships with a critical mass will be financed from programme funds and after this the two universities concerned will be required to assume the funding.

5. The Council recommends setting up a fund under ZonMw for about 3 Ph.D. students per year. They will carry out research over a number of years on the condition that the subject of the doctoral research falls within the theme 'Course of life and ageing' and takes into account the various perspectives. A Ph.D. project will only be eligible for funding if it involves cooperation between a research institute and a healthcare institute.
6. The proposed activities and research programme require a budget of some 7 to 8 million euros. In setting this budget the Council has assumed that a substantial part of the total research programme (i.e. some 40-50%) will be jointly financed by the institutes (Vereniging Gehandicaptenzorg Nederland (Netherlands Association for the Disabled)).

## INLEIDING

De Raad voor Gezondheidsonderzoek (RGO) heeft op 29 oktober 2003 een verzoek van de staatssecretaris van Volksgezondheid, Welzijn en Sport (VWS) ontvangen om informatie over het medisch- en gedragswetenschappelijk onderzoek naar mensen met een verstandelijke beperking\* (bijlage 1). De gevraagde informatie betreft het lopende onderzoek, de behoefte aan onderzoek en de infrastructuur van het onderzoek. Het advies werd voorbereid door een commissie van de RGO (bijlage 2).

Het advies is als volgt opgebouwd. Na kort te zijn ingegaan op de definitie van een verstandelijke beperking volgens de American Association on Mental Retardation (AAMR), bevat hoofdstuk 2 een beschrijving van de populatie van mensen met een verstandelijke beperking en van subgroepen daarbinnen. Hoofdstuk 3 gaat vervolgens in op de maatschappelijke ontwikkelingen op dit terrein in de laatste zestig jaar en hoofdstuk 4 op de bijzondere aard van de zorg, de hier werkzame professionals, hun profiel en opleiding. In hoofdstuk 5 wordt het lopende onderzoek beschreven. Hoofdstuk 6 geeft een beeld van het onderzoek dat gewenst wordt door cliënten, ouders en hulpverleners. Na een korte beschrijving van het internationale onderzoek (hoofdstuk 7) wordt het gewenste onderzoek vergeleken met het lopende onderzoek, uitmondend in prioriteiten voor onderzoek (hoofdstuk 8). Vervolgens komen infrastructurale, financiële en scholingsknelpunten naar voren in hoofdstuk 9. Op basis van het voorgaande worden in hoofdstuk 10 aanbevelingen geformuleerd over de wijze waarop het onderzoek gestimuleerd kan worden.

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\* In dit rapport krijgt de term “verstandelijke beperking” de voorkeur boven de term “verstandelijke handicap”.