

# **RESEARCH ON IMPAIRMENT AND DISABILITY 2002-2010**

- Survey, analysis and suggestions

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Translated by Christine Carter

## Foreword

The Swedish Council for Working Life and Social Research (FAS) has been assigned by the Swedish Ministry of Health and Social Affairs to survey, in consultation with other funders, the existing research concerning obstacles to full participation in society and the workplace for people with disabilities. The assignment has been carried out by the Swedish Institute for Disability Research (SIDR), Linköping and Örebro Universities, with the support of an expert panel of leading researchers. The specific objectives of the assignment are described below. In consultation with FAS, SIDR has been given the task

- to survey and analyse Swedish research from 2002 to the present regarding long-term states of ill-health/functional impairment which are linked to restrictions in activity, participation, and daily life
- and to highlight the relationship of such states to the environment/context as preventing or promoting of activity, participation and everyday life;
- in particular, to assess the existence and need for research in the field;
- to highlight, within this assignment, the different approaches within this field of research;
- to initiate a discussion and make suggestions concerning future research needs within the area of the assignment;
- to discuss and propose forms of support and financing models for the promotion of research within the framework of the area covered by the assignment; and
- to otherwise take into account those requirements and needs for knowledge described in the Swedish Government's assignment to FAS (Decision of the Swedish Government 2011-02-10 /S2011/1516/FST).

Within SIDR, a working group was established under the direction of Professors Jerker Rönnerberg and Berth Danermark, with the active participation of doctoral student and licensed psychologist Elisabet Classon and Associate Professor Thomas Karlsson. The bibliometric work has been carried out in cooperation with Linköping University's library and in consultation with other expertise in the area. Work on the development of analyses and the preparation of the report has essentially been carried out by the research group at Linköping University.

The expert panel for the work consisted of the following members: Raphael Lindqvist, Professor of Social Work with a focus on social care, University of Gothenburg; Mats Granlund, Professor of Disability Research, Jönköping University; Karin Harms-Ringdahl, Professor of Physiotherapy, Karolinska Institute; Raymond Dahlberg, R&D Coordinator and licensed occupational therapist, Swedish Institute of Assistive Technology; Elisabet Cedersund, Professor of Social Work, Jönköping

University; Stig Arlinger, Professor Emeritus of Audiology, Linköping University; and Anne Sjöberg of the Swedish Disability Federation. In FAS, program director Kenneth Abrahamsson coordinated the work with the support of R&D administrator Nina Ginzburg and research secretary Inger Jonsson.

As part of the assignment, representatives of funders, public authorities and organizations in the field were invited to a discussion where they were asked to comment on the assignment – on the on-going survey of research and the draft of the present report – and to share their views on the needs, approaches and cooperation in this field of research.

This discussion included, inter alia, contacts with representatives of the Swedish Ministry of Health and Social Affairs, the Swedish Public Employment Service, the Swedish Work Environment Authority, the Swedish Social Insurance Agency, the Swedish Disability Federation/HSO Handisam (the Swedish Institute for Disability Policy Coordination), the Swedish Institute of Assistive Technology, the National Board of Health and Welfare, the Swedish ESF Council, and individual persons relevant to the assignment.

The assignment is in line with FAS's national coordinating responsibility for research on disability and handicap. It is related to the program of research on disability and handicap which FAS took up in 2001, as well as to the international evaluation initiated by the former Social Sciences Research Council and completed by FAS. It is important to stress that the assignment does not include an evaluation and analysis of the scientific quality and societal relevance of research on impairment and disability in society and working life. It can be seen as an overall mapping of the topography, concentration and interaction of Swedish research, both nationally and internationally. As shown in the summary and the report as a whole, there is highly relevant information and knowledge for the continued direction and development of research in this area.

Research on impairment and disabilities appears to be a field with a strong interdisciplinary profile and potential. The research has made great strides over the last 10 years. The area is dynamic and multifaceted. Many neighbouring fields and society-related areas should be addressed and proposed by the investigation. One such neighbouring field would be research on discrimination, which may be based, in addition to disability, on such factors as age, gender, ethnicity and/or sexual orientation. An exciting synergy also exists between research on impairment and research on aging. Other related fields are research on the workplace environment and health, research on impairment and disability, and research on illness, health and care. This dynamic with neighbouring fields means that research on impairment and disability is an interesting field for cooperation between different providers of funds. This area

of research has also made for an interesting example of user-cooperation: The Swedish Disability Federation has successfully driven the project, From Research Object to Co-actor, in which different methods for strengthening the dialogue between researchers and users has been highlighted.

Particular thanks go to Bengt Westerberg for his close reading of the manuscript; to Professor Olle Persson of Umeå University and Staffan Karlsson, Swedish Research Council analyst, who have contributed valuable comments concerning the bibliometric analysis; and to Professor Eskil Wadensjö, Stockholm University, who has pointed to the need to link to labour market-economics and political science research within the field.

Stockholm, September 2012

*Erland Hjelmquist*

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## Executive summary

The Swedish governmental assignment “to survey and analyse research in the field of impairment” (2011-1631) has been carried out through cooperation between the Swedish Council for Working Life and Social Research (FAS) and the working group designated for this purpose in the Swedish Institute for Disability Research (SIDR). The investigation provides a broad theoretical background to research on impairment and disability.

The definition used is that the impairment be long-term and entail restrictions in everyday life. In addition, impairment in itself is interesting to study, and research on its interaction with environmental opportunities and obstacles is also relevant, as well as how societal hindering/supporting processes affect people/groups with impairments in society.

The data collection was based on the above definition and was divided into two stages. Data was gathered for the period 2002–2010, among other reasons, in order to tie in with previous investigations in this area. In STEP 1 were included projects (n=1411) from the databases sent to us by governmental and non-governmental funders. In STEP 2, publications analyses were carried out based on the names of the above project owners and on the lists of names (n=970) from all of Sweden’s centres for research on impairment and disability.

Apart from basic information on the projects (project year/allocation of funds/diagnostic category, age category, or emphasis on working life), the projects in STEP 1 were classified on the basis of whether they stressed the individual, the interaction between the individual and the environment, or environmental aspects alone. In addition, projects were classified with respect to perspective, i.e., whether the project belonged to a technical/scientific, medical/caring science, behavioural sciences, or a humanities/social sciences perspective, as well as whether or not the project was interdisciplinary, and finally, whether it concerned the area identified by the directive as “disability studies”, that is, whether or not its focus was on hindering or facilitating mechanisms in society.

The results show clearly that the total research funding during the period studied increased from approximately SEK35 million per year to approximately SEK150 million per year. Actual state funding has remained relatively constant since 2008 and has stagnated at a level of about SEK90 to SEK95 million per year. The individual-oriented, medical/caring science projects dominate and have increased during the period in terms of both the number of projects and funding levels. There are few instances of “disability studies” or of the technical/scientific perspective. Fifty per cent of all research funding is interdisciplinary; forty-eight per cent consists of research on the interaction between the individual and the environment, and here, the behavioural perspective dominates. The

interdisciplinary research focusing on different diagnoses concerns international areas of excellence such as hearing impairment, physical disability, stroke, psychological disability and cerebral palsy. Research that compares different groups of people who have impairments is also well represented.

In STEP 2, separate publications analyses were carried out on journal articles and on book chapters/books and dissertations. Detailed analyses show that approximately 200 authors can be considered the “bearers” of the field in the sense that they actively publish more than five journal articles or more than three book chapters or books in each five-year period. Network analyses show that the area has become more integrated over time, that larger clusters of researchers have formed, and that the rate of publishing has increased significantly more than the national average. In addition, citations analyses show that the rate of citations clearly exceeds the global average. Content analyses show that rehabilitation research and research on language, cognition and hearing are two main clusters.

### THE ASSIGNMENT

The Swedish governmental assignment, “to survey and analyse research in the field of disability” (2011-1631), has been carried out through cooperation between the Swedish Council for Working Life and Social Research (FAS) and the Swedish Institute for Disability Research (SIDR). FAS have appointed (2011-05-31) a working group from SIDR and a national expert panel of researchers and general representatives (see Annex 1). The assignment has been carried out by a working group composed of Professor Jerker Rönnerberg (coordinator), Professor Berth Danermark, Associate Professor Thomas Karlsson, and doctoral student and licensed psychologist Elisabet Classon. In consultation with FAS, SIDR has chosen to focus on the period 2002–2010, which ties in with the period of the most recent evaluations of disability research. On the basis of the present survey of existing research, future needs for knowledge in the area have been identified. The assignment is in accordance with FAS’s responsibility for coordinating Swedish research on impairment and disability.

## Introduction

The question of what is meant by impairment and disability<sup>1</sup> and the interaction between these is multifaceted. A comprehensive determination is made in the UN Convention on the Rights of Persons with Disabilities:

Persons with impairment includes, inter alia, persons with enduring physical, psychological, intellectual or sensory impairments which in interaction with various obstacles can counter their full and real participation in society on an equal footing with others (our emphases).

A determination and delimitation of the concepts proceeds from the four aspects highlighted in the text. The following describes views of impairment and disability according to different philosophical and theoretical perspectives. Five somewhat different ways of looking at impairment and disability are presented: an individual, a cultural, a social, a relational, and a biopsychosocial perspective<sup>2</sup>.

### The individual perspective

The individual perspective assumes that a certain ability for various functions is normal and that certain deviations from this normality can be regarded as impairment. Impairment leads, in turn, to the occurrence of disability out in the world, which limits possibilities for participation in different contexts. The interest is directed toward the impairment and toward possibilities to compensate for it. An individual perspective is common in areas such as medical research. One expression of this perspective is the following quote: “Disability is the physical product of biology acting upon the functioning of material individuals (bodies). The unit of analysis are impaired bodies.” (Priestley, 1998, in Danermark, 2005, p. 20). This perspective implies that the basis for disability consists in a pathological condition which can be linked to bodily characteristics.

Many believe that this approach has been completely dominant during the greater part of the twentieth century and that it is still well-represented in both research and practice.

<sup>1</sup>The terms proposed by the Swedish National Board of Health and Welfare are used here. This means that the term handicap is not used other than in referring to texts in which it appears. The term handicap may also be used in referring to entities with proper names containing the term.

<sup>2</sup>In the literature there are other ways to classify different perspectives. For example, Mark Priestley (1998) distinguishes between individual-materialistic, societal-materialistic, individual-idealistic, and societal-individualistic. Anders Gustafsson (2004) categorises the perspectives into essentialist, constructivist and interactionist.

### The social perspective

The social perspective begins with the idea that there is wide variation in functional ability among individuals. Disability arises because the surrounding society is not adapted to this variation. This perspective emerged in the United Kingdom during the 1960s and 1970s with strong political overtones. People who were active in the British disability movement reacted strongly against the dominating medical perspective with its emphasis on individual impairment. A clear distinction was made between functional limitation (impairment) and functional hindrance (disability). Disability research, it was claimed, should not concern itself with the functional impairment but should instead focus on the surrounding environment. To underscore this, the name *Disability Studies* came to be used for this perspective (Thomas, 2004). An important point of departure for this perspective is thus that it should be possible to arrange society so that disability does not occur. It is ultimately a matter of allocation of resources. If insufficient resources are made available for the removal of barriers in the environment, this can be regarded as an expression of the oppression of certain people. Similar ideas are expressed in the proposition, “From Patient to Citizen” (Proposition 1999/2000:79).

The social perspective has been criticised for being too narrow in its view of what is to be included in the understanding of disability by ignoring impairments that are linked to the individual. Proponents of the perspective claim that this criticism is based upon a misunderstanding: One does not mean to ignore the impairment but rather makes a conscious and politically founded choice by focusing on the importance of adapting the environment to people with impairments. This is considered a political responsibility. The approach was motivated by its proponents’ view that politicians did not assume sufficient responsibility but placed the main responsibility for adaptation on individuals.

### The cultural perspective

Similarly to the social perspective, the cultural perspective begins with the notion that there is a natural variation in the abilities of different individuals. The classification of certain deviations as impairment is simply a social construction which stigmatises certain individuals. In this perspective, one does not take the impaired body for granted. It is natural to assume, rather, that all variation fits within the normal (Corker & Shakespeare, 2002). This approach ties in with the discussion taking place currently in society about how perceptions of normality are created and maintained. There are substantial similarities in the fundamental points of departure between the cultural perspective on disability and approaches to gender (feminist theory), sexuality (queer theory) and ethnic minority status (postcolonial theory). This perspective emerged partly as a reaction against the social perspective’s concentration on the distri-

bution of material resources. The cultural approach instead highlights more immaterial societal conditions. Diversity and tolerance are key concepts, and this perspective results in the elucidation of power over our ingrained conceptions and ideas. Also analysed within this perspective are issues of normality and deviation and how norms, attitudes and values, such as xenophobia and insecurity in the face of “others”, are created. Yet it is sometimes difficult to see that this approach leads to any practical conclusions concerning the direction of research, for example, beyond those of the social perspective.

### The relational perspective

The relational perspective begins with the notion that certain functional limitation in interaction with the surrounding society can create disability. Compensatory measures for reducing or eliminating disability can take place both in the individual and in the environment.

This perspective has a long tradition in Swedish disability practice and research. Hjelmquist, Rönnerberg and Söder (1994) defined disability research as aiming to identify and eliminate factors in the environment which contribute to impairments becoming disabilities and to discover ways to compensate for impairment. SOU 1999:21 (“Lindqvist’s nine”) describes an approach which is similar in principle but makes a larger distinction between individual- and society-oriented disability research. In line with a survey carried out by the former Social Sciences Research Council at the end of the 1990s and other reports, studies, and propositions of the 1990s, it can be concluded that, at least since then, research on impairment and disability has had the relational perspective in common.

The relational approach renders it difficult to make a clear-cut empirical determination of whether a person encounters a disability. A person with impairment moves in different environments. Disability may arise in some of these environments and not in others. This may also apply to environments which fulfil essentially the same function for the individual, and differences are then explained by how the environment is designed. It can be considered a strength that this perspective does not focus solely on the individual and characteristics of the individual but also on the relationship between the individual and the environment. At the same time, this means that it is impossible to determine the extent of disability on the sole basis of knowledge of a person’s impairment.

### The biopsychosocial perspective (ICF)

Over the last 10 years, the relational perspective has become increasingly important for how impairment and disability are understood. This has now been codified in the International Classification of Functioning, Disability and Health (ICF). The biopsychosocial perspective can be seen as a development of the relational perspective. This perspective was established by the World Health

Organization (WHO) in 2001. One way in which it is a development of the relational perspective is that it more clearly defines what is to be included in an identification and analysis of disability, with participation as the central, comprehensive concept.

Individual functions and environmental factors are assessed in relation to how they affect people’s possibilities for full participation in all contexts. That participation in all areas of life – in all contexts – are to be taken into account can be seen as a strength of this approach, but it can also be an obstacle to practical assessment, e.g., in research. The task becomes simply impossible and must, therefore, be limited. This is the background as to why there have evolved different sets of indicators for specific diagnostic groups or conditions. These are termed core sets and are developed in a specific manner as determined by WHO; it is also WHO that sanctions these core sets.

In terms of research, both the relational and the biopsychosocial approaches are characteristically inter-/ multidisciplinary. They aim to include both individual and environmental perspectives in the analysis. The other perspectives are more limited or reductionist: Either the body or the environment is studied, but not both.

### The investigation’s approach

In the present investigation, it is not possible to definitively classify research according to these different perspectives. Sometimes an individual study can appear “reductionist” in the sense that it only focuses on one dimension, e.g., the social (environmental), but at the same time, it might be included in a research program which is broadly interdisciplinary. The endeavour here, however, is to determine whether a given project has an individual or a societal focus and whether it treats of the interaction between individuals and their surroundings. It will thus be possible to draw overall conclusions regarding how Swedish research on impairment and disability relates to the five different perspectives.

A more detailed presentation of how the identified projects are categorised is given in the section “Procedure”.



## Procedure

It is necessary to take a position on which research shall be considered as research on impairment and disability. FAS (Hjelmquist et al., 2001) indicates in its most recent review of Swedish disability research that

...the demarcation of what shall be considered disability research is not obvious. It can be research which has to do with factors and processes that turn impairments into handicaps and how these factors and processes can be changed, but it can also include research aimed at better understanding of impairment, changes for the better in impairment, and compensation for impairment, with or without technical aids (page 6).

As can be seen, the first part of this definition encompasses that which all of the perspectives other than the individual perspective include: environmental factors. The second part includes research on impairment, that is, biological and individual factors. The social and cultural approaches exclude this latter type of research. Environmental factors which are disabling are, in principle, less problematic in the context of delimitation. It is more difficult to define impairment. Two questions are central: What is an impairment? Should research focusing on impairment alone be included? An impairment can be extensive or minor, short- or long-term.

In the assignment from FAS, it is specified that the survey shall include research which

1) concerns impairment which is enduring and involves restrictions in daily life and 2) includes environmental aspects.

What is to be considered long-term and how restrictive an impairment must be have to be determined on a case-by-case basis.

The working group, through FAS, has specified the above in its requests for documents from research funders.

### Issues

This assignment by the Swedish government links in a natural way to one of FAS's earlier investigations of Swedish research on impairment and disability (or, in the terminology of the time, on disability and handicap) (Hjelmquist et al., 2001). It is natural to follow up on the conclusions of Hjelmquist et al. on the basis of the scope and direction of current disability research. Trends in disability research since then – regarding content as well as funding – will therefore be analysed here. More precisely, all the analyses concern the nine-year period 2002–2010. The research projects will be classified according to the following categories: scientific/technical, medical/caring science, behavioural science, and social sciences/humanities. The environment-relative (or 'relational')

perspective is assumed to take various forms in the different categories (cf. Hjelmquist et al., 2001, p. 8).

In addition, there is reason to describe the extent to which the social perspective, that is to say "disability studies" and Handisam's basis for research proposition 2008, has had an impact on research; therefore, the analysis will include the extent to which the projects are primarily focused on individuals alone, the relationship between the individual and the environment, or the environment alone.

As described above, the question of interplay between the individual and the environment is central in Swedish disability studies. Therefore, an attempt is also made to characterise research with respect to how interdisciplinary it is: to what extent are individual research projects interdisciplinary in the broad sense of including biological, psychological and social mechanisms?

State and county governments, foundations, and disability organizations are all included among the funders of research. Bibliometric analyses were used in order to describe the collaboration of active researchers, the distribution of publications across universities, the types of content represented by the research projects, and the changes in publishing patterns over time.

### Overview of procedures

The data collection process was carried out in two stages, and the following operational definitions were used:

The time period for which data was collected was 2002–2010, with the exception of SwePub publications (see below), where the period was limited to 2006–2010.

**STEP 1: Project types** included were regular research projects, appointments (e.g., postdoc), program grants, and environmental support (e.g., Linné-Aid/Berzelius Centre, FAS Centres).

**STEP 2: Publications analyses** were based on two sources: ISI/Web of Science and SwePub. For SwePub, the time period was limited to 2006–2010 because records from 2002–2006 were too incomplete. The document types included in the analysis were:

- article, review article (ISI/Web of Science)
- scientific book, scientific chapter of a book, doctoral thesis (SwePub).



# Step 1: Data collection and classification of projects

## Data collection

The project database was created through requests for lists of approved projects from various governmental and non-governmental funders (see Annex 2). The selection criteria were left relatively open. As noted, County Council based R&D is included, but not municipality-based R&D. The guidelines provided to research funders for the identification of disability research were to consider research on long-term impairment which leads to limitations in activity and participation (see Annex 3, letter to funders), and a definition of research on disability used by FAS (see Annex 4). This means that each funder had to “interpret” the definition when they searched in their respective databases of projects. An exception was funders who asked for help with the selection of projects. Here the same principle was applied for delimitation which was used for the selection of relevant publications (see STEP 2).

In searching the County Councils’ R&D-databases, the following keywords were used: disabilities, disabled people, physically disabled, physical disability, impairment, and impaired mobility. The lists of projects, funds granted, project owners, membership (e.g., university/County Council/disability organization) and project summaries (abstracts) which were submitted to the working group have been maintained in the original from the respective funders. Thus, in this first step of the analysis, no projects have been filtered out except those granted less than SEK50,000. In cases involving applications for follow-up financing that were recorded under unique reference numbers, the amounts granted were summed as one if the projects had the same main applicant and title. The database of projects came to be very large, with 1,411 projects.

## Classifications

Furthermore, projects have been classified in terms of their perspective, main focus, whether or not they are interdisciplinary, as well as whether or not they can be categorised as “disability studies”. In addition, there is information on diagnostic categories, any work life orientation, and age group. The latter three classifications were relatively easy to make, while the first four required more discussion and judgments reached through consensus within the working group.

**Perspective.** By perspective is meant the four, relatively broad categories of projects which Hjelmquist et al. (2001) discussed and defined. In some cases, individual projects represented several perspectives. Here, consensus was sought on which perspective could be considered dominant. At the same time, it can be noted that

perspectives sometimes overlap, such as when caring science research makes use of behavioural scientific theories and methods.

**Primary focus.** The classification of projects according to whether they are primarily focused on the individual, on the interaction between the individual and the environment, or on environmental aspects alone is at least partly independent of perspective. Here, the latter aspects can include both social and societal/cultural conditions, such as certain technical aids.

**Interdisciplinarity.** For a project to be classified as interdisciplinary, it must aim to identify mechanisms at several different levels. The question of what is meant by “level” is not developed in further detail here (see, e.g., Bhaskar & Danermark, 2006), but put simply, it may be said to concern biological, psychological and social mechanisms. Thus, projects that only study biological mechanisms, for example, are classified as non-interdisciplinary, whereas projects studying mechanisms of at least two levels are classified as interdisciplinary.

A few examples can illustrate the principles behind the classification.

A project aimed at the study of activity-capacity in daily life in children with spinal bifida and how this affects participation in everyday situations is classified as interdisciplinary. The project studies, in part, purely physical conditions (what a child with spinal bifida can and cannot do), as well as how this relates to participation in certain types of situations. It would not have been classified as interdisciplinary if it had only analysed how children with spinal bifida are able to perform certain types of activities.

Another project examines whether a certain technical aid (a cooling vest) affects heat-sensitive people with MS and fatigue, both physically (as measured with functional MRI) and through its effects on daily life (e.g., working life). This project would not have been classified as interdisciplinary if it had only analysed how cooling can reduce fatigue.

An example of a non-interdisciplinary project is one that describes how use of a corrective brace affects the ability to sit in children with scoliosis.

**Hindering/facilitating mechanisms in society.** A further assessment was made of whether or not a project focuses on hindering/facilitating mechanisms in society. A study may focus on legislation, rights, discrimination or attitudes which, in various ways, hinder people with impairment from living lives in which the full potential of their conditions is realised, or it may focus on the salutogenic aspects that facilitate life with an impairment. Thus, this classification is more restricted and goal-oriented than that which relates to “surroundings” (i.e., environment) in general (see above). At the same time, this classification is

relevant to that which is called “disability studies” in the present assignment.

The classifications were cross-validated by and between the members of the working group through random spot-checks. On those few occasions when consensus was lacking, the issues were solved through discussion.

### STEP 1: RESULTS

The results of STEP 1 are shown in the form of tables and figures based upon the raw data and the classifications made. To show trends over time in a simple and transparent way, in some cases data has been reported broken down into two equal (and thus comparable) five-year periods, 2002–2006 and 2006–2010, together with the data for the whole nine-year period. Overlapping periods (year 2006) were chosen in order to have equally long periods for the purpose of meaningful comparison.

In Figure 1, one can see that the research field has received a gradual increase in resources during the period. The increase excluding County Councils funding is significant until 2008, but stagnates thereafter. It should be noted that certain large special initiatives on hearing research by both FAS and the Swedish Research Council explain the majority of the increase between 2007 and 2008.

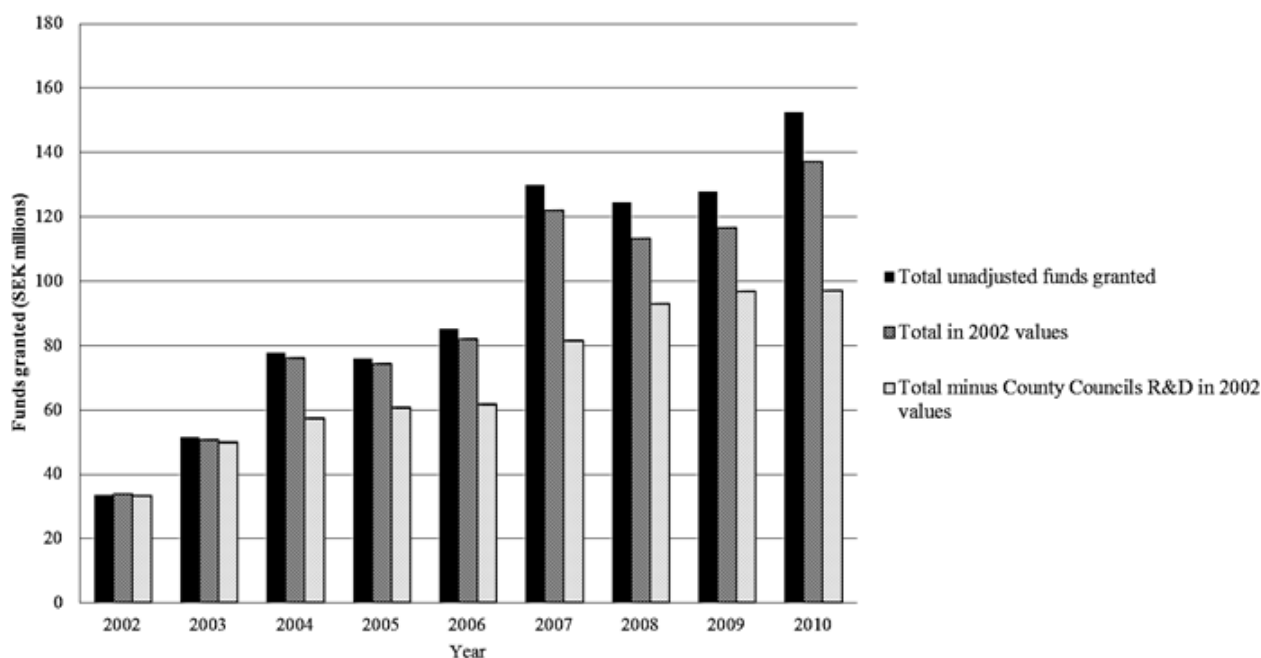
Both in terms of the number of projects and the allocation of funds, the far greatest portion of research is conducted on people of working age (see Figure 2). Thereafter comes research on children, and last, research on the elderly. This is based on the information contained

in the project descriptions. The category “children” was defined as people up to the age of 20, and “elderly” as individuals over the age of 65. It is possible that this definition contributed to an underestimation of the share of research on the elderly, especially when the age of participants was not specifically mentioned and projects were focused on a specific disease (e.g., coronary artery disease), rather than a particular age group.

As can be seen in Figure 2, the research on people of working age increases sharply, whereas research in children increases less significantly and research on the elderly remains more or less unchanged. Participants’ ages were not always specified in the project descriptions of projects that covered several age groups in the same study, and this may have affected the classification of the projects. Also, it is possible that some projects were classified by the funders as belonging to the area of research on aging rather than research on disability; this would mean that research in the “elderly” category has been somewhat underestimated.

Table 1 shows that, of the state funders, FAS and the Swedish Research Council dominate. This result is expected, as FAS has governmental responsibility for the coordination of research on impairment, disability and handicap, and the Swedish Research Council is the main governmental funding body for all Swedish research. As shown in the table, there was, in addition to FAS and the Swedish Research Council, a substantial share of research financed by the County Councils (R&D) and associations/funds/foundations. Of SEK859 million total for the entire period, the Swedish Research Council and FAS account

*In Figure 1 the black bars show the total amount (in SEK millions) of project funds granted per year (all funders). The diagonally striped bars show the real growth (2002 values). The dotted bars (lightest) show the real growth excluding amounts from the County Councils (2002 values).*



for 64 per cent of the financing, and the state for just over 70 per cent. The other state funders are mainly the Swedish Social Insurance Agency, the Swedish Institute of Assistive Technology, and the National Board of Health and Welfare.

It can also be noted that the County Councils (R&D), according to the table, contributed relatively modest amounts in the years 2002 to 2003. This is probably an underestimation of the real investment, as the registration of projects in their database (Webban) did not take full effect until 2004 (<http://www.researchweb.org/is>). It can be noted that, beginning in 2004, a more reasonable level is reached in relation to that recorded for the remainder of the period. One should therefore attach less importance to the County Councils' contribution for the years 2002–2003 in the overall analysis. Two providers of funds have not been included in the project classification, Vinnova<sup>3</sup> and the Swedish Institute for Health Sciences<sup>4</sup>, because no data existed for the period. It is clear, however, that Vinnova and the Swedish Institute for Health Sciences both have significant activities in the area with respect to elderly disabled people and people with mental disabilities.

Further basic data on the projects concern work experience and diagnosis. The absolute majority of the

projects (92%) do not directly treat working life as a research problem. A majority of research, not least the research relating to individual impairments, is largely related to diagnosis group.

As shown in Table 2, the diagnosis of hearing impairment is by far the most studied impairment, measured in terms of funds granted and number of projects. This may partly be due to fact that this area has been built up for a long time as an international area of excellence (cf. the investments in specialty areas by FAS and the Swedish Research Council, see the increase in period 2), but a natural and important explanation is also that this particular impairment is the most prominent in the population.

Other large groups in terms of appropriations are, for example, motion-related diagnoses (motor disabilities, rheumatoid arthritis), stroke, psychiatric illnesses, and developmental disabilities, which also matches prevalence in the population. However, there are research areas for which investment is not in proportion to prevalence. The amount of research on cerebral palsy is very high, in terms of the number of projects, in relation to what one might expect on the basis of prevalence. Focus on a few large projects could benefit the field and would therefore be important.

Dyslexia, ADHD and autism have received a great deal of media coverage, but they are not among the most highly funded diagnoses in the research world: Dyslexia is in 34th place with SEK4,150,000; ADHD is in 24th place with SEK7,717,000; and autism is in 17th place with SEK14,333,000.

An interesting observation is that “impairment” is in second place in terms of financing; if “disability” is added to this, this means that a significant proportion of studies also focus on more general phenomena that may be common to several groups of disabled individuals, research which

<sup>3</sup> Vinnova has no classification for projects in terms of impairment/disability nor does it have any specified mission in this area, although people with disabilities are included as a target/needs group in other projects which directly and indirectly support this area. One program which relates to facilitating “independent” living for the elderly is AAL. More information about this is available at <http://www.vinnova.se/sv/Verksamhet/Ambient-Assisted-Living/>.

<sup>4</sup> The research at the Swedish Institute for Health Sciences is carried out within three platforms: the long-term mentally ill and/or disabled, the elderly and elderly care, and the long-term sick and/or disabled. For the period investigated, it is calculated that approximately SEK51 million have been made available for research on disabilities, according to the criteria used here (materials from Gerd Ahlström). A phasing-out of the funding will begin in 2012. Details on projects have not been available for the period investigated, but the majority of the projects have been multi- or interdisciplinary.

Figure 2 shows the total resources per year (in SEK millions) that were allocated to research on children (0-20 years), adults (20-65 years) and the elderly (65+).

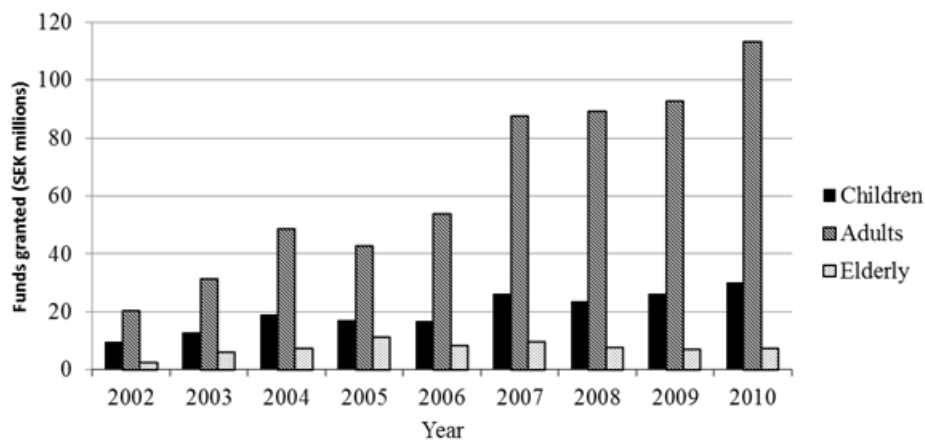


Table 1 shows the funding in SEK thousands by funder and year. At the top are County Councils' R&D, then state funders, and then foundations and funds, arranged according to the total amount of resources they granted during the period.

Funders	Year									
	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
County Councils R&D	566	898	19 142	13 953	21 256	43 308	22 175	21 922	44 613	187 827
Swedish Council for Working Life and Social Research	18 771	23 849	27 751	33 964	27 775	39 986	40 436	33 050	32 284	277 866
Swedish Research Council	6 078	15 961	19 877	18 845	23 526	29 999	43 735	53 579	62 385	273 985
Swedish Social Insurance Agency	1 200	1 271	1 609	820	1 730	1 926	1 763	3 257	1 900	13 478
National Board of Health and Welfare IMS	-	-	1 030	1 449	3 229	1 780	1 975	890	394	10 747
Swedish Institute of Assistive Technology	-	-	-	-	-	4 302	3 637	902	407	9 247
The Crime Victim Compensation and Support Authority	530	650	1 481	890	608	470	594	-	3 100	8 323
National Board of Institutional Care (SIS)	-	1 500	-	-	-	230	-	2 650	-	4 380
Swedish National Centre for Research in Sports	350	415	-	-	235	125	470	325	700	2 620
Swedish Research Council Forums	-	-	-	-	-	-	700	370	-	1 070
Norrböjca-Eugenia	3 642	4 806	3 813	3 671	4 409	3 682	5 552	6 065	4 089	39 678
Swedish Heart and Lung Association	860	720	1 300	1 075	1 500	2 630	2 876	2 700	1 435	13 096
Hörselns fonder (The Hearing Fund)	1 168	1 071	1 574	870	647	850	310	805	975	8 271
Stinzerfonden (The Stinzer Fund)	360	216	144	488	400	180	180	90	165	2 223
Svenska Dyslexistiftelsen (Swedish Dyslexia Foundation)	-	-	-	-	-	-	-	1 300	-	1 300
Jerrinsfonden (The Jerring Fund)	-	150	-	-	50	214	54	-	125	593
Stiftelsen Epilepsifonden (The Epilepsy Foundation Fund)	-	-	-	-	-	150	100	100	-	350
<b>Total</b>	<b>33 526</b>	<b>61 508</b>	<b>77 720</b>	<b>76 026</b>	<b>85 364</b>	<b>129 827</b>	<b>124 568</b>	<b>128 004</b>	<b>162 522</b>	<b>859 064</b>

integrates and develops new knowledge on impairment (see, e.g., Almqvist & Granlund, 2005; Rönnerberg, 2004).

A textbook example of such comparative research (i.e., comparisons between groups of impaired people, or between contexts/test-situations) was carried out by Dahlgren, Sandberg & Hjelmquist (2003). They compared autism-diagnosed children and other children with diagnoses such as ADHD and cerebral palsy with respect to their capacity for perspective-taking, or empathy in its broadest sense, i.e., their ability to take on another child's perspective or role. Their findings revealed that shortcomings in empathy

– previously thought to be a distinguishing trait of autistic children – also occur in the other diagnosis groups. This led the researchers to conclude that the absence of more general linguistic and communicative conditions is probably behind lack of perspective-taking, or empathy, rather than diagnosis-specific shortcomings in brain functions.

Further, when projects are classified on the basis of ICD-10 categories (in Table 3), mental illnesses remain an important group. Other diseases of the nervous system, musculoskeletal disorders, and diseases of the ear closely match the earlier table's higher investments in stroke,

Table 2 shows the number of projects which belong to a certain diagnosis (i.e., stroke) or, alternatively, to a more general category (i.e., impairment/disability), and the amounts, in thousands of SEK (000s), allocated to these over the two 5-year periods of 2002–2006 and 2006–2010 and over the entire 9-year period. Only the 15 most prominent diagnoses are shown in the table.

Diagnosis	Period			# of Projects
	2002-2006	2006-2010	2002-2010	
Cerebral Palsy	8 964 000	13 107 262	20 586 262	63
Diabetes	2 234 800	17 604 601	18 104 601	37
Disability	6 446 000	13 684 145	18 637 145	26
Impairment	38 095 000	41 932 762	69 764 762	66
Hearing Impairment	22 560 773	67 174 026	86 187 599	119
Multiple Sclerosis	8 185 400	13 348 198	19 649 198	25
Neurological Disorder	3 950 000	15 401 500	15 601 500	4
Psychiatric Disorder	14 375 000	20 824 000	31 636 000	20
Rheumatoid Arthritis	2 956 200	19 912 200	21 141 200	42
Motor Disability	7 731 000	12 617 701	18 649 701	45
NOS Illness	19 974 000	25 175 556	41 416 556	29
Language Impairment	11 912 458	10 100 000	19 572 458	9
Stroke	5 286 900	25 339 643	27 757 475	59
Mental Retardation	9 285 200	17 927 000	25 612 200	16
Aging	11 552 000	12 177 419	23 007 419	18
<b>Total</b>	<b>173 508 731</b>	<b>326 326 013</b>	<b>457 324 076</b>	<b>578</b>



Table 3 shows the total appropriations in thousands of SEK (000s) for each ICD-10 category for the two five-year periods of 2002-2006 and 2006-2010 and for the entire nine-year period.

ICD-10	Period			# of Projects
	2002-2006	2006-2010	2002-2010	
No appropriate ICD code	10 778 000	10 335 000	19 213 000	15
Diseases of the respiratory system	4 384 000	5 619 500	9 092 500	53
Diseases of the circulatory system	13 645 458	37 810 591	45 542 581	168
Endocrine, nutritional and metabolic diseases	6 380 800	30 194 701	33 980 701	53
Factors influencing health status and contact with health services	68 213 900	71 803 726	127 379 626	150
Pregnancy, childbirth and the puerperium	1 270 000	6 120 000	6 650 000	11
Diseases of the skin and subcutaneous tissue	690 000	4 920 340	5 160 340	6
Codes for special purposes	0	220 000	220 000	2
Diseases of the digestive system	2 152 900	4 065 320	4 833 820	25
Congenital malformations, deformations and chromosomal abnormalities	4 501 569	8 781 553	11 770 722	27
Mental and behavioural disorders	57 482 658	80 830 124	127 012 782	113
Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	776 000	9 223 200	9 283 200	17
Diseases of the musculoskeletal system and connective tissue	20 039 826	56 813 440	72 094 610	175
Diseases of the nervous system	33 225 354	88 206 671	110 199 981	205
Diseases of the genitourinary system	2 057 800	6 811 983	8 312 983	30
Diseases of the eye and adnexa	6 755 000	10 755 168	14 240 168	19
Diseases of the ear and mastoid process	24 030 873	69 651 026	89 199 699	121
Injury, poisoning and certain other consequences of external causes	4 889 542	5 970 886	9 870 228	41
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	12 325 000	20 026 536	31 096 536	28
Neoplasms	1 175 300	6 539 000	7 097 300	33
Certain infectious and parasitic diseases	4 930 700	7 211 050	10 443 550	35
Certain conditions originating in the perinatal period	4 508 450	7 934 800	9 571 750	33
External causes of morbidity and mortality	12 739 000	21 725 504	28 546 504	27
Information not available	27 240 000	49 495 500	69 151 000	25
<b>Total</b>	<b>324 142 130</b>	<b>621 065 639</b>	<b>859 843 601</b>	<b>1 412</b>

motor disability/rheumatoid arthritis and hearing loss. A more general category relating to “factors of importance for state of health...” is the largest in this table. This category overlaps somewhat with the broad categories referred to above as “impairment/disability” in that it is general and cross-diagnosis. The results are similar over the time periods.

In the medical/caring science perspective, it is common to take diagnosis as the starting point and focus on the individual. To test this assumption, to investigate whether this perspective has a strong correlation to a main focus on the individual, as well as to see how the relational- and environmental-focused projects are distributed by perspective, the distribution of the projects

Table 4. Per cent of projects under each perspective and focus. The figures in parentheses indicate how large a proportion is deemed to be interdisciplinary and “disability studies”, respectively. All figures are given as percentages of the total number of projects granted funds during 2002-2010.

Focus	Perspektive				Total
	Tech/scientific	Med/caring sci	Behav sci	Hum/social sci	
Individual	1 (0, 0)	53 (8, 0)	5 (1, 0)	0 (0, 0)	59
Relation indiv-environment	1 (0, 0)	15 (12, 0)	11 (6, 1)	5 (2, 2)	32
Environment	1 (0, 0)	1 (0, 0)	1 (0, 0)	5 (1, 4)	8
<b>Total</b>	<b>3</b>	<b>70</b>	<b>17</b>	<b>10</b>	<b>100</b>

Table 5. Proportion of funds granted to the respective perspectives and focuses. The figures in parentheses refer to proportion of funds granted to projects deemed to be interdisciplinary and “disability studies”. All figures are given as percentages of the total amounts granted during 2002-2010.

Focus	Perspektive				Total
	Tech/scientific	Med/caring sci	Behav sci	Hum/social sci	
Individual	2 (2, 0)	31 (6, 0)	4 (1, 0)	0 (0, 0)	38
Relation indiv-environment	1 (1, 0)	17 (15, 0)	21 (15, 1)	9 (7, 4)	48
Environment	2 (0, 0)	1 (0, 0)	1 (0, 0)	10 (3, 8)	14
<b>Total</b>	<b>5</b>	<b>50</b>	<b>26</b>	<b>19</b>	<b>100</b>

Table 6. The same variables as in Table 4, broken down by the time periods 2002–2006 and 2006–2010. The total number of projects is larger here because certain projects are reported under both periods.

Focus	Perspektive Tech/scientific		Med/caring sci		Behav sci		Hum/social sci		Total
	2002-2006	2006-2010	2002-2006	2006-2010	2002-2006	2006-2010	2002-2006	2006-2010	
Individual	0(0.0)	0(0.0)	13(3.0)	34(5.0)	2(1.0)	3(0.0)	0(0.0)	0(0.0)	58
Relation indiv-environment	0(0.0)	1(0.0)	5(4.0)	10(8.0)	5(3.0)	5(4.1)	2(1.1)	2(1.1)	34
Environment	0(0.0)	1(0.0)	1(0.0)	1(0.0)	0(0.0)	0(0.0)	3(1.2)	3(0.2)	8
Total	1	2	24	44	9	10	5	5	100

across perspectives was examined. Also examined was how “interdisciplinarity” and focus on “disability studies” correlate with perspective and primary focus.

Table 4, therefore, contains (in the final column) the percentages of the total number of projects that focus primarily on the individual, the individual-environment relation, or the environment, as well as the distribution of these across the different perspectives (middle columns). Within parentheses in each “cell” of the table is the percentage of total projects which are interdisciplinary (first number), followed by the percentage of projects which can be said to have a “disability studies” focus (second number). For example, the “cell” that represents medical/caring science research that is individual-focused shows that 53 per cent of all studies fall into this category; in addition, 8 per cent of all projects fall into this category and are multidisciplinary, whereas none in this category have a “disability studies” focus.

The pattern is thus clear. The largest share of research is concentrated on medical/caring science with a focus on the individual. The research with a humanities/social sciences perspective comprises 10 per cent of all projects, but half of these are relational-focused and the other half environment-focused. In the behavioural science research, which represents 17 per cent of the total projects, slightly less than two-thirds of the projects are relational-focused, and slightly less than one-third are individual-focused. The scientific/technical research represents only 3 per cent of all projects. Overall, the individual-focused projects dominate with 59 per cent. The relational-focused projects constitute 32 per cent of all projects, and the environmental-focused comprise only 8 per cent.

The majority of the interdisciplinary projects are found within the medical/caring science and behavioural science research, with 20 per cent and 7 per cent, respectively, of all the projects. Overall, 30 per cent of all the projects are interdisciplinary. About 7 per cent (almost 100) of all projects can be considered “disability studies”.

Table 5 shows funds allocated within the same categories as in Table 4. The largest amount goes to medical/caring science projects. The behavioural science research has a higher proportion of funding compared to its proportion of projects (26% of total funding vs. 17% of total projects), and the proportion of funding to interdisciplinary projects is significantly greater (50%) than its proportion of

projects (30%). While the individual-focused projects dominate when it comes to the proportion of total projects (59%), projects focusing on the relationship individual/environment dominate when it comes to the proportion of funds, with close to half (48%). Projects which can be described as “disability studies” increase in terms of the proportion of funds compared to proportion of projects, from 7 per cent to 13 per cent.

Table 6 shows the proportion of projects within the respective perspectives and focuses broken down by the time periods 2002–2006 and 2006–2010, i.e., it contains essentially the same information as Table 4 but broken down into the two time periods. Those projects which received funding during both of these periods or only during 2006 are included in both periods. The pattern for the entire period is mirrored in the two five-year periods, with one major exception: the percentage of medical/caring science research projects increases sharply between the two periods, from 24 to 44 per cent.

The increase in medical/caring science projects is due, among other factors, to a significant increase in County Councils funded research. The increase is in fact less than that indicated in the table because the registration of projects in 2002–03 was incomplete, so the figures for these years are most likely an underestimate. In the research policy proposition “Government proposition 2004/05:80, Research for a better life”, additional investment was made in the area of medicine, which may also have spilled over to the research on impairment with this perspective.

Note also that disability research with a scientific/technical perspective is very limited. This may be due in part to the fact that many projects are investigative in nature (e.g., the Swedish Institute of Assistive Technology’s activities) or function as pilot projects (e.g., smart housing). Research projects in our material which concerned technical aids were nevertheless sorted under the technical/scientific perspective. The proportion of projects with a technical/scientific perspective has not, therefore, been underestimated.

A further aspect which has arisen during the last few years is the question of how impairment interacts with other factors to affect the standard of living of people concerned (Grönvall & South, 2008). The interaction with gender, ethnicity and class is most often mentioned. This perspective is usually known as intersectional and is

relatively new in research on impairment and disability. Among the projects included in the database, only a few specifically study gender in combination with impairment. Only five projects mention gender in their titles. The ethnic aspect is present in even fewer projects: Only two projects mention it explicitly. More projects address social class, but it is referred to in different ways. It is most common to study socio-economic belonging. Socio-economic aspects appear in some 20 projects. Only one project is intersectional in a broad sense. It deals with the interaction between gender, ethnicity and impairment in a study on sexuality.

The question of the presence of longitudinal studies has also been raised. It is of great value if a group of people with impairment can be followed over time in order to increase knowledge about the interactions between different circumstances. However, only a few projects can be characterised as longitudinal: 54 projects altogether, or slightly less than 4 per cent.

In recent years, the disability movement has increasingly stressed the importance of persons with impairment becoming involved in the research process. This has received attention, inter alia, through a doctoral course with a focus on participant collaboration. In the present survey, however, it has not been possible to identify whether – much less the extent to which – persons with impairment have been involved in the research processes. This information was not evident in the project descriptions.

#### STEP 1: SUMMARY

During 2002–2010, total allocated funds rose nominally from approximately SEK35 million to approximately SEK150 million. State funding, in real terms, remained relatively constant from 2008 onward, with about SEK90–95 million (in 2002 values). Research mainly concerns people of working age (20–65 years), a trend which has grown stronger over the period. The medical/caring science perspective dominates with its focus on the individual, and the number of projects with this perspective has increased dramatically over the second time period (2006–2010). There are few examples of the technical/scientific perspective within disability research. This may seem somewhat surprising in light of the growing interest for concepts such as design for all and universal design. One explanation, however, may be that many projects within this area concern development rather than research and lie, therefore, outside the realm of what has been studied here.

Hearing loss dominates as an individual diagnosis, but research on physical disabilities (and related illnesses), illnesses/damage to the nervous system (cerebral palsy, stroke), mental illnesses and developmental disabilities also have large shares. The relational perspective is clearly represented and is found in 32 per cent of all projects. Thirty per cent of all projects are interdisciplinary, and 7 per cent can be considered “disability studies”. If we look

at funds allocated, 50 per cent go to interdisciplinary projects and nearly half (48%) to projects with a relational perspective. Add to this the interdisciplinary and relational medical/caring science approach of the Swedish Institute of Health Sciences and the overall picture becomes very clear.

Few studies treat impairment and disability in combination with gender, ethnicity and/or class. Cross-sectional studies strongly dominate over longitudinal studies.



## Step 2: Publications analysis

The Department of Publishing Infrastructure at Linköping University Library was tasked with carrying out publication analyses for the project owners as defined in step 1 and for the other researchers who appeared in the lists of 2010 collaborators collected from institutions/institutes engaged in disability research in Sweden. The task of determining the basis for the analysis, i.e., the publications to be included, can be divided into three stages, as indicated in the diagram below.

The total list comprised 970 researchers. The data collection was done by searching for these names in ISI/Web of Science and SwePub. The searches generated a large number of publications: 8,414 from ISI/Web of Science and 980 from SwePub.

Of necessity, limits were placed on the search volume of the number of publications. All of the publications were assessed for topic, and only those in the field of impairment, disability and handicap were selected for the continued analysis (Table 7 and onward).

The flow chart below (Figure 3) reports the result of manual analyses of all the 8,414 articles, etc., and the 980 books/book chapters/dissertations (phase 3), which resulted in 3,571 publications from ISI and 376 SwePub

publications remaining. The criteria applied in the selection are set out below.

### Selection criteria

Studies which either highlight an impairment/state/illness which is of a lasting character (e.g., cerebral palsy) or a population which has such in particularly serious form (e.g., people who have severe schizophrenia) are included. For example, an epidemiological study of depression was included only if it focused on chronic aspects of the disorder.

Studies that focus on functional aspects of impairment/illness were included. Such may relate to the individual's function in itself or the relationship between individual impairment and the environment (see introduction).

Studies that primarily focus on the origins of or mechanisms behind illnesses and impairments were not included in the assignment. Thus excluded are biochemical and molecular biological investigations that do not link the biological mechanism to an impairment (or to a specific aspect of the impairment or to the impairment's context).

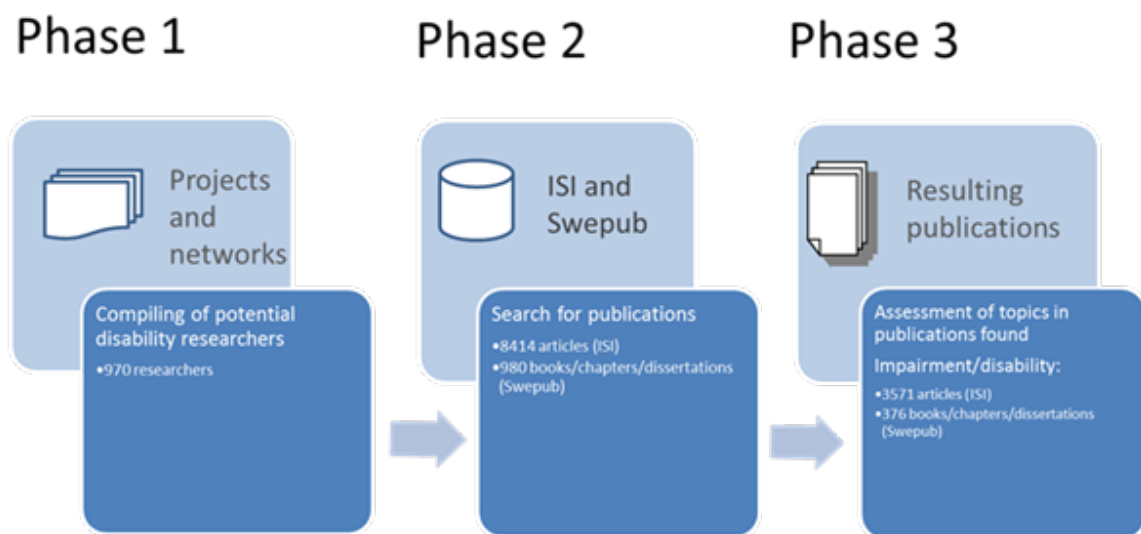
Two examples may clarify the criteria:

(1) Huntington's disease is a neurological disease that gives rise to motor and cognitive difficulties and psychiatric disturbances. The disease is believed to occur as the result of an increased production of glutamine which, in turn, affects

Figure 3 shows the workflow, phase by phase.

## Process for publications analysis:

Figure 3.



the protein huntingtin; huntingtin with many glutamine residues is toxic and causes the disease (Ross & Tabrizi, 2011). A study of glutamine, huntingtin or the gene that codes for huntingtin is not disability research – irrespective of whether the study is about patients or healthy individuals. Conversely, a study which relates function in the individual or the individual’s environment (depression, support to relatives, aphasia, etc.) to the Huntingtin gene would be included.

(2) In cognitive-psychological studies of short-term memory, the ‘phonological loop’ (Baddeley, 2007) is a central concept. The phonological loop is a cognitive system specialised for the temporary storage of linguistic, meaningful sounds. In compiling the studies to be examined, studies about how the phonological loop functions or how it develops during childhood have been ruled out. On the other hand, a study which highlights how the loop functions in connection with hearing impairment or memory-related disability has been included.

As with the project classifications, the selection has been quality-assured through cross-validation of assessments within the working group.

## STEP 2: RESULTS

### Journal articles

The number of articles registered in the ISI/Web of Science which meet the above criteria is shown in Table 7, below. As can be seen, the number of publications increases systematically over the entire period.

Furthermore, one can see that the number of authors increases dramatically for the final two years of the period (1,554 in 2008, 1,813 in 2009 and 2,487 in 2010), whereas the number of authors from the original list does not change as radically (275, 341 and 332, respectively). This

must mean that networking, co-publishing and teamwork increase correspondingly.

Of the 7,597 authors, 63 per cent are responsible or jointly responsible for only one publication, and approximately 15 per cent are responsible for two. The graph representing the number publications falls steeply (Figure 4).

As a complement to Table 7, Figure 5 shows that the number of articles published within the field has increased systematically each year from 2002 to 2010. It is a healthy sign when an area of research substantially increases its production of quality-assured articles in peer-reviewed international journals.

This positive impression is further strengthened by the fact that, percentage-wise, the number of publications in the field of impairment and disability in ISI/Web of Science since 2002 increases significantly more than for overall research in Sweden, taken over all categories in ISI/Web of Science (a 76-77% increase compared to 25%). This can be considered a very significant indication of the scientific maturity and expansion which has occurred in impairment and disability research (see Figure 6).

In addition, a citations analysis was performed<sup>5</sup>. Here, the field-normalised citation rate<sup>6</sup> is used as a measure of impact; it shows that the impairment/disability field is clearly more cited than the global average (1.25). If the publications search is combined with citation rates, this confirms to the highest degree the assertion of scientific maturity and success.

<sup>5</sup> Data supplied by CWTS, Leiden University, based on Thomson Scientific/ISI. An open citation window (1-5 years) was used in the analysis, and self-citations have been excluded. Citations data is reported unfractionalised.

<sup>6</sup> A measure of impact of the articles which are included in the analysis. The number of citations of articles included in the analysis is compared with the average number of citations within the corresponding field (i.e., ISI/Web of Science subject categories), publication year and type of article. A value of 1 is equivalent to the global average.

*Table 7 shows the number of journal articles for each of the years 2002-2010. The table also shows the number of authors from the original projects/networks list and the total number of contributing authors in all publications.*

## Journal articles 2002-2010

Source: ISI/Web of Science

Table 7.

	2002	2003	2004	2005	2006	2007	2008	2009	2010	Total
<b>Number of articles</b>	283	344	361	360	379	415	440	492	497	<b>3571</b>
<b>Number of authors</b>	954	1125	1167	1297	1319	1517	1554	1813	2487	<b>7597</b>
<b>Number of these authors from projects/networks</b>	218	248	242	269	256	284	275	341	332	<b>712</b>

Figure 4 shows the distribution of the number of authors writing a given number of publications.

## Journal articles 2002-2010

Source: ISI/Web of Science

Figure 4.

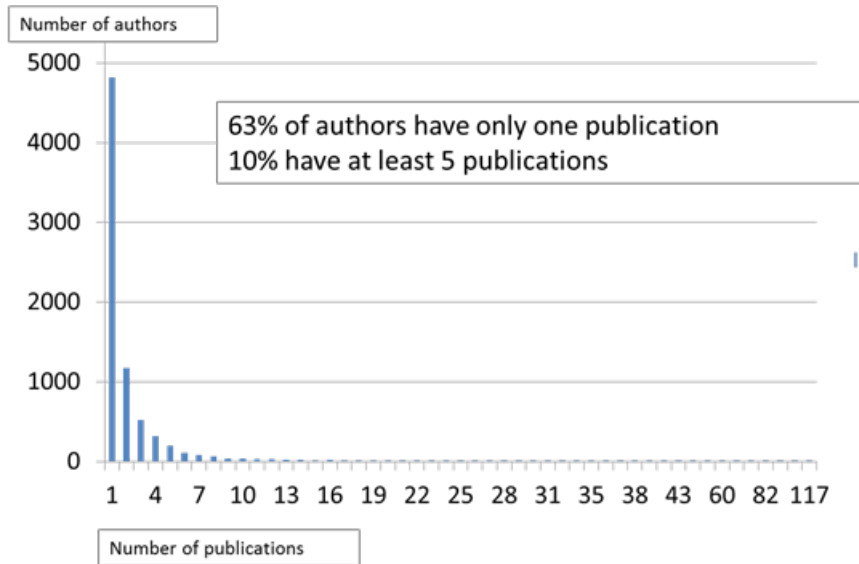


Figure 5 shows the number of journal articles published during the period 2002-2010.

## Journal articles 2002-2010

Source: ISI/Web of Science

Figure 5.

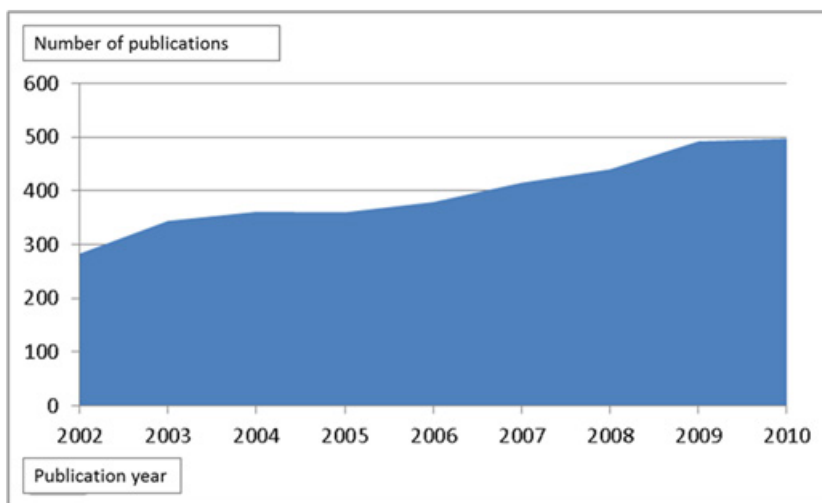


Figure 6 shows the relative annual change in publishing volume in ISI/Web of Science for research on impairment and disability compared with overall research in Sweden. The volume in 2002 is set at 100% for both curves.

## Journal articles 2002-2010

### Annual change in volume in ISI/Web of Science

Figure 6.

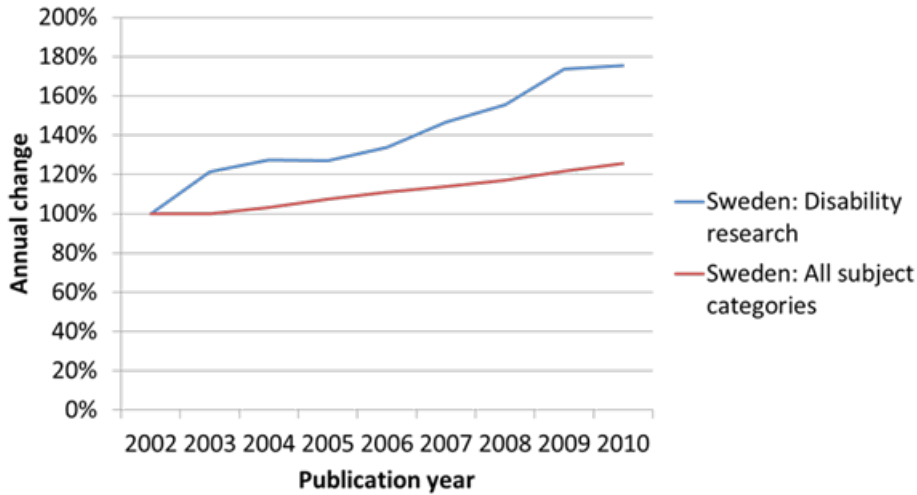


Figure 7 shows a network analysis of the publications during the period 2002-2006.

## Co-authorship

Journal articles in ISI/Web of Science 2002-2006

324 authors with at least 5 articles

Number of clusters: 46

Figure 7.



Each node is an author.

The size of the node indicates number of publications.

The lines illustrate that the authors have co-published.

The width of the lines indicates the number of co-authorships between authors.

Based on the pattern of co-publishing and the number of co-authorships, different clusters in which the authors co-publish more frequently can be identified. These clusters are illustrated in the figure by different colours.

Figure 8 shows the corresponding analysis for the period 2006 -2010.

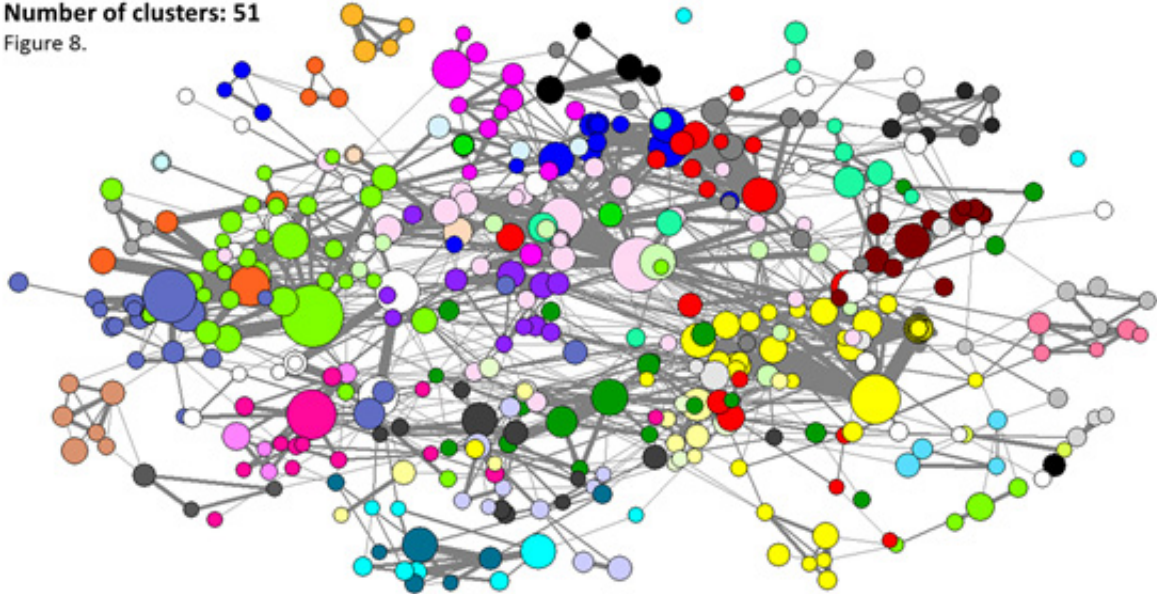
## Co-authorship

Journal articles in ISI/Web of Science 2006-2010

440 authors with at least 5 articles

Number of clusters: 51

Figure 8.



Each node is an author.

The size of the node indicates number of publications.

The lines illustrate that the authors have co-published.

The width of the lines indicates the number of co-authorships between authors.

Based on the pattern of co-publishing and the number of co-authorships, different clusters in which the authors co-publish more frequently can be identified. These clusters are illustrated in the figure by different colors.

Table 8 shows the ten largest clusters of authors and the number of publications per time period.

## Composition of clusters

Size (number of authors) of the 10 largest clusters

Table 8.

Cluster	2002-2006		2006-2010	
	Number of authors	Number of publications	Number of authors	Number of publications
1	20	161	34	412
2	19	243	34	390
3	15	156	33	347
4	15	123	22	222
5	14	122	22	230
6	13	108	17	170
7	12	135	14	175
8	11	113	13	156
9	11	110	12	110
10	9	102	12	113



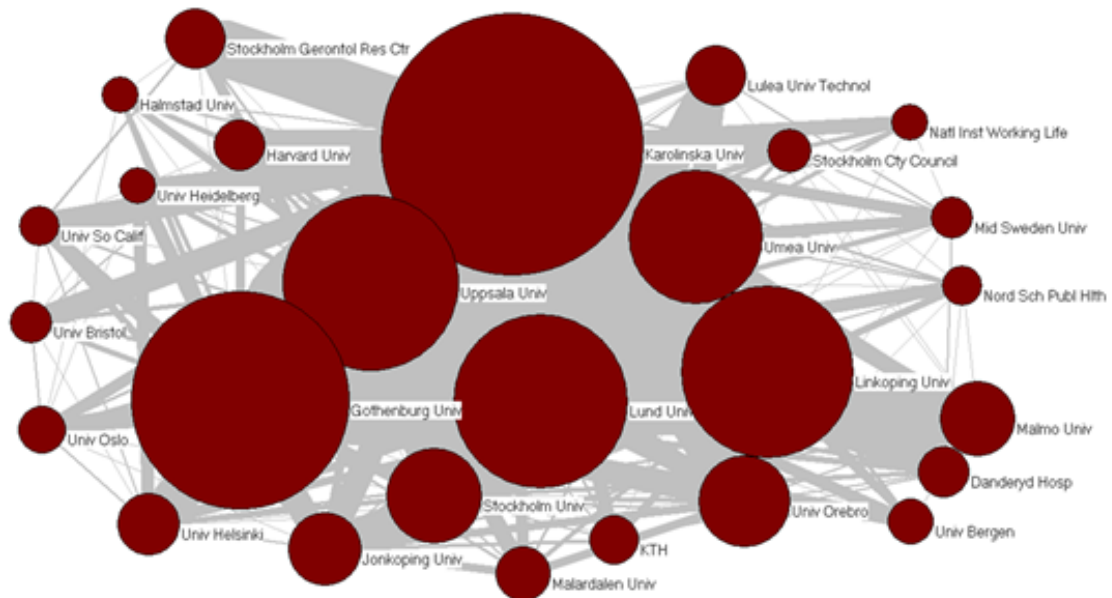
Figure 9 shows the degree of co-publishing between different universities, both nationally and internationally. Where possible, university hospitals have been included with their respective universities.

## Co-publishing among institutions

Journal articles in ISI/Web of Science 2002-2010 (3571 articles)

27 institutions with at least 25 articles are represented

Figure 9.



Each node is an institution/university.

The size of the node indicates the number of publications that can be tied to the university.

The lines illustrate co-publishing between universities.

The width of the lines indicates the number of co-publications.

Further publications analyses carried out are shown in the network maps for 2002–2006 and 2006–2010 for those authors who had at least five publications registered in ISI/Web of Science. Overlapping periods (year 2006) were chosen in order to have equally long periods for the purpose of meaningful comparison. Each large circle in a particular shade represents a main author in a cluster of authors who co-publish together. The size of the rings is in proportion to the number of publications, and the width of connecting lines is in proportion to how often the authors co-publish with one another.<sup>7</sup>

It should be noted that for 2002–2006 (Figure 7, below) there are relatively few large clusters of researchers as relatively autonomous research environments. There are also many smaller groups which are relatively isolated and which look like “satellites” in the large network. If one then goes on to study the network map for 2006–2010 (Figure

8), there is a substantial difference both qualitatively and quantitatively. A greater number of authors published more than 5 articles (440 for 2006–2010 compared with 324 for the period 2002–2006). Qualitatively, one can see that several major clusters have been formed, the network overall has become considerably more integrated, and clustering is more inter-related. Together, this indicates that the area is beginning to form a more distinct scientific core.

The two time periods have a similar number of clusters (46 vs. 51), but the cluster sizes differ significantly, as shown more clearly in Table 8, below. The later period shows significantly larger cluster sizes of authors. For example, the two largest clusters for the period 2002–2006 include 20 and 19 authors, respectively, whereas for the period 2006–2010, the two largest clusters each include 34 authors. In other words, the formation of clusters has had a “magnetic” effect in the development of the research community in the area of impairment and disability.

In a separate analysis of the 324 authors who published at least five articles in 2002–2006 (Figure 7), only 202 had also published at least five articles in 2006–2010. As

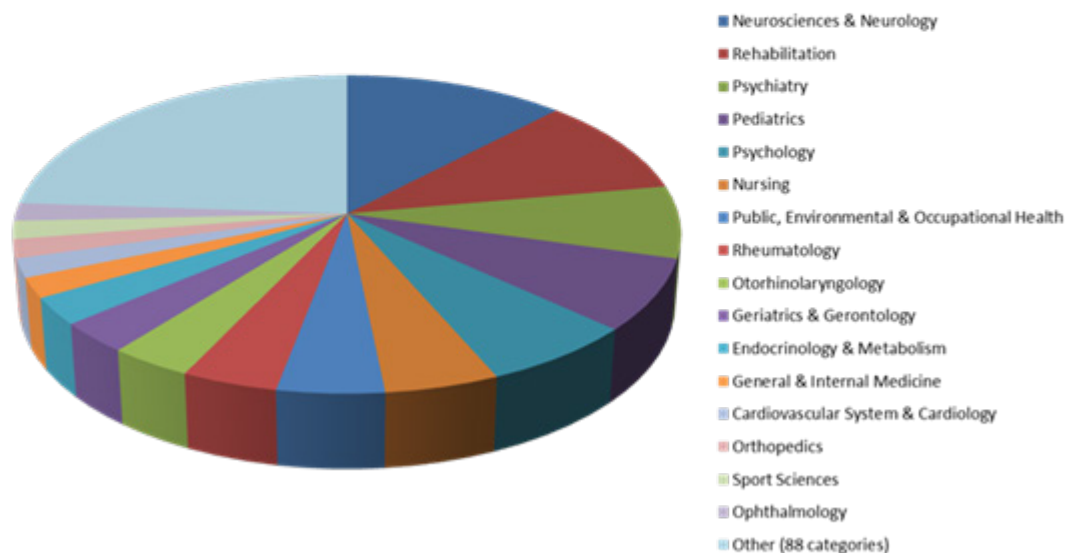
<sup>7</sup> The network maps have been created in the program Pajek (<http://pajek.imfm.si/doku.php?id=pajek>), and the layout used is Fruchterman-Reingold. The clusters have been produced with the help of the clustering procedure “Persson’s Party Clustering” contained in Olle Persson’s program, Bibexcel (<http://www8.umu.se/inforsk/Bibexcel/>).

Figure 10 shows the breakdown of all registered ISI/Web of Science articles throughout the period 2002–2010 according to subject area.

## Journal articles 2002-2010 Classification by subject area\*

Source: ISI/Web of Science

Figure 10.



\*) According to ISI/Web of Science Subject Categories

mentioned previously, 2006 has been included in both periods. Taking account of the fact that 2006 is included in both periods, the number of authors with a continuously high production during the whole period can be estimated at approximately 180. Overall, it can be said that there are 180 authors who can be described as “bearers” of the research area in the sense that they published at least 5 articles during each of time periods.

University networks of collaboration are found in Figure 9. Note that the university hospitals are also included for each university (as applicable). It is clear that the major players in this field are Karolinska, the University of Gothenburg, and Linköping, Lund, and Uppsala Universities. Thereafter follow Umeå and Örebro Universities as key Swedish players in the field. Scandinavian universities which stand out in the network are Helsinki, Oslo and Bergen Universities. In Europe, the University of Bristol and the University of Heidelberg are clear collaborators. In the United States, Harvard University and the University of Southern California are visible. Among the Swedish actors, there are different centres/institutes, e.g., at Uppsala University, the Centre for Research on Disability in Lund/Malmö, which is linked to HAREC (Malmö), and the Swedish Institute

for Disability Research (SIDR), which is a cooperation between Linköping, Örebro, Jönköping, Mälardalen and Halmstad Universities.

From 2002 to 2010, the share of publications with a non-Swedish collaborative partner has increased from 21 per cent to 36 per cent. This indicates that internationalisation has picked up, but there is reason to count on even stronger internationalisation in the next ten-year period.

With regard to content, analysis of the subject categories in the research (see Figure 10) reveals that neuroscience dominates, followed by rehabilitation, psychiatry, paediatrics and psychology. Caring research, environmental and occupational health, rheumatology, otorhinolaryngology, and geriatrics follow thereafter in a cluster of relatively equivalent fields. In total, the articles are classified into 104 subject areas according to the ISI-database’s subject classification.

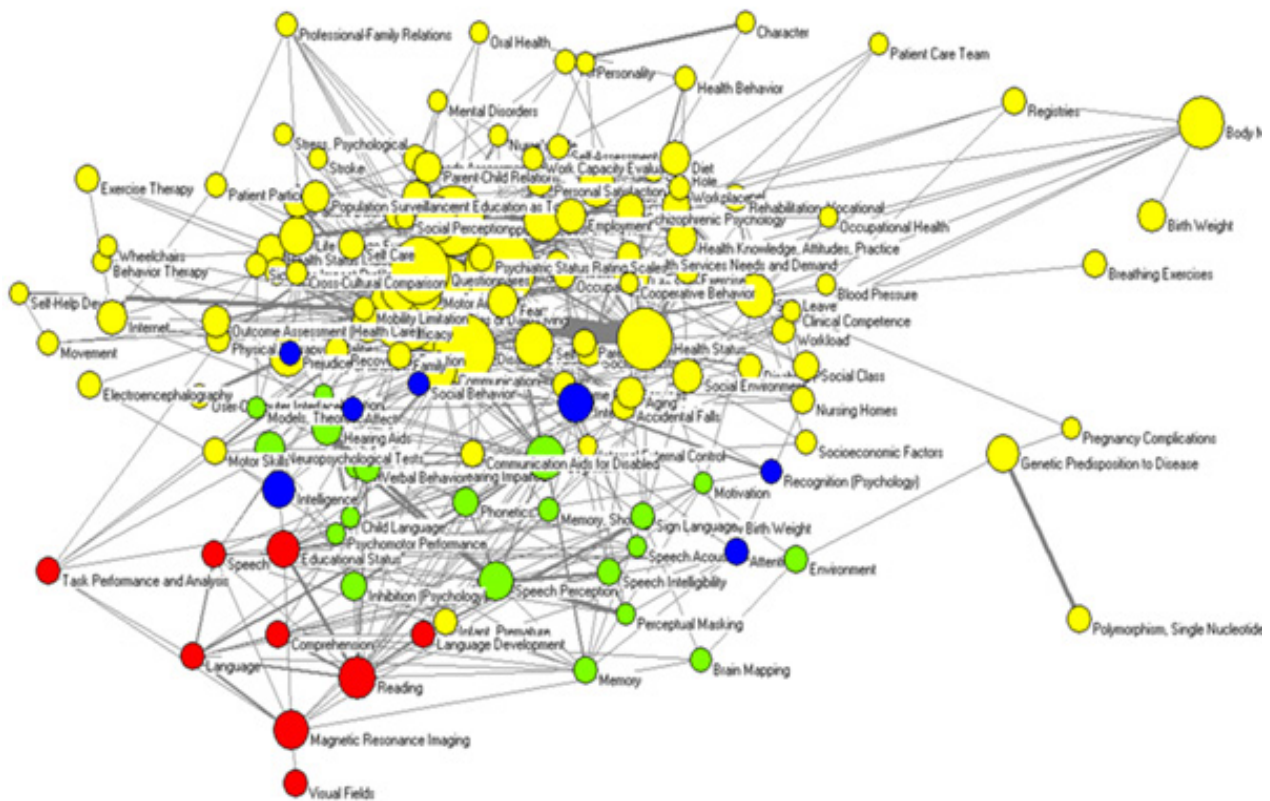
Complementary analyses of the development over time for each subject category have been performed as well. In general, it can be said that “rehabilitation” and “psychology” are the subject categories that have shown the steepest positive development curves. As regards the journals, those most published in are *Acta Paediatrica*, first (despite the proportion of children’s projects being so low, Figure 2),



Figure 11 shows different clusters of MeSH terms used to index content in articles.

## MeSh-terms

Figure 11.



and Disability and Rehabilitation, second, followed by the Journal of Rehabilitation Medicine and the International Journal of Audiology.

Moreover, an analysis of the content based on the subject headings used for indexing articles (known as MeSH terms, see Figure 11) yields a broad rehabilitation cluster in yellow (with terms such as ‘psychiatric health’, ‘mental disorder’, ‘internet’, ‘health status’, ‘health behaviour’, etc.) and also a large linguistic–cognitive–audiological cluster in green (with terms such as ‘memory’, ‘perceptual masking’, ‘speech perception’, ‘sign language’, etc.).

A lasting impression of the terms reported in Figure 11 is that a large number deal with cross-boundary and “integrative” perspectives, mainly in medicine/health sciences and psychology. It therefore appears that it is these aspects of Swedish research on impairment and disability which have had an impact in the international scientific community.

The analysis of journal articles is based entirely on ISI/ Web of Science because this makes it possible to follow developments from 2002 onwards. This was not possible in SwePub because registrations prior to 2006 were too incomplete. A search of SwePub articles was carried out,

on the other hand, to see what falls outside of the analysis. The results show that a clear majority of the articles belong to subject categories that are generally well covered by ISI/ Web of Science. There were relatively few articles (around 3%) in areas not well covered by ISI/Web of Science. SwePub articles would not have any significant impact on the publishing patterns obtained from the ISI-articles.

### Books, chapters and dissertations

In SwePub, there were 376 books/book chapters/ dissertations meeting the criteria written by 461 authors/ co-authors. Only 10 per cent of the authors published at least three times during the period 2006–2010, and 80 per cent of the authors had only one publication (Figure 12).

As illustrated in Figure 13, there is not the same clear upward trend for SwePub-publications as for ISI/ Web of Science-registered articles. If the 2010 figure for dissertations is correct, this must be characterised as grave because it indicates that renewal in the field could be jeopardised. Chapters and books are written, to a greater extent, by senior authors, which means that these publications are not similar indicators of renewal.

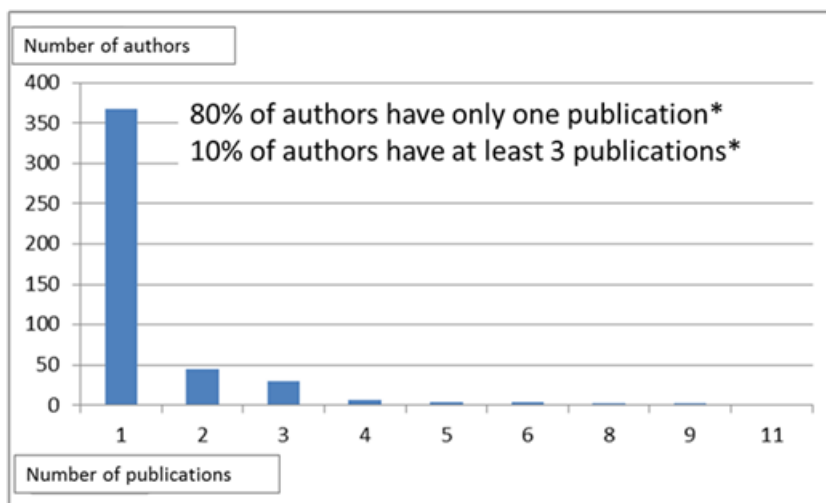
SwePub publications also differ from those registered

Figure 12 shows the number of authors with a given number of publications registered in SwePub during the period 2006-2010.

## Books, chapters and dissertations 2006-2010

Source: SwePub

Figure 12.



\*) Books, chapters, dissertations

in ISI/Web of Science in another way. For books, chapters and dissertations (Figure 14), the network map is significantly less integrated. This may have to do with the fact that books and book chapters, in which an author generally summarises many findings, are more of a “one man’s job” in today’s scientific world, whereas original

articles, not least in an interdisciplinary context, require cooperation between many competencies and individuals. This fact in itself suggests that the production of articles requires an interdisciplinary approach which, in turn, requires several competences/authors.

As noted earlier, it is possible, based on the analysis of

Figure 13. SwePub publications by publication type and year

## Books, chapters and dissertations 2006-2010

Source: SwePub

Figure 13.

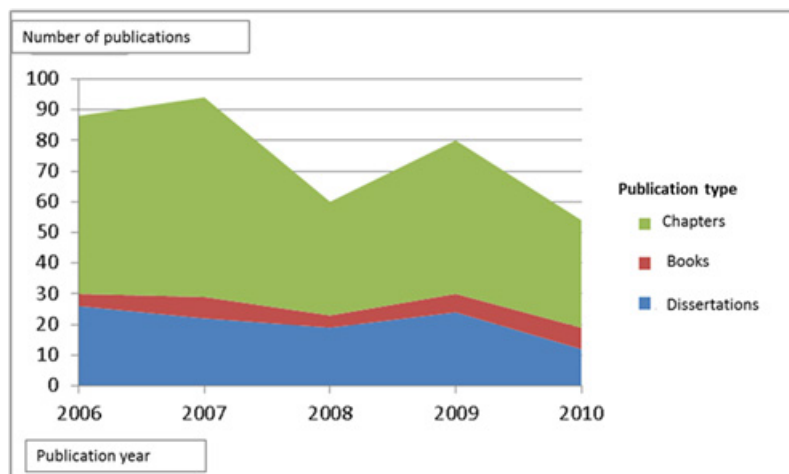


Figure 14 shows a network analysis of SwePub publications for the period 2006-2010.

### Co-authorship SwePub 2006-2010 (Books, chapters, dissertations) 461 authors (of which 137 have not co-published)

Figure 14.



Each node is an author.

The size of the node indicates number of publications.

The lines illustrate that the authors have co-published.

The width of the lines indicates the number of co-authorships between authors.

Based on the pattern of co-publishing and the number of co-authorships, different clusters in which the authors co-publish more frequently can be identified. These clusters are illustrated in the figure by different colours.

journal articles, to identify approximately 180 “bearers” of the impairment research area. A corresponding analysis of SwePub publications indicates around 50 authors who can be seen as “bearers” of the subject. Some of the people who published more than three times in SwePub are the same as those who published more than five articles. Altogether – based on both ISI/Web of Science and SwePub – it can be estimated that the total number of authors who are “bearers” of the subject area amounts to approximately 200.

Earlier, it was noted that many authors (63% for ISI/Web of Science and 80% for SwePub) have only one publication registered. A cautiously positive interpretation of this is that there are many who are interested in the field, i.e., the recruitment potential is great, but that limited resources and opportunities provide few researchers the opportunity to develop seniority in the field.

#### STEP 2: SUMMARY

The field is represented in this publications analysis by 3,571 original articles written by 7,597 authors/co-authors and 376 books or book chapters written by 461 authors/co-authors. Closer analysis of the original list of authors (n=970) shows that very few authors write more than five articles and some books or book chapters. Slightly more than 200 researchers can be considered to be “bearers” of the area. More articles were published during the latter

period than during the first. Network analyses show that the field is becoming both quantitatively and qualitatively more integrated and that more large clusters of researchers are being formed. The area has undergone marked scientific development – considerably more than the national average – and some subject and content areas are forming new areas of expertise (e.g., neuroscience and rehabilitation research, where rehabilitation research has the steepest development trend, followed by subjects in psychology). The rate of citations clearly exceeds the global average. It is important to note that there may be a problem with renewal, if the number of published dissertations is taken an indicator of such. Were this trend to continue, a powerful recruitment strategy would be required. Potentially, there may be a good base from which to recruit, considering that a large proportion of authors (63% for ISI/Web of Science and 80% for SwePub) published only once during the period studied. According to a content analysis of subject headings that are used to index articles (known as MeSH terms), rehabilitation and language-cognition-hearing represent two major clusters. To date, internationalisation and international collaboration have not resulted in many strong partners in the sense that cooperation has resulted in more than 25 original articles. A marked increase is expected over the next 10-year period.

## Discussion of key findings

### The field in general

The majority of research on impairment and disability is dominated by the perspectives of medical/caring science and behavioural science (76% of grants and 87% of projects). The medical/caring science perspective, with its focus on the individual, dominates in terms of the number of projects, and this number has increased sharply during the second time period. At the same time, the behavioural science research is clear in its relational approach, an approach which is also found within the medical/caring science perspective, albeit to a lesser extent.

To tie this in with the introductory presentation, the individual focus dominates in terms of the number of projects but is less prominent in terms of funds granted. The data also clearly shows that this is the orientation that has gained additional ground during the later five-year period.

One-third of the projects are characterised by the relational (individual-environment) perspective, but this perspective receives the greatest share of funding. This is perhaps not altogether surprising, given that this perspective has, as mentioned, a relatively strong foothold in Scandinavian research on impairment and disability.

The third type of research, environment-related research, to which the social model and the cultural approach belong, occupies a very modest position in Swedish disability research. Like the individual approach, these approaches tend to be somewhat reductionist in the sense that the research does not take into account the whole bio-psycho-social spectrum.

One conclusion – with the reservation that only the project descriptions included in applications for funding have been examined, and not the results – is that the individual and the relational approaches both occupy a strong position, whereas the approach that focuses more exclusively on hindering and facilitating factors in the environment has a weak position.

The scientific maturity and development of the research area are reflected in a marked increase in the number of published articles, a strengthening of integrated scientific networks and clear connections between a number of Swedish universities and foreign universities. The field has increased its quality-assured output by almost 80 per cent between the two periods investigated (Figure 7). This result was found despite the strict criteria applied to the selection of articles. Moreover, the rate of citations clearly exceeds the global average.

Against this background, there is good reason to increase investment in the special areas of expertise to be found within the field of disability. This should be emphasised in the research policy proposition planned for 2012. Without greater investment, there is a risk that renewal in the field will be jeopardised. This could mean that the hitherto

successful development could stagnate. Today, the research field has a limited number of “bearers”, in the sense of researchers who continuously and over the long-term contribute to the area’s development. The government has a responsibility to ensure that this base can be broadened.

An increase in quality-assured articles can be seen as an important step in the establishment of a research area. However, more steps must be taken in order for the field to become established as an international area of excellence. Figure 9 shows that there is productive cooperation with a number of universities abroad with which more than 25 articles have been co-produced, but our knowledge of the field tells us there are many more international partners which have not yet reached this level of cooperation because the partnerships have been established relatively recently. This applies, for instance, to a network analysis carried out with the Swedish Institute for Disability Research (Linköping–Örebro) as a model, and it probably also applies to other actors in the field. So a dramatic increase in international partners over the next 10 years is expected.

Interestingly enough, the interdisciplinary projects stand for 50 per cent of all project funds, across all perspectives (summed over all “cells” in Table 5). This figure is relatively high, given that 10 years ago the single-discipline approaches very likely dominated to a much greater extent. Interdisciplinarity clearly manifests itself in different ways within the framework of the various perspectives, with different levels of knowledge being integrated and developed.

Interdisciplinarity is most common within the caring science and medical perspective. Of the 423 interdisciplinary projects, 282 belong to the medical/caring science perspective. Of the 240 projects with a behavioural science orientation, 99 are interdisciplinary (41%), and of the 141 humanities/social sciences projects, 42 are interdisciplinary (30%). It is thus nearly twice as common to have an interdisciplinary approach in the more individual oriented projects as in the humanities and social sciences oriented projects. One might say that it is more common to include additional levels in a project if one is coming from a “lower”, rather than a “higher” level. The tendency to link “upwards” in levels is both obvious and interesting.

To connect this with what was said earlier about how the research can be characterised according to the initial five perspectives, it can be observed that the more individual approach “compensates” to some extent for its reductionist tendency by being more interdisciplinary than the other perspectives, whereas the social model and the cultural approach do not do this to the same extent.

On the basis of the obvious interdisciplinary character of the very phenomenon of impairment and disability, this investigation wishes to underline the importance of prioritising interdisciplinary research. It is particularly important to increase interdisciplinarity in the more

environment-oriented research (disability studies). The same argument applies to research that stresses the interaction between individuals and their environments, the relational perspective. The reason is that this type of research has general applicability and weight. This applies first and foremost to the medical/caring science and behavioural perspectives.

By focusing government investment within the area of disability on interdisciplinary research, the position of certain specialty areas which already have international excellence status can be strengthened, while enabling other areas to reach this level.

Another point, when it comes to the area as a whole, is that it is important that the state radically increase the funding of research on impairment and disability at this time of growing privatisation within the health and social care sectors. As a rule, private actors have neither the resources for nor an interest in research work. Research groups integrated into or cooperating with publicly run health-care operations are in a significantly better position to work with relevant groups of impaired persons and on the development, analysis and assessment of different intervention strategies.

#### Diagnoses, subject-content and comparative research

The project analyses show that research on hearing impairment dominates as an individual diagnosis. Research on physical disabilities (and diseases related to such), illnesses of/damage to the nervous system (cerebral palsy, stroke), and mental illnesses and developmental disabilities are also high up in the ranking of research.

As regards the subject fields in the publications analyses, neuroscience and rehabilitation research dominate, with psychology one of the traditional subjects high in the ranking. In particular, cognitive psychology is a dynamic field of research in neuroscientific and communicative disability contexts. That cognition and language are strong international fields has already been noted in the data shared by six research funders in “For Swedish success in research and innovation 2013–2016 För svensk framgång inom forskning och innovation 2013–2016. Underlag till forsknings- och innovationsproposition”.

The reasons for this can be many, of course, but one explanation may have to do with the fact that these fields have the potential to drive interdisciplinary research. This can be an important insight when efforts are directed toward various diagnostic groups and comparative problem areas. This should also be highlighted in future investments.

Employing a comparative and functional approach (e.g., comparing different groups with respect to a particular cognitive or social function) in which the diagnoses are not central, research on “impairment” comes in second place in the ranking (Table 2) and research on “factors contributing to health” (Table 3) is the largest category. These two categories have in common that they do not focus on a specific diagnosis. The category “factors contributing to

health” even includes projects with a more general focus on aging, quality of life and ill-health. All of the projects in these two categories also have in common that they are inter-disciplinary. In many cases, these projects are related to a biopsychosocial perspective. Such projects might have titles such as “Participation in school activities for pupils with disabilities”, “Children, crime and handicap” or “Disabled - with the right to work?”

*As a principle alternative to a research model in which the diagnosis is central, it is suggested here, based upon these successful project categories, that comparative and interdisciplinary research on impairment and disability also receive support.*

In this respect, ICF might be a starting point. As opposed to ICD, ICF does not classify states of illness but rather focuses on people’s functioning, building upon profiles which encompass physical function, activity, participation in daily life and environmental conditions. With the help of such profiles, the daily functioning of groups with different impairments in bodily function can be described and compared. Therefore, ICF enables research which compares bodily function, activity and participation between different groups or which looks for general phenomena in different groups of individuals. Such research can clarify that which belongs to more general aspects of impairment and that which can be traced to specific impairments in bodily function or states of ill health. More comparative research in which the functional profiles based on ICF are compared between groups of individuals classified according to type of disability or diagnosis is needed.

The universal coding system of ICF also makes it possible to link existing information to codes. This then makes it possible to exchange information between groups of researchers who employ different professional terminologies and to examine the content of research, measures, interventions and services for people with disabilities. One example of how the common coding system can be used is studies of the content of quality registries which are now being created for different diagnostic groups. A possible issue concerns the extent to which the registries take every day functioning and the environment into account. ICF also makes it possible to examine which combinations of physical, activity and participation factors can form profiles that give good prognoses for future functioning at the individual level.

#### Society-motivated research

##### *“Disability Studies”*

As shown by the data, the field identified in this assignment as “disability studies” is under-represented in the Swedish research community (7% of the number of projects and 13% of funds granted). The figures are overestimates, if anything, because a liberal interpretation of what is to be included in the concept has been applied. Included is not only research on “hindering” but also on



health-promoting aspects of society. “Disability studies” with a more interdisciplinary approach could increase interest. In this case, it would be a Scandinavian variant on the theme, rather than the reductionist British variant.

An urgent and “disability studies”-related future area of research is research on cultural values, attitudes toward persons with impairment, discrimination and human rights (see Lindberg & Grönvall, 2011). The survey showed that there were only a handful of projects along these lines. The research area is important for the reason that anti-discrimination laws have existed in Sweden for more than ten years; the UN Convention on the Rights of Persons with Disabilities, ratified by Sweden in 2008, also raises interesting research questions concerning the extent to which there is a gap between the intentions of the Convention the daily conditions for people with disabilities. This field of research, therefore, is highly relevant to society and should be of great interest to people with legal, social science, and humanities backgrounds.

Finally, given the importance that connection to working life has for people with disabilities, it is worth noting that only 8 per cent of the projects had this explicit focus. It is therefore important in future research to emphasise this aspect. When the National Institute for Working Life was dismantled, it was assumed that this type of research would be taken up by the universities and financed through other ordinary channels. This has occurred only to a limited extent. The importance of the work is actually underlined in the government’s current policy concerning impairment.

#### *The young and the old with impairments*

With regard to the distribution of projects over age groups: The research targeted specifically toward children and elderly people with impairments has had a relatively low impact. Impairments are often lifelong and should therefore receive greater attention in these age groups (Figure 2). Figure 2, however, probably underestimates project activities focused on older people with disabilities, as this type of project is found in the activities of both Vinnova and the Swedish Institute for Health Sciences.

Funds allocated to research on children’s and young people’s impairments are relatively low in comparison with those allocated to research on impairment in adults of working age. This is at odds with the level of media interest in, above all, children with neuropsychiatric and psychological impairments and their limited chances to succeed in school and in their transition to the labour market.

The problem area of elderly people with impairment covers three different phenomena:

1. Impairments that result from an individual’s suffering illness in the later stages of life (e.g., stroke or impaired lung function due to asthma).
2. Impairments that are the result of normal aging.
3. Impairments that are congenital or acquired earlier in life and continue into old age.

These research areas are unevenly represented in the category “elderly”. Most of the projects reported in Figure 2 belong to the first of these categories. Whether or not the second problem area belongs to the area of disability is an interesting question but is one which lies outside the purpose of this survey. Extremely few projects highlight the consequences of aging for people with impairments, i.e., the third category above. Given that demographic changes taking place in the population (with a growing proportion of elderly people) also apply to people with disabilities, it will be particularly important to highlight the conditions for this group.

Research should therefore be devoted to this issue of elderly people with chronic ill-health and the consequences of accidents. Impairment often entails that a person has mobility difficulties, which involves high risks for consequential morbidity as well as costs for health care and rehabilitation and indirect costs in people of working age. In elderly people with motion-related impairments, the cost increases significantly for special housing and for home care services if the persons cannot cope with their activities of daily living (ADL) without personal assistance. The challenge will be to study the factors and measures which most optimally prevent or delay the continued progression of the impairment and to evaluate the cost-effectiveness of intervention schemes. Adapted physical activity and individualised training are examples of key measures which could have major clinical implications. In Sweden, there are great opportunities to conduct front-line research on optimisation and cost-effectiveness of, e.g., distance-based rehabilitation with the use of video conferencing technology, as well as on factors that promote healthy lifestyles and enduring, health promoting behavioural changes. Sweden even has access to several large quality registries and longitudinal databases in which the impact of individual- and societal-level measures can be followed over time with regard to impairments and disabilities and calculations of cost-effectiveness. Sweden has comparatively many wellqualified researchers with different professional backgrounds and, thus, unique opportunities to found creative, outstandingly composed research centres where specific issues of importance for human environment interaction can be highlighted from the medical/caring science perspective as well as the technical, psychological and social- and behavioural scientific perspectives.

#### *New technologies and impairments*

Table 4 shows that technical/scientific projects account for only 3 per cent of the total number of projects. This is a remarkably low share considering, on the one hand, the rapid development of technology generally taking place in society, and on the other hand, the amount of development work going on aimed at facilitating children/young people’s entrance into the labour market and increasing possibilities for older people to remain living at home. Above all, this

technical development concerns how to compensate, with the help of various technologies, for reduced cognitive ability in both children/young people and the elderly. Among other things, in recent years the Swedish Institute of Assistive Technology has received several government assignments in this field (“Technology for elderly people I and II” and “Assistive means in focus”, School to work, [www.hi.se](http://www.hi.se)) which are aimed at disseminating knowledge of, and also speeding up and supporting the development of technical aids for both children/youth and older people with impairments.

As an argument for increased research investment from a society-motivated perspective within the fields of children/young people and older people with impairments and projects which have a technical/scientific orientation, referred to below are two new Government documents.

The Swedish government’s *Strategy for the implementation of disability policy 2011–2016* gives large weight to education and labour market policy with the aim to attract more youth with impairments into work. The Government intends to analyse the possibility to implement the free choice of technical aid in upper secondary school in order to facilitate the transition from school to work. The effort focuses on freedom of choice and influence for the user. Here it is also stated that the Government wants to see increased knowledge of aids and new technologies.

Aids and other technical support are very important to the individual’s ability to fully participate in societal life. The technical development, not least within the area of IT, and new methods and new knowledge provide greater and greater opportunities to compensate for impairments. There are a growing number of consumer products that can also function as important aids. What is to be regarded as an aid has evolved as well: in addition to products, this now even includes services and processes, such as services in the telecommunications sector. This is seen, inter alia, in the increasing number of mobile phone applications specifically designed to give assistance to persons with different types of impairments (see Government Offices of Sweden, 2011).

The 2010 report of the Ministry of Health and Social Affairs, “The brightening future of healthcare – Partial results from the LEV-project”, contains suggestions for research and increased use of aids and technical supports as a strategy to increase efficiency and improve health and social care in the future. Here, there is a large unexplored area that could generate efficiency gains in health and social care with technical support in the form of new products, processes and services.

#### *Complex impairments and intersectionality*

Obviously, impairments do not exist in “splendid isolation” but often co-exist with other conditions. Deaf-blindness is an example of an area with very special theoretical and methodological challenges for research. That which

is sought by the disability movement – i.e., participant collaboration – is illustrated well by this group: it can be very difficult for a researcher to adequately and functionally conceptualise the special communicative problems that arise. The highlighting of complex and compound impairments is a major challenge for future research.

Other, more socially complex aspects of impairment can also be related to different circumstances or conditions in what is known as intersectional studies. Here, intersectional studies has to do with describing and understanding impairments in relation to interacting dimensions such as gender, ethnicity and class. As for compound impairments, there is the same need for future research here.

#### *Longitudinal studies*

In the continued research work on impairment, it is very important to create conditions for longitudinal research. This has already been mentioned in connection with research on elderly people with disabilities. Many interventions to reduce disability take a long time to be assessed and analysed. It is also essential to include more cost-benefit analyses, for example, in the form of cost per quality-adjusted life-year, or QALY.

A further concrete example shows the importance of longitudinal research. There are now indications that early intervention for hearing impairment in elderly people can reduce the risks for cognitive decline and dementia, but continued longitudinal research is needed to show that this is actually the case (Lin et al., 2011; Rönneberg et al., 2011). If it turns out that the correlation holds, this would allow for interventions that could yield significantly increased quality of life for individuals, including a continued active and independent life, and thereby also a reduced need for social services. Continued technical development and innovation in which hearing aids are integrated with other technology via wireless communication, e.g., mobile phone, TV and various types of alarms, creates conditions for increased acceptance of hearing aids and can give the hearing impaired increased security in the home as well as in public environments.

#### *Implementation, knowledge acquisition and user participation*

A central task for research on impairment and disability is to create a meeting point and dialogue between research and practice. There are different ways to respond to this challenge. One way is through cooperation with regional or municipal R&D centres within the field or with those responsible for in service training and continuing education of employees. Another approach would be to focus more on intervention research with experimental and control groups and to carry out systematic research surveys in defined areas. It is equally important to develop forms for the implementation of results and working methods. Stakeholders and the actors concerned should not only come in as recipients of ready-made results. They also play



an important role when it comes to identifying needs for research and even in promoting increased resources for the research domain.

The research assignment from the Government stresses the importance of participation in society for people with impairments. The research sometimes lacks, within certain areas, a more direct participation of those affected by the disability research. Partially due to methodological approach, research is done mainly on and not with those who are affected. Against this background, methodologies and procedures need to be developed for greater collaboration between researchers, “participants” (those affected by the research), and the professions (implementers).

Through exploiting users’ experience and knowledge in the research process, the relevance of research is strengthened, and important qualities are added. Consequently, the objectives and results of research can in many cases provide support for policy decisions that improve the life-situations of persons with impairments and others in society. At the same time, it is important to stress the weight of the researchers’ scientific task and critical approach when it comes to the choice of issues, methods and analysis of results. An in-depth dialogue with users works best when roles and competencies are clearly specified.

## SUMMARY AND SUGGESTIONS FOR FURTHER RESEARCH

### Background

As shown in the survey carried out by the Swedish Council for Working Life and Social Research (FAS), Swedish research in the field of impairment and disability has developed in a very positive way over the past decade. This can be seen in the significant and gradual increase in the number of published articles relative to the Swedish national average and in the citations rate, which is higher than the global average. Such statistics cover, by definition, only research published in international journals and the bibliometric method of analysis used in this context.

The field exhibits, in addition, an ever greater integration of interdisciplinary networks and larger research clusters with increasingly clear links between a number of Swedish universities as well as with foreign universities. At the same time, there are troubling indications that state financing in the field has stagnated and that the recruitment of young researchers and the number of published dissertations have decreased in recent years.

On the basis of current governmental and parliamentary research policy, there are strong reasons to increase investment in the internationally well-established areas within the field of disability and to create opportunities for continued development within various society-motivated areas. In the absence of increased investment, there is a risk that renewal in the field will be jeopardized. This could

lead to stagnation of the so far successful developments in the field. There is today a limited number of “bearers” of this research area, in the sense of researchers who contribute continuously and over the long term to the area’s development.

There are two principle and important ways to accomplish this: the first is to build upon the forms of support for research in internationally well-established areas, and the second concerns the existing needs and societal motives for strengthening under-represented research areas in which the international publishing has not yet had the same impact.

### Suggestions for future investments

#### *Increased support to strong research environments*

It is important to continue to provide long term support to interdisciplinary research groups or centres. Analyses of projects, networks and publications support such an approach. Further arguments are that (i) research requires a certain critical mass, (ii) it is difficult for individual researchers to apply for funds for interdisciplinary projects, (iii) the survey shows that high quality research is easier to achieve from within well-developed centres than when funds are spread to individual researchers, and that (iv) centres have greater potential to satisfy the need for recruitment of researchers to the field, including doctoral students. There are a number of such centres in the country today. A recent Danish survey (Bengtsson & Laursen Stigaard, 2011) show that most of these centres are small and that research results, measured in terms of publications, are not optimal.<sup>8</sup> This suggests that several of the existing centres need to be further consolidated.

Also important in this context is user cooperation, where users and stakeholders at the various levels are involved in and contribute to identifying important research questions and involved in the development of user-friendly and relevant research tools and in the implementation of research results.

The investments made in internationally competitive centres in recent years should continue. Within the field of disability, however, there are few such centres of excellence, and FAS decided in the fall of 2011 to phase out support to one such research centre. Resources for granting funds for further centres in the area of disability should increase, and this requires cooperation between funders. Here there are two strategies, both based on the survey. The first is to make a strong investment in internationally successful interdisciplinary diagnosis-areas (e.g., hearing impairments, physical disability, stroke, psychological disability, cerebral palsy and mental retardation) in which the interaction between the impairment and

<sup>8</sup> Bengtsson, S. & Laursen Stigaard, D. (2011). *Aktuel Skandinavisk og Britisk Handicapforskning. En kortlægning af miljøer* [Current Scandinavian and British Handicap Research: A survey of research environments]. SFI, Det nationale Forskningscenter for velfærd. Rapport 11:44.

the environment are central. Here there is a need for interdisciplinary integration, where cognitive functions can play an important integrating role between the biological, communicative and social functions.

The other, complementary strategy – which does not focus on diagnosis – is to stimulate investments in comparative, interdisciplinary, biopsychosocial problems and subject areas. This may involve, for example, bringing together political science, sociology and economics in the study of reform processes and of variations in institutional conditions, care and treatment within this area.

#### *Social sciences research and needs-related areas*

While the survey shows that Swedish disability research has become increasingly international, it also powerfully highlights the problem that certain areas are underrepresented on the basis of various societal needs. There is no straightforward connection between research volume and the incidence of various disabilities in the population. The study also shows that the extent of research on children and the elderly is relatively minor. In general, there is a shortage of society-focused research, and this applies as well to the field of disability studies, research on socio-economic conditions and the effects of various reforms in the area of disability, as well as to research on care, treatment and participation. To promote disability research that is of high scientific quality and addresses the needs- or society-driven areas addressed in the survey and in the policy areas that are prioritised, some broad thematic appeals can be made. This can involve an investment in interdisciplinary research on promoting and hindering societal mechanisms, e.g., work-life relevant “disability studies” or research on rights and discrimination. Other areas are children and the elderly with impairments as well as aging in impaired individuals. Here, IT and technical research in relation to young and elderly people should be given greater scope. Also of weight are research on multiple impairments and longitudinal research.

The applications for funding should be assessed with the same scientific standards applied to broader calls. There is no contradiction between targeted calls and quality of applications accepted. Even funds to be distributed through targeted calls are subject to competition.

#### *Need for promotion*

##### *Young, promising researchers*

The survey showed declining development in terms of doctoral students and dissertations. There is therefore reason to further invest in young and promising researchers. One possibility might be the idea of having national research schools with room for both doctoral students and post docs. These could also be usefully linked to strong research centres where the conditions for individual development are especially good. Increased recruitment is required for the continued positive development of the research area.

#### *Networks*

Scientific communities/networks need to be stimulated. These provide both senior and junior researchers potential contacts and access to expertise which are often indispensable for inter-disciplinary work. Networks may also serve a major future recruitment need for young, promising researchers. Not least, it is important to support international networks in order to bring about the increased degree of internationalization we predict for the field.

#### *International attractiveness*

The survey also shows the context in which Swedish research in the field interacts with leading international research in the field. In increase in international exchanges for both junior and senior researchers should be promoted through, e.g., postdoctoral grants, stipends to cover travel and other expenses, guest researchers and cooperation through conferences and joint projects.

#### *Research dialogue and user participation*

Dialogue with different user groups and stakeholders in the research should be deepened. This can be done through the support of user and stakeholder cooperation in the field, special funds for initiating research, and support of knowledge centres. Here, Handisam plays an important role and could also serve as a hub for support to knowledge processes which have to do with cooperation and exchange between organizations, public authorities and actors in field of disability. For this dialogue to be successful, a clearer division of roles between funders, organizations and actors as well as different user groups is needed.

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## ANNEXES

### Annex 1.

#### **Expert panel**

Raphael Lindqvist, Professor of Social Work with a focus on social care,  
University of Gothenburg

Mats Granlund, Professor of Disability Research,  
Jönköping University, Sweden

Karin Harms-Ringdahl, Professor of Physiotherapy,  
Karolinska Institutet

Raymond Dahlberg, R&D coordinator and licensed occupational therapist,  
Swedish Institute of Assistive Technology

Elisabet Cedersund, Professor of Social Work,  
Jönköping University

Stig Arlinger, Professor Emeritus of Technical Audiology,  
Linköping University

Anne Sjöberg, Swedish Disability Federation

## Annex 2

*Research funders to whom requests for information were sent*

### **Swedish Government funders**

AFA Insurance  
The Crime Victim Fund  
Swedish National Centre for Research in Sports (CIF)  
Swedish Social Insurance Agency (FK)  
Swedish Research Council FORMAS  
Swedish Institute of Assistive Technology  
Riksbankens jubileumsfond (The Swedish Central Bank's Jubileum Fund) (RJ)  
Swedish National Agency for Education  
National Board of Health and Welfare  
Swedish National Institute of Public Health (FHI)  
Swedish Council for Working Life and Social Research (FAS)  
The National Board of Institutional Care (SIS)  
Swedish National Road and Transport Research Institute (VTI)  
Swedish Defence Research Agency (FOI)  
Vårdal Foundation  
Swedish Research Council (VR)  
VINNOVA (the Swedish Governmental Agency for Innovation Systems)

### **Funds and foundations**

Afasifonden [The Aphasia Fund]  
Swedish Hemophilia Society  
Diabetesfonden (The Swedish Diabetes Association's Research Fund)  
Dyslexifonden (Swedish Dyslexia Foundation)  
Elmernäs forskningsfond, RMT-fonden (Elmernäs Research Fund, RMT-Fund)  
Fonden mot Prostatacancer (Fund against Prostate Cancer)  
Hjärnfonden (The Brain Fund)  
Hjärnkraft (Brain Power)  
Swedish Heart and Lung Association Research Fund  
Hjärtebarnsfonden (Children's Heart Fund)  
Hörsselfonden (The Hearing Fund)  
ILCO-Fund  
Njurfonden (Swedish Kidney Foundation)  
Norrbäck-Eugenia Foundation  
Psoriasisfonden, Gösta A Karlssons 60-årsfond (The Psoriasis Fund, Gösta A. Karlsson's 60th Birthday Fund)  
The Swedish Rheumatism Association Fund  
The Swedish Cystic Fibrosis Association Research Fund  
Schizofrenifonden (The Schizophrenia Fund)  
Stiftelsen ala (The Foundation for Adaptation to Life and Work)  
Stiftelsen Astma- och Allergiförbundets Forskningsfond (The Asthma and Allergy Foundation's Research Fund)  
Stiftelsen Autism (The Autism Foundation)  
Stiftelsen Blodcancerfonden (The Blood Cancer Foundation Fund)  
Stiftelsen Epilepsifonden (The Epilepsy Foundation Fund)  
Stiftelsen Laryngfonden (The Laryngology Foundation Fund)  
Stiftelsen Sven Jerrings Fond (The Sven Jerring Foundation's Fund)  
Stingerfonden (The Stinger Fund)  
Strokefonden (The Stroke Fund)  
Svenska Celiakiförbundets Forskningsfond (Swedish Celiac Association's Research Fund)  
The Wenner-Gren Foundations

## Annex 4

### *Definition of the research areas to be included*

#### **Research on impairment and disability**

Research on impairment and disability can have a societal, behavioural-scientific, humanistic, technical/scientific, or medical/caring science perspective. The research may be directed toward the individual, group or societal level. Central to this research is that it has an environment-relative perspective. Characteristically, this research is often inter- and/or multidisciplinary. How the environment-relative perspective is formed varies from one area to another.

The research may address factors and processes that make functional impairments into disabilities and how these factors and processes can be changed. Research aimed at better understanding of an impairment, with or without technical aid, can also be included. Research that studies the origin, development and treatment of illnesses is not included here, even if such illnesses entail serious disabilities. Research on allergy, diabetes or schizophrenia, for example, therefore falls outside the area reviewed. On the other hand, studies of, e.g., schizophrenic people's opportunities for independent living do fall within this area.