Danish disability research across half a century

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(Received 24 January 2013; accepted 29 January 2013)

Social research on disability exhibits a degree of interdisciplinarity. While neither large nor clearly defined, this area of research has political relevance since it is often brought into play when drawing up or evaluating government policy to improve the situation for disabled people. The present article outlines Danish disability research with the emphasis on social research in the last 10 years. It points to forces and framework conditions that have influenced the development of the field of research. It also presents central topics of research as well as some of its findings. It concludes with a discussion of future conditions for disability research in Denmark.

Keywords: disability; research; social; Denmark

Introduction

This article describes disability research in Denmark with the emphasis on social research in the last 10 years. In 2011, the Danish National Centre for Social Research published an account of entities engaged in research on disabilities in Denmark, Norway, Sweden and UK (Bengtsson and Stigaard\textsuperscript{2011}), showing that Denmark has few such entities compared with the other countries. It points out that research communities in Norway and Sweden have evolved partly with the aid of earmarked support from public research councils. In Norway and Sweden, universities and university colleges alike engage in disability research, supplemented by the national research institutions outside the university sector that bind the respective entities together. In Denmark, on the other hand, disability research is in a far weaker position both at universities and university colleges. Moreover, research traditions at the Danish university colleges are less developed than at similar institutions in Norway and Sweden. This overview offers an insight into the entities engaged in disability research and points to some of the forces and framework conditions that bear on their development.

The influence of institutional frameworks on the development of disability research milieus in Denmark is discussed in the light of Bengtsson and Stigaard’s survey. We also show the bearing that interest in social and political quarters in the living conditions of disabled people has on the themes addressed in disability research, and we present selected research themes and findings. We identify the following seven themes: living conditions, economic support, employment, social

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services, disability policy, accessibility and special needs education. While not exclusively in the realm of social science, the two last items are included in view of their strong historical and institutional connection to disability research and the interest they have attracted in social policy quarters.

Some wider areas are likewise not included in this overview although they border on and extend into the realm of social science. They comprise selected aspects of research into disability history focusing on the pre-1950s. Research in the field of developmental psychology and psychology as a whole, ethics, genetics, medicine as a whole, cultural history and the history of ideas and the history of law is also disregarded.

The present article is based on the existing overviews of disability research published by Høgsbro 1997, Olsen 1999, Baltzer and Tetler 2003, Bengtsson and Stigaard 2011, and a review of research carried out under the auspices of the Danish National Centre for Social Research. It also draws on our own research knowledge of the area, including knowledge gained as members of the Board of the Danish section of the Nordic Network on Disability Research (NNDR.dk). We have not conducted a review as such of the area, and there will of course be publications of relevance that are not referred to in our review of the respective themes. Our intention is to provide an outline of issues and topics addressed by disability research and to discuss these themes in light of the conditions for disability research in Denmark.

**Background and institutional framework for disability research**

In this section, we discuss about a number of disability research entities and their institutional footing. Disability research in Denmark is rooted in a small number of research milieus of which the Department of Education (DPU) at the University of Aarhus is the most notable university community in this field (Bengtsson and Stigaard 2011).

Being the sole university institute, the Department of Education has a tradition of research in special needs education. This tradition goes back to the department’s period as the Royal Danish School of Educational Studies, and, subsequently, as the Danish University of Education. The department currently has a research programme focusing on inclusive education and social pedagogy in which topics in the disability field are also addressed. This research entity plays a part in enhancing the teaching professions’ competencies and in recruiting Ph.D. students, and hence coming researchers, to the field (Bengtsson and Stigaard 2011).

Mention may also be made regarding the Departments of Sociology and Social Work at the University of Aalborg whose Social Work Research Group (FoSo) has a research programme focusing on the facilities for persons with cognitive, mental and communicative impairments. This programme addresses aspects of interaction between professionals’ efforts and users’ life world with a view to improving that interaction. FoSo plays a part in training Ph.D.’s in this area of social work and disabilities (Bengtsson and Stigaard 2011).

At the remaining universities and institutes of social science, isolated studies and research projects are conducted in the field of disability research. These initiatives often emanate from individual, or a small group of, researchers rather than from research programmes or undertakings of a more strategic nature. One example is a small research group at the Institute of Psychology at the University of Copenhagen whose focus is on disabled psychology, a study of the empowerment movement.
among people with learning disabilities carried out by Bylov (2011) of the University College South Denmark and the DPU as well as Ph.D. studies at social science institutes where, among others, Lentzer, 2012, has completed a Ph.D. programme in employment policy for persons with disabilities in Europe at the Department of Society and Globalization, Roskilde University.

Besides the above, research is conducted primarily at institutions for applied social research, with the Danish National Centre for Social Research (SFI) playing a key role in research into living conditions, labour market, social policy, etc. (Bengtsson and Stigaard 2011). Financial support has been provided by the Ministry of Social Affairs. The ministry has called for greater knowledge of social policy and services that target citizens with impairments, as well as greater general awareness of disabled persons’ participation in society and their dealings with the public system. To that end, the SFI has also played a part in two major surveys in 1995 and 2006 (Bengtsson, 2008, 1997; Larsen, Schademan and Høgelund 2008) which show that impairment results in limited participation in society. This applies to participation in the form of employment, in the personal sphere and in social contexts alike. The two surveys provide a general overview and have proven to be good starting points for research of a more specific nature (Larsen, Jonassen, and Høgelund 2009).

The Danish Institute of Governmental Research (AKF) has also conducted surveys focusing on special needs teaching, provision of specialized disability services, the counties’ advisory functions and social psychiatry. For example, Olsen, Rieper, and Iversen (2001) have qualitatively investigated on how people experience living with their disability. These research projects have been funded by, among others, Danish Regions (formerly the Association of County Councils).

In addition, studies have been produced and research-based knowledge disseminated by a number of resource centres in the disability area. The resource centres – established in 1993 under county auspices but with nationwide functions – were tasked with facilitating the systematic development, compilation, processing and dissemination of knowledge; their mandate was not to engage in independent research. Some resource centres, however, have produced studies incorporating problem- and application-oriented approaches. These have above all been designed to enhance the services provided by the county and the local authorities and have targeted professions dealing with people with impairments (Olsen 1998). In 2011, the resource centres were dispensed with as independent entities and integrated into The National Board of Social Services to form a new National Resource Centre on Disability, Assistive Technology and Social Psychiatry (ViHS). The Danish Centre for Assistive Technology (HMI), which forms part of the ViHS, carries on applied research in assistive technology, including the interaction between individuals, their activities and the suppliers of such technology. The research examines the utility and outcome of assistive interventions (Bengtsson and Stigaard 2011).

In 1993, the Danish Parliament established the Equal Opportunities Centre for Disabled Persons whose remit was to monitor developments in equal opportunities for people with impairments in Denmark. Like the other resource centres, this centre was not a research institution, but has conducted numerous studies with a view to documenting equal opportunity issues and recommending improvements in various areas of society. Studies conducted by the centre have focused on accessibility, employment, housing and social services, education, access to cultural life etc., for disabled persons (www.clh.dk). The centre has also functioned as a form of campaign organization, investigating and disseminating information about disabled
persons’ rights and their opportunities to participate and exert influence via democratic institutions and local disability councils (Bengtsson 2005). The centre was closed in 2011 and its activities integrated into the Danish Institute for Human Rights (IMR), which was given responsibility for implementing the UN Convention on the Rights of Disabled People in Denmark.

Finally, mention may be made regarding the large number of evaluations carried out over the years of social, labour market and education-related initiatives for disabled people. They are typically undertaken by private consultancies on behalf of government departments and agencies. A number of these evaluations are described in our review on the various topics.

The institutional framework for disability research reflects the fact that only a minority of research entities in Denmark promote a long-range approach to disability research. They are the special education research unit at the University of Aarhus, the sociological research unit at the University of Aalborg, the Danish National Centre for Social Research (SFI) and the Danish Institute of Governmental Research (AKF – now KORA). Researchers who address disability-related issues are typically to be found in cross-disciplinary settings, and the cross-disciplinary dynamic has in many ways been conducive to drawing in a diversity of perspectives on disability-related research topics. It also means, according to Tetler, that researchers tend to have to struggle for legitimacy in the academic world and risk being marginalized by research colleagues and by the research entities still primarily to be found within the academic disciplines (Tetler 2007). The fact that only a small number of research entities are rooted in the universities also means that in many cases there is no direct link between the research-producing institutions and those who teach students, which may result in students failing to become acquainted with the subject as part of their education. This is true for example of the university colleges which lack a research tradition and where only a minority of teachers have a research background (Pilegaard Jensen, Sønderup Olesen, and Olav Dahlgaard 2012). This may in turn adversely affect opportunities to recruit Ph.D. students with an interest in the disability field, and hence the turnover of new researchers (Bengtsson and Stigaard 2011).

The financial framework likewise has a bearing on the conditions for disability research. As mentioned above, much of this research is conducted under the auspices of the SFI and AKF and financed by government departments, agencies, regions and municipalities. Not since the 1980s have central government research funds been earmarked for disability research. Back in 1980–1982, the Danish Social Research Council launched a programme of research into disabilities, which was reviewed in 1982 by Melchior and a number of symposiums were held (Melchior 1982). This programme was designed to stimulate social scientists to get to grips with this area, creating a research community able to exist on the universities’ basic appropriations supplemented by general research council funding.

However, this two-year programme failed to prompt further disability research under the university’s auspices. In the mid-1990s, the Ministry of Social Affairs acknowledged that there was no ongoing research in this field. A couple of projects were initiated, and current research in Denmark was outlined in a report by Olsen (Olsen 1999). The Ministry of Social Affairs decided on a programme starting in 1999, conducted primarily under the auspices of the SFI.

Hence, no funds have been allocated specifically to disability research by the state-run research councils since 1982, and the research programmes in this field have
thus invariably been short term. The research often comprises isolated studies and evaluations which typically start out from a problem- and application-oriented approach in which political and vested interests have a bearing on the topics and issues that are addressed. Funding is often procured by government departments and agencies. Moreover, the research findings will often be geared to the needs of decision-makers and the welfare professions.

We can therefore state that disability research is produced primarily within an institutional framework akin to a Modus 2 context (Gibbons et al. 1994). This means that social interests have a bearing on the issues and topics addressed and that interest groups and public institutions exert a major influence on the actual demand for research (Larsson 2003). In the following, we look into the role played by particular authorities and disability organizations in the demand for disability research.

Role of government and disability organizations in disability research

Among the institutions that have played a part in relation to the demand for disability research is the Danish Disability Council (Bengtsson, Bonfils, and Olsen 2008). The Council was established by the Danish Parliament in 1980 and acted in an advisory capacity to the public authorities up to 2011. The Council monitors compliance with the rules and legislation in the disability sphere. Since its inception the Council has sought to develop and propagate a broad perspective of disability and society based on a relational understanding of disability. In many respects, the work of the Council has been closely aligned to the United Nations’ Standard Rules on the Equalization of Opportunities for Persons with Disabilities of 1993 and, with a basis in Standard Rules, the Council has argued that research and dissemination of information and knowledge are vital for their implementation (see Rule 13). In 2011, the Council’s mandate and composition were revised when the Council was incorporated into a mechanism for monitoring compliance with the United Nations Disability Convention (www.dch.dk).

At the end of the 1990s, the Danish Disability Council was instrumental in persuading the Ministry of Social Affairs to initiate a series of research activities. This led to a programme under which the National Centre for Social Research (SFI), which is an autonomous institution under the Ministry, undertook to conduct research on disability policy and the development of impairments and their distribution in the population. The Ministry of Social Affairs has funded the bulk of the studies instigated by the SFI and regularly initiates evaluations and reports that add to the knowledge of how social policy for disabled people functions in Denmark.

In 2006, the Danish Disability Council again instigated the launch of a series of activities designed to draw attention to the need for a strategic, long-range research effort. The Council took a basis in the experience gained in Norway and the strategic steps taken by, among others, the Norwegian Research Council to facilitate the build-up of research entities with competencies in the disability research field (Det Centrale Handicapråd 2006). The Council called for the development of a research programme for the disability sphere with a footing in universities and educational institutions and including the training of Ph.D.’s. A working group was set up by drawing representatives from the Danish Disability Council, the Board of the Danish NNDR and Disabled People’s Organizations – Denmark (DPOD).
Apart from the announcement of three Ph.D. positions that were filled in 2012, it is difficult to point to direct results of the Council’s initiatives. The Danish Disability Council has, as pointed out, solely an advisory function and exerts its influence by inducing other public authorities to put particular topics and issues on the agenda. However, by virtue of its position as a recognized and unbiased body the Council is well placed to contribute to change in the disability sphere (Bengtsson 2005).

Inasmuch as the disability organizations play a significant role in the development of national policy, it is worthwhile dwelling for a moment on how the Danish disability organizations have viewed the question of disability research. In Denmark, the disability organizations are brought together in an umbrella organization, Disabled People’s Organizations – Denmark (DPOD), representing 32 different associations.

Historically speaking, a slight aversion to research on people with disabilities can be detected among the disability organizations, ascribable to the fear of disabled persons being turned into objects and displayed without their own voice being heard. Some disability organizations are involved in promoting medical and treatment-oriented research in certain diagnostic groups, but, apart from that, research is, generally speaking, not a subject that preoccupies the disability organizations. While the DPOD has formulated neither a policy nor explicit wishes with regard to disability research in Denmark, it has, with the ratification of the UN Disability Convention, called for disability research to be closely allied to the Convention and thereby contribute to documenting its implementation (KL and DH 2010).

The disability organizations are, in general, attentive to the current political agenda and to how the legislation is implemented across regions and municipalities. Moreover, they are traditionally concerned with social and physical barriers and the significance of such barriers for disabled persons’ opportunities to live a life on equal terms with other people (Bonfils, 2006). Accessibility and access to information are areas that greatly preoccupy many disability organizations. The disability organizations are however consumers of social research and apply research-based knowledge in their political argumentation. Hence, it is odd that they have not shown greater interest in promoting general disability research in Denmark.

Existing research entities are broadly concerned with social issues and their aim is to produce applied research, which can be thought to fit well with the disability organizations’ interest in creating better living conditions for persons with impairments. Hence, there is a clear potential in Denmark for building links between research institutions and interest organizations with a view to promoting a more strategic, long-range research effort in the disability sphere.

In the following sections, we describe a number of themes that have informed much of the disability research and discuss these themes in light of the institutional and financial conditions for disability research in Denmark. We would point out that the description should not be viewed as an exhaustive review of research findings in this field, and that reference to significant publications may have been omitted. Our intention is to outline issues and topics addressed by disability research.

**Research on living conditions**

Back in the 1950s, disability organizations engaged in social research to a degree not seen since. And they applied this research to place themselves firmly at centre stage in the development of Danish social policy. This was in a period that saw the passage of
the Rehabilitation Act 1960 (Socialstyrelsen, Revalidering, and Forsorg4 1971), a marked expansion of disability pension in 1965 (Betænkning om Invalidepension5 1965) and the work of the commission underlying Seierup’s social reform in the years 1965–1972 (Socialreformkommissionens 2. betænkning6, 1972).

The latter half of the 1950s saw growing interest in political quarters in improving disabled people’s opportunities to support themselves through employment, accompanied by an improvement in the pension available to them if they were unable to do so. The Danish National Centre for Social Research (SFI) was established at the same time, and a survey of the conditions for people with physical impairments was on the research programme from the outset. This required cooperation between the disability organizations and the authorities (Haahr and Karlsson2008).

Concurrently with the establishment of the SFI in 1958, the disability organizations instigated discussions that led to the setting up of a committee, on which the SFI and the Ministry of Social Affairs were represented, which was to plan the first survey of living conditions of people with physical impairments in Denmark (Andersen1964). This committee discussed plans, closely monitored the preliminary study and the final planning of the survey, and 12 disability organizations contributed to its funding. To our knowledge, this is the only time this has happened.

The survey probably had some consequences at the time. The interviews were completed in 1962, the publications are from 1964 to 1968, and in 1965 the Social Reform Commission was appointed. The Commission chair was the survey’s initiator, H.C. Seierup from the Danish Association of the Blind, who had now become the chairman of Disabled People’s Organizations – Denmark, and the Commission’s secretary was the survey’s research manager, Bent Rold Andersen (Bengtsson and Stigaard2011). This conjunction between the individuals who were behind and conducted the survey on the one hand and the Social Reform Commission’s key senior government officials on the other meant that social policy reflected the survey results, as the survey demonstrated.

The social policy which by this means has become coloured by disabled people’s views includes the decentralization of institutions for people with intellectual disabilities in 1980 (Kirkebæk2001), the establishment of the Danish Disability Council in the same year (Bengtsson and Kristensen2006), the entire social reform’s thinking with regard to service provision, of which rehabilitation figured as the most important example in the reports (Socialreformkommissionen, 1973), and the entire mainstream line of thinking which was to leave its mark on the Social Assistance Act of 1976 (Bengtsson and Kristensen 2006) and the Social Pensions Act in 1984 (retsinformation.dk). Decentralization of the rehabilitation system and the development of cash benefits are also part of this picture.

Thirty-three years later, another study was made of living conditions of people with disabilities (Bengtsson 1997). While Andersen in 1964 based the study on a concept of medical disability, this concept was now replaced by the term functional ability, which was measured using scales developed by the Office of Population Censuses and Surveys (OPCS) in a number of British studies. A random sample of 11,000 persons was asked if they had a disability or a chronic illness. Those who said yes were asked a large number of questions on the same topics as in 1962.

Both the degree of impairment and the self-confidence that were measured by the same questions as in 1962 had a bearing on occupation. The 1995 study revealed a group of people with disabilities who wished to get a job but who required
consideration for their special needs to make this possible. The study was to be of significance for the legislation on disabled employment programmes (flexjob), which was implemented in its initial form in 1998.

Experience from the 1995 survey was of great significance for the study of living conditions, conducted on an interview basis in 2006 (Bengtsson 2008). The most important improvement over 1995 was the far larger number of questions put to the non-disabled group. This provided greater opportunity to compare the disabled group with the non-disabled group. In purely survey-technical terms, the numerous questions to the non-disabled group also mean that the number of respondents on which the assessment of the statistics is based is far larger than if only the disabled group had been available. This permits a safer assessment of the significance of varying degrees of impairment (Bengtsson 1997, 2008).

The 2006 survey is thus the first survey to give a clear picture of the significance of impairment for people’s occupation, education, range of social contacts, quality of life, housing conditions, mobility and use of means of transport, support from the government in the form of home help, assistive technology or housing changes, personal expenses in connection with disability, and experience with local authority case-handling.

The first survey in the Nordic region outside medical auspices to provide a picture of children with disabilities and their families compared with children and families in general was recently conducted (Bengtsson, Hansen, and Røgeskov 2011). More than 700 11-year-olds with disabilities were interviewed along with their mothers using forms which a couple of years ago had been given to a random sample of 11-year-olds and their parents. The study tells of a group of children who despite integration and support from their families are very isolated.

The series of surveys of living conditions will continue with a repeat survey every fourth year. The surveys will be on a slightly larger scale than the previous ones; they will also illuminate the significance of disability in a family member and will be conducted on a panel basis. In other words, research into living conditions of people with disabilities will once again be at centre stage in the debate and the political process with regard to the development of the Danish welfare state.

**Research on economic support**

The SFI’s first study, entitled ‘Recipients of long-term public assistance’, was from 1960. It covered a group of recipients of poor relief who had been monitored since the end of the 1940s. It showed that most of these clients were suffering from chronic illnesses or had disabilities which effectively prevented them from making a living by employment (Friis and Warburg 1960). The study gained significance in connection with the legislation passed in 1961 under which poor relief was abolished and replaced by social assistance based on entitlement.

The SFI’s disability pensioner surveys of the 1970s are an example of a survey programme that was politically coloured and whose political thrust was realigned en route. The studies are rooted in a debate that arose in connection with a number of smaller analyses from preceding years. At the heart of the debate was the question of whether the number of disability pensioners had increased because more and more people were disabled by their work, as found by Scocozza and Søndergaard (1973), or whether the increase was due to administrative changes. This was clearly a political issue with a right–left dimension which it was left to the SFI study to decide.
The pilot study by Per Hübbe (1976) presents the results of a medical examination of the 1971 applicant cohort. The study shows the assessments of the Disability Insurance Tribunal to be of highly variable quality. The tribunal’s assessment of the earning capacity is often at variance with the assessment made by medical specialists. A large portion of the disability pensioners had normal or almost normal physical capacity when there was no requirement as to occupational employment. Hence, the Disability Insurance Tribunal’s practice was criticized for awarding pension to a substantial portion of the ineligible applicants, and because a large group were awarded disability pension despite there being nothing wrong with them.

However, criticism of the Disability Insurance Tribunal is absent in Hübbe and Westergaard (1978). Here, to the contrary, the tribunal is said to display a consistent practice with doctors positioned as the actual dispensers of disability pension. The reason may be that the political process and debate have spawned a new agenda: to replace the medical definition of disability with a social one. The replacement of the Disability Insurance Tribunal by 15 regional boards in 1976 brought a change in doctors’ position in the assessment process, since there are no medical members on the boards. Hübbe (1978) sees here an intention to bring about a less medically coloured attitude to disability and to change the concept of disability so as to better encompass persons lacking the ability to work. Hübbe (1979) similarly concludes that health-related assessment criteria are insufficient.

The final publications in the series did not break with this line of thinking. Sten Martini (1980) took a closer look at disability pensioners’ living conditions and found, all in all, that pensions fulfilled their purpose by providing this group with a reasonable level of support. Inger Koch-Nielsen (1980) found that disability pensioners had a more troubled upbringing than other groups in the sample, in particular due to onerous work in childhood, and also an occupational background differing from the average.

When early retirement pension was again taken up as a topic by the SFI in the mid-1980s, the aim was to investigate whether decentralization had led to regional differences. Bengtsson (1987) showed that there were regional differences in the awarding of early retirement pension. However, the study’s chief finding was a large unexplained variation between local authorities. What is striking is that this difference appears at a time where, in a formal sense, local authorities had no influence on the decisions made on early retirement pensions.

Bengtsson (1989) finds that while a number of differences are connected with social variables such as occupational structure and unemployment, there are also differences due to the way local authorities administer the legislation. Hence, the decision on a case does not rest solely with the board as it formally speaking should; its actual outcome is also decided by the local authority. Local authority attitudes have a bearing on how many applicants are awarded a pension.

The studies of early retirement pension in the 1980s were studies of the public provision system rather than of the maintenance of individuals (Bengtsson 1987, 1989). Indeed they were primarily used in connection with the reform of early retirement pension undertaken in the 1990s onwards up to 2003 (retnformation.dk), whereby the number of awards of early retirement pension was halved (Bengtsson 2002).
Research on employment

It is often asserted that there is room for disabled persons on the labour market when employment is high, but that they are squeezed out on a pension during downturns. This has not been the case in Denmark. Pensioning off was rife in the boom conditions of the 1960s and 1970s, whereas the policy of encouraging a more active approach on the part of municipalities came about during the economic contraction in the 1980s (Bengtsson, 1989).

When implemented in the 1990s, the above policy was facilitated by a period of economic expansion. Moreover, changing governments have run campaigns to get more disabled persons into employment, in particular with their encouragement of corporate social responsibility since the mid-1990s (Bengtsson 2002) and ‘employment strategy for persons with disabilities’ since 2005 (Larsen and Høgelund 2009). The SFI has conducted a series of studies and evaluations in connection with these programmes. Research into disability and employment has accordingly existed in recent decades. This research has focused partly the impact of the various schemes that have been introduced, partly on the overall impact of government policy on the employment of the disabled.

Enterprises’ social commitment has been illuminated by a large number of SFI studies, duly reported in the Yearbook published since 1999. The results of the studies are assembled in ‘Danish jobs – jobs for everyone?’ The function of disabled employment programmes (fleksjob) in particular has been the subject of interest. Hohnen (2000) finds that the employee on a ‘fleksjob’ programme on the one hand functions as an ordinary employee at his or her workplace, but on the other hand has an ambivalent status. Larsen, Kløft Schademan, and Høgelund (2008) find that such persons have the same level of functional capacity as disabled persons without employment. In other words, the ‘fleksjob’ scheme serves to increase the employment of disabled persons.

An important point has been to decide whether the current legislation is what is needed to enable people with a disability to get employment. Clausen et al. (2004) find that the bottleneck preventing more disabled persons from getting employment is not the legislation. Rosenstock et al. (2004), which deals specifically with people with mental impairments, draws the same conclusion: the current legislation is what is needed – it is simply a matter of using it to enable more people with a disability to find employment.

Mølgaard, Høgelund, and Geerdsen (2006) compare the employment of people with disabilities in two studies conducted in 2002 and 2005. In the course of a three-year period, the figure rose from 53% to 56%, equivalent to 25,000 persons, at the same time as no corresponding development was seen in the case of the non-disabled. Those 56% are however some way short of the 83% of non-disabled who are in employment. However, familiarity with the legislation is slight, also among people with a disability.

Kjeldsen, Houlberg, and Høgelund (2013) track the development of disabled persons in employment up to 2012. The study did not report the same success in getting disabled persons into employment as previous studies had. In fact, the survey results show that the number of disabled persons in employment has again started to fall. It is however unclear whether this result is due to respondents’ redefinition of their status from disabled to non-disabled after a period of employment. When the same individuals are followed over the period, this decline in fact disappears.
But does it really pay in economic terms to get disabled people into employment? That question has been considered in only one study. Jensen and Boll Hansen (1999) assess the economic consequences of a four-year work-retention project for persons with brain damage. It shows a sizeable economic loss by the project, and an even larger loss for the public purses. Only if employment is sustained for eight years after the project is there a profit.

**Public care, service provision and institutions**

The themes public care and service provision are among the research topics about which most studies have been produced. According to findings from 1999, research on public care and service provision to people with disabilities was the absolutely highest scoring Danish disability research in the period 1990-1998 (Olsen 1999). A large number of studies and evaluations have also been conducted since then with regard to the social policy trend in support arrangements and compensation schemes for persons with disabilities. Much of this research starts out from the relationship between disabled persons’ housing situation and their personal need for support and assistance, and is thus linked to the welfare policy deinstitutionalization and normalization of disabled persons’ life and housing situation.

Going back to the 1980s and 1990s, a number of research initiatives were based in research and development projects in the social sector that were instigated by the Danish Parliament in 1988 under the designation ‘SUM Programme’. The projects addressed a broad spectrum of themes such as housing, employment, leisure, self-help, communication and new technology, and the interaction between public and private social work. A number of these studies started out from the everyday life perspective, life quality and the concept of way of life and focused inter alia on disabled people’s life situation (Clausen 1992, Holm, Holst, and Balch 1994).

The same theme was the subject of a joint Nordic research project supported by the Nordic Council and the Nordic Council of Ministers (Nordisk Råd 1995). In his evaluation of the SUM Programme, Clausen finds that efforts for disabled persons are instigated by the social sector’s institutions and disabled organizations, whereas no interest is seen on the part of other public institutions or NGOs in designing projects to resolve the housing, educational or employment problems of persons with disabilities.

Clausen also points out that disabled groups and development-oriented institutional milieus that are already well resourced become even stronger via project funds, whereas small and poorly resourced disabled groups and entities are overlooked (Clausen 1992). Clausen thus points out that the driving force behind deinstitutionalization is provided primarily by the very same institutional milieus.

Another research and development project concerned youngsters and adults with severe mobility problems, some of whom also had communication difficulties (Høgsbro et al. 1999). The project took as its starting point a group of youngsters who were found to be at risk of being overlooked by the system, in part because they had acquired a behaviour of patience, meekness and quietness. They were highly dependent on their parents and encountered barriers to employment and education and to establishing friendships and an active leisure life. The development project led the youngsters, though a creative and collective process, to formulate wishes for the future. It also recommended the public authorities to initiate a special effort targeting young people with severe mobility problems which would rest on a cross-disciplinary
collaboration between the public authorities, devotion of more time to working with the young persons’ plans of action and the establishment of collective social forums for young people (Høgsbro et al. 1999).

Other studies focused on deinstitutionalization through the establishment of new forms of community living and housing benefits for people with severe functional impairments or mental illness (see Olsen 1999, note 7: Gottschalk 1996, Nielsen 1991, Zobbe and Hegland 1992). Other studies focused on disabled persons’ opportunity to influence the public authorities’ care and service provision as users by participating in self-help groups (Holm and Perlt 1991).

The question of users’ influence on public care benefits has similarly been a recurrent theme of research in the 1990s and subsequently. The study of deinstitutionalization thus becomes part of a broader perspective focusing on whether and to what extent different groups of disabled people achieve influence on and power over decisions concerning their housing and everyday situation.

In the post-2000 period the families of children with disabilities and their encounter with the public system were the subject of several studies under the ægis of the Ministry of Social Affairs. The studies pointed unanimously to the families’ call for better information on their rights and on the various facilities available under the public system. The studies also showed that the parents did not wish to be treated as social welfare clients; on the contrary they wanted to be consulted on how the support for their children should be organized (Bengtsson and Middelboe 2001, PLS Ramboll Management 2001).

Another study focused on children in institutions and the parents’ opportunities to maintain contact with, and their parental role towards, their children. The study shows that when a disabled child is placed in a 24-hour care facility the parents often lose the disability compensation benefit which previously enabled them to have their children at home. The loss of this benefit made it difficult subsequently to have the child come to visit. Parents also call for more guidance and counselling, in particular to tackle the emotional aspects of allowing their child to be placed in a 24-hour care facility. (Center for Ligebehandling af Handicappede 2005).

A study from 2008 took a closer look at facilities for children with disabilities who are in need of training and treatment. The study was initiated as part of a social policy debate on the effect of public training facilities compared with alternative training methods, partly carried out at home (Wüst, Thorsager, and Bengtsson 2008). The study brings to light a lack of standardized measures and methods for assessing public training facilities, making it difficult to document their effects. Parental assessment of the facilities provided to their children is however generally speaking favourable, and parents viewed their children’s development as positive. However, like a number of its predecessors, the survey documented parental concerns over poor coordination and information on the part of the local authorities. In 2007, Høgsbro conducted a research-based evaluation of rehabilitation and training for children with autism, including an evaluation of the method of treatment known as ABA (Applied Behaviour Analysis). The evaluation showed that the children in the ordinary facilities developed further in terms of IQ, language skills and self-help skills than children in the ABA facility. Children in the ABA facility, on the other hand, show more positive development in terms of social interaction skills (Høgsbro 2007).

In 1998, the Danish Social Assistance Act was replaced by the Social Services Act. Among the innovations was a decision in political quarters to abolish the term
‘institution’ as applied to the accommodation offered to citizens with a disability. This signalled a fundamental separation between service provision and the citizen’s dwelling, in the sense that the citizen’s dwelling is to be regarded as his/her own home, with staff support provided on an individual basis and organized to that end. In 2000 the Ministry of Social Affairs initiated a number of evaluations with a basis in the new Social Services Act, including an evaluation of whether the abolition of the term ‘institution’ had been followed up with changes in the accommodation offered to disabled persons by county and local authorities.

The evaluation showed that the large institutions had been replaced by smaller, more diverse dwelling units and that residents had gained greater influence over everyday practical activities. It also pointed out that people with substantial physical impairments and people suffering from severe mental illness, and who at the same time had great difficulty expressing themselves verbally, had not experienced the same level of change. Their everyday life still reflected a degree of institutionalization and routines and activities that were set by the staff (COWI and SUS 2002).

However, for the best placed of those with physical disabilities, opportunities appeared that were quite different from a life coloured by institutionalization. With the advent of personal assistance in the 1970s, it proved possible for persons with a major physical disability to live a far more independent life in which they themselves were entitled to employ assistants and dispose over their labour. Indeed, a study from 2005 showed that users of the personal assistance scheme were extraordinarily pleased with this mode of organizing their support, since it gave them the freedom and independence needed for them to participate in the activities they personally value (Jensen and Evans 2005).

As, from the 1980s onwards, psychiatry evolved from a treatment-oriented and hospital-based regime towards one of regional and social psychiatric services, so too an interest in social psychiatric services arises in research quarters. In conjunction with the Centre for Research in Social Work, the Danish Institute of Governmental Research conducted a research project on programmes for persons suffering from homelessness, substance abuse or mental illness. The project included ethnographic studies of the interaction between the users’ lifeworld, social networks and public initiatives, as well as a study of how programmes for these target groups were organized (HMS-undersøgelsen: Høgsbro et al. 2003a, Høgsbro et al. 2003b, Brandt and Kirk 2003, Ebsen, Henriksen, and Rieper 2003).

With the passage of the Social Services Act of 1998, it became mandatory for local authorities to offer a personal-support-contact scheme (PSC) to persons suffering from mental illness. The scheme is also available to the homeless and substance abusers. The City of Copenhagen had previously participated in a trial project involving PSCs for persons with mental illness, which was evaluated by Karpatschof in 2001. The study was based on a thoroughgoing preliminary study and clarification of the methodological difficulties by including the users’ own experiences (Karpatschof and Rue 2003).

A pilot study showed that users, after attending a meeting where they spoke of their relationship with their PSC, had become psychotic or had increased their abuse. This prompted a heightened research-ethical caution and prudence to ensure that informants did not suffer harm as a result of participating in the study. The study showed that the users expressed extraordinary satisfaction with their PSCs and documented a small or clear improvement in their life quality, in particular for the young users.
In 1997, Høgsbro published a survey of Danish research on conditions for people with mental illness which showed this research to consist mainly of process evaluations linked to ministerial development projects which tended not to place empirical findings in a theoretical frame of reference. This prompted Høgsbro to call for a more coherent, theory-based and politically independent research strategy whose point of departure should be people with mental illness themselves, not their role in relation to given institutions and development projects (Høgsbro 1997:20). In 2004 Høgsbro edited an anthology presenting key contributions with regard to conditions for people with mental illness, social policy and theoretical perceptions (Høgsbro 2004).

As in other countries, the users’ recovery process has become a focal point of attention of social psychiatry, and Pernille Jensen’s research provided an interesting introduction to this process (Jensen 2006). Her methodological design was based on interviews with users and relatives where the interviewer has personal experience of recovering from a mental illness or as a relative. The study uncovers some of the factors that promote and impede the recovery process and paints a picture of the manifold factors that play a part – factors related not only to treatment, rehabilitation and social support but also to societal conditions and close personal relations and social networks. An evaluation from 2009 likewise takes a close look at the significance of social networks for people with mental illness and how the government can help to build up and strengthen social networks for people with mental illness (Bengtsson and Røgeskov 2009).

In 2007, a comprehensive structural reform was carried out in Denmark whereby a number of special needs institutions which had previously belonged under the county authorities were now taken over by the municipalities. After 2007 a series of evaluations were undertaken of how initiatives for disabled people were shaping up in the new municipalities. In the period 2006–2010 the Danish Institute of Governmental Research conducted a study at the user and institution level which tracked selected users, staff and managers at a number of the previous county special needs institutions and the transition to municipal operation. The study showed that in this period users were not aware of changes worth mentioning in service delivery and the quality of the facilities and benefits provided to them by the special needs institutions. The managers’ working life, on the other hand, has greatly changed since special needs institutions’ benefits are now based on a scale of charges and managers sell their benefits on a form of internal public market.

This has led to the closure of some special needs institutions due to lack of demand, and in other locations to the development of new programmes and an increase in the number of places and benefits due to rising demand. Hence, the reform is causing special needs institutions to evolve from relatively autonomous entities controlled by care professionals into entities governed by municipal priorities and a general adjustment to market conditions (Bonfils and Berger 2010).

Disability policy

Research in disability policy is in part tied to aspects of disability history research, in part to research in the field of political science and sociology. Disability history research has concerned itself inter alia with the interaction between disabled persons’ living conditions, institutional structures and government policy (see for example www.handicaphistorie.dk). Since this article focuses primarily on research on social
conditions over the last half century, it disregards some disability history research. However, mention should be made of Kirkebæk who has conducted several disability history research projects, including one focusing on the period of normalization in Danish care of people with learning disabilities, and care manager N.E. Bank-Mikkelsen’s role in this process (Kirkebæk 2001).

Since 2000, some research projects focusing on disability policy and the Danish disability movement have been conducted within the sociological and political science tradition. These projects are concerned with both historical and current conditions in Danish disability policy and address themes bearing on policy development, political institutions and disability organizations’ role in disability policy.

The interaction between the public authorities and the disability organizations has received a fair amount of attention. Both Bengtsson and Bonfils find via historical studies that the Danish disability organizations have played a significant role in the evolution of Danish disability policy (Bengtsson 2001, Bonfils 2006). Bonfils shows in her Ph.D. thesis how the umbrella organization (Disabled Peoples Organizations – Denmark (DPOD)) has since its formation in 1934 developed into an influential actor in Danish disability policy. The organization has pursued a strategy of adjusting its organizational set-up to the administrative and institutional framework in order to gain influence on policy making and implementation.

Today, the DPOD organizes 32 disability organizations and has local branches in all municipalities. The DPOD is represented on a large number of public councils and committees and nominates representatives to the Danish Disability Council and the municipal disability councils. However, its powerful position also means that disabled groups not affiliated to the DPOD find it difficult to make their voice heard in Danish disability politics. A further consequence is that the disability organizations exert their influence primarily via formal channels which may be hidden from the general public. This means that they rarely channel their interests via the media or resort to protest actions. The DPOD is characterized by a certain restraint, which is reflected in a strategy of negotiation and consensus (Bonfils 2006).

Bengtsson has analysed the rise and spread of a central principle of Danish disability policy termed ‘sectoral responsibility’ – in English known as disability mainstreaming (Bengtsson 2005). Sectoral responsibility means making each and every public and private authority and institution individually responsible for ensuring that people with disabilities are able to participate on an equal footing with others in diverse areas such as education, leisure pursuits, labour market etc., without being referred to special needs institutions and specific authorities. Bengtsson analyses the term in the light of theories of disability and as a specific form of governance based on networks.

The network form of governance has been institutionalized in a structure – the Danish Disability Council (DDC) – which functions as a network between the central government authorities and the disability organizations. Bengtsson finds that the DDC has functioned as a driver of sectoral responsibility. Bonfils has likewise concerned herself with the DDC and with the role of the municipal disability councils in Danish disability policy (Bonfils 2006, 2007, Center for Ligebehandling af Handicappede 2002).

Bonfils shows how the disability councils qua political institutions play a decisive role in the establishment of structures enabling disabled interests to be drawn into policy making. The municipal disability councils, which became mandatory in 2006,
are an interesting innovation in Danish disability policy and are causing the municipalities to a far greater extent than previously to include and listen to the disability organizations when decisions are taken that are of consequence for disabled people.

A study from 2008 shows that the municipal disability councils, after just two years of operation, have had an effect on the number of municipalities that formulate their own disability policy (Velfærdsministeriet 2008). Prior to 2006 only a minority of municipalities had formulated a disability policy. In 2008, more than 50% of municipalities had a disability policy and the bulk of the remaining municipalities were planning to formulate a disability policy for their municipality (Center for Ligebehandling af Handicappede 2003, Velfærdsministeriet 2008).

While on the subject of disability policy we would also mention Olsen’s ‘Attitudes to Disabled People’ from 2000 which sheds light on the attitudes of a random sample of the population. It shows that equal numbers of respondents perceive disability as something medical, as something to do with functions and as something ‘odd’. It also shows that wide differences are likely between people’s general attitudes and the attitudes that determine their actual behaviour. Additionally mention may be of Faureholm’s report ‘One has to fight’, which addresses the question of persons with learning disabilities becoming parents (2007).

Special needs education

Research in the fields of special needs education and education as a whole emanates in broad measure from the Danish University of Education, now the Department of Education at Århus University. Of other research institutions engaged in this field, mention may be made of the Danish Institute of Governmental Research.

Research in special needs education has historically speaking been characterized by a psycho-medical paradigm where emphasis was given to developing test material with a view to diagnosis and compensatory educational treatment and teaching programmes (Glæsel et al. 1974, Tetler 2007). From the 1990s onwards growing criticism has been levelled at this paradigm and, as a part of the general development of society and understanding of disabilities as a relational phenomenon, research interests turned in the following period towards sociological, organizational and social structure aspects of the special needs education effort.

In this article, we disregard psycho-medical research and describe a number of main tendencies in Danish special needs education research. A basis is taken in Baltzer and Tetler’s article on current tendencies in Danish special needs education research in the child sphere from 2003 onwards and a number of other sources, including contributions from central researchers in the field (Kirkebæk 2009, Tetler 2007, Baltzer and Tetler 2003).

Baltzer and Tetler split special needs education research into a number of categories. One category deals with studies of pupils’ problematic social relations and behaviour in schools. The studies in this category indicate that many teachers want restless pupils removed from the classroom (Jørgensen and Ertmann 1997, Egelund and Foss Hansen 1997). However, other research shows that it is possible to facilitate teaching that minimizes children’s restless behaviour (Trillingsgaard 2000, Baltzer and Tetler 2003:145).

Another category of research concerns special needs education issues at the level of the organization and examines the means by which municipalities resolve special

The fourth category addresses the theoretical basis for special needs education. Academic discussions in the field of special needs education have been analysed as well as theoretical discourses (Clausen and Kirkebæk 1996, Langager 1992, 1994, 1997, Holst, Langager, and Tetler 2000).

In 2000, a number of researchers at the Department of Education (DPU) at Aarhus University put the focus on the mismatch between schools policy and educational intentions on the one hand and the practical realities of Danish primary and lower secondary education on the other. The view that schooling should do more to accommodate children with impairments via for example greater differentiation of teaching, decategorization and inclusion are in practice met with a number of opposite tendencies in which new diagnoses and neuro- and biomedical descriptions exclude more and more pupils from normal tuition at primary and lower secondary schools.

Researchers point to the paradox that Denmark abolished social education training in the 1990s and that, as a result, competence in special needs education is weakened at precisely those primary and lower secondary schools that are now facing the renewed challenge of including pupils who would otherwise be referred to special needs education programmes.

Special needs education is said to be undergoing a period of unrest and upheaval (Holst, Langager, and Tetler 2000). Since 2000 increased attention has been given to inclusion and exclusion processes in schools, and to the effects of special needs education. Researchers’ interest needs to be viewed in light of the sharp rise in the number of pupils who are referred to special needs education programmes. This raises the question of what effect adapted teaching has – and hence what benefits accrue to pupils and society, just as it raises interest in looking into the exclusion mechanisms that underlie the rise in referrals.

A study from 2009 provides evidence that adapted teaching serves its purpose and that for the bulk of pupils who are referred to special needs education there is a strengthening of personal, academic and social development. However, a small portion of the pupils gain no benefit. The study also shows that about 25% of teachers are unable to create a more inclusive regime that enables them to work on differentiated instruction. It points to teachers’ lack knowledge of adapted teaching and to a major need for continuing training in special needs education (Egelund, Tetler, and Andersen 2009).

A study conducted by the Danish Institute of Governmental Research (Mehlbye 2009), similarly shows that most pupils in special needs classes benefit academically and socially from special needs tuition. However, after lower secondary school they find it difficult to gain a foothold in the labour market. The study encompassed 128 young people at special needs schools and in special needs classes who in 2006 and 2007, respectively, completed the final year of lower secondary school. Many of them find it difficult to complete an education or training and to hold down a work placement after leaving school, for one thing because they lack reading skills and the perseverance to stay the course. The youngsters, their parents and the schools all
consider it a problem that pupils in special needs classes present a very wide range of learning difficulties and functional level, which imposes very diverse requirements on teachers’ knowledge and competencies.

An evaluation undertaken for the Ministry of Education by the consultants Capacent in 2009 showed that children and young people with disabilities have a difficult time in the education system. Compared with non-disabled pupils they achieve lower grades, more of them drop out and fewer apply for further education. The study built on a survey of education outcomes for children and young people with disabilities who were born in 1990.

Recent years’ studies have accordingly focused on what benefits pupils with disabilities gain from the tuition in primary and lower secondary school, and on how they fare subsequently in their educational career. It may be pointed out that a gap still exists between the education policy goals of inclusion of disabled pupils and schools’ practices in this area. Young people who receive special needs tuition continue to experience problems in the wider education system.

Accessibility

Research on accessibility for people with disabilities is a new area of research in Denmark that can be said to inhabit the border between technical science and social disability research. In this section, we touch on research programmes which in various ways address social factors’ significance for accessibility for disabled people, and accordingly disregard technical and design-related research.

Prior to 2006 a series of praxis-related studies of the accessibility of the physical environment were conducted under the auspices of the Danish Centre for Accessibility. The Centre originated from the Danish Centre for Assistive Technology and was for some years from 2001 onwards an autonomous institution under the Danish Business and Housing Authority. The Centre’s primary task was to offer information and advice on accessibility for disabled people in the fields of construction, IT, transport and accessibility products.

In addition to the work done by the Centre for Accessibility, the Equal Opportunities Centre for Disabled Persons has in the period from 2000 carried out a number of studies of the physical accessibility of, among others, primary and lower secondary schools, libraries, cinemas, pharmacies, banks and student housing. These studies document the extent to which the buildings concerned are compliant with various accessibility standards (www.clh.dk).

The general impression given by these studies is that problems involving physical accessibility for, among others, wheelchair users exist to a greater or lesser degree and that the needs of, among others, the blind and hard of hearing are rarely considered in the public buildings mentioned. In 2006, the Danish Building Research Institute (SBi) took over the activities of the Centre for Accessibility in the fields of construction, outdoor areas and transport.

This area has since been strengthened by the establishment of a research position and development of a research plan. The Building Research Institute’s work in the field of accessibility is praxis-oriented and closely allied to the accessibility advice it offers public and private institutions. Its research effort is dependent on external co-funding. Among the themes focused on by the Institute are ‘The rationality and concepts of accessibility’, and in that connection it has analysed Denmark’s
understanding of the concept of accessibility in the light of the UN Convention on the Rights of Disabled People (Ryhl 2009).

Ryhl also addresses accessibility and universal design; she has investigated the optimal contrast value for persons with impaired vision and the most appropriate model for contrast measurement. Ryhl likewise concerns herself with acoustics as an accessibility factor, including the significance of acoustic quality as an accessibility parameter.

The Building Research Institute is also participating in a research project on hospital construction dealing with the significance of the physical setting for patients’ healing, including architecture's significance for stress reduction and optimizing the well-being of patients, relatives and staff (Frandsen et al. 2009).

According to the Institute's research programme, further projects will be launched on accessibility in newer buildings, measurable accessibility requirements, inter-modal transport accessibility and accessibility requirements with regard to outdoor areas. The Institute's research programmes mark the first ever establishment in Denmark of an entity devoted to research into accessibility for disabled people and its development, and combining technical competence in accessibility with disabled policy and social science perspectives.

Concluding discussion

Disability research is in the main commissioned research, funded by government departments and to some extent by regional and local authorities. It comprises applied research, often with a social policy aim geared to the needs of public authorities. Research in public care, social service provision, institutions/residential accommodation, employment and living conditions accordingly figures fairly strongly. It has been drawn on in framing new legislation or in evaluating the same, and often plays a part in social and political discussions of the living conditions of disabled people in Denmark. The knowledge produced about people with disabilities and their lives accordingly reflects them as users or clients of public welfare schemes. Although, over time, the Danish Social Science Research Council, the Ministry of Social Affairs and the Danish Disability Council have called for broader-based social research, their calls have not borne fruit. Bengtsson and Stiggaard’s survey of Danish, Norwegian, Swedish and British entities engaged in disability research could well provide a backcloth for reflections on the driving forces that promote its development. Norway, Sweden and the UK have a far greater number of entities engaged in disability research, and their funding has benefited from state support to research programmes. This has undoubtedly facilitated the training of new researchers and the creation of stable research environments. In Denmark research funding appears to be on a project-by-project basis which has not created the same possibilities for training Ph.D.’s. As for the driving forces that appear to promote the development of research entities in other countries, attention can be drawn to the role played by university colleges. Denmark has neither the same tradition nor the possibility or requirement that university colleges should engage in applied research. Hence, research with a firm footing in relation to the training of the professions that work in this field is a force that could promote applied disability research. Attention can also be drawn to the fact that the Danish disability organizations do not have the same interest in research as their counterparts in, say, the UK. Although Denmark's disability organizations turn disability research to
account in their political argumentation, they have no strategy or targeted policy to influence the framework conditions for engaging in this type of research. The question is whether we will see growing interest on the part of the disability organizations in the years ahead. One factor that suggests we will is that research can play its part in monitoring Denmark's compliance with the UN Convention on the Rights of Disabled People, which will be in the disability organizations’ interest.

Notes
1. http://www.psy.ku.dk/Forskning/Fokusomraader/handicappsykologisk_forskning/
3. AKF has recently merged with two other institutions, DSI and KREVI. The new institute is called KORA, Danish Institute for Local and Regional Government Research.
5. Report on disability pension etc.
6. The Social Reform Commission’s second report.
7. The following description is based in part on a presentation by professor emerita Birgit Kirkebæk at an internal seminar at the Danish NNDR association on 30 November 2009.
9. The Equal Opportunities Centre for Disabled Persons.
10. Equal Opportunities Centre for Disabled Persons.
12. Equal Opportunities Centre for Disabled Persons.
14. The reader is referred to these articles for further explanation and discussion of the main tendencies.

References


