Two decades of disability research in Norway – 1990–2010

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The aim of this article is to outline the main trends in Norwegian disability research over the last two decades. Prior to 1990, the research area was dominated by medical perspectives and was mainly research on impairments. Contributions addressing social problems, everyday life issues, equality and participation were few and sparse. This changed in the early 1990s and a social scientific research tradition emerged and grew into an institutionalized area of research. It is argued that the development was related to funding schemes, and also that two main attributes of Norwegian disability research were present from the early years: (1) evaluations of disability policy provisions, and (2) research intended to disclose social problems. The article discusses (1) the profile of Norwegian disability research, (2) its institutionalisation, and (3) the main topics and themes that have been raised.

Keywords: disability research; social problems; evaluations; participation; equality

In 1992, Lange (1992) published a review of Norwegian research on disability. One conclusion was the predominant role of health issues. The topic was, however, not the health of disabled people. It was disability as a health issue – addressing diagnostics, prevalence, aetiology, treatment and rehabilitation. Similar conclusions were also reached in other relevant reviews, such as Befring and Sæbo's (1993) review of special education research. Thus, the main body of research was dominated by what Priestley (1998) termed “a preoccupation with impairment”.

It is therefore reason to claim that until the 1990s, the profile of research on disability was out of keeping with the ongoing changes in the understanding of disablement and also the agenda of disability politics. Since the 1981 UN International Year of Disabled Persons, the overall disability policy aims in Norway have been formulated as “equality and participation”, whereas the understanding of disability left the medical model and took an environmental turn, pointing at the interaction between the individual with impairments and barriers in the man-made environment (Stortingsmelding (White paper) no 23, 1977–78). There were of course exceptions to the “impairment profile” in research, such as Ingstad and Sommerschilds (1984) study of families with disabled children and Eriksen, Næss, and Thorsen’s (1989) study of disabled peoples’ quality of life. Contributions with a social scientific profile were however few and sparse. Lange (1992) thus called for disability research addressing social problems, everyday life issues, inequality, living conditions and social participation.

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During the 1990s, the Norwegian research on disability changed. A social science tradition emerged and gradually took the shape of an institutionalised area of research. It did not replace impairment research, but added to the total body of research on impairment/disability. The aim of this article is to describe and analyse the background, development and current state of art of this Norwegian branch of social scientific disability research. It goes without saying that a brief paper must focus on some broad issues, and cannot do justice to the variety of approaches and themes that constitute Norwegian disability research.

The points of departure

Uncovering social problems

Roughly speaking, there were two starting points for the current Norwegian disability research tradition, and the combination of the two set the agenda for the emerging activities. One starting point was related to the above-mentioned report by Lange (1992). The report was the outcome of 10 years of activity from the Norwegian Federation of Organisations of Disabled People (FFO) to promote disability research. The initiatives can be traced back to the 1981 UN International Year. In the wake of this year, FFO and also the State Council on Disability, argued for funding of disability research. They approached the Ministry and one of the then existing research councils. The research council funded a few, minor projects, whereas the Ministry was not very forthcoming. This partly changed after 1987, when the Parliament’s Committee on Church and Education agreed that action should be taken. In the remarks to the State Budget for 1988, the Committee emphasised the importance of disability research and requested initiatives from the Government. Thus, the 1989 State Budget included a small grant to the research council, with the purpose to review and promote disability research, and also to propose models for future organisation of this field. The work was expected to be done in collaboration with the FFO. The outcome was Lange’s report, and also the proposal that a 5-year research programme was set up (cf. NOU 2001, no. 22, 252–254). This came into being in 1995 (The Research Council of Norway 1995), and was followed by subsequent programmes.

Politically speaking, this starting point is strongly related to the work of disabled peoples’ organisations to promote disability research. Their approach was fairly wide regarding research profile, but the initiative was nevertheless related to the political role research can play through documentation of social problems, unacceptable disparities and poor living conditions. Research can reveal problems “politicians have to act upon!” Thus, one starting point for Norwegian disability research was linked to the expectation that research could provide information and documentation supporting the political activity of disabled peoples’ organisations and also promote policies that would improve the living conditions of disabled people – by disclosing inequalities and social problems.

Reform evaluation

The other starting point was related to one specific social reform that attracted unexpected media attention. In 1988, the Norwegian Parliament voted for a mandatory dismantling of all institutions for intellectually disabled people. The
institutions were to be replaced by community care. The implementation was due from 1991 to 1995. In this case, the relevant association (the Norwegian Association for People with Developmental Disabilities, NPFU) did not ask for research. They strongly supported the reform, and initially saw no point in evaluation. The evaluation came about as an initiative from social scientists, and also the State Council on Disability. However, the initiatives were fuelled by unexpected conflicts and negative media attention regarding the reform. This moved the Ministry to fund a fairly extensive evaluation programme, and one of the then existing research councils was asked to organise this.

The evaluation programme ran from 1990 to 1995 and funded a number of research projects, most of them of a social scientific nature. Many researchers had a disciplinary background in sociology or political science. The programme funded projects on changing living conditions, local implementation of the reform, changing service provision, the welfare state context of the reform, legal issues, economic issues, etc. (Romøren 1995). The reform ideals of normalisation, integration and improved living conditions were important yardsticks that the outcomes of the reform were to be measured against, and also of course to what extent the new services was an improvement compared to institutions. In short, the welfare state provisions to a group of disabled people were to be evaluated through the outcomes of a social reform.

These two points of departure, uncovering social problems and evaluation, had a significant impact on the development of disability research in Norway from 1990 onwards, in several respects. (1) A kind of institutionalisation of social scientific disability research gradually took place, including a funding structure. (2) Many of the prevailing topics and themes were present, such as normalisation, integration, participation and equality, and (3) some main characteristics of the research profile were there from the onset. These three developments will be discussed below, starting with the research profile and the relation to the welfare state – which has placed disability research in a somewhat ambiguous position between social engineering and social critique (Gustavsson, Tøssebro, and Traustadottir 2005; Tøssebro 2009).

**Research profile – between social engineering and social critique**

*Trapped in the reformer’s perspective?*

A significant body of the Norwegian disability research from 1990 onwards had the same profile as the two roots. It was closely related to the welfare state; some would say that it was “a child of the welfare state” (Gustavsson, Tøssebro, and Traustadottir 2005; Tøssebro 2009). The links to welfare programmes are obvious in a number of evaluations of social reforms or service programmes, such as deinstitutionalisation (summed up in Romøren 1995), personal assistant schemes (Guldvik 2003) or so-called “user pass” in the provision of technical aids (Høyen and Tøssebro 2009). The link is also apparent in research projects trying to reveal problems facing for instance families with disabled children (Tøssebro and Lundebø 2002; Askheim, Andersen, and Eriksen 2004), tensions between providers and users of technical aids (Ravneberg 2009), problems facing disabled students in higher education (Magnus 2009), or practices of employment agencies (Vedeler 2009).

This profile can be seen as an intended and positive aspect of the research tradition. It provides a link to disability politics and prevents the construction of
ivory towers. But on the other hand, the profile has been criticised for being too dominated by the agenda of disability politics and the themes that are an issue for the government administration. The links to politics may have hampered the development of perspectives, theories and research problems that are not related to the perceived information needs of the public administration. In a review of Swedish social research on people with intellectual disabilities, Gustavsson and Söder (1990) argued that research was trapped in what they called “the reformer’s perspective”. By this they meant that the research was dominated by the issues on the agenda of public policy bodies and that social reforms set the agenda for research. In a subsequent review of disability research, Söder (1995) claims that the problem applies to social scientific disability research in general. He argues that evaluations have become a trap: “that research is locked to the perspective of the political reformer” (Söder 1995: 232, my translation). Even though these reviews address Swedish research, the profile of Norwegian research was very similar. Dalen and Skårbrevik (1999) pointed for instance out exactly the same problem in Norwegian special education research.

This profile is, however, not unique for disability research. Welfare policies play a crucial role either as background or a topic for large parts of applied social research, and with a taste of social engineering. The prototypical example is the role of economics in national economic planning and policies since World War II. Applied welfare research never became the kind of tool that economics grew into, teaching politicians “how to do it”. The profile was rather post fact analyses – “did it work?” One evaluates whether programmes had the expected outcomes and to what extent policy aims were fulfilled. Welfare research took on the role of a feedback mechanism.

Evaluations of reforms will by necessity follow after policy initiatives, and are in part locked to the framework of the reform. Research on social services, social problems or unacceptable inequality, on the other hand, does also have the potential to put issues on the political agenda. When a 2001 Public Committee Report (NOU 2001, no. 22) advocated the funding of more social scientific disability research, their point was exactly the possible role of putting problems or disparities on the political agenda. I have not seen any review of disability research that analyses to what extent this function really operates. As for applied welfare research in general, however, Martinussen (1998) scrutinised where new concepts and problem formulations in research emerged, in research itself or otherwise. His conclusion was that public committee reports tended to be ahead of research. He found “little support for the hypothesis of social research as spear head” (176, my translation).

Problem oriented empiricism and opposition research

The critique of disability research as trapped in the reformer’s perspective raises important points, but is nevertheless biased and overlooks the ambiguous nature of the relation between research and welfare programmes. The image of the reformer’s perspective easily associates with uncritical research. However, that is hardly a striking description of Norwegian disability research. One does not find much enthusiasm with regard to the current state of welfare policy or living conditions of disabled people. The opposite is a better description: criticism and opposition are more typical. Even though this is also a simplification, a large body of disability research is inspired, consciously or not, by a research tradition called “problem
oriented empiricism” which grew out of critical sociology in the 1960s. This was empirical research intended to reveal social problems, injustice and to identify groups with unacceptable living conditions.

In a book about people and traditions that have had an impact on the Norwegian society, Slagstad (1998) characterised this research as opposition science. The distinctive feature is that research employs the expressed ideals of the welfare state in order to criticise the realities experienced by marginalised groups, i.e. to reveal social problems. The idea is to reveal and document problems in order to support the demand for political action. In this context, disability research evaluates reforms by the yardsticks provided by reform objectives and policy aims. Research on living conditions or participation compares realities with specific or general policy ideals. This applies to research on deinstitutionalisation (Tøssebro 1996), employment (Ose et al. 2009), higher education (Magnus 2009), families (Lundeby 2008), inclusion in school (Wendelborg and Tøssebro 2008), etc. – a significant body of the disability research throughout the 1990s and 2000s.

One might argue that this type of research is not only critical, but also over-critical. This is related to the logic of the research model for two reasons. Firstly, this research takes the policy ideals very seriously – sometimes more seriously than the people that formulated the ideals. This is related to the role of ideals in politics. They are guiding stars and tools for selling reforms, and hardly meant to be taken too seriously. Thus, goal achievement is likely to be partial at best. Secondly, the logic of the research is to disclose problems, which in turn is likely to foster an affinity to areas with lack of achievements and/or prevailing problems, rather than successes.

My point is not that critical empiricism is a better description of disability research than research locked into the reformer’s perspective. Neither is it the point that there are two branches of disability research – the critical and the uncritical. The point is that the same publications might very well be in keeping with both profiles. It is critical, but nevertheless within the framework of the reformer’s perspective. The research is rarely critical to the policy ideals and the reformer’s agenda is taken for granted, but it is critical to the implementation and the realities that in practice face disabled people. In this way, the bulk of Norwegian disability research places itself in a somewhat ambiguous position between (a weak version of) social engineering on the one hand and social critique on the other – being both at the same time. As such, it is not very different from the role that much applied social research has in modern governance.

### Institutionalisation of disability research

The institutionalisation of disability research has many interrelated aspects: funding, continuity, networks, scholarships, and positions at universities. In the early 1990s, the majority of people that became involved had little background in disability research, few were senior researchers or held university positions. People became involved because they were interested, either in disability or reform processes – or simply because research money was available. From my perspective, the gradual institutionalisation initially grew out of the evaluation of the reform for people with intellectual disabilities. This was the first major programme, it had a funding structure that lasted beyond the programme itself, and the activities led to the establishment of academic networks.
This evaluation was funded by the government, with money originally allocated to reform implementation. The government did not, however, commission research but asked the then existing research council for applied social research (NORAS) to organise a research programme. NORAS organised the research as a special task for the existing Velferdsstatsprogrammet (the Welfare State Research Programme). The research council called for project proposals, as usual, but also initiated meeting places between the researchers receiving funding, the relevant ministries and other stakeholders. The emerging research network gained an unexpected momentum due to initiatives from Swedish colleagues. In Sweden there existed a network for research on intellectual disabilities, with a hub at Centrum för Handikappforskning (the Centre for Disability Research) at Uppsala University. The leader of this centre, Lars Kebbon, saw the opportunity for Nordic collaboration and comparison. The same trend (normalisation, deinstitutionalisation and decentralisation) was evident in all Nordic countries, but was carried out at a different pace, underpinned by different legislation, and by employing different implementation strategies. The Uppsala group organised Nordic seminars and subsequently initiated a Nordic research association on intellectual disabilities (Föreningen forskning om utvecklingsstörning i Norden, FUN). The Swedish group was also associated with international research networks. This brought Norwegian researchers in contact with the international scientific community. A rapid growth in international contacts was facilitated by the reputation of the Norwegian reform: A government that decides to close all institutions, that’s something!

During these years, the planning of a research programme on disability started in the new Research Council of Norway (NFR). This was the outcome of FFOs activities and Lange’s 1992 report, and the planning involved some of the same people that also were active in the evaluation of the deinstitutionalisation reform. The funding structure was also similar: It was based on government money, in this case the budget of the Government Action Plan for Disabled People 1994–1997 (cf. Stortingsmelding (White paper) no 34, 1996–97). NFR was asked to organise the programme, and it established the activities as a special task for a new research programme on “welfare and society” (Velferd og Samfunn) for the years 1995–1999.

During the late 1990s, the “evaluation of the deinstitutionalisation reform” and the “programme for disability research” merged. The continuation of the disability research programme (1999–2004) also included follow-up research on services for intellectually disabled people, and was funded by three ministries. A similar merger also took place with regard to research networks. This was, however, a Nordic rather than a Norwegian development. In 1997, FUN dissolved itself and in its place initiated the Nordic Network of Disability Research (NNDR). Thus, the network on intellectual disability became a network for disability research, and a number of new people joined.

During the following years, both academic networks and funding followed the outlined trajectory. By the end of 2008, the NFR had organised research on disability as a special task with earmarked funding for 14 years. NNDR organises a conference every other year. A Norwegian branch was established in 2004 (similar national networks were established in all Nordic countries) and organises conferences the alternating years. The Nordic conferences attract people also from outside the Nordic countries and provide the opportunity to establish international relations. In 1997, NNDR also initiated the Scandinavian Journal on Disability Research (SJDR), which published its first issue in 1999. Since 2004, the SJDR is published by a large
international publishing house, Taylor & Francis, and with an increasing share of articles from outside the Nordic countries.

Since the early 1990s, much has also changed regarding the formal position of disability researchers. When I was appointed Associate Professor of sociology in 1990, the scientific evaluation committee “excused” my involvement in research on services for people with intellectual disabilities. Today, there are a number of professors with a disability research background (partly or fully) at universities and university colleges, in Trondheim, Oslo, Bodø and Lillehammer. The Norwegian University of Science and Technology (NTNU) has established a master programme in Disability and Society, and master programmes of a related nature exist elsewhere. Scholarships exist at several universities and university colleges, and since 2000, a number of people have achieved their PhDs in disability studies. Disciplines include among others sociology, social work, health science, law and anthropology. Research groups with a disability research profile exist at independent social science research institutes in Oslo, Bergen, Trondheim, Lillehammer and Bodø.

Thus, there is no doubt that one has seen the establishment and institutionalisation of disability research as a multidisciplinary social science field in Norway during the last two decades, and also that this institutionalisation is in part Nordic rather than national (the NNDR and SJDR).

The funding structure did clearly have an impact on the development of disability research in Norway. From 1995 to 2008, the NFR organised three subsequent funding schemes, organised as part of welfare research programmes but with more or less earmarked funding. The size of the funding was increased in 2004 after the recommendation in a white paper on disability policies (Stortingsmelding (White paper) no. 40, 2002–03). However, NFR is not the only source of funding. A foundation (Extrastiftelsen) with disability associations on the board uses the surplus from a weekly national betting set-up to fund scholarships in health and rehabilitation. The statutes include social science perspectives, and a few studies are funded, but the foundation tends to prioritise research with a medical profile. Ministries and directorates also commission disability research projects related to their on-going tasks, e.g. evaluations. The projects are often highly relevant for disablement issues, but the people involved rarely take part in the disability research networks (but with exceptions). Thus, even though research on disability and disablement goes far beyond what is funded by the NFR, the role of NFR in the institutionalisation of the disability research tradition was of utmost importance. This also includes grants for conferences and the journal (SJDR).

**Topics and themes**

It is not possible to pay justice to the variety of themes and topics raised in Norwegian disability research in a brief overview. The research is neither easily grouped under a few headlines, not even for analytical purposes. The definition of disability research also causes problems. The distinction to impairment research is quite blurred, and a number of disability relevant projects occur outside the network of disability researchers, especially research on social security and employment. The people involved would tend to call it labour market research and/or social security research. The outline below is but one possible way of describing typical characteristics and developments, and it is derived from employing a “continuity
and change”-perspective on developments since the early 1990s. Hopefully, I am excused for biases, misrepresentations and omissions.

**The onset**

The research agenda in the early 1990s was set by the political agenda, not least the dismantling of institutions for people with intellectual disabilities but also integration in regular schools and classrooms. The issues of integration, normalisation and deinstitutionalisation were core topics in the early disability research. There existed a significant body of international research on such issues at the time, but the profile of Norwegian studies took a Nordic twist. A number of scholars have pointed out two distinct profiles in integration research (cf. Söder 1997). One profile is instrumental, and asks to what extent integration leads to certain desired outcomes. The most popular outcome variables are learning and adaptive/maladaptive behaviour, but there are also other examples (cf. for instance Larson and Lakin 1989 and Evans 1993 for reviews). This research profile was predominant in integration research in the US and the UK, but with a few exceptions, absent in Norway.

Most Norwegian studies were according to the other profile. In this case, integration and normalisation are seen as values in themselves. The typical research question is to what extent the ideals are realised. The realities are compared with the policy ideals. Thus, one asks to what extent children with disabilities are in the same classroom as nondisabled peers, and whether alternatives to institutions means integration and new patterns of care or merely is a reproduction of segregation and institution-like practices in a new outfit. Within this second profile, one can also identify a special Norwegian and Swedish profile (Jones et al. 2003). The concept of normalisation in Scandinavia comprises the ambition of normal living conditions. Thus, researchers’ combined studies of deinstitutionalisation with the tradition of living condition surveys for the population at large (developed by Statistics Sweden and Statistics Norway around 1970). The deinstitutionalisation studies asked about housing standards, employment, poverty, social networks, cultural activities, etc. (Tøssebro 1996; Tideman 2000). One asked to what extent living conditions for intellectually impaired people could be deemed acceptable according to the prevailing standards of the Scandinavian welfare state. And the main result was that a lot happened during reform years, for instance regarding housing, but also that much remains to be done in areas such as occupation. Limited development was particularly evident in life domains where the direct impact of policies is limited, such as social networks.

The research on the reform for intellectually disabled people also raised a number of other research questions. Some were directly related to the changing services, such as qualitative research on changes in staff behaviour and style of care (Jensen 1992; Wuttudal 1996; Sandvin et al. 1998) and anthropological studies of the everyday life of people that resettled in the community (Sundet 1996). There were also political science research of the local implementation (Andersen 1996) and policy analyses which discussed reforms of the 1990s in the context of wider policy changes (Sandvin 1996; Haug 1999).

A number of the themes that were raised in relation to the integration and normalisation reforms in the early 1990s can be identified in the Norwegian disability research since, but within a wider context. The early focus on intellectual disabilities vanishes, new reforms and policy developments enter the agenda, and the ideals are
rephrased according to the overall disability policy aims of “equality” and “participation”. There is continuity, but definitely also a widening of the scope and an introduction of new themes and research problems.

From integration to participation in everyday life
Integration continues to be a prevailing theme but is eventually termed inclusion and also widened to participation in general. Some research projects follow more or less directly the trajectory from the early 1990s, such as the study of Wendelborg and Tossebro (2008) that ask to what extent disabled children take part in the regular classroom, and the consequences of classroom participation for social relations outside the school setting (Wendelborg 2010). Other publications address social mechanisms that facilitate or hamper participation. Ytterhus (2000), for instance, observed the social interaction between disabled and nondisabled children in day care centres. She found this social environment pretty inclusive, and also that mechanisms of exclusion tended to be situated in the rules at work in children’s typical play.

A number of studies address barriers to participation in a way that bridges over to everyday life studies and the construction of identities. An early example is Solvang’s (1993) study of the experiences of young people with dyslexia or mobility difficulties in the school and the labour market. A more recent example is Magnus’ (2009) exploration of the experiences of disabled university students. This study analyses barriers to participation in higher education, but relates this to practical issues in the wider everyday life of disabled students, and also the interaction between accessibility issues and identity defence. Other examples of the bridging of participation and everyday life issues are Grue’s (2001) study of the experiences of young people with physical impairments, Kittelsaa’s (2008) study of young adults with intellectual disabilities, and Söderström’s (2009) study of the impact of new communication technology in the lives of adolescents with mobility or vision impairments. There are also a number of studies addressing barriers to participation in the labour market (Kilian 2005; Anvik 2006; Vedeler 2009).

The ideal of participation is also present as a background theme in studies where the topic as such is different. Few would call Alm Andreassen’s (2009) survey of employer attitudes, for instance, a study of participation. However, it is about a very important precondition for participation in the labour market, and thus not very different from traditional studies of for instance teachers’ attitudes to inclusion. In a similar way is Lundeby’s (2008) longitudinal study of families of disabled children also about participation, for instance mothers’ participation in working life – which is less frequent than other mothers with children at the same age. However, the gap is smaller than expected.

From normalisation to equality and living conditions
The concept of normalisation in Scandinavia implied among other things the ambition of normal living conditions, and was as such closely related to policies for equality. This guided part of the deinstitutionalisation research, and the same approach is evident in a number of recent studies. The specific link to deinstitutionalisation is history, whereas the influence from the general living conditions approach has grown stronger, not least because this facilitates comparison with other
social groups or the population at large. The living conditions approach was initially developed around 1970 in order to be a tool for monitoring social problems and social inequality, and as such, it should be no surprise that it eventually was introduced in disability research.

The studies of living conditions are mainly based on large national datasets that are gathered regularly by Statistics Norway. These datasets provide the opportunity to identify disabled people by items included in the survey. Hem (2000) reanalysed the living condition surveys from 1987 to 1995, and Jørgensen and Claussen (2007) explored available data in the surveys from 2001 to 2004. At two points in time, special surveys of the living conditions of disabled people, in 1995 and 2007, were also conducted. The first led to few publications, whereas publications from the 2007 survey so far include Bjørkan and Veenstra (2008), Molden, Wendelborg, and Tossebro (2009), Molden and Tossebro (2010, 2012) and Sæther (2009). Issues such as employment, housing, poverty, and education are among the other areas addressed. One also finds examples of Norwegian scholars being involved in the study of disabled peoples’ living conditions in developing countries (Loeb and Eide 2004).

The living conditions approach, covering a wide range of themes where disparities possibly occur, is a typical Norwegian/Swedish tradition. The quality of life tradition is less prominent in Norwegian disability research, but there are a few examples, such as Eriksen and Næss’ (1998) study of people with epilepsy or diabetes, and Grue’s (1999) study of young people with impairments.

Even though equality is an important theme, it is worth noting that there is little disability research that explicitly addresses prominent equality issues such as income or poverty, and the same goes for social security. There are surely a few studies on the income and poverty status among disabled people (Ramm 2006; Reiakvam 2006; Sæther 2009) and there is a substantial body of research on social security. But this is typically decoupled from the disability research network. The three references mentioned above are not by people involved in the disability research community, and the overlap of people attending the annual conferences on disability and social security is limited. This is in part due to the fact that disability research primarily addresses the lives of disabled people, whereas social security research is about systems and inflow to benefits. In disability research, the benefit system tends to be taken for granted or benefits are seen as an unwanted outcome of labour market exclusion. But in my opinion, more links between disability and social security research would benefit both.

The concept and measurement of disability

In the early Norwegian disability research, the concept of disability was not much discussed. Research projects tended either to address specific groups that received a certain service or benefit (e.g. people relocated from institutions), or referred to the official concept of disability. The official concept of disability has been relational in Norway since the mid-1970s, pointing at the interaction between the individual with impairments and barriers in the environment. However, both in policy and research, this expressed definition did not necessarily have consequences for the definition-in-use. In reality, many research reports started out by defining disability in environmentalist terms, but the practical operationalisations in the empirical studies were nevertheless individualistic. The same goes for policies, which were traditionally geared at individual compensation rather than adapting the environment to human diversity.
During the last decade, one has seen the development towards more consciousness regarding the concept. This is partly due to the influence from the UK social model, and partly to policy changes (see below). This consciousness has not led to a redefinition of disability. Few object to a relational understanding, but one is more conscious about what such definitions really mean. In some cases where the research is about people with impairments rather than disability, one tends to be explicit about this. There is not much research on the concept of disability, but the issue is regularly raised in textbooks. One also finds research reports scrutinising which concept of disability is explicitly or implicitly guiding different provisions and laws in disability policy (Hedlund 2009).

The use of survey data to explore the living conditions of disabled people also led to a debate on disability measurement, that is, how to identify disabled people in survey research (Eriksen and Næss 2004; Tossebro and Kittelsaa 2004). This was in part related to the debate on the concept of disability, but more importantly, there were extreme differences in prevalence rates across studies using different disability indicators. This applies to Norwegian surveys, but also across countries (Fujiura and Rutkowski-Kmitta 2001). The 1995 disabled peoples’ living conditions survey used recipients of the so-called basic benefit as operationalisation. This benefit is granted to 3% of the adult population. A county survey of Bliksvær and Hanssen (1997) employed a disability measurement that included more than 30% of the population, whereas most measurements lead to prevalence rates of 15–20%. This has fostered activities to renew disability measurement, for example, in the context of the International Classification of Functioning, Disability and Health (ICF, WHO 2001) (Ramm 2006; Loeb, Eide, and Mont 2008). Molden and Tossebro (2010, 2012) are summing up the consequences of the different measurements that are currently in use, concluding that agreement between measurements is unexpectedly low (the same people are classified differently according to different definitions).

Disability policy research

Research on policy and policy developments has changed from research on integration and deinstitutionalisation to the reforms that gained momentum in the late 1990s. This applies to new concrete reforms, such as Andersen’s (2003) study of the politics governing the emerging personal assistance scheme and Askheim’s (2001) Nordic comparative study of the same scheme. More important, however, is that disability policy in Norway took a new turn from around 2000, partly in the wake of a 2001 public committee report (NOU 2001, no. 22). Disability policies in Norway (read: the Nordic countries) has been characterised by the predominance of redistribution policies and service provision, whereas regulation policies played a minor role. Regulation policies mean measures where the role of the public is to regulate activities in the civil society. Regarding the combating of disability inequality and barriers to participation, this includes measures such as antidiscrimination provisions, accessibility regulations (for instance building codes or public transport), social requirements in public procurement, etc. This type of policy became more important after 2000, inspired by international developments and in particular new provisions in the EU. The policy is also more in line with a social concept of disability, not least because the target is rarely the individual, but rather an environment that hampers the everyday life of people with impairments.
In a number of studies, Hvinden and Halvorsen have addressed this development. This includes comparative analyses of disability employment strategies, provisions for accessible ICT, implementations strategies, international policy influences and the prospects of the new policies (e.g. Hvinden 2003; Halvorsen and Hvinden 2009; Hvinden 2009). These studies have also brought a comparative perspective more clearly into Norwegian disability research.

**Researching services – evaluations and empowerment**

Services play an important role in disability policies and in the lives of disabled people. Thus, the study of intended and unintended consequences of service provisions, and also service reforms, was and is a major research area. Recently, this includes studies of reforms such as personal assistance (Guldvik 2003), services to particular groups such as children and families (Tøssebro and Lundebø 2002; Askheim, Andersen, and Eriksen 2004; Lundebø 2008), technical aids (Ravneberg 2009), education (Wendelborg 2010) or labour market provisions (e.g. Amundsveen and Solvoll 2003; Ose et al. 2009).

Research on families with disabled children can act as an example. The current policy in Norway is based on two main principles: (1) inclusion and (2) a division of labour between families and the public: children are expected to grow up at home and the public should support families in order to ensure a normal childhood and a normal family life – in short, normalisation. The research suggests that families are fairly satisfied with the quality and type of services, once they have access to them. On the other hand, the frustrations related to the access process, lack of information, lack of coordination, appeals, etc., is the predominant theme in the narratives of the families (Tøssebro and Lundebø 2002; Askheim, Andersen, and Eriksen 2004).

A crosscutting theme in service research, but not exclusively service research, is a strengthened interest in empowerment, user participation and self-determination. This is of course important in services where empowerment is an issue in itself, such as personal assistance schemes or programmes to promote user participation (Alm Andreassen 2004). However, the theme is one part of many projects on services. One also finds analyses of the role of empowerment in social services in general for disabled people (Askheim 2003) and easy readers on self-determination among people with intellectual disabilities (e.g. Ellingsen 2007).

One last example from service research provides a transition to the next theme. Ravneberg’s (2009) study of the provision of technical aids suggests conflicts between users and service providers. Service providers tend to see technical aids as purely functional, whereas for the people using the technology, it is also a part of their identity equipment. The hearing aid or the wheelchair is a part of peoples’ visual front, and is expected to be in keeping with the identity they want to expose – similar to haircut or clothes among other people. In the service provision process, this conflict is about self-determination, but it is also obviously a part of the disability identity theme.

**Disability identity**

There hardly exists a substantial body of research on disability identity in Norway, but on the other hand, the issue is frequently addressed in reports raising other research problems. A number of the above mentioned studies discuss issues related to
disability identity, and also stigma management. Magnus (2009), for example, argues that it is virtually impossible to pass as a typical university student if you need individual accommodation. And if your impairment is not a part of your self-presentation, adaptations are unlikely to be provided. Kittelsaa (2008) discusses the identity construction and management among young intellectually disabled adults in an everyday life setting, Kermit (2010) explores issues like peer interaction, identity and recognition among children with CI, whereas Grue (2001) addresses identity and stigma issues related to disabled adolescents in school, family and peer relations settings. In short, identity issues are included in a number of studies, and in particular research with an everyday life focus.

A few researchers address identity issues more specifically. Breivik discusses deaf identity in a number of publications (e.g. 2000, 2007). He addresses issues such as deafness as disability vs. linguistic minority, the role of deaf communities and the trend towards transnational communities among deaf people. The role of communities of disabled people as identity support is also discussed for other impairment groups, such as people with mental health problems (Lillestø and Hanssen 2000) and intellectually disabled people (Tronvoll 2000). Furthermore, a group of researchers in Bodø addresses the role of technical aids in the interaction between people and their environment. Their focus is not identity as such, but how technical aids provide both functional support and information to the environment; a kind of self-presentation that facilitates environmental support (people clearing the way when someone with a white stick is about to pass) but also clearly signalling the impairment (Anvik 2009; Grotland and Máseide 2009).

Solvang (e.g. 1999, 2000) discusses identity issues related to medicalisation, normality and deviance. He is critical to the consequences of our image of normalcy and also medicalisation, but he makes the interesting observation that medicalisation (that is, a diagnosis) actually can provide identity defence. He refers to the fact that for many people, a diagnosis means that the problem is easier externalised – as sickness. He refers to a man recently diagnosed with dyslexia, claiming that “it was a relief to know what it was, that it was not me it was something wrong with” (98, my translation).

**Employment**

Research on the employment of disabled people could of course have been subsumed under some of the headlines above. It is about participation and very often also about services, that is, labour market provisions. The reason why I make it into a category of its own is to illuminate a specific point: this research is so far mainly conducted by people that do not see themselves as disability researchers, but rather primarily involved in research on labour market, rehabilitation (return to work) or working life.

This research has three distinct profiles. (1) A number of studies evaluate concrete (new or existing) labour market provisions, such as transport (Amundsveen and Solvoll 2003), the agreement on inclusive working life (Ose et al. 2009), wage subsidies (Econ 2001), supported employment (Econ 2004), the programme for recruitment of disabled people to state jobs (Bull and Alm Andreassen 2007), etc. (2) The second type of study takes the experiences of disabled people as their point of departure, looking at the diversity of labour market measures and problems people encounter (Anvik 2006; Vedeler 2009). A predominant theme is frustrations regarding services – even that the services in practise may become a barrier to
employment (Vedeler 2009). (3) The third type is descriptions of labour market participation, generally based on the annual Labour Force Survey disability supplement (Skog Hansen and Svalund 2007; Bø and Håland 2009) or other large-scale surveys (Bliksvær and Hanssen 2006; Molden, Wendelborg and Tøssebro 2009). This type of research also addresses the employment of different groups of disabled people, and for instance the impact of education on disability employment rates – which is substantial.

Parts of this research is conducted by people in the disability research community, but the major bulk is not. In part, this is logical: many provisions are not exclusively (nor primarily) for disabled people. The issues are nevertheless of vital importance for the participation and equality of disabled people. More bridges are likely to be an advantage, and this has actually been the trend in recent years.

**The future – possible changes in institutional preconditions**

An old Nordic saying is that “prediction is difficult, especially about the future”. I am not going to end this overview with any predictions or wishes for the future, but instead raise a couple of recent trends regarding the institutional preconditions for disability research in Norway. During the last two decades, disability research was no doubt established as an area of research in Norway. There are active research units at universities and research institutes in several cities, and a number of topics and themes related to the everyday life of disabled people are addressed. One important precondition for the developments was government resources allocated for disability research through research council programmes. This appears to change in a way that might have consequences for the profile of disability research.

In principle, the government continues to provide resources to the Research Council of Norway in order to fund disability research. However, the resources appear to no longer be earmarked. Furthermore, the welfare research programmes that administrated the disability research funding are merged with other areas into a large programme on Welfare, Work and Migration. This programme now allocates the no-longer earmarked disability research money. This does not in itself have any consequences, but there is an increasing risk that project proposals in disability research are evaluated by people who are not very interested in the issue, and who might see the theme as special or of marginal general interest. The experiences so far appear to go beyond such worries. Disability research is by and large out.

There is obviously the risk that this will lead to a major setback in disability research. However, on the other hand, disability research is currently institutionalised to such an extent that the future prospects are better described as uncertain. People in disability research with university positions are not dependent on the funding from the Research Council, and both universities and university colleges allocate substantially more scholarships to disability research. Thus, there is a better opportunity to move disability research in directions preferred by the research groups themselves. However, both the university-based research groups and in particular research groups at independent research institutes have always been, and continues to be, dependent on external funding. They will now, to a larger extent, have to rely on commissioned research from ministries and directorates through a tendering process. Such money is generall short-term and also, to link back to the earlier “profile” discussion, more likely to be “locked into the reformers’ perspective”. Thus, one might see a development in a direction were the earlier
warnings about the “reformers’ perspective” turns into a prophecy. The stronger foothold at universities might balance this, but the two diverging trends in funding might also cater for a more fragmented profile and less of a distinct research area.

Note
1. Parts of this paper are based on an earlier published book chapter in Norwegian: Tøssebro (2009).

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