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Liveable disabilities

Life courses and opportunity structures across time

1. AIMS AND OBJECTIVES

In Europe, disabled people comprise a significant population of some 65 million persons (10%). Yet they are remarkably marginalized in both society and research. Consequently, little is known about how disabilities are lived and become liveable. To challenge this bias in recognition, the DISLIFE project investigates human experiences of disabilities from a long historical perspective. Proposing the concept of ‘liveable disabilities’, the objectives are to analyse how disability impacts on individuals’ possibilities in life and inclusion in society by uncovering how their life courses vary as a function of disability and opportunity structures. The project focuses on key transitional events in the life course that indicate the level of liveable disabilities among disabled people. Researching **four themes** concerned with their (1) health and well-being; (2) involvement in education and work; (3) in a partner relationship and family life; and (4) in some leisure structures, the project will establish factors that have helped make disabilities liveable before, during and after the Swedish welfare state. This enables DISLIFE to answer three basic questions that scholars to date have been unable to answer:

- **When?** Have liveable disabilities increased or fluctuated across time?
- **Who?** What variations in liveable disabilities are found between different individuals with different impairments?
- **Why?** Which opportunity structures and individual features work to impede or further liveable disabilities?



The DISLIFE project is the first worldwide to employ mixed-methods life course research on disabilities both over **historical time** and **individual lifetime**. First, it involves quantitative analysis of Sweden’s long-term digitized population databases, which reflect how disability impacts on people’s educational, occupational, marital and survival chances. The statistical outcome is novel in demonstrating how different impairments intersect with human characteristics relative to society’s structures of the past 200 years. Second, qualitative analyses uncover how disabled people today experience and talk about the thematic dimensions (Themes 1-4) themselves, and how mass media depict them. Third, the project makes innovative studies of leisure structures (e.g. culture, sports, online), which may promote liveable disabilities.

Figure 1: An illustration of the conceptual model of the DISLIFE project.

Sweden is internationally known not only for its social welfare-oriented policy, but also for having a competitive advantage thanks to its access to rich population registers and datasets. Yet these diverse databases are under-explored in disability research and quantitative analyses are needed to advance our knowledge of how disability impacts on human life, as this project does. The results on liveable disabilities are extendable and of great cross-national interest as they will form a useful baseline for what constitutes liveable disabilities across time. Such information can help social institutions and governing bodies create inclusive spaces to allow disabled citizens participate fully in society, in line with policy documents such as the UN’s Convention on the Rights of Persons with Disabilities (2006). This convention and research show that nations have difficulties fulfilling their obligations, in particular in periods of economic recessions, and thus disabled people tend to dominate in underprivileged groups. Even in Sweden, which exhibits one of the highest measures of human equality and GDP growth worldwide, disabled people confront limited access to education, employment, social activities, political representation, and material resources compared to non-disabled citizens. Identifying liveable disabilities across time, the DISLIFE project will suggest how society can maximize the opportunity structures for disabled people in relation to health and social policy.

2. THE FOUR RESEARCH THEMES

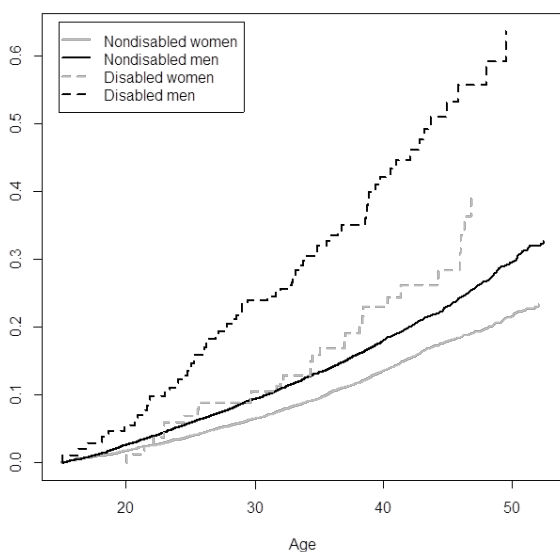
The DISLIFE project focuses on the early- to mid-phases in the life course with regard to four themes:

- 1) Health and well-being
- 2) Education and work
- 3) Partner relationships and family life
- 4) Opportunity structures in leisure activities

Themes 1-3 are examined during Sweden's pre-welfare, welfare and post-welfare regimes with regard to the opportunity structures they provide, while Theme 4 concerns the recent regime. Analysing these themes helps to reveal continuity and change *between* the regimes and *within* them to distinguish temporal differences concerning liveable disabilities relative to the individual features (type of disability, gender, age, socio-economic status, residence, access to kin network, etc.).

2.1. Theme 1: Health and well-being

Regardless of the time-space context, individuals' survival chances are indicative of their well-being, here whether disabilities are liveable. Some first multivariate regression results on disabled people in past Sweden exemplify the advantages of using event history methods. The event of death could easily be replaced by events such as education, employment, occupational mobility, marrying, etc. (Themes 2-3). The graphs (Figure 1) show that if being disabled, men run the largest mortality risk compared to disabled women and non-disabled



men (the higher the curves, the higher the risk to die). Thus, men paid a higher 'price' for disability in terms of health. This gender difference is most interesting and statistically significant ($P\text{-value} < .05$). The project will map how gendered mortality risks developed across time and how different disabilities influenced survival.

Figure 2: Plotted cumulative curves showing the mortality hazards among disabled and non-disabled men and women over their life course and during the observation period in the Sundsvall region 1835-1892, Sweden (Source: Digitized parish registers, Demographic Data Base, Umeå Univ.)

Estimating mortality, marital and occupational propensities, this theme contributes new and differentiated evidence of liveable disabilities. This project is the first attempt to quantitatively uncover what disabilities imply for human inclusion in society, from the 19th century until now. We also conduct qualitative interviews with

individual persons and in focus groups to gain further data on their well-being in post-welfare Sweden, and how it is manifested in the mass media, by the disabled persons themselves, their relatives, professional social workers, journalists and others.

2.2. Theme 2: Education and work

Working life has strong symbolic value linked to the economy, normality and morality in society, past and present. Having a job and being economically self-sufficient is key to recognition in society and regarded as desirable by most individuals and the state. Work is also imposed by society for its socio-cultural values and provides prerequisites for social inclusion in society. Studies show that disabled people are weaker positioned in education or the labour market than the 'able' majority, but the variations in this weakness among the disabled and across time remain unknown. Making use of the databases this theme differentiates statistically the educational and occupational chances among disabled people from the 19th century until today, and check what type of job they end up with. Interviews with individuals and in focus groups are conducted to gain more in-depth knowledge of how they view their opportunities in the labour market during the recent decades, as well as how they manage the transition from education to work. Similar to Theme 1, this theme analyses how the mass media voice the disabled themselves or how they otherwise communicate their engagement in education and working life.

2.3. Theme 3: Partner relationships and family life

In the past, marriage and family were the aims of most young people. They were also encouraged to marry by parents and institutions such as the church and the state. Still today, having a partner and family signify the 'normal' transition into adulthood, and becoming a parent constitutes an important aspect of being recognized as a 'real' man or woman. In research scholars debate whether the high likelihood of living alone among disabled is the result of low chances to contract a partner and why disabled women marry less frequently or late in life compared to their non-disabled peers. There is no systematic historical research on the marriage opportunities of disabled men and women to date. This theme fills this gap by studying the marital/cohabitation

prospects and reproduction among disabled people in the databases the project has access to. Interviews help to trace insiders' experiences of partner relationship and family building, seen from a normative perspective or as an actuality. These transitions are very important for disability research as they form critical phases in life and involve issues of identity, normality and social positioning. Like education and work, they are key contributors to achieving liveable disabilities. As with Themes 1-2, mass media studies are conducted to trace personal and mainstream societal views on disability and family life, and diverse representations or rejections of it. Celibacy cannot only be seen as indicative of failures in finding a partner, but also as an index of changing alternatives in society and people's opportunities to pursue them, disabled or not.

2.4. Theme 4: Opportunity structures in leisure activities

Similar to other countries, Sweden's post-welfare society has become differentiated and characterized by fewer clear confirmative structures. Citizens are now faced with an ability (or requirement) to construct their own life with less attention to 'normative' pathways. This theme examines how disabled individuals interact on the Internet (e.g. social media) and in sport and culture (e.g. theatre), hence activities usually occurring during leisure time. However, when one lacks a job, colleagues or a family to engage with, activities in such structures can be of the utmost importance for making disability liveable. The Internet has rapidly created new venues to gain knowledge and create networks, where individuals represent, or construct, themselves. Sport and culture bring people together and may add to a meaningful life or identity, but the research incorporating disabled people on this topic is limited. Allowing self-representation and social interaction, these activities may also serve as a potential partner market or as keys to finding employment, or they may work to compensate for a missing family or job. Through interviews and questionnaires involving the stakeholders and by studying how they use the Internet (e.g. mapping blogs, forums, tweets, videos) and how traditional mass media document their sport and cultural activities in public, the project will provide exceptional findings of whether these activities help disabled people develop strategies to cope with everyday life and society.

3. THE TEAM

The DISLIFE project brings together scholars with expertise in quantitative and qualitative methods, from different centres at Umeå University studying populations (CEDAR, DDB), gender (UCGS), disability (CDR) and digital humanities (HUMlab). The team is in a unique infrastructural position to combine methods, promote the exchange of theories and disability results across academic fields. In disability studies, life course analyses are rarely employed in a systematic way with regard to the quantitative examination of disability as this project does. Our qualitative analyses (e.g. interviews) and media studies will show both the normative perceptions and actual experiences of events and transitional phases in disabled people's life (e.g. entry into education or the labour market, family formation) in recent society that add depth to the statistical findings we obtain.



4. DATA AND METHODS: World-unique databases and mixed-methods research

The DISLIFE project has access to internationally renowned databases in Sweden that detail information on millions of persons from the past 200 years in Sweden. These databases extend over people’s lifetime and indicate their impairments and demographic attributes. Quantitative analyses of continuous data on disabled strata of populations from the past to the present enable the project to form a baseline recognizing liveable disabilities across time and how different opportunity structures make them more or less liveable.

Table 1: The accessible databases of the DISLIFE project.

<i>Database</i>	<i>Time period</i>	<i>No. of person</i>	<i>Area in Sweden</i>	<i>Type of data</i>
1. HISTORICAL Database Demographic Data Base (DDB) Umeå University, Sweden	c. 1700-1900	c. 1.2 million	c. 80 parishes	Parish registers (in-/out- migration, birth & baptism, marriage, deaths & burials, catechetical lists)
2. HOSPITAL Database Demographic Data Base (DDB) Umeå University, Sweden	1844-1900	c. 20,000	Town of Sundsvall	In-patient registers, diagnosis, partly integrated with the DDB’s parish registers
3. POPLINK Database Demographic Data Base (DDB) Umeå University, Sweden	1900-1968	c. 300,000	Västerbotten county	Parish & population registers
4. LINNAEUS Database Demographic Data Base (DDB) Umeå University, Sweden	1960-2012	c. 12 million	All Sweden, Västerbotten more detailed	Extensive longitudinal socio-economic & demographic data, in-patient & medical birth & drug prescription registers, school performance, hospitalization, social & health questionnaires etc.
5. SIMSAM Database Umeå SIMSAM Lab Umeå University, Sweden	1960-2010	c. 12 million	All Sweden	performance, hospitalization, social & health questionnaires etc.
6. ULF Database (National Survey of living Condition, Statistics Sweden) Dept of Sociology Umeå University, Sweden	1975-2011	6-8,000 (annually)	National sample	Rich data on people’s living conditions, indicators of disability, cross-sectional panel waves
7. PSAE Database (Panel Survey of Ageing & the Elderly) Dept of Sociology Umeå University, Sweden	2002-2011	12,000	National sample	Panel partly data integrated with the ULF Database (see above)
8. LISA Database (Longitudinal Integration Database for Health Insurance & Labor Market Studies, Statistics Sweden) Dept of Sociology Umeå University, Sweden	1990-2011	All Swedes, aged 16 yrs or older	All Sweden	Annual data on health and income partly integrated with the ULF and LINNAEUS Databases (see above)

On the **one hand**, the project makes use of the databases to obtain quantitative data on liveable disabilities in different comparable opportunity structures from the 19th century until the present. The databases indicate disabled individuals, their families and demographic features, and enable statistical event history methods as well as the construction of datasets of controls (non-disabled people). Demographic life course events, such as entering education and working life, social (occupational) mobility, marriage/ cohabitation and family formation, and mortality, are analysed. These events and controls indicate whether disabled people were denied a social life and participation in society, for instance, whether they were less fortunate in the labour and partner markets. Social exclusion would also be indicated by untimely death caused by poor health and/or weak social relationships. If they chart a pathway similar to that of the non-disabled, we would expect them to face opportunity

structures that were beneficial to their participation in society. Such statistical findings are key to form a baseline for what constitutes liveable disabilities across time.

On the **other hand**, to further identify this baseline given the recent societal developments in Sweden, this project incorporates qualitative methods. Individual or focus group interviews are exceptionally useful for identifying human perceptions and strategies for how disabilities become liveable and in relation to normative discourses, for example, as regards family and work, or through leisure activities. Disabled people will narrate their experiences of the life course as they appear in their thoughts, feelings, attitudes and perceptions. The project also mixes quantitative and qualitative methods through text/discourse analyses and questionnaires to study how disabilities and norms associated with the four themes are communicated in the mass media (e.g. TV, magazines, newspapers) that depict or give voice to disabled people. Despite the recent research interest in cultural, sexual and ethnic minorities, few communication studies have been entirely devoted to disability, as this project is. It is even more innovative in making use of Internet/online communication of disabilities (Theme 4). With this mixed-methods research, the DISLIFE project will obtain highly nuanced evidence of how, over the life course, disabilities are exercised and negotiated in life and society.