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Liveable Disabilities: Life Courses and Opportunity Structures across Time in Sweden (Project Overview and Critical Reflections)

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Abstract

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Abstract

People with disabilities make up the largest minority group in the world (15% or 1 billion). Despite advocacy work and political advances in disability rights such as the UN Convention on the Rights of Persons with Disabilities, they are still marginalized in society and disability is often considered solely a medical condition associated with personal tragedy and exclusion. Since 2016, the European Research Council has funded the DISLIFE project's proposal to research 'liveable disabilities' in Sweden from the 1800s until today. In this chapter, we present the project and its results on how societal circumstances have shaped the opportunities and lives of people with disabilities across time. We discuss the project's use of the life course concept and from ableist perspectives and propose avenues for future research. Since the project results indicate that there have been little progress over time concerning the life opportunities of people with disabilities, a paramount work is ahead to which research aware of ableism can contribute.

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1. Introduction

People with disabilities make up the largest minority group in the world of about 15% or 1 billion (UN 2020; WHO 2011). Despite advocacy work and political advances in disability rights such as the UN Convention on the Rights of Persons with Disabilities (2006), disability largely persist to be perceived solely as a medical condition and personal tragedy being associated with stereotyping and exclusion. To investigate these issues further, the DISLIFE project researches the life courses of people with disabilities and their opportunity structures from the 1800s until present time. The project is interdisciplinary and brings together a team of 15 scholars from the humanities, social sciences and medicine, who seek to increase the understanding of how and why disability has shaped individuals' opportunities in social life and society across time in Sweden and the consequences of it. Researching four life-course themes, the project aims to identify 'liveable disabilities' before, during and after the Swedish welfare era, making use of quantitative as well as qualitative analysis. During 2016–2021, the European Research Council (ERC) has funded the project entitled 'DISLIFE Liveable Disabilities: Life courses and opportunity structures across time'.

The aim with this chapter is not only to present results from the DISLIFE project but also to reflect upon them and on how the project makes use of the life course concepts. As the project is approaching its end, we can revisit its aims and results including the ways in which the life course concept has been used to identify circumstances in society that have affected the opportunities and lives of people with disabilities across time.

Scandinavian countries and particularly Sweden have long held a reputation internationally for their welfare-oriented policy providing public service and social security to limit citizens' dependence of support and care from relatives (Esping-Andersen 1990, 1999; Ginsburg 1992; Lindqvist 2000). However, about 150–200 years ago, Sweden was one of Europe's poorest countries. Since then, it has witnessed large-scale transformations that have shaped peoples' opportunity structures such as urban-industrial changes, shifts in gender regimes, democratization, and advancements in medical treatment, and the advent of New Public Management promoting a dismantling of public welfare in recent decades. Whether and how such societal changes in opportunity structures have affected disabled people has not been studied thoroughly and largely due to a lack of data covering extended periods and populations. The DISLIFE project has unique access to such data concerning Sweden and applies life-course perspectives on disabilities to make up for that dearth in research.

In the next section, we present the life-course research of the DISLIFE project and recall some of its novelty. Section 3 presents the findings having generated more than 40 scientific works. These works provide further results of disabled people's opportunities in Swedish society across time, which indicates their liveability. Section 4 provides a critical reflection on the promises and limits of the project's analytical approach drawing upon ableism, and suggests a few avenues for future research. In Section 5, we draw some conclusions.

2. The DISLIFE project: four life-course themes and 'liveable disabilities'

Estimations suggest that between 1.3 and 1.8 million in the Swedish population (10.3 million) have some kind of disability (<http://www.funika.com/design-for-alla/tillganglighet/statistik/>.) In

Europe, the corresponding number comprise some 65 million persons (EC 2017). Despite making up a sizeable group, these people are remarkably marginalized in society as well as in research and 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 notion of ‘liveable disabilities’, it examines how disability influences people’s possibilities and participation in social life and society by uncovering how their life courses vary as a function of disability and opportunity structures. The project regards disability as liveable when surrounding structures enable opportunities in social life and society on equal terms with equal value regardless of one’s functionality or abilities. The project pursues four themes to find out how disability impacts on (1) the health and wellbeing of people; (2) their involvement in education and work; (3) in partner relationship and family life; and (4) their opportunities in structures made up by leisure, culture, sports or social media. Researching these themes using quantitative as well as qualitative methods, the project aims to identify ‘liveable disabilities’ before, during and after the heydays of the Swedish welfare state (from c. 1800 until today).

Scholars conceive the life course in terms of trajectories that reflect people’s living conditions, constraints and possibilities in society (Elder 1985; Giele & Elder 1998; Kok 2007). Individuals are considered to follow a life-span development with phases such as childhood, adolescence and adulthood, which include transitions to education, work, partnership and parenthood before entering into old age. In turn, these phases and transitions affect people’s status, behavior, identity, social activities and rights in society. Finding a job or a spouse, or acquiring disability, can influence the social wellbeing and health and the subsequent course of life and thus the sustainability, or liveability. Examining such transitional events in the life course is key for the project to trace liveability among people with disabilities moving through different opportunity structures across time in Sweden. In disability studies, the life course concept has come in use the recent two decades (Priestley 2001; Shah & Priestley 2011), but not with regard to the quantitative examination of disability or for past times, as the DISLIFE project contributes new results to.

In multiple ways, the DISLIFE project and its sub studies consider a set of analytical principles within the life-course concept (Mortimer & Shanahan 2003), one of which is the *life-span development* referred to above. It further proposes that past experiences shape present life and circumstances and even future developments, as (dis)advantages can accumulate across time. Such developmental processes can include individuals as well as societies. Another principle recognizes humans as *agents* who make their own decisions. The choices and actions they take over their lifetime define the life course such as whether or when to take up work or engage in sports or in relationships. However, a person’s opportunities also depend on the surroundings as the principle of *time-space setting* recalls. It concerns socio-economic structures in societies including norms about gender and (dis)ability, and legal regulations. Most societies expect people to progress along specific life courses governed through policies and institutions (e.g. education, work, family, welfare) to ensure not only that certain events occur, as employment, but also occur within certain timeframes in life, as the principle of *timing* stresses. Societies exhibit opportunity structures that can differ across time and space in providing opportunities and support for groups that need it, as the principle of *heterogeneity* suggests. It includes

individuals as well, since different characteristics give people different socio-cultural capital and material resources, which influence their opportunities to adapt to surrounding structures. According to the principle of *linked lives*, familial and social networks mark the life course because humans depend on each other. They link their lives together at workplaces, in leisure activities (both on- and offline) and through partnership. People's opportunities largely depend on the assistance from society and relatives, especially in times and societies where social security benefits are less available.

3. Results on the four life-course themes from quantitative and qualitative analysis

The DISLIFE project makes *quantitative analysis* (e.g. Cox proportional hazard regressions, logistic regressions, sequence analysis, descriptive statistics) of the rich population databases in Sweden to obtain information on how disability played out in different opportunity structures in 19th-century until recent decades. Central life events like the transition to work, marriage/cohabitation or family formation and death are studied. These events and comparisons with non-disabled groups suggest whether and how disability affects people's participation in social life and society. If so, it would compromise their opportunities in the labor market and partner pool and their survival as a possible outcome from poor health and/or weak social relationships. If disabled people would chart a life course similar to others, they likely faced opportunity structures that were beneficial to their participation in society. Such findings are key to form a baseline for what constitutes liveable disabilities across time.

To identify this baseline further given the recent societal developments in Sweden, the project applies *qualitative analysis*. Interviews work as one means for identifying human perceptions and strategies for how disabilities become liveable in relation to normative discourses concerning partnership and family or the transition from education to work. Disabled people narrate their experiences as well as expectations of life as these appear in their thoughts and feelings, and the attitudes they meet from others. Text/discourse analyses and questionnaires are conducted to find how disabilities and norms are expressed in structures made up by sports, the media (e.g. TV series, films) and online (internet communities). This enables the project to obtain highly nuanced results on how disability is experienced and negotiated in human life as well as society, which can suggest the level of liveability.

DISLIFE Theme 1: Health and wellbeing

Irrespective of time-space setting and opportunity structures, people's survival chances indicate their health and wellbeing and provide one means to estimate whether disabilities are liveable. While the UN's Convention on the Rights of Persons with Disabilities (UNCRPD 2006) states the highest attainable standard of health for the people concerned, reports and research show that they experience a narrower health margin than others and lesser access to care and services (EC 2017; WHO 2020; Forman-Hoffman et al. 2015; Mithen et al. 2015). The association between disability and mortality is poorly investigated, as is how different disability types and gender shape people's survival. Further, there is scant knowledge on whether today's health disparities in the population with disabilities go a long way back in history and have decreased over time due to societal change and advancement in medicine, improving welfare provisions

and health care. One way to know would be to analyze how disability relates to humans' health evidenced by mortality risks.

Our long-term mortality trends provide a unique window into how disability has shaped the health and liveability in shifting opportunity structures of Swedish society from the 1800s until the 2000s (Vikström et al. 2021; Haage, Häggström Lundevaller & Vikström 2016). We would expect to find periodic changes marked by a mortality decline in line with the general increase in health and life expectancy in most Western populations since the 19th century, and because Sweden has witnessed profound societal transformations and welfare in parallel. Improvements in health care, economy, education and social services have increased the material and medical conditions of average citizens and decreased the inequality between them. However, these developments did not modify the relative mortality gap between the people with and without disabilities. In the 1800s, the death risk was twice as high in the group with disabilities while this risk was almost ten-folded at the turn of the 21st century. This is a remarkably result and suggests that even though the health and survival increased for both groups, the mortality gap between the two groups persisted and even grew over time.

The overall disadvantage in survival likely reflects disadvantages earlier in life concerning the access to work and income or to social ties. For recent Swedish populations, the project can establish a strong link to disability in young adulthood, which goes back to perinatal health issues (Namatovu, Häggström Lundevaller, Vikström & Ng 2020). Our historical studies show time-span developments in people's lives by taking a series of events across their lifetime into account simultaneously. Employment, migration, marriage and parenthood were less frequent events or postponed in humans' life courses if having disabilities, which help explain their mortality excess (Vikström, Häggström Lundevaller & Haage 2017; Lundevaller, Vikström & Haage 2018). That they did not die from infectious diseases to similar profound degree as others suggests that they 'escaped' airborne diseases as possible consequence of low interaction with peers in the community (Vikström, Edvinsson & Häggström Lundevaller 2021). It seems as if disability made people subject to lock-in mechanisms, which limited their opportunities and survival.

As Sweden moved towards a welfare state (1900-1960), there was a strong confidence in the knowledge of experts and authorities regarding healthy lifestyles and medical treatments. The number of mental hospitals grew immensely from around 300 to 3,500. While this put people with mental disabilities at risk for confinement, these risks differed by distance to asylums and access to family relatives (Eriksson, Junkka, Sandström & Vikström 2021).¹ Men and high-status groups were more likely to be diagnosed with mental disabilities until the 1950s; by then, women and low-status groups emerged to be, similar to today (Junkka, Sandström & Vikström 2020). This emergence indicates a shift in the perception of mental health when increasing medicalization made mental health among poor people and women increasingly pathologized. Another study examines the Swedish censuses 1860–1930 to follow how contemporary medical knowledge and perceptions in society about (dis)abilities worked to inform and affect the public

¹ While many of the disability concepts we come across in the historical data, such as 'mental disorder', may be offensive due to the derogatory meaning they carry today, we have no intention to offend anyone when occasionally using these concepts ourselves to avoid translation issues across time and language.

registration and definition of disabilities in the population (Wisselgren & Vikström 2021). The growing concern to measure and report disabilities resulted in increasing numbers of people objectified as disabled.

DISLIFE 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 self-sufficient is crucial for recognition in society and regarded as desirable by most people and the state. Work is also imposed by society for its socio-cultural values, and because it brings health and wellbeing to people. In Sweden, women have entered the workforce in large numbers since the 1960s, making it less necessary to find subsistence through a husband. Welfare reforms like parental leave have further encouraged women's work and gender equality in society. This illustrates how access to work and supportive structures can help achieve independence. However, studies show that disabled people make up one, or even the most, significant underemployed group in the global workforce (Jones 2008; Lengnick-Hall, Gaunt, & Kulkarni, 2008; OECD 2010), and Sweden is no exception (National Board of Health and Welfare Report 2009, 2010; Norberg 2019; Tideman et al 2018). There have been efforts to reduce this under-employment through welfare programs regarding (sheltered) work, financial support to employers hiring disabled people and reforms in education to better prepare students with disabilities for the labor market, some of which the DISLIFE project examines beside historical variations in work opportunities.

Already since the 1950s, working-age groups with long-term limitations due to impairments or ill health could access some income support from the Swedish state through different disability benefits, although small to begin with. Studying nationwide cohorts born in the 1970s about to entering the labor market in the 1990s, the project finds that women were subject to such benefits to a significantly higher extent than men were (Namatovu, Häggström Lundevaller & Vikström 2021). The negative effects of unemployment is evident in the relationship between paid work and self-rated good health for people having disabilities due to psychiatric and musculoskeletal diagnoses (Nordlund, Larsson & Stattin 2021). In 19th-century populations, disability impeded the job chances with between 30% and 75% depending on type of disability and especially among men (Vikström et al. 2019). Regardless of gender, the lowest chances were associated with mental disabilities while sensory disabilities had the least negative impact on the work chances. These results suggest that the weaker access to the labor market among disabled people today has a long history to which past patterns might have contributed. Even when finding a job, this was not the road to marriage or family life to the same extent as among non-disabled groups (Vikström, Häggström Lundevaller & Haage 2017). While disabled women took up similar domestic occupations as other women (e.g. maidservants, seamstresses), they did to a far lesser degree. Manual work within the agricultural sector (e.g. farmhands, cottagers) were more predominant among disabled men who found a job compared to other men who worked as laborers in the sawmill industry and increasingly as it established itself in the study area from the 1860s onwards. Our comprehensive results both support and differentiate previous research suggesting that industrial production jeopardized the job possibilities for disabled people because they were less able to cope with manufactory work.

For recent time, the project has conducted qualitative analysis with surrounding stakeholders involved in the transition from education to work (teachers, employers and officials at the Public Employment Agency). This has helped to pinpoint and understand the difficulties as well the possibilities young adults with disabilities experience when trying to enter the labor market. The results show that their job opportunities and contribution at different workplaces improved with support from and social interaction with the surrounding stakeholders and a more efficient collaboration between these stakeholders regarding the planning of students' practice periods during education (Ineland, Karhina & Vikström 2021; Karhina, Ineland & Vikström 2021). These results stress the role and importance of a supportive surrounding for creating opportunity structures for young adults with disabilities within educational and employment organizations. Such surroundings increase their motivation and self-confidence and problem-solving but put high demands on teachers regarding normative notions of the learning process. Changes in organizational or surrounding structures require staff as well as students to re-evaluate their position in relation to both the physical and social space, which can cause both parts confusion (Ineland 2020; Wickman & Berggren 2021).

DISLIFE Theme 3: Partner relationships and family formation

Partnership and family formation signify two key transitions for becoming adult and for social recognition in society. These transitions are very important as they form critical phases in life and involve issues of identity, normality and social positioning, and thus contribute to make disabilities liveable. Contemporary studies associate disability with low partnership levels (Clarke & McKay 2014; Fekete et al. 2020; Vikström, Shah & Janssens 2020), but the bulk of results is scant compared to disability studies on health, education or labor issues. One plausible reason to this paucity of research is that disabled people, traditionally as well as historically, have not been expected or afforded the rights to occupy the social role as partner or parent on an equal basis with others. This theme combines disability with partnership and compares recent results with the past, which seldom come together in research.

The long-term disability results of the DISLIFE project show a continuity in partnership from the 1800s until the 2010s. Disability narrowed both men's and women's partnership opportunities significantly (with about 60%), although there were some significant differences across disability types, the genders and periods (Haage, Vikström & Häggström Lundevaller 2017; Namatovu, Häggström Lundevaller & Vikström 2020; Vikström, Karhina & Junkka 2021). Up until 1960, disability made women's partnership chances slightly lower, while this gender gap was almost gone by 1990. This might mirror Sweden's move toward a more gender-equal society. Welfare reforms like parental leave had promoted this move during the preceding decades and in parallel women's incomes improved through their increasing participation in the workforce. Although these developments tend to have balanced the gendered difference in partnership between disabled people as well, their partnership chance stayed less than a half of others across the two centuries we study. During the 1800s and throughout the 1900–1960 period, mental disabilities implied the ever-lowest partnership opportunities within each gender (decrease between 75–80%). Physical disabilities did not impede men's partnership prospects as much (45%) as did sensory disabilities (63%), while women show slight reverse pattern (62% vs. 58%). Sensory disabilities did not have such a negative impact on women's partnership

opportunities as among men. During the 20th century, there were some changes. While a sensory or physical disability decreased partnership in women with 70% and 78% respectively, the equivalent ratios for men were only 22% and 52%. Physical disabilities were thus less limiting for men's partnership than for women (Vikström, Karhina & Junkka 2021). One plausible reason is that especially disabled women's bodies have been asexually objectified by medical and legal discourse that have made them be perceived as undesirable partners. Our studies on recent decades provide indications that physical disabilities kept having adverse effects on women's partnership, as mobility difficulties made them more likely to live alone than men, hence the reverse side of partnership (Sandström et al. 2020). This suggests that having a non-normative body still makes women less regarded as potential partners due to stricter gendered ideals concerning their bodies. That similar high dissatisfaction from living alone characterized both men and women with moving disabilities indicates that they both hold normative expectations in wanting to experience partnerships just like others (Sandström et al 2020).

Limited opportunities in partnership suggest why disability is also associated with low levels in family formation. Focusing on parenthood/childbearing the project provides information of this association in Sweden 150–200 years ago as well as 15–20 years ago. Insufficient access to a job and income seems to have contributed to the low levels in partnership as well as parenthood among people with disabilities (Namatovu, Häggström Lundevaller & Vikström 2020; Vikström, Häggström Lundevaller & Haage 2017). Welfare provisions like disability benefits or parental leave have not come to change that profoundly, it seems. There are some indications that receiving disability benefits in young adulthood promoted parenthood in subsequent years and particularly among women (Namatovu, Häggström Lundevaller & Vikström 2021). One project study targets about 360 young men and women with disabilities who married in 19th-century Sweden (Vikström, Haage & Häggström Lundevaller 2020). It appears that their marriages did not differ markedly from other couples in the same time-space setting regarding the social and geographical background of the spouses, except some minor delays in the age of marriage. There was no evidence that disabled men and women married each other in being rejected as possible partners by others. While these results stress the agency and possibilities of people with disabilities in the past, the fact that disabled women became mothers to illegitimate offspring to a higher extent than other women mark marginalization.

That disabled people did not enjoy a greater access to a partner relative to others while Sweden moved from a poor country to a modern welfare state, suggests that disability keeps on distributing the opportunities to partnership unequally and with negative consequences for people's family formation, as well. Demographic developments in the 1900s such as the decline in marital rates and de-familiarization process have not come to narrow this disadvantage in partnership, neither have more tolerant attitudes towards partner preferences in recent decades. To investigate these issues further and from international perspectives, the DISLIFE team has led a special issue in *The History of the Family* (Vikström, Shah & Janssens 2020), which collects eight studies from different countries that research disability, partnership and family across time and space. One recurrent result in these studies is that people with disabilities face significant social and societal barriers when aiming at partnership, due to low participation and

recognition in the community and social life. This special issue also reports valuable results of disabled people who are married/cohabiting and survive in their partnerships.

While the quantitative DISLIFE studies uncover long-term trends in which disabled people are less likely to have a partner or start a family, the qualitative studies investigate partnership, family and sexuality from a normative perspective as a possible explanation for these trends in recent times. These studies scrutinize cultural notions and perceptions of disability, for example, by analyzing contemporary Swedish fiction films depicting characters with disabilities. Mainstream film seldom depicts characters with disabilities as sexual subjects and Swedish cinema is no exception. In the few films about sexuality and partnership, only one film challenged ableist norms related to time, adulthood and sexuality, and hence problematized the normative relationship between sex and disability (Wälivaara & Ljuslinder 2020). Interviews have further helped the project to identify insiders' experiences of partnership and family building in Sweden, both seen from a normative perspective and as an actuality. One ongoing interview study analyzes the shifts in welfare provisions since the middle of the 20th century regarding the possibilities to have a partner and form a family for people with disabilities. The results reveal that an ableist understanding of disability, gender and sexuality has structured the Swedish welfare state and its changes and continue to do (Bylund forthcoming). We will return to this notion in Sections 4 and 5.

DISLIFE Theme 4: Culture and leisure

Involvement in leisure structures are becoming increasingly important for the social well-being in contemporary life. For people having limited access to a job or a family, activities in such structures can be of the utmost importance to lead a liveable life. Sports bring people together and might enable a meaningful life or identity. Internet has rapidly created new venues to gain knowledge and create networks, where individuals represent, or construct, themselves. Representations in culture and media influence the perceptions of ourselves as well as of others, but research on these topics concerning disability is limited. The DISLIFE project examines these issues and how disabled individuals interact on social media and in sports, and thus uncovers disability representations in culture (e.g. film, television); hence, activities that primarily occupy people in leisure time but can positive effects for other areas in human life such as those addressed in Themes 1–3 above. Small chances to experience partnership or work or recognition in schools, sports or diverse activities online can have detrimental outcomes and risk to reinforce existing inequalities between people, as representations of disability can if keeping emphasizing 'otherness'.

By scrutinizing the opportunity structures for sports participation in national, regional and local policies in Sweden, the DISLIFE project shows that a supportive environment is crucial for persons with disabilities to pursue sports. In recent years, the Swedish sports movement has searched for ways to create such environments through a shared understanding among the stakeholders concerned (Wickman & Torege 2021), which the project studies. Another study focuses on the ongoing re-structuring of the Swedish Sports Confederation in order to include sports organizations previously governed by the Parasport Federation, and indicates that the stakeholders welcome this organizational change although it entails many political and ideological tensions. There is further need to include the experiences of Paralympic athletes

considerably more to make this change become empowering and non-discriminatory (Nordlund, Wickman, Vikström & Karp 2021).

Representations in the cultural sphere influence the ways people understand disability and the values they assign to it. Film, television, newspapers, literature and social media contribute to perceptions of disability in society. Both Swedish films and television series from the US depicting characters with disabilities have been analyzed. One study of disability stereotypes in *Star Wars* shows that there has been a progression towards more inclusive and less stereotypical disability representations in the popular franchise, and stresses the necessity to engage critically with popular genres from disability perspectives (Wälivaara 2018). Moreover, contemporary norms and preconceptions about disability based on a medical understanding tend to permeate film narratives about the future (Wälivaara 2018b). The results illuminate how popular culture narratives both challenge and perpetuate normative notions about disability. As these stories reach a wider audience there is need of continued scrutiny on how they conceptualize disability.

Social media provide a venue for representations of disability where people also have the opportunity to create self-representations and can access a more public voice. One project study of a Swedish podcast shows how humour works to question ableism and make normative notions of disability visible (Söderlund, Wälivaara & Ljuslinder 2021). A study of Twitter discussions regarding disability policy in Sweden contends that even though private twitterers reached out to politicians, media, and advocacy organizations, the public debate did not pick up these tweets and the established power structures in the discussions prevailed (Ineland, Gelfgren & Cocq 2019; Gelfgren, Ineland & Cocq 2020). An analysis on disabled persons' self-representations in an Instagram campaign against discrimination demonstrates similar results in addition to uncover how representations both adhere and challenge normative discourses about disability (Cocq & Ljuslinder 2020). These representations showed a variety of experiences of discriminations, but did not reach the targeted group for the campaign, i.e. non-disabled people. Instead, the campaign gained interest from other persons having experiences of disabilities and discrimination themselves. The difficulties to communicate and make way for disability issues is further shown in films and television series in which contemporary norms and preconceptions about disability based on a medical understanding tend to permeate narratives about the future (Wälivaara 2018). However, the results also illuminate how popular culture narratives both challenge and perpetuate normative notions about disability.

4. Reflections on the DISLIFE project and future avenues for research

Like with every study or project, there is need to reflect critically upon its analytical approaches and how the research and results are conceptualized. This section provides such reflections by drawing upon some of the DISLIFE project's premises and limits in relation to another concept, ableism. We also make some suggestions for future research.

The DISLIFE project's use of quantitative life-course analysis and access to long-term digitized population data is exceptional. Exceedingly few works within disability studies, if any, can base the results on such a scope and large quantity of individuals using advanced statistical life-course methods. Consequently, the project and its publications show sound empirical evidence on how disability played out in individual life and society from the past to the present making

comparisons between disabled and non-disabled groups in populations. Such findings serve as a useful baseline of international research interest regarding the temporal effects disabilities have on life, especially since the project can estimate the level and significance of it. Such findings can further yield a greater interest from quantitatively-oriented scholars within the social sciences or medicine to contribute more to the field of disability studies. It would benefit from this, as the field is predominated by qualitative-oriented research and there is need of both types of scholarships in any field. The statistical outcomes of the DISLIFE project encourage quantitative cross-country comparisons to gain new knowledge on time-space (dis)similarities of disability in human life.

However, in large datasets allowing aggregate analysis of events like mortality and partnering or getting a job, less typical patterns tend to fade away in general results or trends that are statistically significant. It is important to recall that our findings do not suggest that neither work nor marriage was impossible if disability was part of life, hence pivotal events that stress the agency and possibilities of people. They just did not do to similar high extent as others did, when having disabilities. A couple of historical publications highlight some individual persons from the aggregate data to narrate their experiences beyond the results in tables and graphs, to counteract this bias in agency recognition (Vikström, Häggström Lundevaller & Haage 2017; Vikström, Haage & Häggström Lundevaller 2020). There is a need for more such studies by both us in the project and other scholars to make liveable disabilities become more visible in individual life and not just in aggregate groups across disability types and genders.

Normative life courses and liveable disabilities

While the life-course concept implies many strengths that the DISLIFE project exemplifies and has benefitted from, this concept also carries limitations. One major limit is its normative implications of how life is to be lived in taking the life course of able-bodiedness/mindedness for granted. In the remainder of this section, we will reflect critically upon how the project conceptualizes ‘liveable disabilities’ in relation to ‘life course’ and ‘opportunity structures’ by drawing upon ableism. It is a power order that de-values disability in relation to able-bodiedness/mindedness and positions all disabilities as unacceptable and unwanted (Campbell 2009, 2012). Fiona Kumari Campbell asserts that ableism is a “network of beliefs, processes and practices that produces a particular kind of self and body [...] that is projected as the perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human” (Campbell 2009: 5). This situates disability as something to eliminate if the opportunity arises (Campbell 2012). Based on an able-bodied and able-minded ideal, ableism structures human life (life course) and society (opportunity structures) in which disability is always considered negative, abnormal, less human, and of less worth. This divide between the normal and the deviant is constitutional and one central feature of two through which ableism sustains itself. The other feature is the idea of normativity (Campbell 2012), which we will primarily discuss below with regard to the life course.

Along the lifetime of the project, some of us have come to engage critically upon the life-course concept in terms of its ableist implications. This is exemplified in some DISLIFE publications (cf. Themes 3–4) and a guest-editorship of a special section in *Scandinavian Journal of Disability Research (SJDR)* entitled ‘Crippling Time: Understanding the life course through the

lens of ableism' (Ljuslinder, Vikström & Ellis 2020). It brings together six studies that challenge the life-course concept from the perspective of crip temporality. In different ways, these studies show that the very notion of life course is fraught by ableism, as it charts life course from birth to death via life phases such as childhood, adolescence, adulthood and old age. Certain transitional events are assumed to occur within certain phases. This expects people to have a job and a partner during young adulthood and then become a parent. Such linear development becomes normative by referring to life courses of specific bodies and minds, all of which are able-bodied/minded, cis-gendered or heterosexual (Halberstam 2005, Kafer 2013). This epitomizes the normal and everlasting type and way of life that all should aspire to. Such 'abled' and taken-for-granted lives not only perpetuate and confirm a normative life course, as it extends to structure all areas in people's lives and in society as well, some of which the DISLIFE project considers (education, work, partnership, family, leisure, culture, media representations). Those who do not follow a normative life course including the expected events associated with it, are deemed deviant while those who adhere to a normative life course gain advantages because society is structured based on normative ideas.

According to the DISLIFE project, gaining access to areas in life and society such as education and labor market, partnership and family, and leisure activities and culture, is important for making disability liveable. However, can disabilities ever become liveable when ableist norms structure human minds and a world based on the assumption that disabilities make people impossible, unattractive, bad/deviant, and most of all, less-than-human? Conceptualizing 'liveable life' as whether someone fits into or adapts a normative life course has influenced the research design of the project. It makes comparisons with non-disabled controls and estimates time to experience events like employment, partnership or death to get information on opportunity structures. Such an approach expects people to attain education, take up work or engage in a partner and family and to do it within a certain timeframe in life. This illustrates how ableism interferes with science, e.g. what types of questions to address and how, and the analytical tools and theories selected to frame the research and findings, here about disability. Since disability in general is assumed to equal suffering, "people think it is related to impairment and not other issues like lack of support and belongingness", Campbell argues (2009: 216). She also calls scholars to increasingly "explore what the experience of impairment produces and ask how does disability productively colour our lives?" (Campbell 2009: 216). Her call includes not only research enabling a differentiation of the experiences of people with disabilities, but also research that challenges normative views on disability and questions the ableist fabric of contemporary and past societies. The DISLIFE project has done a little of both but this is far from enough. Disabilities will not become entirely liveable until people with disabilities are seen as fully human and treated as such. One major task for future research is to eliminate this bias in recognition to which research aware of ableism can contribute.

The constitutional divide in ableism between the normal and the deviant is relevant to reflect upon, since it refers to and is dependent on clear-cut definitions and categories, and even construct them. Legal or governmental administration and social service also depend on definition of abled-bodied and disabled in order to function and distribute welfare. Similarly, in science and in quantitative analysis in particular, categories are often a necessity. The DISLIFE project represents such analysis and qualitative research as well, the latter of which

is more critical to the use of categories because this risks reproducing normative notions if left unquestioned. While this risk exists and thus requires caution, analyses using categories can help trace the consequences of being subject to categorical thinking embedded in every culture. Research can help unfold the logic behind categories and how they work to structure the way people view the world and each other, and thus to pinpoint inequalities originating from categories, as partially ableism does. The Crippling Time section in the SJDR referred to above, provides insights on how certain life courses or events are deemed as pivotal and normal or not, thus categorized, but also on how this deeming can shift depending on the specific situation or context. The cultural understanding of what defines disability depends on understandings of time and the idea of normative life. Depending on the nature of the impairment and when in one's life it occurs, it is not necessarily understood as a disability. Norms are subject to change over time and space, and so are categories, since the understanding of disability differ today from one century ago. This notion is promising, as it entails a change that the DISLIFE project wished to have found clear evidence of but did not.

5. Concluding remarks

Identifying two centuries of liveable disabilities is exciting yet disappointing because disadvantages have primarily come to the fore. Internationally, and especially among progressive-thinking people and scholars, Sweden might still hold its welfare reputation of being particularly good to women, children, immigrants, ill citizens or those without employment or to people with disabilities ((Gunnarsson 2013; Tøssebro 2016). Our disability findings cannot support this reputation or that all the policy efforts implemented during the Swedish welfare era have made disabled people participate in wider society on a more equal basis with others. Recurrent economic recessions since the 1990s and ideas of individualism and New Public Management have resulted in a dismantling of welfare provisions as elsewhere, including the Act for Support and Service (1994) for Persons with Certain Functional Impairments (*Lagen om Stöd och Service till vissa funktionshindrade, LSS*). It was and still is exceptional in an international context, as it provides disabled citizens the right to apply for a personal assistant to facilitate participation in society on more equal terms with others regarding work and in social activities and everyday life to achieve an independent living (Askheim, Bengtsson & Richter Bjelke 2014). However, the recent 10–15 years citizens have been increasingly rejected this right or afforded significantly less assistance if entitled at all (Norberg 2019; Bylund forthcoming). This has made people with disabilities become more dependent on their relatives like partners, parents or children, similar to the past.

Overall, the long-term DISLIFE findings suggest there have been little improvements over time in Sweden and a paramount work is ahead to make disabilities become more liveable. There is little point in distinguishing whether this situation is primarily due to characteristics either in individuals and their life courses or in their opportunity structures, since the two interdepend and require examination in conjunction. While the project considers this conjunction as key to trace factors and circumstances that generate liveable disabilities, this does not exactly explain why disability continue to be associated with exclusion in a society like Sweden that has seen several socio-economic and political advancements and welfare measures have been undertaken to equalizing participation, some of which have proven to work. The long-term

trends in disability disadvantages that the project unfolds, calls for alternative ways of thinking into how disability can become more liveable in the future and leads us to some final remarks.

We think that ableist normativity constitutes a persistent hindrance that helps explain why disabilities have not become more liveable in human life and Swedish society across time. Even though discriminatory barriers have been limited or even removed and certain political gains achieved, it seems as if ableist norms continue to uphold some barriers or raise new ones. This suggests that a critical examination of ableist norms and perceptions of disability can make a significant impact to decrease oppressive structures in society and increase opportunities instead. James L. Cherny (2011) argues that “naming and calling into question *the view itself* raises the possibility of altering the very strands out of which the oppressive institutions are spun.” This notion does not mean that material or political gains or welfare improvements in society are unnecessary, it just calls attention to the norm itself to uncover and question the oppressive ways it operates in society. Not until we know and understand more about how ableism has acted as a powerful phenomenon throughout history until today, will it be possible to change dominant mindsets and avoid ableism in all human lives in future societies.

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