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Summary for Publication



Liveable disabilities

Life courses and opportunity structures across time

Summary of the results within the DISLIFE project

Recent statistics show that about 65 million people (10%) of the European population have disabilities. As they are marginalized in both society and research, there is dearth knowledge about how disabilities are lived or become 'liveable'. This project contributes results on the life courses of disabled people and their opportunities in Swedish society from the past to the present. Identifying long-term disability impacts using quantitative and qualitative methods and inter-disciplinary research, the project can promote more equal opportunities for disabled people.

Four objectives (WPs) are pursued to examine disability in the early- and mid-phases of life (c. ages 15–55) and different opportunity structures concerning:

1. Health & well-being
2. Education & work
3. Partner & family life
4. Leisure activities (sport, culture, media and on the Internet)

WPs 1-3 cover three periods in Swedish society, 'pre-welfare' (c. 1800-1930), 'welfare' (c. 1930-1990) and 'post-welfare' period (c. 1990 to present), while WP4 concerns the latter period. This scope of results enable the project to answer the three basic questions it originally raised:

I. WHEN? Have liveable disabilities increased or fluctuated across time?

Temporal fluctuations were modest. There was a persistent trend according to which disabled groups relative to non-disabled groups faced significantly fewer opportunities in education, work or to partnership/family or social well-being/health. Although material resources and health conditions improved in general population over time, disabled groups kept being disadvantaged in major life domains.

II. WHO? What variations in liveable disabilities are found between different people with different impairments?

Disability is a strong determinant ruling out other effects associated with individual or societal conditions. Some differences in health/well-being, work and partnership/family indicate variation in liveable disability depending on disability type. The ever lowest level is associated with mental difficulties while sensory or physical disabilities show more variations over time and by gender.

III. WHY? Which opportunity structures and individual features work to impede or further liveable disabilities?

No opportunity structures or individual features make disability irrelevant for people's life opportunities. However, a close supportive surrounding is key to transition from education to work and to engage in sport. Making use of the opportunities online disabled people promote their rights and self-representation but receive poor recognition from wider society which keeps associating disability with incapacity similar to popular culture and media.

Work performed from the beginning of the project to the end

The project brings together a team of in all 19 scholars from 12 disciplines within the Humanities, Social Sciences and Health Sciences, having accomplished the research in joint work led by the PI (Lotta Vikström). Significant progress was made the 1st half-time. Ethics approvals for studying all data were approved by the National Ethics Board, the data then analyzed contributing initial results to all WPs to present at conferences and publish. The 2nd half-time was 'harvest time' due to this work and advancements generating more findings and publications across all WPs. Major achievements are the guest-editorship by the PI and team of two special journal issues contributing to WPs 3-4: *Scandinavian*

Journal of Disability Research 2020 Vol. 22(1); *The History of the Family* 2020, Vol. 25(2). Guest researchers were hosted, one for a whole month (2019), Catherine J. Kudlick (Prof. of History and Director of Paul K. Longmore Institute on Disability, San Francisco State University, USA), with whom the team organized scientific and public events involving disability stakeholders.

The team's research and results cover all four WPs. Quantitative life-course examinations of Swedish populations, past and present, show that disability implied fewer opportunities in education, work and to partnership/family also jeopardizing the well-being/health. The level of liveable disabilities was low and remarkably persistent over time. Results from qualitative analyses show how disabled people today experience and talk about their life opportunities, interact on the Internet or in sports, and how media portray disability. Negative values associated with disability in society and culture compromise their opportunities in present-day and help explain their low prospects in major life domains evidenced by the project's quantitative analyses.

The results are disseminated in 40 publications being OA available (see DISLIFE website), 28 of which are in print in scientific journals/volumes. The other 12 works are completed and upcoming, one of which shows all project results (thus entitled similarly, 'Liveable disabilities', see website). The findings have been presented and well received at leading conferences/workshops worldwide at which the team has held about 55 presentations and organized sessions or workshops. Information about the project and results are further disseminated in media, social media and at public events.

Major achievements

The scope of the project takes it beyond the state of the art in examining disabilities across three centuries in Sweden (1800s, 1900s and 2000s). The results provide clarification on the adverse effects disabilities have had on human life historically until today relative to not having disabilities and suggest these effects persisted. This was surprising thinking of all societal developments Swedish society has witnessed moving from a poor country to a modern welfare state.

The project would not have obtained such long-term results without its unique access to individual-level population data from past Sweden to recent, enabling estimations of disability effects using advanced statistical techniques. Exceedingly few studies, if any, can base their disability findings on such measures and large quantity of cases across time as this project does. It benefits disability studies predominated by qualitative-oriented research and yields interest from quantitatively-oriented research to take disability into account.

For recent time, the project involves innovative studies on how disabilities are experienced and viewed in society as expressed on the Internet, in sport or in popular culture, which both manifest and shape current perceptions of what life is like if being disabled. By associating disabilities with non-normative conditions, surrounding structures work to narrow disabled people's opportunities to engage in social life through work or partnership. Social media provide arenas where they increasingly represent themselves to challenge stereotyped views and voice their rights to equal opportunities, but mainstream society responds poorly and they remain largely sidelined.

Although discriminatory barriers have been cut or removed and political gains achieved over time along with improving health care and welfare systems, negative views towards disability tend to persist and uphold barriers or raise new ones. There is still paramount work ahead to make people's opportunities more equal irrespective of disability, or their life more 'liveable'. The project recalls this and promotes the identity of a marginalized group in providing new knowledge on disability in past and present society, which there is dearth awareness about.