

## BACKGROUND, AIM AND RATIONALE\*

While the UN's Convention on Rights of Persons with Disabilities (CRPD 2006) states the highest attainable standard of health for the people concerned (Article 23), reports from the EC and WHO tell they experience a narrower health margin and lesser access to health services than others. Scholars confirm this disability-health disadvantage and often link it to disadvantages in education, labor, social life and society at large (Ahlström et al. 2017; Kavanagh et al. 2013; Schur 2013). While these disability disadvantages are recurrent in research, the association between disability and mortality is poorly investigated, as is how different disability types and gender shape people's survival (Thomas & Barnes 2010). Further, there is scant knowledge on whether today's disability-health gap goes a long way back in history and has narrowed due to societal change and advancement in medicine, welfare provisions and health care. An examination of the relationship between disability and death would contribute clarification to this issue.

The major aim of this study is to identify long-term disability effects on humans' health evidenced by mortality risks in Swedish populations during two centuries. We expect to find periodic changes primarily marked by a mortality decline in line with the general increase in health and life expectancy in populations worldwide, and because Sweden has witnessed profound societal transformations since the 19th century.

Our mortality results originate from the ERC-funded DISLIFE project\* and are exceptional in longitudinal scope. Uncovering long-term trends helps identify continuity and change in how disability determines human survival and provide a useful baseline of cross-national interest in enabling time-space comparisons of health disadvantages from disability dimensions.

## DATA AND METHODS

This abstract shows a selection of mortality findings from the 1800-1960 period, while similar results for recent Swedish populations are underway due to ongoing analyses of the databases that the DISLIFE project has access to itself or through collaboration (Table 1). As for the 1800-1960 period, the data consist of parish registers from the Sundsvall region c. 1800-1890s (N=36,500) and Västerbotten region 1900-1960 (N=196,000). These registers are digitised by the Demographic Data Base (DDB) at Umeå University, Sweden (Vikström et al. 2006; Westberg et al. 2017) and are presented below as this abstract provides results based on them.

<i>Dataset</i>	<i>Time period</i>	<i>N persons per sample</i>	<i>Swedish area</i>	<i>Type of data (and disability indications)</i>
<b>1. POPUM Database</b> Demographic Data Base (DDB), Umeå University, Sweden Total population: c. 1 million	c. 1800- 1900	c. 36,500 (Disabled: 550)	Sundsvall region (14 parishes)	Parish registers showing micro-level data on individuals' birth & baptism, occupations, migrations, marriage, death, death causes (ministers' impairment notes)
<b>2. POPLINK Database</b> Demographic Data Base (DDB), Umeå University, Sweden Total population: c. 400,000	c. 1900- 1960	c. 196,000 (Disabled: 4,000)	Västerbotten region (11 parishes)	Parish registers (same type of data as above)
<b>3. STOCKHOLM 1953 Birth Cohort</b> Stockholm University, Sweden Total population: 15,117	c. 1953- 2010s	Men: 7,700 (Disabled men: c. 450)	Stockholm	Rich socio-economic & demographic micro-level data on work, income, family formation, in-patient care (men's impairment from conscription age 18)
<b>4. SIMSAM Database</b> Umeå SIMSAM-Lab, Umeå University, Sweden Total population: c. 12 million	c. 1970- 2010s	c. 1 million (Disabled: 32,000)	All Sweden	Extensive longitudinal socio-economic & demographic micro-level data, in-patient & health at birth registers, drug prescription registers, hospitalization (impairment from disability income pension)
<b>5. SILC/ULF Database</b> (National Survey of Individuals' Living Conditions, Statistics Sweden), Dept of Sociology, Umeå University, Sweden	c. 1975- 2015	c. 16,500 (Disabled: 750)	Nation-wide sample	Detailed micro-level data on people's living conditions, income, education cross-sectional panel waves (self-reported disabilities and disability income pension)

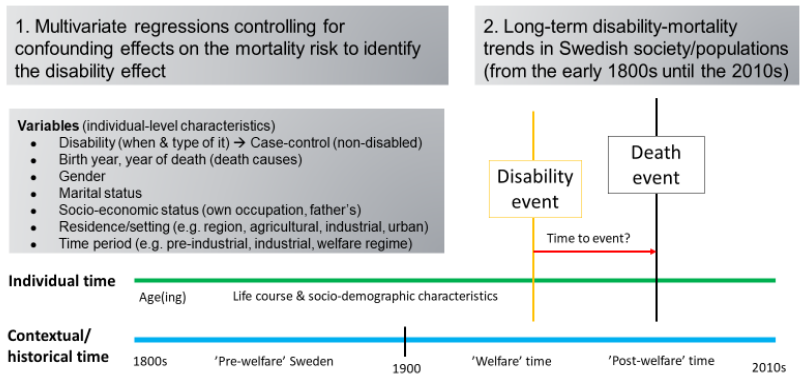
*Comments:* DISLIFE members' recent collaboration with Alessandra Grotta (Dr. in Statistics, Karolinska Institutet, Stockholm, Sweden) enables the inclusion of the Stockholm 1953 Birth Cohort to further extend the time-space comparison of the paper proposed.

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As the parish registers are recorded longitudinally at the micro-level, we can reconstruct the life course of individuals and observe whether and when disability interfered with life and if it rendered premature death due to possible health disadvantages. The ministers' documentation of impairments enables differentiation between sensory (visual and auditory dysfunctions), physical (bodily defects) and mental disabilities.

Parishioners who did not have any of these disabilities reported and lived in the same time-space context serve as references to help assess the disability effects on mortality. We use event history analysis (Cox proportional hazard regressions) to estimate how different disabilities affect the mortality risks by gender and across time (cf. Figure 1; Broström 2012; Giele & Elder 1998; Mayer & Tuma 1990), adjusting for confounding factors that can influence these risks (e.g. SES through occupational status, age, socio-demographic features like marital status). As for the 1800s, all impairments notes recorded between the age 15-34 are accounted for, and above age 15 for the 1900-1960 period.

Figure 1: Model of the analytical approach of this study on the disability effects on mortality.



## RESULTS

The below results show how disability affected mortality in the 1900-1960 period while some findings from the 1800s enables temporal comparison. Our final paper will extend this comparison by providing similar mortality outcomes for the recent fifty years (c. 1960-2010s). During the entire study period (cf. Figure 1), Sweden moved from a 'pre-welfare' regime (c. 1800-1930) with low levels of state provisions to a 'welfare' regime (c. 1930-1990) showing an immense expansion in welfare distribution and rapid urban-industrial processes (Esping-Andersson 1990), into today's 'post-welfare' regime (from c. 1990). Recurrent economic recessions and New Public Management ideas have come to increasingly replace the state-governed welfare with strong beliefs in citizens' ability to plan their life if becoming ill, disabled or old and in need of support.

Figure 2: Relative risks (hazard ratios) in mortality by disability and gender in the Sundsvall region, Sweden, 1810s-1890s.

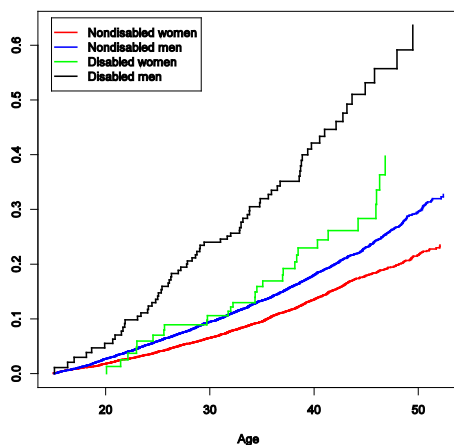
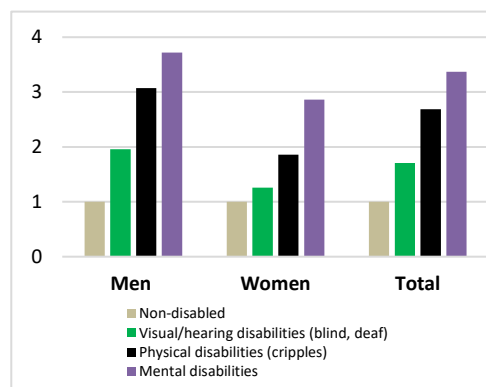


Figure 3: Relative risks (hazard ratios) by type of disability and gender in the Sundsvall region, Sweden, 1810s-1890s.



Before we take a closer look at the disability-mortality results of the 20th century, there is reason to go further back in time. As for the 1800s, Figures 2-3 plot the mortality risks by gender and disability types from Cox regression models (not shown here) adjusting for other covariates such as SES, residence, marital status, birth year, age at which disability was acquired using a case-control approach (Haage, Vikström & Lundevaller 2016). If disability was present in life, this increased the mortality risks to a substantial and statistically significant extent, especially among men. For women, the disability gap in mortality was less profound yet significant. While the negative effect of all-types of disability remained fairly consistent across the 19th century, Figure 3 shows the hazards by disability types. Regardless of gender, mental disabilities

implied the ever-lowest survival chances. Physical disabilities made men three times as prone to face an untimely death while similar disabilities doubled women's mortality risks. Sensory disabilities did not afflict the latter to any substantial degree but men. In all, these findings provide empirical evidence of the negative association between disability and survival, probably linked to an accumulation of health disadvantages rendering an untimely death. However, there were a great many variations depending on gender and type of disability.

Now, did the disability-mortality trends from the 19th century persist or shift during the 20th century? Figures 4-5 provide some answers, one of which is that disabilities persisted to promote mortality to high and significant levels. As the disability documentation is more detailed for the 1900-1960 period than in the 1800s and due to a higher number of cases in the study population (Table 1), we can distinguish between intellectual (since birth) and mental disabilities (psychiatric dysfunctions acquired across life) and make finer time comparisons. A few temporal patterns by disability type and gender stick out in the graphs plotting the mortality risks (Figures 4-5). First, across the whole period and genders, visual and auditory dysfunctions implied the lowest mortality risks relative to not having disabilities and compared with other disability types, just as was the case in the 19th century. There was an increase in men's death risk if being sensory disabled (this risk about doubled btw 1900-60) while it did not shift among women. Second, the mortality propensity coupled with physical disabilities rose profoundly during the period and especially among men (risk tripled btw 1900-60), while this rise for women was less extreme yet obvious, as well. Hence, and like in the 1800s, physical disability had gendered effects in having limited the survival chances of men the most and increasingly after the turn of the 1900 century. Third, over time mental disabilities in terms of psychiatric dysfunctions added to the mortality risks of both genders. While these risks decreased among women having intellectual disabilities, the reverse trend is found among their male counterparts.

Figure 4: Relative risks in mortality (hazard ratios) by disability type among **men** in the Västerbotten region, Sweden, 1900-1960.

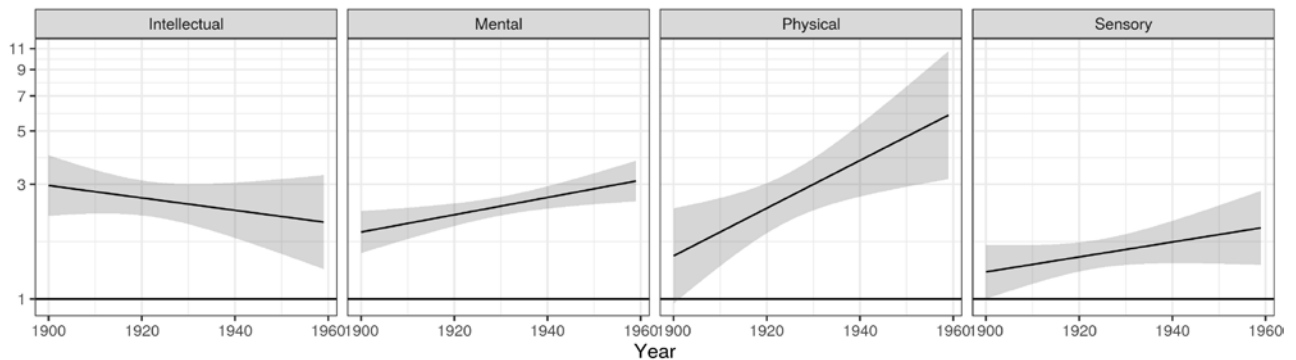
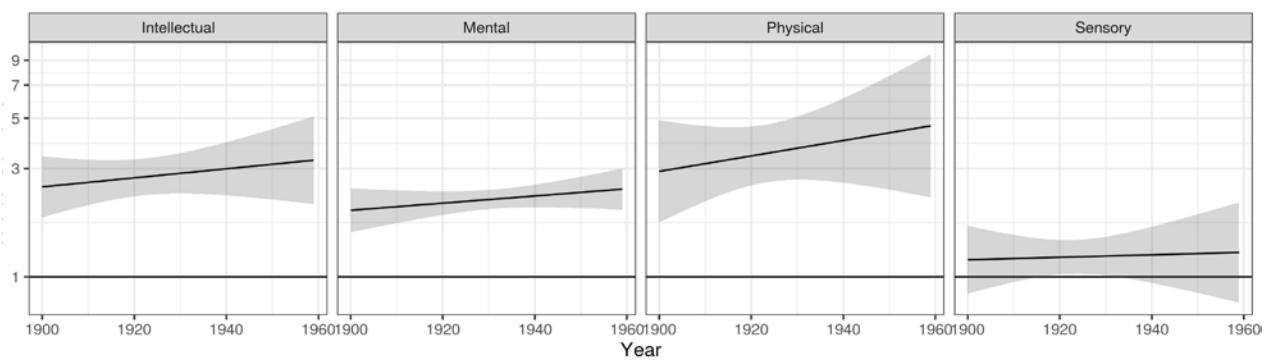


Figure 5: Relative risks in mortality (hazard ratios) by disability type among **women** in the Västerbotten region, Sweden, 1900-1960.



## SUMMARY AND DISCUSSION

Our long-term mortality trends provide a unique window into how disability shaped humans' health in Swedish populations from the early 1800s until 1960. In the full paper, this window will extend to recent time. This study is among the first to show sound empirical evidence that disability implied significantly higher mortality risks, as it doubled or tripled these risks or even more throughout 150 years of investigation. This is the major and remarkably persistent result that the long-term mortality trends bring into light. They also show persistence in that the death risks largely depended on type of disability and gender and in similar ways across time. The highest risks continued to be associated with mental disabilities and the male gender. Men seem to have paid a higher price marked by a wider disability gap in death than among women. While sensory disabilities added to the mortality risks as well and regardless of gender, they did to a profoundly lower level compared to both mental and physical disabilities. The latter disability type shows a sharp increase in mortality during the first half of the 20th century, which we will follow up in our upcoming studies.

Identifying disability disadvantages in health for one century and a half in Swedish populations is interesting and shows continuity rather than change. The long-term mortality trends we unfold make us argue that disability even implied a disadvantage leading to premature death up until the middle of the 20th century. There is little evidence that people with disabilities came to enjoy a higher health status along with improving living conditions and the general rise in life expectancy, since the disability gap in mortality risks basically stayed the same relative to non-disabled populations. Why this gap did not narrow more despite the societal transformation that Swedish society underwent during the 1800-1960 period is hard to tell without more research. The early welfare state exerted a strong control over groups not fitting into perceptions of being 'healthy and normal' and institutionalization programs were established, many of which were directed at peoples with disabilities. Insufficient access to a job and a partner and family may further help explain why they experienced a disadvantage in survival, since income and social support have positive health effects. Although disability did not bring an immediate death, our mortality findings suggest that disability had long-term negative impacts for individuals' survival as a plausible outcome of health issues and marginalization from society. The paper we are working on will find out whether the disability gap outlined above will shift or persist as Sweden moved into the heydays of welfare in the 1960s and 1970s until recent 'post-welfare' decades.

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