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## Introduction: disability, partnership, and family across time and space

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## Introduction: disability, partnership, and family across time and space

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### ABSTRACT

Notions of family life and romantic partnership, like notions of disability, have been culturally constructed and socially produced over historical time, and our understandings of these notions are being continually challenged and re-negotiated across time and space. Policies, institutions, and cultural practices across the globe have brought about changes to the construction of the family and to the rights and inclusion of disabled people in private and public life. This special issue brings together a collection of studies from different countries and time periods to explore the interplay between disability, romantic partnerships, and family life across the individual lifetime and between generations. With this interdisciplinary collection, we seek to merge disability research and research on family and partnerships through a life course lens. This offers unique insights and opportunities to interconnect historical and cultural location and changing social institutions with individual and family experiences. This introduction presents the eight studies in the collection and discusses them within a life course frame that views disabled people's roles as partners, spouses, and members of a family. In so doing, it engages in an analysis of (dis)similarities concerning how family dynamics, romantic relationships, and disability have developed over time and in different spaces.

### KEYWORDS

Disability; family; life course; marriage; partnerships

## 1. Introduction

Our introduction to this special issue is divided into five sections. First, we present and discuss some of the key concepts and background to the topics addressed. Second, the articles are presented by positioning a selection of their unique results and analytic approaches within a life course framework, which we revisit using a disability lens. Third, we take a closer look at some longitudinal analyses about of how disability has affected disabled people's partnership chances over the past two centuries. Fourth, we review the existing literature and refer to some of the articles in this collection to explore experiences of disability in relation to romantic relationships. The scant social-scientific and historical research around the topic to date is one rationale for this special issue. Our

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interdisciplinary collection seeks to bring together disability research and research on family and partnerships within a life course frame in order to encourage future investigations into how disability has affected human life in present as well as past societies. In so doing, the collection takes a significant step forward in the strategic plan to facilitate the global value of this interdisciplinary research area, both within and beyond the academic gates. In the fifth and concluding section, we propose further few steps that can be taken.

### ***1.1. Concepts and terminology: disability, partnership, family relationships and the life course***

For much of the 20th century, research concerning health and illness perceived disability as something that was wrong with the individual, as a bodily or cognitive imperfection that needed curative and rehabilitative medical intervention (Barnes & Mercer, 2004; Kaplan, 2000; Kudlick, 2018). This view has long governed the definition of disability and was termed the medical or individual model of disability (Oliver, 1990, 2013, 2017). If rehabilitation fails or is not accessible, the ‘disability problem’ remains with the person. Focusing only on the bodily deficiency, studies based on medical models neglected the role of societal structures in the creation of disability for people with impairments. Public policies, relationships, environments, and institutions such as the family, employment, and marriage influence individual and collective choices and chances and can trigger turning points to new trajectories and pathways for individuals (Shah & Priestley, 2011). They can also have unintended consequences, and they can place restrictions on people with impairments from participating in roles and following life pathways similar to people without impairments. This includes developing partnerships and forming families, which is an expected milestone to independent adulthood for non-disabled people. However, people with impairments, especially lifelong impairments, have not been expected to have romantic partnerships, get married, or form a family. From a young age they have been excluded from the dominant processes of socialisation that provide opportunities for them to participate in activities that would encourage romantic and sexual relationships (Shah, 2017; Wiegerink et al., 2010). This, together with the pervasive misconceptions that disabled people are asexual beings, has created barriers to their choices and opportunities to become partners and parents. Statistically, disabled people are more likely to remain single over time and less likely to head families or households (e.g. Clarke & McKay, 2014; Fujiura, 2014), as we will discuss below (sections 3–4).

The medical model was dominant until the emergence of the disability movement and disability activism in the 1970s and 1980s, at which time disability became increasingly conceived of as exclusion and oppression imposed on people with impairments by the organisation of society. This interpretation was known as the social model or social barriers model, where disability was described as ‘the outcome of an oppressive relationship between ... people with impairments and the rest of society’ (Finkelstein, 1980, p. 47). A meaningful solution according to this model involved societal changes instead of fixing individuals’ impairments. Advocates of the social model conceptualise disability as a socio-cultural construction, just as gender has become an analytical category. Disability is not just a pathological condition based on universal or medical grounds being located to the individual. Instead, it is socially constructed by environmental factors that create barriers of both physical and attitudinal kinds that hinder people’s choices and

participation in society. Environmental factors and attitudes can differ depending on time and space, and thus have different influences on the construction of disabling behaviours and attitudes. The social model enables scholars to determine how and why surrounding barriers are created, deconstructed or persist and how they impact people with and without impairments. Such knowledge is useful so that strategies can be put in place for their removal in order to enable a more equal society for all.

In line with the social model of disability, we consider disabling barriers to be the product of the interaction between societal barriers and the individual with an impairment. Disability is thus not purely the result of the impairment, nor of the societal barriers alone. This complexity is fruitful to study but makes it almost impossible to establish a single clear-cut definition of disability, even though perceptions as well as evidence of (dis)abilities would likely be found in all human cultures and societies if we were to look closely enough. Influenced by the social model, Article 1 in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) provides the following definition of disability, to which we adhere. It has also governed the approach of the research subjects among the contributors to this collection.

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. (Article 1, UNCRPD, 2006)

This definition is further useful for conceptualising disabilities across time and space. However, the documentation and differentiation of disabilities and of the people experiencing them can vary considerably and can be incomplete or difficult to find, especially in historical sources. This collection makes use of a variety of materials, ranging from interviews with men and women having different disabilities, to investigations of legislations and policy documents concerning disability. Other contributions make use of population registers from the 1800s as well as the 2000s to identify and study people with impairments through history. Consequently, both quantitative and qualitative methods are employed to examine the interplay between disability and partnership and family life across time.

With fifty binding articles, the UNCRPD (2006) was the first international treaty to afford disabled people full civil rights and fundamental freedoms in all aspects of life. Article 23 is particularly relevant to this collection, stating that disabled people should be afforded the right to participate in marriage, partnerships, and parenthood on an equal basis to their non-disabled contemporaries. In this issue, partnership refers to romantic or sexual relationships represented by marriage or cohabitation, where one or both spouses happens to have an impairment. Although such relationships do not only include heterosexual couples, these are the types of couples examined in the studies collected here, which occasionally include parenthood. Family relationships between elderly parents caring for their adult children with disabilities are also explored.

Taking the surrounding context into account, the social model of disability has had a big impact on disability research in many disciplines and on the studies in this collection. Such an approach is key to understanding the restrictions, or barriers, to participation in private and public life that individuals might come across because of impairments or other features regarded as disabling. Our collection includes restrictions that shape disabled people's possibilities to form romantic relationships or to sustain them or to

form close relationships between family members. It shows micro (i.e. the individual) and meso level approaches, the latter of which includes the partner/spouse or couple or the family, and occasionally a wider circle of relatives or friends in the community. The meso level provides an interface between the individuals and the large-scale societal structures, or macro level, which shape the choices, trajectories, and transitions of disabled people and their relatives. The macro level refers to the labour and partner markets, welfare provisions, and normative attitudes pertaining to romantic relationships, gender, or disability in specific times or places. How disability and family formation through partnership and/or parenthood have been treated in legislation historically and from a human rights perspective exemplify other macro level phenomena considered in this collection. These spectra of results position the articles within the life course framework as we present them further below adopting a disability lens (section 2).

Our thinking around the 'life course' approach is influenced by Glen H. Elder (1985) who suggested the importance of time and place in shaping individuals' lives. People live interdependent lives, so each life is influenced by the lives of people they are closely linked to. In brief, Elder (1985) identified the following five concerns. 1. *Life-span development* means that human development and ageing are lifelong processes that reflect events that people experience over their entire lifetime, such as marriage/cohabitation or parenthood. 2. *Agency* acknowledges that individuals are in a position to construct their own lives, such as whether to marry and to whom, through the choices and actions they take within the opportunities and constraints of history and social circumstance. 3. *Time and place* refer to the idea that the life course is embedded and shaped by the current context people experience. 4. *Timing* refers to the developmental antecedents and consequences of life transitions, which implies that events and behaviours associated with family formation, for example, can vary according to their timing in a person's life. 5. *Linked lives* stresses the fact that lives are lived interdependently but also that socio-historical influences are expressed through networks of shared relationships.

Following Elder's notions, scholars have conceptualised the life course in terms of pathways and trajectories that reflect people's living conditions, constraints, and possibilities in society (e.g. Giele & Elder, 1998; Kok, 2007; Mortimer & Shanahan, 2003; Priestley, 2003). While ageing, all of us follow a course of life including generational locations of childhood, adolescence, adulthood, and old age. Typical milestones of adulthood include developing partnerships, getting married and becoming parents, roles that influence our status, behaviour, identity, social activities, position, and rights in society. Finding a spouse can be seen as a major event or turning point in the life course, influencing people's wellbeing whether they are disabled or not. How human lives are linked together through partner relationships and family generations when disability is involved is considered in the studies collected here. In what ways and with what outcomes is highlighted below as we present each study in relation to the life course frame.

## **1.2. Background and rationales for this special issue and its topics**

Transition to marriage and family life has been a global expectation for most young people across centuries and geographical boundaries, and national and international policies have declared them as fundamental human rights. The Universal Declaration of

Human Rights (1948) was a milestone in asserting that everyone of 'full age' has the right to marriage (Article 16). It recognised that family life was a fundamental unit of society and declared it would be protected, as asserted by subsequent international human rights legislation, including the UNCRPD (2006). Article 23 states that disabled people are not to be discriminated against in matters relating to marriage, family, parenthood, and relationships, which are significant parts of the life course and considered as transitional events from childhood to adulthood. Parenthood and family life are also roles and social organisations that are part of the social timetable of a normative individual life course. However, traditionally, disabled people have not been expected or indeed afforded the rights to occupy such roles on an equal basis to non-disabled people. Disability and marriage or partnership do not sit together comfortably in popular or academic discourse. Furthermore, historically, disabled people have not been portrayed as romantic/sexual partners in literature and the media, but more as dependent asexual beings (McRuer & Mollow, 2012; Schalk, 2016; Smith & Hutchison, 2004; Wälivaara & Ljuslinder, 2020). Although there has been a plethora of research on marriage or partnership on the one hand, and on disability on the other, there is a dearth of research on how disability, family, and partnership work together and impact each other. As the sociologist Erving Goffman (1963) argued, the stigma or societal disadvantages associated with having an impairment not only affect people with impairments, but can also be experienced by their family members who support them (including their parents or partner). This has been coined 'courtesy stigma' or stigma by association. Although there has been a significant body of research on parents of disabled children, relatively little has been written about the everyday experiences of the partners of disabled people and of elderly parents in the role as caregivers to adult children with disabilities.

This special issue addresses this dearth by bringing together a collection of eight articles, all of which combine issues of disability with partnership or family relationships. They contribute new knowledge to fields of disability studies and family studies within history and sociology, reflecting the experiences, opportunities, and challenges encountered both by people with and without impairments when in romantic partnerships together; disabled people's lived experiences of being part of a couple or a family; and the experience of being a partner or parent of a disabled person. Showing results on the almost 'incompatible relationship' between disability and partnership, as the authors of one article in this collection call it (Sigurjónsdóttir & Rice, 2020, this issue), makes this issue special. It further brings to the fore a minority population having received little recognition in both society and research, although this population is not that small after all. In fact, individuals with disabilities make up the largest minority group worldwide consisting of 1 billion people (15%) (UN Factsheet, 2020; World Health Organization [WHO], 2011, 2018). In the EU countries, estimations suggest that disability affects about 50 million (14%) of the working-age population (EC Eurostat, 2017). Considering the family and social ties linked to these millions of people would make the numbers affected by disability considerably higher. While studies from across the globe report the correlation between disability and inequalities in healthcare, access to education and career progression (EC Eurostat, 2017; UN Factsheet, 2020; WHO, 2011, 2018), research on the relationship between disability and partnership or family is scarce.

## 2. Presentation of the articles: the life course and linked lives through the lens of disability

The life course concept refers to a non-disabled life, which tends to set the 'standard'. People are expected to progress along specific pathways within certain timeframes that are governed through policies and institutions (school, work, welfare, family) and relationships in order to ensure that certain choices are made and that trajectories are followed in specific locations. This view holds a normative dimension concerning how life is to be lived, and deviating trajectories can lead to social inequalities or even to a stigma (Halberstam, 2005; Ljuslinder et al., 2020; Priestley, 2003). All lives are not linear, however, and they are 'messy' and can change direction when triggered by turning points involving policies, resources or the social capital available to individuals at certain times of life. Acquiring an impairment can constitute a turning point and a fundamental change of one's possibilities to take the path one would otherwise have taken. However, an individual life course does not stand alone. It is linked to past and present generations of people and is influenced by the socio-historical context in which the life is embedded. This is emphasised by the eight studies in this collection. While introducing them below, we recall some concerns that Shah and Priestley (2011) suggest are important to consider when applying the life course framework to disabled lives. One of their concerns considers the time in terms of whether and when and how significant life events occur because the life course has normative implications. Certain life events are expected to happen at certain times in life such as when to leave the parental home, attain education, or take up work, or when it is 'time' to engage in romantic relationships and form a family. Such events can occur earlier or later in people's lives or even not at all depending on culture, socio-economic status, gender, generation, or disability. This will shape an individual's subsequent life course, their choices, opportunities, and the pathways that are expected and those that are followed.

In one of the qualitative studies in our collection, Aizan Sofia Amin, Azianura Hani Shaari and Khairul Farhah Khairuddin (2020, this issue) present the psycho-emotional experiences of single women with mobility impairments in contemporary Malaysia. These women were constantly reminded by society that they were unworthy of a husband and family because of their physical impairments. Yet, they had aspirations of a family life and had made some attempts to achieve this but with little success. The authors found that the struggles and attitudes experienced by these women, who wanted to live a life like other women, were largely due to patriarchal values about women's reproductive roles as a wife and mother, which still predominate Malaysian society. Women who do not meet the expected roles of womanhood, or who are perceived as not having the capacity for it, are viewed negatively by both society and their relatives. A woman's life and wellbeing depend on the appreciation and support of the latter, because there are limited public welfare provisions for Malaysian citizens to enjoy. These circumstances put women in a vulnerable position, especially when they have impairments. This helps explain why typical events in the life course like marriage and family formation were absent or limited in the lives of the 32 women with mobility difficulties in this study. It is rare in reporting disability results from the Global South, and it exemplifies the kinds of results that a social model approach can contribute. This study further illustrates how non-normative life courses are shaped by disability, gender,



and culture, as Shah and Priestley (2011) argue (as mentioned above). Like Elder, they suggest that the context in terms of time and place matters for the life course development and must be taken into consideration in order to understand how and why disability affects life events like partnership.

Fredinah Namatovu and co-authors' study (Namatovu et al., 2020, this issue) moves to Sweden, presenting results that differ substantially from the patriarchal society of Malaysia. Yet there are similarities regarding the effects of disability on partnership. Examining nationwide Swedish populations between 1993 and 2010, this study shows that receiving disability benefits in young adulthood, aimed at limiting exclusion from society, impeded the chances of marriage or cohabitation for both genders. As we will discuss below (sections 3–4), the negative association between disability and partnering is a recurrent result in a few other studies as well, and it seems to go a long way back in time. However, our collection does include one study uncovering the marriage patterns of no fewer than 188 men and women with various impairments in the Sundsvall region of 19th-century Sweden (Vikström et al., 2020, this issue). For them, being born with or having acquired impairments at a young age did not influence their opportunities to marry, nor did it make them differ significantly from other spouses in terms of exceptionally high or low marriage age, for instance. The results are an important reminder that having impairments does not always restrict people from developing partnerships and marrying. In turn, this finding indicates the agency that disabled people have and suggests that they participated in social life and were not negatively influenced by their environment. The personal agency disabled people have is important to recognise as it contributes to the choices they make within the opportunities available, according to Shah and Priestley (2011). Like Giddens (1984), they argue that social norms and structures do not exist independently of the social actions of human agents but are shaped by them. This can make individuals or groups resilient to challenges rather than be defeated by them.

Two of the studies in this collection show evidence for how the acquisition of an impairment causes a turning point in an individual life course as well as in the life of married/cohabiting couples. The quote from one of the female participants in Hyun Seung Kim and Kyung Mee Kim's qualitative study from Australia illustrates how the spinal cord injury (SCI) of her male spouse came to affect the couple as a whole: 'It happened to him, but it also happened to our relationship' (Kim & Mee Kim, 2020, this issue). While SCI is known to cause a disruption in the individual's life in terms of identity and self-concept and to lead to breakdowns in relationships (Bury, 1982; Shah, 2005), this study recounts how nine couples experienced and coped with this disruption in order to remain as a couple. There were many challenges due to the SCI as the gender roles and intimacy between the spouses changed. For instance, the female partners became caregiver to their male partners. The men felt they had lost their masculine identity, and both spouses experienced an inability to live up to the socio-cultural expectations of a romantic partnership. Interestingly, the authors apply a life-course approach that treats the couple as the major unit for analysis, rather than the individual spouses themselves. The couples' joint efforts to establish some continuity in their relationships by reconstructing their past lives as a couple was one means for them to handle the present disruption and to move forward together. Although the couples experienced many losses, their spousal bonds had become even stronger than before. The authors conclude that these bonds and interdependence made the couples resilient to the many challenges the SCI had brought to their relationship.

Also accounting for the experiences of both partners, the qualitative study of Elaine Schembri Lia and Angela Abela (2020, this issue) fills in the knowledge gap on how disability impacts couples' relationships. In their case, however, the turning point in terms of having acquired mobility impairments was found among three female spouses living in Malta. In coping with their post-disability relationships, these women and their male spouses faced similar challenges to the Australian couples in the study of Kim and Mee Kim. In the Malta study it was the male spouses who were providing care and support to their partners in need, including taking care of the household work, tasks normally performed by the women. Schembri Lia and Abela found that these men managed well in shifting their gender roles, while the women were more uncomfortable with being cared for by their husbands. They felt ashamed about their 'misfit' bodies and by being unable to fulfil their feminine roles, while they also strove to be as independent as possible in order to sustain the relationship. Their husbands were very supportive and flexible and were determined to make the relationship work by helping the women they loved. The men experienced that they had grown as persons from it. Mutual patterns of interaction, discussions and support developed over time between the partners and made their relationship survive, Schembri Lia and Abela argue, even if the mobility disability entailed burdens in terms of self-sacrifice and adjustment for both spouses, and considerable pain and trauma for the women.

Although the authors of the latter two studies emphasise that their results are based on a positive selection of 'surviving' couples, they have provided precious insights into how disability can impact individual lives and partnerships and how these pathways can be negotiated. Based on Elder's notion of linked lives, Shah and Priestley (2011) point out that we all live relational and interdependent lives. Our biographies are constructed and reconstructed over time through interactions with other individuals and networks made up by, for example, parents, peers, partners, and colleagues. In terms of disability, such interactions also include carers, or imply a high level of dependency upon relatives, as we have just seen from the studies above. The latter type of dependency predominated in past societies when welfare provisions were scarce, as it still is in many low-income countries worldwide. Such a dependency can negatively affect the individual life course and put extra pressure on the members of a network or family, but it can also make these ties become stronger and act as cultural capital or a resource with positive effects on life and its challenges.

The study by Carol-Ann Howson and Elizabeth A. McKay (2020, this issue) shows both the benefits and challenges associated with dependency across generations due to disability. In the area around London, the authors interviewed older parents providing care to their adult children with learning disabilities. Transfers of care between generations and research about this tends to focus on the reverse direction, where elderly people are recipients of care rather than recognised as caregivers, especially in our time of ageing populations. In parallel, recent decades have witnessed a dismantling of public welfare provisions and de-institutionalisation in many countries across the Global North, partly due to the idea of New Public Management. As Howson and McKay discuss, in the UK this development has extended the caring responsibilities of the family and relatives to the persons in need of care and support, many of whom have impairments. The 27 parents caring for their adult children with learning disabilities in the study had mixed experiences. They described their situation as a continuation of their earlier care role when their

children were young. Among the many challenges they encountered were the loss of sleep and time to work or socialise with friends, and exhaustive battles with authorities either to get some support, or to obtain a diagnosis of their children's conditions to possibly apply for support. Further, the parents experienced the breakdown of relationships with friends who avoided them because of their 'disturbing' children. How their children would cope with everyday life when they themselves had passed away was another worry. However, the parents also experienced advantages. They appreciated the company of their children and having them at home providing help with household and garden tasks, which some parents found difficult due to old age. The parents expressed a sense of interconnectedness with their children and regarded their quality of life as high as a result of taking care of their adult children the way they did. Ethical issues, such as the need for informed consent, made it difficult to study the experiences of the children, which is why Howson and McKay focused on the parents.

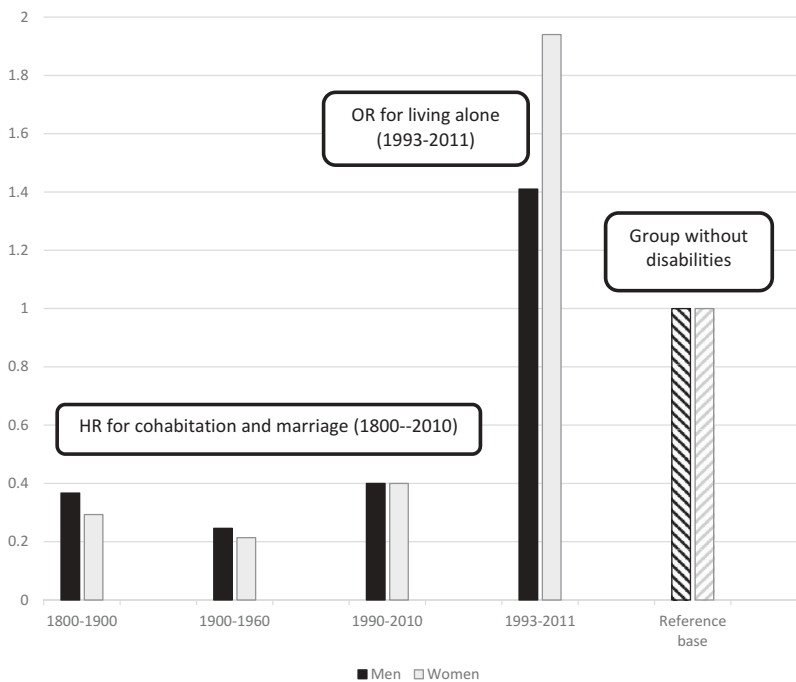
Shah and Priestley (2011) emphasise the need to account for different historical times during which people lived and the opportunity structures that affected their choices and chances in life, including macro and micro historical changes in social roles and attitudes, technologies, laws, policies, and public institutions. The access to socio-economic resources and support from meso level networks such as a spouse or family can be crucial for disabled people, as the studies above exemplify. At the macro level, medical and technological advancements – like polio and TB vaccination, lifts, electric wheelchair, cochlear implant, eyeglasses, and online devices – can make some impairments become less disabling and thus increase the chances to participate in working and social life. The development and distribution and type of health or welfare provisions differ across time and space, and not all people in need can access such services, and family members might lack resources or be unwilling to come to the person's rescue. Some 100–150 years ago, North-Western Europe and North America witnessed a wave of institutionalisation. People who were perceived to be poor or deviant were institutionalised as recommended by medical experts at the time who complied with the eugenics way of thinking. The intentions were to restore these people or remove them from society and control their reproduction.

The study by Hanna Björg Sigurjónsdóttir and James G. Rice (2020, this issue) reports on the eugenicist ideas of institutionalisation and sterilisation of disabled people in 20th-century Iceland. The authors examine national legislation that governed the lives of disabled people, especially the reproduction and parenthood of people with intellectual disabilities. The authors address Foucault's (1978/1990, 1984) bio-political governance concepts and found that the Icelandic legislation reflected developments in continental Europe in the early 1900s when the ideas behind eugenics made their way into policy documents and were implemented in practice. According to the Icelandic laws, people with intellectual impairments should not have or raise children. When they bore children, the authorities interfered accordingly and separated parents from their children in order to protect the latter, or so it was argued. The authors contend that the law made disabilities, and especially intellectual disabilities, incompatible with the parenting role. They found that this perception was rooted in the eugenic ideology and persisted in shaping the law throughout the 20th century and even affects contemporary legislation in Iceland. This indicates the 'weight of history' on subsequent developments, just as the title of the study states. In addition to tracing macro level developments of legal frameworks, the authors conducted a micro level analysis of interview data to uncover the experiences of those who had to contend with the legislation.

In his study, Paul van Trigt (2020, this issue) traces another macro level development across time concerning disability and reproduction, namely the right to form a family as enshrined in UN policy. This right is stated in Article 23 of the UNCRPD (2006) as mentioned above, which says: ‘States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships.’ As the studies outlined above illustrate, the interplay between disability, romantic partnerships, and family is complex, and the foundation of the right in Article 23 has been controversial and its development in history untold. In his study, van Trigt recounts this history and explains how and why the right to form a family in relation to disability was finally established in 2006. By then, more than thirty years of discussions within the UN policy had taken place. The 1990s saw the reproductive rights of disabled people being addressed from a human-rights approach in order to safeguard their legal protection.

### 3. Long-term trends in disability and partnership

Figure 1 shows results concerning the marital/cohabitation chances in Swedish populations over a period of about 200 years. Sweden is internationally known for its social



**Figure 1.** Regression results showing how disability affects the chance/risk to experience partnership or singlehood in Swedish populations from the early 1800s until 1960 and between 1991 and 2011. Hazards ratio (HR) refers to Cox regression while the odds ratio (OR) refers to logistic regression.

*Sources and comments:* Swedish parish registers (for the period 1800s-1960) hosted by the Demographic Data Base (DDB), Centre for Demographic and Ageing Research (CEDAR), Umeå University, Sweden, and nationwide population registers or samples (for the 1990–2011 period). For further information about the data, see the separate studies (Haage et al., 2017; Namatovu et al., 2020, this issue; Sandström et al., 2020).

welfare-oriented policy to decrease inequality in society and for having a research advantage thanks to its access to population registers and datasets going far back in time. These databases have been under-used within disability research. Their scope helps in identifying long-term trends in the relationship between disability and partnering, which are of cross-national interest and are relevant to this collection by providing a background for time-space comparison.

The results of [Figure 1](#) run from the 1800s until the 2010s (except the 1960–1990 period). They are based on data drawn from studies within the ERC-funded DISLIFE project led by one of the co-editors of this special issue (Vikström). One of the studies emanating from this project is found in this collection (Namatovu et al., 2020, this issue) and makes use of nationwide data. This study provides statistical evidence that individuals born in Sweden during the 1970s who received disability pensions during young adulthood experienced significantly lower odds to marry or cohabit. In another contribution (Vikström et al., 2020, this issue), the authors discuss some previous life course results using Cox regression models on digitised parish registers in which ministers reported impairments (Haage et al., 2017). The disability outcome is shown in [Figure 1](#) in terms of hazard ratios (the first pair of bars). Disability reduced the marital chances by about 60–70% depending on gender. There were also some significant differences between disability type (sensory, physical, mentally), which we discuss in the next section.

The four pair of bars of [Figure 1](#) show that disability had a downward influence on the partnership chances in Swedish populations over time by about 60% or even more. This disability influence was substantial and statistically significant across time and genders. Women's partnership was slightly more negatively affected in the 1800s up until 1960 (the first and second pair of bars), and from then onwards there is a lack of data until the 1990s when the gender gap is closed (the third pair of bars). The fourth pair of bars of [Figure 1](#) cover the period 1993–2011 and show the risk of being a single person in a lone household, thus the opposite of partnering. Singlehood was less frequent for disabled men than their female counterparts.

Throughout the entire period, disability weakened people's position in the partner market and to a similarly profound degree. This has been a stark and remarkably persistent trend despite the societal transformation that Swedish society has witnessed since the 1800s, having moved from one of the poorest countries in Europe to exhibiting one of the highest measures of human equality and GDP growth worldwide in the 1960s and 1980s. During the long period of social democratic hegemony, Sweden became known for its comprehensive welfare programmes, many of which were meant to benefit poor and disabled citizens and their participation in society (Esping-Andersen, 1990). However, especially during the period 1930–1960, the rapid welfare expansion was characterised by strong beliefs in the knowledge of experts and authorities' opinions about who was entitled to welfare provision and what the treatment should consist of to be successful. The state and its welfare institutions increasingly became 'normative advisors' of lifestyles in relation to disabled people (Ambjörnsson, 1986; Hirdman, 1989). Eugenics ideas were also a part of the early Swedish welfare state discourse. The most invasive aspects were sterilisation programmes directed at individuals with 'undesirable' hereditary conditions such as impairments (Broberg & Tydén, 1991). Between 1935 and 1975, more than 60,000 individuals were sterilised in Sweden (Runcis, 1998; Tydén, 2002). These invasive measures came under ever-increasing criticism and were finally abolished

in the 1970s, but they reflect the dual character of the Swedish welfare state in relation to disabled people. Although increases in health care, education and social services probably improved the material and medical conditions for many disabled people and made them less dependent on their families for basic welfare, the state was paternalistic and exerted strong control over groups that did not fit into the definition of normality.

Why the disability gap in partnership did not narrow more over time in Sweden is surprising and difficult to explain. If disabled people in Sweden in the past had been institutionalised in large numbers and for extensive periods, this might have provided some explanation for the first two pair of bars of [Figure 1](#), because confinement likely implied few possibilities to engage in the partner pool. However, in Sweden institutions were not established on a larger scale until the early 1900s (Engwall & Larsson, 2012; Förhammar & Nelson, 2004; Grunewald, 2009). In 1900 when the population consisted of about 5 million people, the number of beds in mental hospitals was only 4,600. In the 1960s, this number had increased to around 16,000 and the population to about 7.5 million (National Board of Health and Welfare, 1907–1939, 1940–1959; cf. Junkka et al., 2020). This suggests that during the 1800s and until the early 1900s many disabled people lived their lives outside institutions in towns and parishes across the country, as well as because authorities could not afford to confine or entitle poor relief to all those in need. Located in the community this way, disabled people had the possibility to participate in the marriage market if they could access it. According to [Figure 1](#), this access was limited given the small marital chances associated with disability in the 1800s. These chances became even smaller during the first half of the 20th century. It is possible that the era of institutionalisation during the paternalistic period of the Swedish welfare state contributed to this negative trend when disability had to be ‘removed’ from society through confinement and eugenics.

In all, the persistent trends of [Figure 1](#) suggest that societal change, economic progress, and policy efforts implemented in Sweden during the period under study did not result in greater access to partnerships for people with disabilities. This indicates that they continued to be subjected to social marginalisation and disablist attitudes that did not recognise them as potential partners. Perhaps the persistent trends of [Figure 1](#) reflect the impact historical patterns can have in shaping subsequent patterns that continue into the present period. Negative views and values from the past – here concerning disability and its association with partnership – can be transferred across time and continue to impede the lives of the afflicted. A similar ‘weight of history’ is echoed in the Icelandic study of Sigurjónsdóttir and Rice (2020, this issue).

#### **4. Literature review: partnership and family from disability dimensions, past and present**

There are relatively few scientific works that specifically address the topics of this collection. This notion holds for our own time, as well as for the past. Below we discuss the reasons for this gap in historical research before presenting results from contemporary studies and recall a few findings from this collection. We will conclude this section by presenting some theoretical considerations regarding the relationship between disability and partnership.

Issues with source materials have narrowed the opportunities for historians to study the life courses of disabled people and their experiences of partnership and family formation in the past. Although to some extent disabled people can be identified in records of poor relief institutions or from various asylums, these records tell us very little about their families and lives outside of these institutions. Many disabled people were never institutionalised or entitled to any poor relief because it was too expensive to provide this for them. Their survival depended on themselves, the type of impairment, their working capacity to gain an income, and support from relatives or the goodwill of others through begging or charity. While there are today many large databases on past populations, and technical tools enabling advanced analysis of data on aspects of individual lives, including their marriage and family formation, most of the data have no or insufficient documentation of impairments. This explains why the empirical knowledge is scattered concerning how disabled people lived their lives in previous centuries. Another reason for this dearth is that, in the 1980s and 1990s when historians showed an increasing interest in researching minority groups, this primarily concerned ethnic or cultural identities, not disability (Kudlick, 2003). Although historical works existed on how diseases and epidemics, which could result in impairments, had affected individuals, families, populations, and societies in the past, these works seldom related the findings or discussions to disability issues, and studies generally adopted the medical model of disability (Kudlick, 2018; Linker, 2013). Insufficient, scant, or biased historical knowledge might lead us to think that there is little point in studying the experiences of disabled people in the past, or that disabled people led poor lives having no or few opportunities to marry or to form a family. The few works we refer to below uncover a more nuanced picture, and two studies in this collection differentiate the picture further (Sigurjónsdóttir & Rice 2020, this issue; Vikström et al., 2020, this issue).

In her PhD thesis, Sofie De Veirman (2015) provides results from a statistical life-course study on people with hearing difficulties in Flanders from 1750 to 1950. Her usage and linkage of different sources is impressive and has enabled De Veirman to reconstruct the lives of 284 individuals who were deaf or had auditory impairments. Comparisons with their hearing siblings helped her identify how auditory impairment shaped their lives. Such impairment implied significantly lower marital chances, partly because many of them spent extended periods of their lives in special institutions or asylums, but also because they were largely unemployed and could not afford marriage. Their poor marriage prospects persisted throughout the whole period De Veirman studied and were not significantly affected by industrialisation. She suggests that they were either avoided by the members of their community or were forced to refrain from marriage due to negative attitudes towards deaf people. If they married, they were likely to be considerably older than their hearing siblings, and also to marry a spouse of a different age. These factors illustrate their disadvantages in the partner pool. Sometimes deaf people married amongst the deaf community, hence individuals they had met in the institutions or in communities for deaf people. Because they probably had difficulties building relationships with hearing people, they looked for a marriage partner within their own group, De Veirman argues. From the 1860s onwards and influenced by eugenics ideas, Belgian authorities recurrently debated the inappropriateness of marriage between two deaf persons. Up until the mid-20th century, schools for the deaf separated boys and girls to prevent them from forming romantic relationships.

The PhD thesis by Helena Haage (2017) uses the analytical life-course approach of De Veirman in her quantitative study of people with diverse impairments living in the 19th-century Sundsvall region of Sweden. In a co-authored study with one of the guest editors (Vikström), Haage found that impairment had a significant negative influence on the marital chances of both men and women (Haage et al., 2017; cf. Vikström, Haage et al., 2017; Vikström, Häggström Lundevaller et al., 2017). The extent of this disadvantage is shown in Figure 1 above (first pair of bars) and suggests that it lowered marital chances by about 60–70%. Impairment had a slightly more negative effect on marriage chances for women than for men, but this difference was not statistically significant. There were other significant differences coupled with gender and impairment type (sensory, physical, mentally/cognitive). According to the data, mentally/cognitive impairments implied the lowest marital chances (about 80%) regardless of gender. Auditory or visual impairments did not affect women's marriage chances as much as for men, while physical impairments impeded marriage opportunities for women much more than for men. All of these findings are based on digitised parish registers that report impairments among the parishioners in addition to the socio-demographic information and life events that are typically found in these registers, such as marriage. Such data enabled Haage and Vikström to identify a comparatively large number of disabled people (more than 500 within the age group of 15–35 years) in order to examine how their lives developed compared to their non-disabled counterparts in a population of approximately 35,000 individuals. In a collaborative study on how auditory difficulties affected marriages in Flanders and the Sundsvall region, De Veirman et al. (2016) found that individuals with such impairments who lived in the Swedish region had higher marital chances than their Belgian counterparts. These differences in results from studies investigating the same type of impairment in two countries illustrate that context matters a great deal and can influence the outcomes. Even if an auditory difficulty decreased the marital chances in the Swedish region as well, it seems to have had lesser negative effects than in Flanders. Possibly, the lower level of institutionalisation and industrialisation in 19th-century Sweden, compared to Belgium at that time, contributed to the easier access to the labour market and to society for people in Sweden with hearing difficulties. Historians argue that industrialisation reduced the employment possibilities for disabled people because it was perceived that they did not have the same ability to perform work tasks in manufacturing as they had in agricultural production and handicrafts (Oliver & Barnes, 2012; Rose, 2017; Stone, 1984; Turner & Blackie, 2018; Turner et al., 2017; Vikström, Häggström Lundevaller et al., 2017).

The social model of disability has influenced historians' way of thinking over the years. They are now less inclined to view a person's impairment to be the sole cause of the disadvantages, and instead see how obstacles arise more indirectly as a result of how the surroundings respond to the person with the impairment. Recent historical works have increasingly uncovered the diverse disadvantages that disabled people experienced in societies where they were considered to be inferior, damaged and unable to follow the 'normal' or 'standard' life course (Anderson & Carden-Coyne, 2007; Burch & Sutherland, 2006; Longmore & Umansky, 2001; Rembis et al., 2018; Verstraete, 2007). Their disadvantaged position in the labour market has been found to be a major obstacle to engaging in romantic relationships, as indicated by the correlation between labour participation and marital status in the studies discussed



above. Another recurrent obstacle is the negative attitudes in society towards disability, especially in regards to sexual relationships. Catherine J. Kudlick's study (2008) of blind women in the 19th century indicates how people who were labelled as disabled were not expected nor did themselves expect to form romantic relationships, get married, or have a family. A few historical works have focused on the opportunities of disabled individuals to have a partner and a family. Daniel Blackie (2014) found that war veterans disabled from their involvement in the American Revolutionary War (1775–1783) married and formed families to about the same extent as other men did. Even though Blackie's study concerns a specific group consisting of men who acquired impairments in adulthood and through a perceived courageous act, it indicates the agency in the lives of these disabled men and suggests they were not negatively viewed by their peers. Similar conclusion around agency and opportunity structures can be seen in one study of this collection (Vikström et al., 2020, this issue), which focused on disabled people who did marry. Such results challenge the view that disability entailed marginalisation from social life in past society.

#### ***4.1. Present patterns of disability, partnership, and family and theoretical considerations***

Contemporary disability research and disability policies continue to focus on education, employment, welfare and healthcare as a priority, giving little recognition to the importance of family and romantic partnerships in the lives of disabled people today. Although there are fewer studies on these latter issues, and more than for past times, they clearly show the negative impact of disability on the formation and sustainability of romantic partnerships and families, either formalised by marriage or not. For instance, disabled people have lower partnering chances and are more likely to remain single as adults or to live in their parents' households compared to their non-disabled contemporaries (Clarke & McKay, 2014; Fujiura, 2014; Helmius, 1999; Janus, 2009; Liu & Zhang, 2013; MacInnes, 2011; Sandström et al., 2020; Scott-Marshall et al., 2013; Tumin, 2016). Furthermore, when disabled individuals do form partnership unions, they do so later in life compared to their non-disabled counterparts and are more likely to divorce (Franklin, 1977; Singleton, 2012). These and other international studies also indicate the adverse economic, social, and psychological effects disability can have on family relationships and romantic partnerships (MacInnes, 2011; Osgood, 2005; Queirós et al., 2015; Reynolds et al., 1993; Savage & McConnell, 2016; Singleton, 2012). For example, Diana J. Wiegerink et al. (2006, 2008) show that although people with physical impairments do go out on dates, when compared to their non-disabled counterparts they are less likely to experience romantic relationships. They are also more likely to encounter disapproval from others and to become consensually sexually active at an older age. Wiegerink et al. (2010, 2011) also found that disabled individuals face greater disabling barriers in adulthood because services and support are reduced and often stopped altogether. This hinders their opportunities to become fully independent and increases their dependence on their parents, thus compromising their opportunities to develop romantic relationships. Hence, disability seems to be an obstacle to partnership today just as it was in the past.

Theories have been adopted to explain the negative association between disability and partnership in terms of the disadvantages faced by disabled people from following

normative life courses and achieving milestones of adulthood such as developing romantic partnerships and forming families. One theme of theories concerns socio-economic disadvantages and seeks to go beyond the impairment itself in accordance with how the social model conceptualises disability. Having an impairment does not directly jeopardise the formation of romantic relationships, but it does mean that opportunities to enter employment and build a career are reduced (Shah, 2005, 2008). Disabled adults are the most underemployed group of people in the global workforce (Colella & Varma, 1999; Colella & Bruyère, 2011; Lengnick-Hall et al., 2008; Vornholt et al., 2018; WHO, 2011). This is detrimental to their financial and social wellbeing because being part of the workforce not only provides income, but also presents opportunities for activity, to have social status, and to build social relationships (Jahoda, 1981; Paul & Batinic, 2010). In many countries with civil rights legislation, the unemployment rates for disabled people are approximately twice what they are for non-disabled people (WHO, 2011). Employment is important for reducing social isolation and for forming social contacts, which might include prospective romantic partnerships, but also to gain an income and to gather the material resources necessary for successful family formation. One study in this collection exemplifies this approach drawing on Valerie K. Oppenheimer's uncertainty theory (1994, 1997), which stresses that sufficient resources, attained through work, are required for enabling union formation, especially for potential male partners. Namatovu and her co-authors (this issue) argue that receiving disability pension in young adult years is an indication of insecure financial circumstances, which persist in subsequent years and contribute to the low partnership rate of disabled men and women. This result suggests that partnerships for men, at least in contemporary Sweden, are similarly affected by disability as women. One plausible reason is that men are still largely expected to be more independent and self-sufficient than women. However, as the studies in this collection demonstrate, it is primarily disabled women who, are or have historically been, asexually objectified by the media and by medical and legal discourse. Gender and disability studies research has shown that disabled women have been actively discouraged and sometimes physically prevented from exercising their reproductive capacities and becoming parents (Kallianes & Rubenfeld, 1997; McFarlane, 2004; Priestley, 2003; Smith & Hutchison, 2004; Smith et al., 2004; Thomas, 1997; Waxman, 1994).

The theory of homogamy suggests that persons select a partner resembling themselves and their values and social status (Kalmijn, 1998; Van Leeuwen & Maas, 2019; Van Poppel et al., 2001). Some scholars argue that such assortative preferences might manifest 'disablist views' in society and among non-disabled populations, thus not recognising those with impairments as potential partners (Crawford & Ostrove, 2003; Kallianes & Rubenfeld, 1997; McRuer & Mollow, 2012; O'Toole, 2002; Robillard & Fichten, 1983; Savage & McConnell, 2016; Tumin, 2016). Yet one possible explanation to the homogamy theory is the fear of becoming a carer to a disabled partner, which may cause people to avoid entering a partnership with someone with impairments (Fiduccia, 2000; Gill, 1996; Savage & McConnell, 2016). However, one of the studies in our collection (Vikström et al., this issue) suggests that partner selection in the 19th century was not really governed by assortative preferences based on disability. The study it discussed found that, 95% of the 188 disabled men and women who had married, had married a non-disabled spouse. These couples resembled the homogamy in marriage patterns typically found at the time, i.e. a low age gap between the spouses and a preference for marrying someone from

a similar socio-spatial background, just as average spouses did. This suggests that disabled people who did marry participated and 'competed' in the general partner pool and were regarded as potential partners 'for life'.

## 5. Final remarks and lessons for the future

Although the above review of the existing literature does not cover all works in the area of our special issue, it becomes clear that they primarily concerned contemporary western societies in the Global North. Far less is known about disabled people's experiences of partnership in the Global South and in historical worlds. This is one lesson to learn and develop in future research. Our collection has contributed to this, as it brings together research from the Global North and Global South, and from historical and contemporary societies focusing on themes of disability, romantic partnerships and family life. Further, our special issue is underpinned by a life course approach and the social model of disability to provide an understanding of the way disability is culturally constructed and socially produced across time and space. The impact of disability on the pursuit and achievement of normative life events has become evident through our collection's examination of the interplay between disability, romantic partnerships, and family life across time and space. This scope has helped to identify dis(similarities) regarding the influence of disability on human life, thus enabling novel temporal and cross-national comparisons in terms of family and romantic partnership, which has remained largely absent in disability studies, on the one hand, and studies on the family, on the other. Drawing together these two areas, this collection has made a significant step regarding a) the research on romantic partnerships and family formation, in the past as well as the present, that has not engaged with the subject of disability, and b) disability research that has not engaged with the subject of partnering or marriage. Below we make some final remarks from all the results presented in this special issue and suggest a few next steps to take in the strategic plan to facilitate the global value of this interdisciplinary research area, both inside and outside of the academic gates.

Spanning different time periods and contexts, our special issue has revealed the macro level barriers that disabled people experience in the development of sexual and romantic relationships and the formation of families in historical and contemporary societies. One recurrent result is that these barriers contribute to the unequal opportunities disabled people face in relation to forming partnerships, regardless of different economic structures and welfare provisions, or the increasing recognition of human rights of disabled people (UNCRPD, 2006). However, the studies on past patterns and temporal fluctuations pertaining to the negative association between disability and partnership or family formation are scant and the historical knowledge is insufficient, partly due to unreliable or tricky sources. The fact that just two of the eight studies of this collection go back to the 19th and 20th centuries illustrates this gap in research. Even if the long-term Swedish trends presented above showing that disability more than halved the partnership chances can act as a baseline for time-space comparison, Sweden is a country with special properties. Only new research on past populations from other areas can indicate whether the empirical evidence from Sweden holds for other historical contexts as well regarding the strong negative impact disability had on people's partnership chances from the 1800s until recent decades. There are a number of other demographic and family-related

outcomes worth studying to trace how disability influences the life course, and these can help indicate disabled people's positions in different societies over time. The subject of disabled persons' experience of fertility and parenthood has escaped historical investigation, although motherhood has received increasing attention in contemporary disability studies (e.g. Smith et al., 2004; Thomas, 1997). The calls we make concerning research on historical worlds apply to worlds of the Global South as well, especially because the majority of disabled people are living there.

The bias in partnership identified in this collection as well as research from the Global North also indicates the level of participation in social life and society among people with impairments. Moreover, it reflects the social inequality that impacts the lives of disabled people at different levels and societies across time and space. This partnership bias can have wider implications in making the disabled people feel and appear less equal to non-disabled counterparts in other life domains as well, since many other benefits come with living in partnership. For example, accessing a partner is often coupled with firm social bonds and emotional support that can promote the social wellbeing and health, and combining partners' socio-economic resources might facilitate an increase in living conditions and the quality of life (Dafoe & Colella, 2016; Kalmijn, 2017; Robles, 2014; Ross et al., 1990; Van Hedel et al., 2016; Waite, 1995). However, partnerships may also have negative effects, for instance, when domestic violence is involved. In relation to disability, domestic violence has been under-researched. Some studies suggest that disabled people are three times as likely to be victims of domestic violence (Shah et al., 2016; Thiara et al., 2011). This issue certainly deserves further research.

Our collection has more and other messages to bring to both research and society. For instance, it challenges the persistent perception and recurrent notion that disability limits the opportunities for partnership or family formation. Exploring disability and partnerships in both the past and the present, our collection uncovers many diverse cases of disabled people who have experienced partnerships and who have sustained their relationships through strong and mutual bonds with their close relatives. Examining disabled people and their relatives in this way is a result of meso level analysis. Studying this interface between the individual micro level and the societal structures at the macro level help make the choices, trajectories, and transitions of disabled people and their relatives become more evident. It contributes nuanced results that can both reject and confirm the aggregated findings, which tend to compare the partnering chances by disability to show how it reduces these chances significantly. Although we acknowledge that disabled people do experience greater ablist barriers to form partnerships or a family compared to their non-disabled contemporaries, our collection reports evidence which suggests that disabled people do indeed engage in romantic relationships or family life, and have done so across time and space. Such findings contribute to building on the body of history about the largest minority group worldwide. Showing disabled individuals as social agents who are capable to initiating, building and sustaining partnerships is valuable for their non-disabled peers and stakeholders in society to recognise them as potential partners, instead of focusing on their disability.

Yet another message emanating from our special issue on sexual-romantic partnerships makes us call for a further examination of disability and gender in history and present-day society. Our collection shows evidence of the pervasive misconception that disabled people and especially disabled women are asexual beings and unable to pursue successful

reproductive journeys. This has discouraged and sometimes physically prevented them from exercising their reproductive capacities and becoming parents (Smith et al., 2004; Thomas, 1997). This has created a healthcare culture that might impact negatively on disabled women's life choices and trajectories. Today's organisation of social structures, processes, and systems means that disabled women, compared to non-disabled women, are particularly susceptible to inequalities across different spheres of public and private life across the life course, including sexual relationships, romantic partnerships, pregnancy, and motherhood (Shah et al., 2020). More interdisciplinary research is required to explore this topic further, both from scholars within the disability studies and those within family and/or history research. In times and societies witnessing increasing equality between men and women, the experience of disability can be more prominent than before, particularly if the gendered expectations traditionally in work, sexual-romantic relationships, and family responsibilities are losing ground. Studying partnership and family is one way to identify and comprehend the gendered effects of disability and what this means for human life still today. However, there is a need to take both men and women into account and to apply historical perspectives.

We think our collection shows the benefits of researching disability in relation to romantic partnerships and family formation in different time-space contexts. Perceptions that disability cannot be combined with romantic partnerships have created few incentives to research this topic, not being much or many cases to study. Our collection suggests the opposite. It also suggests that such preconceptions may go far back in time and have little to do with the actual impairment, person, or situation, but rather disabling attitudes that can have far-reaching effects on the wellbeing and social equality of disabled people in society today. We are convinced that the topics and findings of this special issue will encourage more research regarding how disabled people experience partnership and family formation from a normative perspective or as an actuality.

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