## **Narrative Works**

**Issues, Investigations, & Interventions** 



## Identity and Masculinity in Two Cases of Early-Onset Disability Autobiography

Hanna Pohjola et Merja Tarvainen

Volume 9, numéro 2, 2019

URI : https://id.erudit.org/iderudit/1076526ar DOI : https://doi.org/10.7202/1076526ar

Aller au sommaire du numéro

#### Éditeur(s)

Centre for Interdisciplinary Research on Narrative, St. Thomas University

ISSN

1925-0622 (numérique)

#### Découvrir la revue

#### Citer cet article

Pohjola, H. & Tarvainen, M. (2019). Identity and Masculinity in Two Cases of Early-Onset Disability Autobiography. *Narrative Works*, 9(2), 71–87. https://doi.org/10.7202/1076526ar Résumé de l'article

This article examines the construction of identity and masculinity in two cases of disability autobiography. Retrospectively written autobiographical accounts of early-onset disability were analyzed abductively by using the model of narrative circulation (MNC), with a thematic content analysis being used to organize the data. Both narrators constructed their adult identity as men in relation to the available disability narratives and living conditions. Three intertwined dimensions regarding the construction of identity could be observed: external expectations, internal intentions, and locally situated narratives of work. The narratives may be considered to represent an alternative way to bypass, overcome, and refresh the culturally dominant stock of stories.

© Hanna Pohjola, Merja Tarvainen, 2021

érudit

Ce document est protégé par la loi sur le droit d'auteur. L'utilisation des services d'Érudit (y compris la reproduction) est assujettie à sa politique d'utilisation que vous pouvez consulter en ligne.

https://apropos.erudit.org/fr/usagers/politique-dutilisation/

#### Cet article est diffusé et préservé par Érudit.

Érudit est un consortium interuniversitaire sans but lucratif composé de l'Université de Montréal, l'Université Laval et l'Université du Québec à Montréal. Il a pour mission la promotion et la valorisation de la recherche.

https://www.erudit.org/fr/



# Identity and Masculinity in Two Cases of Early-Onset Disability Autobiography<sup>1</sup>

## Hanna Pohjola & Merja Tarvainen University of Eastern Finland

This article examines the construction of identity and masculinity in two cases of disability autobiography. Retrospectively written autobiographical accounts of early-onset disability were analyzed abductively by using the model of narrative circulation (MNC), with a thematic content analysis being used to organize the data. Both narrators constructed their adult identity as men in relation to the available disability narratives and living conditions. Three intertwined dimensions regarding the construction of identity could be observed: external expectations, internal intentions, and locally situated narratives of work. The narratives may be considered to represent an alternative way to bypass, overcome, and refresh the culturally dominant stock of stories.

Keywords: disability, identity, masculinity, narrative, model of narrative circulation

The first ever *World Report on Disability*, produced jointly in 2011 by the World Health Organization (WHO) and the World Bank, suggests that at present there is a global population of more than one billion people experiencing some form of disability. The diversity of disability is both wide and heterogeneous: disability may be visible or hidden, permanent or temporary, may exert a minimal or substantial impact on an individual, and can be in-born or acquired, to name just some examples (WHO). Different kinds of impairments entail very specific and context-dependent implications for how gender and disability might intersect (Staples, 2011). For example, physical impairment and disability impose concrete limitations on activities of daily living and may create friction for an individual's social identity and agency (Coleman-Fountain & McLaughlin, 2013; Nolan, 2013; Smith & Sparkes, 2004). Disability also poses challenges to what might be considered as normal life expectations such as education, forming relationships, and finding

<sup>&</sup>lt;sup>1</sup> This work was supported by the Academy of Finland (Grant Number 299172).

NARRATIVE WORKS: ISSUES, INVESTIGATIONS, & INTERVENTIONS 9(2), 71–87 ©Hanna Pohjola & Merja Tarvainen, 2019

employment (Pohjola, 2018). These challenges will be discussed, based on the autobiographical accounts of two men.

Narratives and narrative methodology have been considered to be fruitful ways of studying the construction of identity and masculinity when combined with disability (Shuttleworth et al., 2012, p. 183). Narratives enable one to make sense of illness or disability, allowing the individual to give expression to their memories, (re)construct a sense of identity, and assist in formulating the experience of illness and suffering (Bury, 2001; Glintborg & Krogh, 2015; Smith & Sparkes, 2008, pp. 18– 19). These stories allow those with disabilities to be heard in their own voices and provide valuable means of recovery and resources for the (re)construction of identity. They also add a vital element to the larger cultural stock of life stories (Pohjola, 2018). Thus, life narratives "can provide controlled access to lives that might otherwise remain opaque or exotic, and offer an important, if not unique, entrée for inquiry into one of the fundamental aspects of human diversity" (Couser, 2006, p. 401).

The theoretical basis of this study is the model of narrative circulation, or MNC (Hänninen, 2004). The MNC presents the relations among three modes of narrative: inner, told, and lived. The inner narrative is an individual's interpretation of his or her own life in which the past events, present situation, and future projects are understood using cultural narrative models as resources. It is (partly) made external by told narratives and revised during that process. The lived narrative refers to real-life drama, which is shaped by the interplay between situational constraints and the inner narrative that guides an individual's actions when faced with changing life situations (Hänninen, 2004). In this article, we focus on these narrative forms of MNC in the context of an early-onset disability in two men. We aim to illuminate the interplay between their inner narrative, their living conditions, and the cultural stock of stories as told through the narratives of the writers.

#### Background

The dominant disability narrative in Western societies has been ableism. According to Fiona Kumari Campbell (2009), ableism is "a network of beliefs, processes and practices that produces a particular kind of self and body (i.e., the corporeal standard) that is projected as the perfect, species typical and therefore essential and fully human" (p. 5). Disability is perceived as a conflict between an individual's capabilities and the given socio-material and societal conditions. These conditions are encountered as bodily restrictions, but the body has been a contested area in disability studies (see, for example, Coleman-Fountain & McLaughlin, 2013.) This dispute stems from a medicalized approach to disability: the medical model of disability considers disability to be an individual's pathological condition. In contrast, a sociological understanding of disability is intended to correct this misconception by examining disability in relation to social, material, and political conditions (see, for example, Coleman-Fountain & McLaughlin, 2013; Tarvainen, 2019). Disability studies distinguishes between disability and impairment; impairment refers to an impairment of a part of the body, whereas disability is an interplay between individuals with different capabilities in the given socio-material conditions (e.g., Coleman-Fountain & McLaughlin, 2013).

Generally, culturally dominant narratives on disability speak about "overcoming" a disability or represent disability as an individual tragedy (Campbell, 2009, pp. 29–35; Loja et al., 2013, p. 193; Oliver, 1996, p. 34). A platitude such as "triumph over adversity" may predetermine experiences of disability (Couser, 2006; Garden, 2010). To rectify this misconception, first-person accounts can offer a critical resource for allowing people with disabilities the possibility to express their point of view and provide a means of examining the social context and social determinants of disability (Garden, 2010).

In disability studies, hegemonic masculinity has been referred to in different ways, including as stamina, strength, and courageousness (e.g., Gibson et al., 2014; Nolan 2013; Sparkes and Smith, 2002). For example, the most characteristic description of masculinity and disability in Western societies has been the narrative of the wounded hero (Sandahl & Auslander, 2005; Shuttleworth et al., 2012). This primarily concerns men who have acquired some physical impairment after their childhood and subsequently have somehow (re)constructed their masculine identity. More and more autobiographical books are being published by authors with disabilities; there seems to be an expanding market for stories that challenge prevalent stereotypes associated with disability. In these texts, disability is presented as a diverse and ever-changing set of conditions and experiences that prohibit any sort of universalizing metanarrative (Mintz, 2006). Thus, in addition to the saga of the wounded hero, other narratives have also appeared. For example, aspects of disabled manhood have been suggested to intertwine in three ways: as lost masculinity, as an attachment to alternative ways of being a man (instead of hegemonic masculinity), or as a battle to regain manliness (Nolan, 2013).

Rather than diminishing masculinity in all its aspects, some disabilities might even be viewed as hyper-masculine: impairments have been shown to reshape understandings of masculinity sometimes in unexpected forms (Lindemann & Cherney, 2008; Staples, 2011). There have been variations in the ways that disabled men assess their ability and gender: responses have ranged from mourning, defying, accepting, and/or embracing their daily performances in terms of physically disabled masculinity. Through their bodies being defined as the negation of "normal," men attend to and expose the nuances of the interacting cultural components of hegemonic masculinity that all human beings negotiate, interpret, create, and re-create through our interactions (Scott, 2014).

In summary, previous studies on masculinity and disability have focused mainly on acquired disability or "wounded masculinity" due to injuries occurring in adulthood (e.g. Shuttleworth et al., 2012, p. 183; Sparkes & Smith, 2002). Much less research has been conducted with men with early-onset disabilities, such as disabilities that appeared during their childhood or adolescence (e.g. Gibson et al., 2014; Shuttleworth et al., 2012, pp. 183–184). Generally, the typical narrative of masculinity and disability regards early-onset disability as some form of deviance or simply as a tragedy (Shuttleworth et al., 2012). Men with early-onset disabilities have been viewed as abnormal because they have never reached their full, socially accepted forms of masculinity (Shuttleworth et al., 2012, p. 183).

Shuttleworth et al. (2012, p. 184) noted in their study among men who had acquired a disability at a young age that, while many of the participants tended to expand their so-called "masculine repertoire," they had not totally abandoned the culturally typical characteristics of masculinities. Instead of abandoning this stereotype, they seemed to remodify and "expand" it (p. 184). Gibson et al. (2014), investigated gender, disability, and emerging adulthood in 15 young men with Duchenne muscular dystrophy. The study suggested that disability, masculinities, and generational (life stage) identities intersected through "narratives of nondifference," in which participants worked to establish their identities as typical "guys." Within the limited fields of school and work, the participants tended to distance themselves from being "disabled" and instead discussed their successes and challenges in terms of normative developmental trajectories.

This research indicates that in constructing their identity, men with a disability have to face the cultural assumptions of masculinity, that is to say, hegemonic masculinity, in the cultural stock of stories. According to Hänninen (2004), the cultural stock of stories is the totality of narrative representations that the person hears or reads in the course of his or her life. In any culture or sub-culture, some stories are more hegemonic or powerful and normative than others and are therefore referred to as dominant stories or master narratives (Hänninen, 2004, pp. 73–74). Another important concept to be considered in conjunction with the cultural stock of stories in the MNC is that narratives are adapted in (different) situations. The term "situation" refers here to the actual conditions of life and the various possibilities, resources, and restrictions of action which the disabled person has to face. Some of these are outside the individual's control, but some are results of his or her actions. (Hänninen, 2004, p. 74) Thus, narratives do not exist in a vacuum, but are written in relation to socially available and constructed narratives. As a result, individual stories become connected to these circulating narratives, which then offer resources through which one can interpret life events (Tarvainen, 2019).

## **Materials and Methods**

## **Autobiographical Accounts as Data**

This article analyzes the autobiographical texts of two men with early-onset disabilities. The material is drawn from a collection of autobiographical narratives written by disabled persons who responded to an open call (1.10.2013–31.05.2015) for life-history writings *Vammaisena Suomessa 2013–2014* [Life of Disabled Persons in Finland, 2013–2014]. The collecting of the data was organized by the Finnish Literature Society (SKS) and a Finnish disability policy organization, Kynnys (SKS, 2013).

According to the cover letter of the call, the respondents were encouraged to write about significant events or about their life in general in their own words and preferred form as well as from a perspective of their own choosing. In addition, they were informed that the texts would be archived and possibly used for research purposes, but only after their consent (SKS 2013). The complete data consists of autobiographical accounts from 37 disabled persons (1,799 pages) and includes both narratives of inborn and acquired disabilities as well as some stories written by people who discuss the living conditions of people with disabilities in Finland. The archived data is available for research use, and users can apply for permission from the archive. As most of the disability research on men has been conducted in adulthood, as discussed earlier, we read the stories seeking narratives relating to early-onset disability in men (i.e. in childhood or during adolescence). Two out of the total of 37 narratives met these criteria.

#### **Narrators and Their Narratives**

We will use the pseudonyms "Paul" and "Ed" to refer to the writers of the retrospectively written autobiographies analyzed in this article. These narratives differ from each other in both their style and format: Paul has a coherent and chronological storyline, whereas Ed writes fragmented short stories. Despite these differences, the two autobiographies share similarities. Both narrate events in their lives spanning several decades, and both have an early-onset disability. Paul was injured in a traffic accident that occurred during his adolescent years, whereas Ed's disability was evident from childhood.

Paul entitled his narrative "Being Disabled in the Mainstream" (*Vammaisena valtavirrassa*) and it consists of approximately three pages (pp. 529–531 in the data). A father, husband, and disability pensioner doing volunteer work in a disability organization, Paul wrote the narrative when he was in his 40s. The accident that led to his traumatic brain injury occurred during his late teenage years. His retrospectively written account spans 20 years of his life and offers his views on adolescence, emerging adulthood, and adulthood, in chronological order. The structure follows Aristotle's plot model: it has a clear beginning, a middle section which has a kind of climax (thoughts of suicide), and then a long and rich coda where life regains true meaning. The emphasis on the account lies in the coda.

Ed's life story consists of 42 typewritten pages (pp. 337–492 in the data), though the original text was handwritten and untitled. The narrative consists of short stories about people with disabilities that he has met or about whom he has heard stories during his childhood, adulthood, and older age; the last half of his narrative consists of these short stories. Ed's narrative is structurally fragmented and consists of episodes where he moves backwards and forwards in time. The beginning of Ed's story seems to follow the conventional narrative of a life story format: he begins from his early childhood memories and later intertwines short episodes of adolescence and adulthood with childhood as (re)presenting versions of himself. Even though the narrative can be defined as broken in terms of chronology, it still has an inner logic (e.g. Hydén, 2010). Both narratives are written in Finnish; the texts used here have been translated by the authors. (Due to space limitations, only English translations of the excerpts are included.)

### Analysis

The two cases presented in this article have been analyzed abductively. In this respect, abductive analysis means that we have applied MNC as the methodological basis and interpreted the sociological significance of the stories (e.g., Baldwin, 2013, pp. 24–25; 31–46) as well as the construction of identity in relation to disability (e.g., Smith & Sparkes, 2008), but we have organized the data with a thematic content analysis (e.g., Braun & Clarke, 2006; Riessman, 2003; Riessman, 2008). First, the texts were read several times (i.e. familiarization with data) with a concentration on disability and masculinity and then distilled into the initial main theme: both stories outlined the significance of developing independence, identity, and creating "their own paths" as disabled men. This stage was done separately and individually by both of this article's authors to ensure validity in the analytical process. Subsequently, we collaborated in determining how the narrators had come to some particular outcome. We noticed that these texts concerned the construction of identity as a struggle between external expectations (i.e., what others think that the narrator should or can be) and internal intentions (i.e., narrator's motives in their stories). In the last phase of our interpretation, we paid attention to the ways in which the narratives referred to the cultural stock of stories according to MNC.

In the following sections, we present findings emerging from the analysis. We first summarize each of the two narratives, supplemented by our interpretations. We then juxtapose the two cases as they relate to identity and masculinity to point out their differences as well as their similarities.

#### Findings

## Paul's Narrative: "The New Life"

Paul starts his story with two introductory sentences where he states that "a person who has experienced a TBI [traumatic brain injury] does not differ much from so-called normal people," and that this is why he relates his "story of what he has received from society in twenty years." Thus, Paul emphasizes the relationship between society and disability as the red line running through the narrative. He then describes the traffic accident that caused his TBI and then moves to his rehabilitation process that lasted a mere three months. Additionally, he refers briefly to his life before the accident in the beginning of the narrative:

Life was rather okay at that time (i.e. after the accident and rehabilitation), because the life that I had been living before the accident was rather fuzzy. Of course, the disability brought different troubles, but still anyway.

Even though Paul had undergone a successful rehabilitation, he was granted a disability pension due to "[medical] professionals that did not see any other future for me." Still, he was able to finish his comprehensive school at a special school for disabled students. Thus, despite the accident, the beginning of his story seems full of promise. Then, the narrative describes how things took a turn for the worse. An intended gap year in studies because of fatigue turned into three years and Paul admits this was a big "mistake": incoherent gap years led to a loss of focus in life, alcohol abuse, growing debt, and thoughts of committing suicide. As he states, his processing of the accident had just started: "To some extent, I had severe depression as well. I was given time to really mull over what had happened."

He emerges from the fog when he realizes that he is thinking of taking his own life. Instead of committing suicide, he decides to start to find a solution for his problems: he decides to change the direction his life is taking. He returns to school, but this does not go well until, to his surprise, he receives help from a teacher who starts to sort out the mess in Paul's life and arranges a debt-restructuring program for him. Soon, Paul's life starts to blossom. In his words, "life had started again." For Paul, this is the beginning of "the new life" as he describes it: he finds solace in writing, meets his future wife, becomes a father, experiences "years of growing" as a human being, and discovers his own path to contribute to society through volunteering. Thus, a frozen and latent identity grows rapidly, both personally and socially: a teenager turns into a man, a husband, a father, and an active member of a disability organization.

Neglect by different institutions is one of the main themes which emerges from Paul's story when he wants to develop a social identity in the contexts of education and work. He undergoes a series of psychological tests and evaluations to prove that he can return to education and working life. Unfortunately, his insurance company declines the application to fund his professional (re)education due to general economic reasons. There is another rejection when his municipality turns down his requests for apprenticeship training due to the poor economic situation. Both neglect and discrimination are also evident in Paul's narrative in a paradoxical way. By some authorities he is considered to be too disabled to work, but by others he is viewed as too healthy to be provided with assistive devices to support his locomotion skills, even though he has challenges with balancing and vision. To sum up, Paul's struggle in developing his social identity is constantly clashing against a one-sided conversation, or even a conviction, that has been set by others. This diminishes his possibilities for agency and a construction of his identity. In his own words, the clashes inspired him and "triggered the thought of participating" in voluntary work at disability organization.

Despite these setbacks, he maintains a positive spirit in his writing and overcomes the obstacles of the discrimination, even turning them to a source of empowerment. The darker years and obstacles are left behind, and now the narrative seems mainly to focus on discovering his self and finding a meaning for his life. However, the end of Paul's story remains open, and there are no clear indications about what he expects from the future. In the narrative, Paul's identity is gradually developing and agency is introduced as contextual, situational, and social. Thus, he builds his agency as a man in regard to his personal growth as it relates to his family and the social environment. Hence, he is not willing to adopt the fixed/ pre-categorized role of a disability pensioner but stresses that he is a man of action with a unique personal identity. In short, his acquired disability has been transformed into ability, agency, and becoming an active participant.

## Ed's Narrative: "My Way"

Ed introduces himself as "a pensioner" and writes that he had worked in a warehouse for several decades. He begins his narrative from his childhood, and, at this stage, the text follows the so-called ordinary life script:

I begin with my own childhood memories. The beginning [of my life] was hard, because I was so weak. My parents took me to see

a [special] doctor .... He did a thorough job. My parents got a report that I was completely normal. ... But weak. ... I acquired a reputation as a weak person. ... When my schoolmates got to know that I had been at this doctor's, they started to think of me as a screwball.

Ed writes how his physical impairment ("weakness," as he describes it) becomes a disability as his peers at school started to treat him as an alien. Ed writes how he was bullied because of his physical appearance. However, he "fought back." For example, Ed got into constant scuffles with his childhood peers:

I started to fight. ... It changed my whole life. [Even worse] I started to bully others and pay them back, but I soon realized that I could go on my own way. Strangely enough, I became stronger. I was able to cope along with my able-bodied peers.

Ed discusses how his disability was misunderstood by his peers: he thinks that his "able-bodied peers" bullied him and did not respect him due to his disability before he started to fight back. Unfortunately, he became a bully himself, but he soon realized that neither the role of a bully nor that of a bullied person was a role he wished to adopt. Additionally, Ed utilizes an able-bodied narrative as he describes disability in relation to his identity: disability is literally dis-ability, weakness, and even otherness as viewed by his peers. He narrates how he tries to compensate and prove his own able-bodiedness:

I tried to do chin-ups [i.e. pull-ups] every possible moment.... Although my knees were as they were and my back was bent, I got on somehow and sometimes I got on well, actually.

Ed describes several occasions in his gym classes, with one having notable importance for him with regards to his disability: the pupils were taking part in a rope-climbing competition, in which Ed "guaranteed the victory" for his team. This contest seems to have had a vivid impact on Ed and on the development of his identity as his able-bodied peers respected him.

In Ed's life story, childhood memories seem to be both lifespanning reminiscences as well as a foundation for the construction of his identity. He describes a kind of continuum in the growth of his personal identity. In Ed's life story, entering adulthood is described as going smoothly. He describes a crucial life phase: his adolescence and entry to adulthood and working life. Ed writes that studies were not a "piece of cake" and he began to search for a job:

After elementary school, I went to a vocational school. I was bored.... I began to search for a job, any kind of job, even as a helper or a gofer. At one point, I chopped firewood. All the chinups I had done were so good for that. ... It was such nice work.

Ed refers to how doing "all the chin-ups" had made him strong enough to do hard physical work. He states that work was "one of [his] favourite things" and according to his life story, he was well accepted into the working world. Thus, as an adult, Ed is living an ordinary working life under his own terms and conditions that offered him a way to re-assess his body-based ability. In this respect, his inclusion into working life despite early-onset disability was crucial to Ed. The value of work is emphasized several times in his narrative. He also discusses the meaning of work in the society at a general level and gives the following example:

Are times are better now or not? Has society changed in a way that a person with disabilities can gain access to work life? I have described some cases in which the work and the worker have been matched in such a way that a person is capable of working.

## **Negotiations of Identity**

Rather than coping with or overcoming their impairments, many disabled people see their impairments as an integral part of their lives and sincerely value the way their impairments have shaped their identities (Garden, 2010, p. 73). This aspect was apparent in the narratives of Paul and Ed, as they constructed their adult identity as men in relation to the available disability narratives (i.e., the cultural stock of stories), their living conditions (i.e., lived narratives), and their aspirations (i.e., an inner narrative). Three intertwined dimensions regarding the construction of identity could be found in the data: external expectations, internal intentions, and locally situated narratives of work.

First, both Ed and Paul narrated how they had to construct their identity in the face of external norms and cultural assumptions about disability and masculinity (e.g., Loja et al., 2013; Mik-Meyer, 2016;

Tarvainen, 2019). They write about how there are collisions between their life narrative in terms of social and material conditions, attitudes, and misconceptions of bodily appearance that do not fit into socially acceptable categories. This reveals able-bodied prejudices in which disability is considered unwanted. Both men were expected to adopt the role of a disabled man, i.e., a man who is unfit according to the terms and conditions of the dominant masculinity narrative. Institutions, especially medical doctors and something that the narrators called "bureaucracy", e.g. health and social services, seemed to offer this viewpoint which included, in this respect, the stereotypical categories defining masculinity and disability. Thus, the narratives revealed the kinds of moulds into which a person with disabilities should be fixed.

Second, both narrators were able to construct their own identity and their unique path in life according to their intentions, and to find a balance between external expectations and inner aspirations. Additionally, this opened a new relation to belonging that offered inclusion. For Paul, working in a disability policy organization was important. The body was a crux for Ed, while he negotiated with an ablebodied-based, ableist external narrative (Campbell, 2009): on the one hand, he tried to link his story into the dominant narrative strategy but on the other hand, he seemed to modify the able-bodied disability narrative by stating that a person with disabilities is still a worthwhile person. This corresponds with several theoretical concepts presented in disability studies and social justice, in which disability is thought of in terms of capabilities (e.g., Baldwin, 2013; Nussbaum, 2007). Social relationships were also meaningful-for Paul, family relations were crucial. For Ed, immediate relations and a group of fellows with disabilities emphasized his relationship with a wider world.

Third, both men based themselves on the traditional role of a Finnish man who is supposed to be hard-working, principled, and silent, as well as a man being one who never gives up (Heinonen, 2006, p. 7). This was especially challenging for Ed, who entered school as a child with disabilities. He tried and re-tried to succeed in areas where he could show that he was able-bodied. As a result, this aroused feelings of anxiety, inadequacy, and exclusion, but paradoxically it enabled him to find his strengths and contribute to his identity continuum. In his story, Paul was gradually pursuing a dyadic body (see Frank, 1995) that allowed him to connect to others. The obstacles that Paul faced in finding his identity run through his narrative as frustrated attempts to study and find suitable employment. In both of these instances, there are struggles with

authorities. For Paul, there is a constant need to ease this friction, to have a working dialogue with society so that he can (re)integrate himself into society. Paul's narrative also reveals the ways in which disability is viewed in the working life and addresses both educational and political aspects of disability: it is crucial that people with disabilities have the possibility to participate in working life, as from a broader viewpoint, these are issues of human rights and citizenship.

## Discussion

This article aimed to offer insight into how men with early-onset disability construct their identity as men. Our findings in this rarely discussed research topic are in line with the previous study conducted by Gibson et al. (2014). Both studies highlight the significance for these men of living "ordinary lives," just like their non-disabled peers; the development towards adulthood through education and / or work; as well as maintaining a positive attitude. It was noticeable that manhood was referred to implicitly. The same was observed by Gibson et al. (2014) who reported that the men struggled when discussing the notion of being a man or guy, as it was likely a difficult topic. While the younger participants more often linked "being a guy" to their interests (video games, sports, and technology), older participants directly related manhood to sexuality and experience (Gibson et al., 2014, p.12). In our study, these themes were not evident at all.

The cases presented in this paper stress the importance of work as an entry into society. This is not surprising, as inclusion lies at the heart of contemporary disability policy (e.g., Nussbaum, 2007; UN, 2006), and refers to recognition and access to ordinarily shared resources in society. All around the world, people with disabilities are generally underrepresented in working life (Östlund & Johansson, 2018). Though people with disabilities face exclusion from the workplace, Ed's narrative offers an opposite version as he is a working person. Paul's narrative also reveals the ways in which disability is viewed in working life. As a subsidized disability pensioner, Paul is concerned with both the educational and political levels of disability. This was also apparent in the study of Gibson et al. (2014), where work was viewed as both an end that signaled social membership and inclusion and as a means toward staying busy (Gibson et al., 2014, p. 8).

Even though both men emphasize the importance of work, there are differences to be found in their narratives. It seems that Ed speaks

against hegemonic masculine ideals embodied as physical strength and able-bodiedness, whereas Paul formulates an alternative masculinity in his political and community commitments. Interestingly, Ed describes his internalized feelings of inadequacy and his attempts to (over)compensate for them. Thus, he strives to fit himself into the dominant social conception of (hyper)masculinity (Lindemann & Cherney, 2008; Staples, 2011). Paul, on the other hand, seems to position himself as an agent of change: his volunteering work may reflect the change and diversification of perceived masculinity and disability in society (Shuttleworth et al., 2012, pp. 180–186). Furthermore, Paul's narrative links "the personal" and "the political" (see also Baldwin, 2008, p. 227; Oliver, 1996). Paul's contribution to society and acting as a role model may generate social change; furthermore, through his broad socio-cultural storytelling, he offers a wider perspective on disability, identity, and agency (see, for example, Smith & Sparkes, 2008; Sools & Murray, 2015, p. 251).

In summary, the findings suggest that disabled men's narratives can also refresh the cultural stock of stories on disability and masculinity. While creating their identity in relation to the culturally dominant expectations of masculinity, they expanded the ways that disability and masculinity should be viewed regarding the construction of identity and in narrative circulation. Both cases presented in this article challenge the dominant narratives of masculinity and disability and give a voice to alternative interpretations of being a disabled man.

There are some limitations to be noted. As there were only two narratives, they offer a rather small window through which to view the phenomena discussed in these cases. In other words, it should be noted that these narratives do not represent all people with disabilities. It should also be taken into consideration that the identities discussed in this paper were written as stories. Nonetheless, as it is only possible to gain access to a person's inner narrative through their own words, these accounts may have been produced for and aimed at a particular audience (Riessman, 2003, p. 7), but written according to the terms of the call announcement which may have influenced their contents. It is also noteworthy to remember that sometimes words are inadequate and the emphases of spoken life experiences may differ from those of written accounts. This element applies to different life situations, phases in life, and the social landscape at some specific time. This is particularly so as Ed and Paul have lived their formative life phases at different times.

### Conclusion

The two cases discussed in this article suggest that negotiating one's identity bears a close relation to culturally dominant forms of masculinity and disability; evidently, they form a crucial part of the construction of identity among men with disabilities. As hegemonic masculinity is portrayed in the narratives as obstacles to social inclusion and deterrents to finding one's identity, the dominant narrative also sets concrete surroundings for the narrative to be lived by a person with an early-onset disability. However, this narrative can be challenged. As both men have struggled and succeeded to construct their identity and found their own way of living a meaningful life, they highlight that this inner narrative may represent a basis for bypassing or overcoming the culturally dominant stock of stories.

#### References

- Baldwin, C. (2008). Narrative, citizenship and dementia: The personal and the political. *Journal of Aging Studies, 22*(3), 222–228.
  - https://doi.org/10.1016/j.jaging.2007.04.002
- Baldwin, C. (2013). Narrative social work: Theory and application. Policy Press.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Bury, M. (2001). Illness narratives: Fact or fiction? Sociology of Health and Illness, 23(3): 263–285. doi:10.1111/14679566.00252
- Campbell, F. K. (2009). Contours of ableism: The production of disability and abledness. Palgrave Macmillan.
- Coleman-Fountain, E., & McLaughlin, J. (2013). The interactions of disability and impairment. *Social Theory & Health*, *11*(2), 133–150. https://doi.org/10.1057/sth.2012.21
- Couser, T. (2006) Disability, life narrative, and representation. In J. D. Lennard (Ed.), *The disability studies reader* (pp. 399–404). Routledge.
- Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics*. University of Chicago Press.
- Garden, R. (2010). Disability and narrative: New directions for medicine and the medical humanities. *Medical Humanities*, 36, 70–74. doi:10.1136/jmh.2010.00414
- Gibson, B. E., Mistry, B., Smith, B., Yoshida K. K., Abbott, D., Lindsay, S., & Hamdani, B. (2014). Becoming men: Gender, disability, and transitioning to adulthood. *Health*, 18(1), doi: 10.1177/1363459313476967
- Glintborg, C., & Krogh, L. (2015). The psychological challenges of identity reconstruction following an acquired brain injury. *Narrative Works*, 5(2), 50– 70. Retrieved from https://journals.lib.unb.ca/index.php/NW/article/view/25014

- Heinonen, J. (2006). *Työläismies ahdingossa? Kolme miessukupolvea rakennemuutosten Suomessa*. [Workman in distress? Three generations of men and structural changes in Finland.] Helsinki University Press.
- Hydén, L-C. (2010). Identity, self, narrative. In M. Hyvärinen, L-C. Hydén, M. Saarenheimo, & M. Tamboukou (Eds.), *Beyond narrative coherence* (pp. 33–48). John Benjamin.
- Hänninen, V. (2004). A model of narrative circulation. *Narrative Inquiry*, 14(1): 69–85. https://doi.org/10.1075/ni.14.1.04han
- Lindemann, K., & Cherney, J. L. (2008). Communicating in and through "Murderball": Masculinity and disability in wheelchair rugby. Western Journal of Communication, 72(2),107–125. doi: 10.1080/10570310802038382
- Loja, E., Costa, M. E., Hughes B., & Menezes, I. (2013). Disability, embodiment and ableism: Stories of resistance. *Disability & Society*, 28(2): 190–203. https://doi.org/10.1080/09687599.2012.705057
- Mintz, S. B. (2006). Ordinary vessels: Disability narrative and representations of faith. Disability Studies Quarterly, 26(3). http://dx.doi.org/10.18061/dsq.v26i3
- Mik-Meyer, N. (2016). Disability and "care": Managers, employees and colleagues with impairments negotiating the social order of disability. *Work, Employment and Society, 30*(6), 984–999.
- Nussbaum, M. (2007). Frontiers of Justice: Disability, nationality, species membership. Belknap Press.
- Nolan, M. (2013). Masculinity lost: A systematic review of qualitative research on men with spinal cord injury. *Spinal Cord*, 51(8), 588–595.
- Oliver, M. (1996). Understanding disability. Palgrave.
- Pohjola, H. (2018). Acquired disability in young women: a challenge for identity? Journal of Youth Studies. doi: 10.1080/13676261.2018.1529864
- Riessman, C. K. (2003). Performing identities in illness narrative: Masculinity and multiple sclerosis. *Qualitative Research*, 3(1), 5–33.
- Riessmann, C. K. (2008). Narrative methods for the human sciences. Sage.
- Sandahl, C., & Auslander, P. (2005). *Bodies in commotion: Disability and performance*. University of Michigan Press.
- Scott, J-A. (2014). Illuminating the vulnerability of hegemonic masculinity through a performance analysis of physically disabled men's personal narratives. *Disability Studies Quarterly*, 34(1). Retrieved from http://dsqsds.org/article/view/3570/3526
- Shuttleworth, R., Wedgewood, N., & Wilson, N.J. (2012). The dilemma of disabled masculinity. *Men and masculinities*, 15(2):174–194. https://doi.org/10.1177/1097184X12439879
- SKS. (2013). "Life of Disabled Persons in Finland 2013–2014 [dataset]: Version 1.0 (2015-08-12)." Finnish Social Science Data Archive [distributor]. http://urn.fi/urn.nbn:fi:fsd:T-FSD3040
- Smith, B., & Sparkes, A. (2004). Men, sport, and spinal cord injury. An analysis of metaphors and narrative types. *Disability & Society*, 19(6): 613–626.
- Smith, B., & Sparkes, A. C. (2008). Narrative and its potential contribution to disability studies. *Disability & Society*, 23(1): 17–28. https://doi.org/10.1080/09687590701725542
- Sools, A., & Murray, M. (2015). Promoting health through narrative practice. In M. Murray (Ed.), *Critical Health Psychology* (2<sup>nd</sup> ed., pp. 235–253). Macmillan.

- Sparkes, A., & Smith, B. (2002). Sport, spinal cord injury, embodied masculinities, and the dilemmas of narrative identity. *Men and Masculinities*, 4(3), 258–285.
- Staples, J. (2011). At the intersection of disability and masculinity: Exploring gender and bodily difference in India. *Journal of the Royal Anthropological Institute*, 17: 545–562. https://doi.org/10.1111/j.1467-9655.2011.01706.x
- Tarvainen, M. (2019). Ableism and the life stories of people with disabilities. Scandinavian Journal of Disability Research, 21(1), 291–299. http://doi.org/10.16993/sjdr.632
- UN (United Nations General Assembly). (2006). Convention on the rights of persons with disabilities and optional protocol. Full text of the Convention on the Rights of Persons with Disabilities. Retrieved from https://www.un.org/development/desa/disabilities/convention-on-the-rights-ofpersons-with-disabilities.html
- WHO (World Health Organization). (2011). *World report on disability*. WHO. Retrieved from https://www.who.int/disabilities/world report/2011/en/
- Östlund, G., & Johansson, G. (2018). Remaining in workforce: Employment barriers for people with disabilities in a Swedish context. *Scandinavian Journal of Disability Research*, 20(1), 18–25.

**Hanna Pohjola,** PhD, is a post-doctoral researcher at the Department of Social Sciences at the University of Eastern Finland. In addition to her master's and doctoral degree in dance, Pohjola has a bachelor's and a master's degree in health sciences (exercise medicine). She has also graduated as a physiotherapist. Her current research interests lie in dance biomechanics, injury prevention and rehabilitation, and disability within sports and dance.

**Merja Tarvainen,** MA, DSS, is a post-doctoral researcher at the University of Eastern Finland. She has focused on disability studies during the past few years, and currently, she is investigating narrated relations between disability and embodiment, especially with and from the viewpoint of agency.