

# Old, disabled, successful?

## Transfigurations of aging with disabilities in Switzerland

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### Abstract

Aging – both the definition and the actual process of aging – has undergone fundamental local and global changes in the past decades. Various advances in technology and medicine increasingly allow senior citizens in Switzerland to ‘age successfully’ and have shifted societal expectations about what aging should include. This article looks at a group of senior citizens who encounter an increasing discrepancy between the demands fostered by the dominant discourse of ‘successful aging’ and the infrastructure made available to them. At the same time, seniors with disabilities are transfigured and come to stand for dependence, frailty, and decline because of this reconceptualization of aging. This article analyzes the cases of three senior citizens with disabilities which show the consequences of changed normative imaginaries, practices, and infrastructures on how senior citizens with disabilities experience their socialities.

### Keywords

aging, disability, sociality, transfiguration, Switzerland

### Introduction

If they say all these old people must go dancing and be in good shape, people with disabilities fit even less into society. (Anna, aged eighty-one, May 2016)

While there lies great potential in the current paradigm shift towards healthy, productive, and active aging, these recent aspirations of societies to foster self-responsibility and health in older adults can also lead to new marginalization (Foster and Walker 2014; Hank 2011; Katz and Calasanti 2014; Lamb 2017; Minkler and Fadem 2002; Rickli 2016). Switzerland is one of the richest countries worldwide and has the second highest life expectancy.<sup>1</sup> In public discourse, the country is generally represented as treating people with disabilities and the elderly with respect, ensuring a ‘good’ old age through a well-established collaboration between the public sector and civil society. This suggests that Switzerland is a model case of successful management of an aging population. Yet, as will become evident in this article, there are structural issues and asynchronicities in the Swiss system that work to exclude or further marginalize certain groups of senior citizens. This article analyzes one such group, which, by default, does not correspond with currently changing paradigms of aging: elderly people with mobility disabilities.

This contribution to the Special Section, *Rethinking sociality and health through transfiguration*, is based on empirical data from sixteen months of ethnographic fieldwork in the German-speaking part of Switzerland, carried out in 2015 and 2016. I asked the simple question of what differentiates the aging process of people who age with a mobility disability from people who only acquire a mobility disability in the later years of their lives. How, I wondered, did the two groups experience their disabilities? How was the impairment affected by the aging process? And how did individuals in the two groups manage to age in place? The criteria for participation in the study were that both groups were comprised of people who were dependent on mobility assistive technologies to move further than fifty meters and who were above the age of sixty-four.<sup>2</sup> I conducted in-depth interviews with thirty-five people who met these criteria, visited them repeatedly in their homes, and observed their daily routines as far as it was possible. The first group consisted of older adults who had had a disability *before* they were retired (e.g., those who were born with a disability, seniors who had polio as children, or seniors who had acquired their disabilities during their working years as a consequence of an accident or illness). The second group was composed of individuals who had aged into a disability or acquired their mobility impairment *after* their retirement (e.g., seniors who had had a stroke, an accident, or a fall later in life, or whose ailments from decades before only manifested themselves as limited functionality in later life). Members of the latter group never

1 Switzerland has the world’s highest life expectancy for men at 81.3 years and sixth highest for women at 85.3 years (Swissinfo 2016).

2 At the time of writing (2018), the statutory retirement age in Switzerland was sixty-four for women and sixty-five for men.

spontaneously referred to themselves as having a disability, though some of them had lived with their impairments for up to twenty years. Though the differentiation of these two groups is not crucial to the argument made in this article, I mention it here, because the two groups are rarely regarded together. Yet, as part of the recent changes of what it means to age, both groups are affected due to their impairments. In this article I will introduce three participants from my study. Henry and Emma grew up with a mobility disability, while Emil's disability only manifested itself in his seventies.

That older individuals have mobility disabilities is not a new phenomenon, though their numbers are on the rise (WHO 2015; WHO and World Bank 2011). However, I argue that what it means to live with a disability in old age is currently in the process of transfiguration. The global re-shaping of old age, along with shifting Swiss aging and disability policies, practices, and narratives, impact the ways in which old age with a disability is understood and lived in Switzerland. As this process is still ongoing, it has contradicting effects on the multi-level social matrix within which both groups of seniors with disabilities age. While policy shifts encouraging positive aging paradigms increasingly concern the way in which societies expect their members to age, the group of elders presented in this paper have not (yet) been provided with the means to follow suit. There is, in other words, an increasing discrepancy between the demands fostered by the dominant discourse of 'successful aging' and the infrastructure made available to aging citizens with disabilities. By means of the three case studies, I will show how these retirees with different disabilities subjectively experienced and made sense of the changing socialities within which they were embedded.

Aging paradigms have undergone changes through a range of advancements in the areas of medicine, technology, and demography, not only in Switzerland but also on a global scale. In line with Nicholas Long and Henrietta Moore's (2013) conceptualization of sociality, these technical and medical advancements influence the sociality of elderly people with disabilities. According to Long and Moore (2013, 2), sociality has to be 'understood as the dynamic and interactional matrix through which human beings come to know the world they live in and [...] find their meaning and purpose within'. Sociality, grasped in this broader way, is therefore constituted as a constantly changing social matrix, which is shaped and re-shaped by a multitude of actors, discourses, and practices, and which goes beyond solely health-related aspects, i.e., beyond biosociality (cf. Rabinow 1996).

It is the overall aim of the Special Section of which this paper is a part to render the notion of transfiguration an analytically productive and useful resource for medical anthropological analyses (see Mattes, Hadolt, and Obrist, this issue). Transfiguration, as an analytical tool, matches well with the idea of a 'dynamic and interactional matrix' (Long and Moore 2013, 2) because it helps identify inconsistencies and discrepancies that form part of the non-

teleological, multi-level process of how my interlocutors age. What it means to age is changing, in part due to positive aging discourses and practices such as successful aging. This also influences the social matrix within which the socialities of older individuals with disabilities are formed. In this paper, I will analyze the effect of these changes through the concept of transfiguration.

Similarly to João Biehl and Peter Locke's (2017) notion of the 'unfinished', transfiguration describes an ongoing process whose outcome is as of yet unclear (i.e., is not yet resolved). In this sense, transfiguration is not to be viewed as a process of substantial re-formation of matter where, for instance, subject A, an apple, becomes subject B, a banana. Rather, it describes the effect of an ongoing process, without a clear beginning and end, which exerts a transformational force on subject A. Analytically, transfiguration is a better fit for the analysis of my empirical material than the notion of 'the unfinished', because it accounts for the phenomenon that some components remain constant within this larger process of change, while others do not.

With the use of transfiguration, I want to underline three aspects that are present in my ethnographic material. Firstly, the aforementioned ongoing and processual nature of larger societal shifts defy a clear identification of both a beginning and an end. Secondly, on a more granular level, I understand transfiguration as a multi-level process. And thirdly, depending on which aspect within this process one chooses to focus on, even components which remain constant may appear different and seem changed in the process of transfiguration. Based on these conceptual considerations, the main claim of this paper is that, in the process of the transfiguration of what it means to age with a disability at a time of positive aging paradigms, the person with the disability is re-evaluated and left transfigured. As a consequence of the introduction of successful aging and similar paradigms, elderly individuals with disabilities are disvalued.

In the following, I will briefly explore the social matrix (i.e., some of the main actors, discourses, and imaginaries) that influences what it means to age in Switzerland. This will provide an understanding of the socio-economic, political, and moral contexts in which the elderly people are embedded and the positive aging paradigms which are at the core of the described changes. In the main part of the paper, I will present three different vignettes of elderly people with a disability in order to show how the multi-level transfiguration of ideas and policies about aging impact their lived experience. Three topics will be explored in more detail in relation to successful aging: (1) the preparation for a good old age and how the changing disabled body is perceived; (2) the daily aspirations for independence and ways of coping with the dependence inherent in mobility disabilities; and (3) ideals of personhood and control as they relate to assisted suicide. The article closes with open-ended considerations on the use of transfiguration as an analytical tool.

## Aging and disability in Switzerland: The social matrix

The way we age has dramatically changed over the last few decades (see Special Issue on Aging in Europe, e.g., Bozon, Gaymu, and Lelièvre 2018; Comas-d'Argemir and Roigé 2018; Galčanová and Kafková 2018; Gusman 2018; Roigé, Soronellas-Masdeu, and Bastien-Henri 2018). This is true in the global North as well as in the global South (see Kaiser-Grolimund, this issue). As lifespans lengthen, the strains on the welfare state, the care industry, and caregivers increase, while at the same time people gain years during which they may enjoy life in good health (see Buch 2015, 2018; Grøn 2016). In this context, the idea of 'successful aging' – which posits that the cohort of the 'baby boomers' has the potential to age in an active, healthy, and productive way – is an appealing counter-narrative for government authorities as well as concerned families and individuals. But who are the main players that constitute the social matrix within which elderly individuals with mobility disabilities are embedded?

A plethora of actors are catering to the needs of elderly people with mobility disabilities. The fractured nature of Swiss federalism makes the political landscape of disability in old age complex. There are national level organizations and service providers, such as Pro Infirmis, for those with a disability, and Pro Senectute, catering for the elderly. Activist organizations (such as Seniorenrat, Procap, Agile, or Inclusion Handicap) lobby for issues concerning either the elderly or those with disabilities. The main administrative body, the Federal Social Insurance Office, operates as a large bureaucratic apparatus in the cantons and controls, administers, pays, and demands proof for the social security benefits given to elderly people with disabilities.

In addition, there are various interest groups representing different diseases and specific disabilities. Depending on their size and influence, some of them take on the role of service providers. The forms of support that are offered to individual members do not only depend on the particular disability they have but vary also depending on the specific material conditions of their homes and the geographical place in which they live. This is because, in administrative terms, responsibility for all matters concerning old age is located at the level of the municipality (i.e., villages and cities). Disability, on the other hand, is regulated on the level of the cantons, of which Switzerland has twenty-six. Municipalities administer housing, community nurses, accessibility to public transport, and toilets. Food delivery, accompanying services, and household help is often organized by smaller companies or volunteers. Care and medical assistance, neighbors, partners, kin, and friends, finally, are further crucial elements which make up the daily fabric as well as the support structures which allow elderly individuals with a mobility disability to age at home.

Technology has radically changed aging and old age in countries with developed health care and welfare, and it has become a signifier for both dependence and independence of seniors (Long 2012; Loe 2011). As a means to participate, contribute, and be active, (assistive) technologies have become increasingly important for seniors with and without disabilities. In her work on assistive devices, anthropologist Susan Long (2012) describes the material culture of elderly Japanese people as ‘silver technologies’. The aging of the ‘technoscape’ (Danely 2015) has not only introduced a whole and well-functioning industry of supposedly helpful and more or less useful devices to use in and facilitate seniors’ daily activities, but also subjected them to highly technologized medicine.

Because Switzerland is a direct democracy, Swiss citizens have to vote on referendums and people’s initiatives roughly four times a year and the law-making process is subject to public debate. Therefore, public discourse and discussions on issues concerning both aging and disability are common. In 2017, for example, the Swiss pension system, which is in dire need of a reform, dominated public discourse for months, culminating in a vote on a reform of the pension system in September. Health insurance, assisted suicide, disability benefits and rights, and pre-implantation genetic diagnostics (i.e., the genetic testing of fetuses before implantation through IVF) are only a few of the many topics which have been discussed publicly and sometimes polemically during recent years. In conversations I had with almost all of the elderly individuals in this study, these various political issues surfaced – many of them followed the different debates through radio, TV, newspapers, and discussions with friends and families.

Aske Juul Lassen and Jessica Jespensen (2017) show that in the case of Denmark and other Nordic countries, systems of old age insurance were reformed with the aim to incorporate goals of active aging, as an answer to the demographic shift and prolonged lifespans. Switzerland has implemented some of the active aging strategies on the communal and cantonal levels, but has been struggling to reform old age insurance for decades. According to J. W. Rowe and R. L. Kahn, who introduced the successful aging paradigm in 1987, active engagement with life is one of the key pillars that enables an individual to age successfully. Central to such an active engagement with life are ‘relationships with other people and behavior that is productive’ (Rowe and Kahn 1987, 40). What does this directive entail for people with mobility disabilities living in Switzerland? How far beyond retirement are people with disabilities in old age enabled to also participate in a lifestyle of activity and productivity?

To answer this question, a look at Switzerland’s social security system and underlying assumptions about disability helps us to understand how positive aging paradigms may become discriminatory towards people with disabilities. As argued elsewhere on the topic of disability within the Swiss social security system, with the comparatively early statutory retirement age of sixty-four for women and sixty-five for men, people with disabilities enter a new status and are no longer labelled *disabled*, but *old* (Rickli 2016). This classificatory shift is

closely tied to the fact that disability is defined in terms of the inability to work within the *Invalidenversicherung* (disability insurance). Consequently, only those who fall into this definition are entitled to benefits, which range from receiving support, such as assistive technologies which make a workplace accessible, to livelihood support in the form of a pension. Because retired individuals are per se thought of as not working, they are no longer seen as needing these benefits.

Social security benefits are granted on the basis of a normative conceptualization of the life course, which ascribes certain roles and activities to different age-sets (Rickli 2016). Within positive aging paradigms, expectations and roles of individuals beyond retirement have changed. However, for younger retirees with mobility disabilities, wanting to be active or even productive is especially hindered by the change in status from disabled to old. No longer paying for new assistive technologies, the old age pension system ignores the fact that a disabled body – as every other aging body – undergoes constant changes and processes, leading to different needs in order to continue fulfilling a social role. Thus, certain assistive technologies that were covered by disability insurance during the working years of ‘a disabled person’ can no longer be claimed once the same person has reached retirement age and is classified as ‘elderly’. The underlying rationale is that seniors with disabilities no longer need to participate in society: their role now expects them to stay at home. In today’s changed social context, where senior citizens are supposed to lead a healthy, active lifestyle, seniors with disability are denied support by the state to ‘adequately function-in-context’ (Jenkins 1999) and therefore to age in the same active ways expected of their non-disabled peers.

According to positive aging paradigms, old age generally is a project of self-fulfillment, focused on a healthy mind in an active and well-functioning body. But what does this mean for people with disabilities, whose bodies have not conformed to ideals of functionality even in younger years? In terms of juridification on a global scale, the situation for people with disabilities has improved in the recent decades. The UN Convention for the Rights of People with Disabilities (UNCRPD) was adopted in 2006 and to date has been ratified by 172 countries – Switzerland signed the convention in 2014. Although the convention does not explicitly address the case of seniors with disabilities, it states that all people with disabilities have the right to participate in mainstream society. In spite of not being legally binding, ratifying the convention has pushed the agenda of disability rights into the arena of mainstream politics in Switzerland.

As this non-exhaustive overview shows, a multitude of actors, discourses, organizations, and imaginaries constitutes the matrix through which disability in old age is pre-structured and experienced in Switzerland. It is important to understand that this matrix is not orchestrated. Rather, different actors within it operate according to various timelines towards achieving their

specific goals. Such varying processes of change may have contradicting effects on the sociality of seniors with disabilities.

Here we can detect some first traces of the effects of transfiguration. The ratification of the UNCRPD contributes to a new understanding of disability which is grounded in participation and independence. Policies centered on active aging also demand activity and engagement on the part of elderly individuals (BfS 2018). Other elements of the matrix, however, remain unchanged: the structural transition from disability to old age insurance at the age of sixty-four or sixty-five, for example, is based on a rather different conceptualization of disability. In the first case study we examine, one of the elements making up the social matrix of elderly people with disabilities has changed while another remains constant, and both of these elements have an equal effect on the older individuals.

Another example can be found in the fact that the bodies of people with disabilities are often sites of different imaginings about old age and disability. The bodily experiences of an older person with a mobility impairment might be comparable to one of a different person with a mobility impairment some decades ago. Yet, through the changed social matrix, the old and impaired body as a site of cultural imagination is transfigured and signifies something different today. Through the process of transfiguration – understood here in the sense of a steady substance, but a changing context – a discrepancy emerges between the expectations for an aging population and the services provided by the health and social security system for older people with disabilities.

## Responsible bodies or preparation for a good old age

In her article on the retirement narratives and planning of senior citizens, Debbie Laliberte Rudman (2015, 16) writes about ‘the ways in which they disciplined their bodies and engaged in various types of activities, such as dieting, exercising, consulting with experts, and consuming health promoting and age defying products, to monitor, maintain and optimize their bodies’. Preparing for aging is therefore closely tied to bodywork. Monitoring, maintaining, and optimizing their bodies were key strategies of preparing for old age in the case of the able-bodied participants in Laliberte Rudman’s study. The main difference between the individuals in her study and the people with mobility disabilities I have worked with lies in the type of attention they give to the body. The bodies of people with disabilities have been sites of the manifestation of their difference for decades, inasmuch as they have constantly prevented them from participating in mainstream society in the same way as able-bodied others. As the following example of Henry shows, attentiveness to their bodies and bodily practices are therefore second nature to persons with a physical disability.

Henry, a retired psychoanalyst and passionate photographer, lives with his wife and son in a rural part of Switzerland with a wonderful view of a glistening lake. He was eight years old when he contracted polio. After a period of full paralysis, during which he had to spend time in an iron lung, the muscles in his upper body recovered well. With the help of a stick, he was able to walk for many years. Exercise and sports have always been important to him and he is proud of the fact that he still managed to climb high mountains when he was thirty-five. At the age of around fifty-five, however, the paralysis in his upper body started returning, and he had progressive pain, felt tired, and had difficulties in concentrating. Henry did not understand what was happening to him and decided to commence training to rebuild his strength. He started lifting weights daily and initiated a self-imposed fitness routine, though to no avail. His strength did not improve. One day, he had a coincidental encounter at a gas station with a person who told him about post-polio syndrome (PPS). Alarmed by this information, Henry made an appointment with one of Switzerland's few remaining polio doctors and was indeed diagnosed with PPS. Even though it is not entirely clear what causes the syndrome, PPS is generally attributed to the 'excessive long-term stress on the motor neurons that survived infection [which] leads to their premature degeneration' (Groce, Banks, and Stein 2014, 173). This means that Henry and others affected by PPS experience increasing pain or paralysis in their lower limbs, and often encounter shoulder problems, worsening eyesight, and concentration wanes. Henry was strongly advised to change his fitness routine. He explained that it was difficult to find acceptance for practices of preserving strength and sparing one's energy in today's society:

Because everyone says, 'Why don't you train your muscles, why can't you re-build your strength?'. The fact that one should do nothing is not part of popular belief, people don't want to accept it. Because today there is this tendency to be fit and to go jogging in the forest, etc. And people maybe are also projecting their own fear of loss of functionality [...]. They say: 'Can't you inject something into your muscles? Protein?'. I hear that a lot. Accepting that there is a different way of preparing for old age, which isn't being active, but passive, so that it simply remains the same, this to me is societal, because activity has a much more positive connotation. (Henry, May 2015)

One key assumption of positive aging paradigms is that each person has the agency to control their health and wellbeing and should also want to take on this responsibility in old age (Lamb, Robbins-Ruszkowski, and Corwin 2017, 8). Rowe and Kahn (1987) defined the three key directives leading to a successful old age as: (1) avoiding disease and disability as far as possible; (2) maintaining physical and cognitive function; and (3) continuing active engagement with life. Resonating with other imperatives of healthy living, such as avoiding becoming overweight, not smoking, or staying fit through regular exercise, positive aging paradigms require the individual to take responsibility for their own health and wellbeing. Consequently,

for the individuals with a disability who participated in this study, thinking about aging and acting accordingly started long before they retired.

Henry's case shows that the assumption that responsibility for a healthy body lies with the individual entails that a decline in wellbeing, health, or functionality starts to be seen as the consequence of an unhealthy lifestyle. Intriguingly, many other participants with PPS told me similar stories – they had to accept that they must treat their bodies in a sometimes-counterintuitive way (e.g., holding back and sparing their energy instead of constantly pushing themselves to the limit). Therefore, while 'decline and passivity are being fashioned as problems that can be solved through correct activities and proper lifestyle choices' (Lassen and Jespersen 2017, 148), realizing that prevention for their bodies might just lie in passivity, rather than activity, requires an act of resistance against dominant morally loaded discourses.

Henry, and many others who are aging with a disability, were told by medical professionals at some point in their lives that it is their task to restrain or train their bodies to prepare for a good old age. Though aware of his body's difference, Henry's subjectivity – fostered through decades of proving his abilities to function in the job market, at home, or in personal relationships – also motivated him to maintain this practice of self-care. Interactions with neighbors or friends about his changed attitude to physical practice are met with incomprehension. This indicates that the people surrounding him have been equally influenced by the dominant discourse of healthy aging, leaving Henry and other individuals with a mobility disability in an awkward position.

In Henry's case, not listening to his surrounding's advice and acting counterintuitively was a form of resistance. Other elderly individuals with mobility disabilities have found further ways of resisting the dominant order of successful aging and the behaviors of activity prescribed within it. One such example which comes to mind are forlorn-looking sports devices which had found their ways into households to promote active movement, which have clearly not been used for years and are now only commented on by their owners with a smile and a shrug.

Discourses and practices of positive aging paradigms feed into the social matrix within which Henry and other senior citizens with mobility disabilities are embedded. They influence moral imaginaries of what a responsible member of society is supposed to do in order to reach a good old age. Though, as was shown in the case of Henry, they might not hold useful directives for older individuals with mobility disabilities, they still have a transfigurational effect on them. Especially because successful aging holds such promise to lighten the burden of old age, it leaves those who cannot follow marginalized even further.

## (In)dependence

The current trend towards more individual responsibility and independence can also be traced in the public discourse leading up to the reform of the pension system in Switzerland.<sup>3</sup> One of the key arguments made by opponents to the reform was that it was not fair for the younger generation, due to an increasing dependency ratio caused by the number of retiring baby boomers. Interestingly, in these heated debates it seemed to be forgotten that this very solidarity between the generations, the so-called ‘generational contract’ inscribed in the system, used to be considered key to a well-functioning co-existence of the generations in Switzerland. Sarah Lamb’s (2017, 10) analysis of the American case also holds for Switzerland, in that ‘this focus on independence obscures the actual interdependence that exists throughout the lifecourse’. Dependence on care at the end of the life cycle used to be an expected marker of old age (see Jenkins 1999; Lamb 2017). Today, that dependence has negative connotations. How is it understood by individuals whose frail bodies make them physically dependent on others?

Consider the case of eighty-two-year-old Emil, whose sick bed, rented from the hospital in town, stands under a large map of the world, hung across the width of the room. With his back propped up against a couple of pillows which make it easier for him to talk to me, the former businessman, who used to work in the fabric trade, tells me about bygone journeys to countries around the world and his lifelong passion for hiking. We are sitting in his son’s childhood bedroom, which is now Emil’s as it is situated on the ground floor. The room is only slightly wider than his bed and accommodates a cupboard with care equipment in it and a portable toilet, which is covered with a sheet when visitors come. His bed, the adjacent living room – decorated with bright wallpaper and some pieces of art from Indonesia – and a large TV have been Emil’s realm for the last one-and-a-half years. That is how long it has been since he last ventured down the three steps outside his front door, walked along the narrow stone path in his garden and around the house, climbed up two more steps, and strolled down his quiet residential street, lined with large old houses.

In terms of his frailty, Emil would have been considered congruent with the image of old age a few decades ago. He lives with his wife in a two-story building. When Emil moves without his walker, he hardly manages to defy gravity. He walks bent over with his back at an angle of about ninety degrees in relation to his legs. This is due to polyneuropathy, for which, he

3 On 24 September 2017 there was a popular referendum on the Swiss pension system that put to the vote a package to reform old age insurance. Among other issues, citizens voted on whether the pension age for women should be raised to sixty-five and VAT increased to ensure increased financing for senior citizen pensions until 2030. The vote was rejected.

laments, there is no satisfactory treatment. Due to his advanced age, he might be subsumed as being in his fourth age, where increasing frailty and dependence is expected and accepted (Loe 2011; Gilleard and Higgs 2011). Nevertheless, his musings about being both dependent and independent show his internal struggles with his social role. He explains to me:

The good thing is I am still independent [*selbständig*], I can go to the toilet on my own, can put on my clothes, I can shave, wash myself. I can adapt to the circumstances. Even if my wife goes on a holiday, I tell her: 'Go enjoy yourself, I will manage somehow'. Because I rely on my wife a lot, it is important to me that she gets time off to relax. Yes, of course I rely on my wife [*abhängig sein*], but I am also independent. (Emil, June 2016)

Being independent and self-determined are topics which often came up in my conversations with elderly people. In an insightful piece on 'comfortable aging', Meika Loe (2017) describes the ability to ask for help as one of the key elements of dealing with extreme old age. Her findings contrast with what I have found in my research: many of the elderly people I have worked with feel uncomfortable accepting help, especially in cases where they cannot reciprocate. What was often mentioned in this context by my participants was a desire or a need to be self-reliant and not dependent on an entity, such as the state, the wider family, or the community. Rather than being a class or gender issue, I think this difficulty in asking for and accepting help stems from core Swiss values such as independence (*Selbständigkeit*), self-determinacy (*Selbstbestimmtheit*), and humbleness (*Bescheidenheit*), which were mentioned in some form by all my participants and which I consider of particularly high value for the generation I have worked with.

Emil's case shows that he attempts to re-negotiate what independence means to him. I found similar efforts in other senior citizens in my sample. With increasing impairment and loss of functionality, senior citizens with disabilities steadily adjust their understanding of independence and, in so doing, mirror dominant discourses about the desire for as much independence as possible even in advanced old age. What is striking about Emil's case, though, is the fact that he has not tried or been enabled to leave his property in ways other than walking. Theoretically, he would be entitled to a simple wheelchair through his old age insurance. A wheelchair could be of use to Emil on the ground floor of his home and it might even enable him to go beyond his house. It appears, however, that he was never told about this option by a social worker or his physiotherapist. It is Emil's goal to restore his ability to walk, rather than deal with his present situation of immobility and therefore his actual limited functionality. This is curious: would a larger radius of mobility not also mean more independence?

Vis-à-vis the main publicly funded actors, the label of ‘elderly person with a disability’ is non-existent. While the labels ‘old’ and ‘disabled’ exist in the context of insurance, the double label ‘old and disabled’ does not, because disability in old age is not explicitly framed as a problem. In the case of disability in old age, what is at stake is a process of non-labelling and non-framing, which ‘means that certain issues and peoples can be omitted from policy and programme agendas’ (Moncrieffe and Eyben 2013, 3). As noted above, cities and villages provide services for ‘the old’, but this does not necessarily mean that these services can be accessed by those with a disability above sixty-five years of age. Yet, services targeted at people with disabilities are often limited to the age before retirement. The inexistence of the category ‘old and disabled’ has largely to do with the two categories of insurance and the needs that existed when they were established in the 1950s and 1960s. At that time, it was assumed that disability insurance would help integrate a person into the working environment or compensate for the inability to do so, while old age was understood as a period of declining activity for everyone, whether they had been disabled before or not. As outlined above, however, the latter assumption has undergone a substantial transformation: aging is no longer framed as a period of passivity, but activity, productivity, and by implication mobility.

Emil’s example thus shows how the expectations of and from elderly persons in terms of their mobility are not congruent with what is offered or actively promoted in terms of mobility assistive technologies or accessible surroundings, though it would contribute to their independence. In the multi-stranded process of transfiguration of what it means to age well, mobility devices are not seen as part and parcel of enabling a person to be independent. Rather than being incorporated into positive aging paradigms for their potential to give freedom and independence, wheelchairs, walkers, or rollators in Switzerland are still associated with fragility, decline, and dependence.

## Pondering the end of life

Towards the end of my research, a new topic was repeatedly mentioned by different senior citizens. There was one instance, for example, when two spouses asserted that no matter what, they would eventually ‘leave their house together’. This referred to the fact that, if one of them were to fall ill seriously, they said they had a plan B: assisted suicide. Other participants were deeply troubled by the topic and found it hard to discuss. In Switzerland, *Freitod* (assisted suicide) is legally allowed and is performed through organizations such as Exit or Dignitas. Both associations support and administer accompanied suicide in cases of medically proven ‘unendurable pain or an unendurable disability’ (Dignitas 2018). One has to be a member of the organization in order to take up their services. The organizations have become part of the matrix which makes up the sociality of old age in Switzerland and, as I will show in the

following, increasingly influence the subjectivity of elderly people with disabilities (see Andrade de Neves, this issue).

Following Lamb et al.'s (2017, 11) critique of the idea of successful aging, I question the 'vision of the ideal person as not really aging at all in later life but rather maintaining the self of one's earlier years, while avoiding or denying processes of decline and conditions of oldness'. This ideal of keeping up one's personhood until the end of the life course (i.e., until one's death) is a rather extreme aspect of successful aging. It entails pushing back against facts of life, such as a changing body, increasing frailty, and dependence as one becomes older. In my research, I have found traces of this discourse reflected in older people with disabilities' experiences with the discourse around assisted suicide. It could be argued that with liberal regulations on assisted suicide, dying can become a matter of choice, before the above-mentioned 'processes of decline' sets in. The following example of Emma illustrates the potential impact of the discourse around self-determined dying on the subjectivity of older people with disabilities.

Emma is seventy-seven years old and moved into a small apartment in an expensive old-age residence about two years ago. From her small balcony she has a magnificent view of an almost turquoise lake set against a backdrop of snow-covered peaks. The stately complex feels more like a hotel than a nursing home. Emma grew up in a poor family of farmers and worked as a disability insurance administrator for decades. She saved her and her late husband's money with the aim of being able to afford a good life in old age. She, too, had polio and is now affected by PPS. When she moved to the residence, she was still able to transfer from her electric wheelchair to her bed. About a year after moving, her hips stiffened, and she now needs assistance in transitioning to and from her bed to the wheelchair, personal hygiene, dressing herself, and going to the toilet. Emma describes most of the other residents as wealthy and highly educated. Her expectations of living with elderly people – many of them are ten years older and more – were that they would understand and accept her disability.

It came as a surprise to her, then, that so many of them have asked her from which home for the disabled she had been transferred (she had owned a flat and worked her entire life) and how she was now able to afford to live in this elegant residence (which she was because she had sold her flat). Sensing the prejudices held against her, she refuses to answer these questions unless the ones asking show genuine interest in her life in more general terms. Emma is irritated by the way death and dying are talked about and handled by some of her peers. In a weekly discussion group that she attends, and which is led by a pastor, the topics of dying and a good death are often discussed. The attitudes of some of the other attendants sadden her: many of them say that they would want to die rather than to live on if they were no longer able to go to the toilet on their own or needed help dressing. When she described the day of the assisted suicide of one of her friends at the residence, her narrative expressed how much

she understood her friend's decision as a commentary on her own life: many of the fellow residents see her as having a lesser quality of life.

Personhood, as discussed in anthropology, has been connected to functionality since Mauss's (1938) seminal lecture on the concept of the person. If the ideal of permanent personhood is taken to an extreme, waning functionality of the body is concomitant to no longer having an intact personhood. What is the impact of such a narrative? Can Exit and other organizations offering assisted suicide be read as an ultimate strategy of successful aging? Thinking along these lines, one must not forget that assisted suicide can enable suffering individuals to die with self-determination and grace. Therefore, it is not the actual practice that is the problem, but rather the imaginative space which is opened up through it. This space is in line with successful aging's central theme of having control. At the point where the much-dreaded decline and frailty of the body threatens to win the upper hand, control can be regained, rather than adjusting one's sense of self to encompass changing functionality and mortality. I do not know why the elderly individuals in Emma's retirement home chose to die. However, their wish is threatening and loaded with negative connotations for Emma and other individuals with mobility disabilities who had to learn to cope with successively losing control, independence, and bodily functionality.

Some individuals, Emma among them, experience assisted suicide as a real and looming threat to their right to exist. Positive aging discourses and Swiss regulations on *Freitod* influence the social matrix within which the participants of this study age. Through this process, the subjective understanding of what it means to age and die with a disability is transfigured. In the course of this transfiguration, subjectivities linked to disability are contested. Subjectivities fostered around being able to deal with pain, needing to let go of ideals of independence, and capping the ties between intact functionality and personhood are deeply questioned by the practice of being able to choose death. Consequently, questions of independence (*Selbständigkeit*) and self-determination (*Selbstbestimmung*), which were key elements in decades of activism for disability rights, become difficult terrain within discussions about the choice to end life.

## Conclusion: Transfiguration incomplete

The discourses and expectations, practices and infrastructure concerning old age (i.e., the social matrix within which seniors with disabilities age) have changed substantially in recent decades, sometimes leading to paradoxical outcomes for the socialities of senior individuals with mobility disabilities. While frailty and dependence were regarded as normal traits of old age for a long time, today they have been replaced with activity and self-determination. This shifting normative aging paradigm slowly induces a new set of aging practices. Yet, many

seniors who feel frail or have disabilities do not feel represented in this changed understanding of aging and fear discrimination in old age, because, as was shown, the Swiss social security system, among other factors, has not been adapted to the changing circumstances. As a consequence, seniors with mobility disabilities are left transfigured – while their physical condition remains the same, they have come to stand for frailty and dependence in a society that values youth, activity, and productivity. In light of the current normative imaginaries of old age, those with functional limitations such as mobility disabilities appear less successful and run the risk of being de-valued.

The process of change in terms of what it means to age is ongoing. The aim of this paper was to take a closer look at how people with mobility disabilities in old age currently deal with and make sense of both disability and aging. As shown, rather than aiming to age successfully according to ideals of control, activity, independence, and permanent personhood, Henry, Emil, Emma, and others in my study re-negotiate their subjectivities within the new aging paradigm.

In this analysis, it should have become clear that an ideological turn towards more individual responsibility in the aging process and societal striving for healthier, longer lives should also be accompanied by structural changes in the social security system. For example, taking the paradigm of active aging seriously, the definition of *Invaliddität* (disability) in the context of *Invalidenversicherung* (disability insurance) could be widened. Instead of only supporting those who show ‘the incapacity to work’, a phrasing such as ‘the incapacity to participate meaningfully’ would include senior citizens with disabilities and support them with assistive technologies and assistance to contribute within the social roles of the old.

Finally, what then is the benefit of using the notion of transfiguration? The open-ended, fast-paced nature and multitude of actors involved in many of the health-related processes that we analyze as medical anthropologists need analytical tools – tools which can deal with their complexity. Naturally, processes of change are hardly ever characterized by linearity, but rooted in the messiness of life. My analysis of the changing social matrix and its consequences for the two groups of senior citizens portrayed is a mere snapshot of an unfinished process. In this context, I found value in the notion of transfiguration because it helped me to map which aspects of a larger process have changed and are new, and which ones, though they remain unchanged, appear new due to a changing larger context.

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## References

- BfS. 2018. 'Aktives Altern – Demos 1/2018'. 26 April. <https://www.bfs.admin.ch/bfs/de/home/statistiken/kataloge-datenbanken/publikationen.assetdetail.5046989.html>.
- Biehl, João, and Peter Locke, eds. 2017. *Unfinished: The Anthropology of Becoming*. Durham, NC: Duke University Press.
- Bozon, Michel, Joëlle Gaymu, and Eva Lelièvre. 2018. 'L'expérience du vieillissement autour de la soixantaine en France. Âge subjectif et genre'. *Ethnologie française*, 171 (July): 401–412. <https://doi.org/10.3917/ethn.183.0401>.
- Buch, Elana D. 2015. 'Anthropology of Aging and Care'. *Annual Review of Anthropology*, 44: 277–293. <https://doi.org/10.1146/annurev-anthro-102214-014254>.
- Buch, Elana D. 2018. *Inequalities of Aging: Paradoxes of Independence in American Home Care*. New York: NYU Press.
- Comas-d'Argemir, Dolores, and Xavier Roigé. 2018. 'Les nouveaux visages du vieillissement en Europe, entre famille et État'. *Ethnologie française*, 171 (July): 389–400. <https://doi.org/10.3917/ethn.183.0389>.
- Danelly, Jason. 2015. 'Of Technoscapes and Elderscapes: Editor's Commentary on the Special Issue "Aging the Technoscape"'. *Anthropology & Aging* 36 (2): 110–111. <https://doi.org/10.5195/aa.2015.121>.
- Dignitas. 2018. [www.dignitas.ch](http://www.dignitas.ch) (accessed 15 April 2018).
- Foster, Liam, and Alan Walker. 2014. 'Active and Successful Aging: A European Policy Perspective'. *The Gerontologist*, 55 (1): 83–90. <https://doi.org/10.1093/geront/gnu028>.
- Galčanová, Lucie, and Marcela Petrová Kafková. 2018. 'Self-Perception during the Transition to the Fourth Age in the Czech Republic'. *Ethnologie Française*, 171 (July): 413–426. <https://doi.org/10.3917/ethn.183.0413>.

- Gilleard, Chris, and Paul Higgs. 2011. 'Frailty, Disability and Old Age: A Re-Appraisal'. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* 15 (5): 475–490. <https://doi.org/10.1177/1363459310383595>.
- Groce, Nora Ellen, Lena Morgon Banks, and Michael Ashley Stein. 2014. 'Surviving Polio in a Post-Polio World'. *Social Science & Medicine* 107 (Supplement C): 171–178. <https://doi.org/10.1016/j.socscimed.2014.02.024>.
- Grøn, Lone. 2016. 'Old Age and Vulnerability between First, Second and Third Person Perspectives. Ethnographic Explorations of Aging in Contemporary Denmark'. *Journal of Aging Studies* 39 (December): 21–30. <https://doi.org/10.1016/j.jaging.2016.09.002>.
- Gusman, Alessandro. 2018. 'Mourir chez soi. Le cas de la médicalisation du domicile en Italie'. *Ethnologie française*, 171 (July): 503–514. <https://doi.org/10.3917/ethn.183.0503>.
- Hank, Karsten. 2011. 'How "Successful" Do Older Europeans Age? Findings from SHARE'. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 66 (2): 230–236. <https://dx.doi.org/10.1093%2Fgeronb%2Fgbq089>.
- Jenkins, Richard. 1999. *Questions of Competence: Culture, Classification and Intellectual Disability*. Cambridge: Cambridge University Press.
- Katz, Stephen, and Toni Calasanti. 2014. 'Critical Perspectives on Successful Aging: Does It "Appeal More Than It Illuminates"?. *The Gerontologist*, 55 (1): 26–33. <https://doi.org/10.1093/geront/gnu027>.
- Laliberte Rudman, Debbie. 2015. 'Embodying Positive Aging and Neoliberal Rationality: Talking about the Aging Body within Narratives of Retirement'. *Journal of Aging Studies* 34 (August): 10–20. <https://doi.org/10.1016/j.jaging.2015.03.005>.
- Lamb, Sarah, ed. 2017. *Successful Aging as a Contemporary Obsession: Global Perspectives*. New Brunswick: Rutgers University Press.
- Lamb, Sarah, Jessica Robbins-Ruszkowski, and Anna Corwin. 2017. 'Introduction: Successful Aging as a Twenty-First-Century Obsession'. In *Successful Aging as a Contemporary Obsession: Global Perspectives*, edited by Sarah Lamb, 1–23. New Brunswick: Rutgers University Press.
- Lassen, Aske Juul, and Jessica Jespersen. 2017. 'Getting Old and Keeping Going: The Motivation Technologies of Active Aging in Denmark'. In *Successful Aging as a Contemporary Obsession: Global Perspectives*, edited by Sarah Lamb, 141–153. New Brunswick: Rutgers University Press.
- Loe, Meika. 2011. *Aging Our Way: Lessons for Living from 85 and Beyond*. Oxford: Oxford University Press.
- Long, Nicholas J., and Henrietta L. Moore, eds. 2013. *Sociality: New Directions*. Oxford: Berghahn Books.
- Long, Susan O. 2012. 'Bodies, Technologies, and Aging in Japan: Thinking About Old People and Their Silver Products'. *Journal of Cross-Cultural Gerontology* 27 (2): 119–137. <https://doi.org/10.1007/s10823-012-9164-3>.

- Mauss, Marcel. 1938. 'Une Catégorie de L'Esprit Humain: La Notion de Personne Celle de "Moi"'. *The Journal of the Royal Anthropological Institute of Great Britain and Ireland* 68: 263–281. <https://doi.org/10.2307/2844128>.
- Minkler, Meredith, and Pamela Fadem. 2002. "'Successful Aging': A Disability Perspective'. *Journal of Disability Policy Studies* 12 (4): 229–235. <https://doi.org/10.1177/104420730201200402>.
- Moncrieffe, Joy, and Rosalind Eyben, eds. 2013. *The Power of Labelling: How People Are Categorized and Why It Matters*. London: Earthscan.
- Rabinow, Paul. 1996. *Essays on the Anthropology of Reason*. Princeton: Princeton University Press.
- Roigé, Xavier, Montserrat Soronellas-Masdeu, and Sara Bastien-Henri. 2018. 'Vieillesse, divorce et recomposition familiale. Nouveaux défis dans les relations d'aide aux personnes âgées'. *Ethnologie française*, 171 (July): 465–478. <https://doi.org/10.3917/ethn.183.0465>.
- Rickli, Francesca. 2016. "'No Longer Disabled" – Reflections on a Transitional Process Between Disability and Aging in Switzerland'. *Review of Disability Studies: An International Journal* 12 (2 & 3): 1–15.
- Rowe, J. W., and R. L. Kahn. 1987. 'Human Aging: Usual and Successful'. *Science*, 237 (4811): 143–149. <https://doi.org/10.1126/science.3299702>.
- Swissinfo. 2016. 'Swiss Men Have World's Longest Life Expectancy'. 19 May. [https://www.swissinfo.ch/eng/business/who-statistics\\_swiss-men-have-world-s-longest-life-expectancy/42165428](https://www.swissinfo.ch/eng/business/who-statistics_swiss-men-have-world-s-longest-life-expectancy/42165428).
- WHO. 2015. *World Report on Ageing and Health*. Geneva: World Health Organization. <https://www.who.int/ageing/events/world-report-2015-launch/en/>.
- WHO, and World Bank. 2011. *World Report on Disability*. Geneva: World Health Organization. [https://www.who.int/disabilities/world\\_report/2011/report.pdf](https://www.who.int/disabilities/world_report/2011/report.pdf).