

## ‘Extreme Forms of Aging:’ The Case of Sam Berns

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ABSTRACT: By discussing the aging disorder progeria as depicted in the HBO documentary *Life According to Sam*, this paper argues that extraordinary forms of aging allow us to gain new insights into the cultural construction of age. The paper explores the ways in which age is culturally constructed through physical and behavioral aspects. The condition of progeria, puts individuals in between these categories, providing an angle to look at the way subcategories of age influence a person’s perception about age and aging in a given social context. Moreover, the essay connects methods from age studies as well as disability studies and suggests a dialogue between the two fields. Progeria, causing the body to age at a tremendously accelerated rate, serves as a suitable point of inquiry. On the one hand, it is an aging disorder at the junction between disability and age while, on the other, it challenges normative assumptions of age and aging by juxtaposing different subcategories of age within a single individual.

KEYWORDS: Progeria; Age Studies; Disability Studies; Documentary Film; Cultural Constructions of Age; Extreme Aging

### Introduction: The Biological and the Cultural Realm of Age

In his discussion of the doing and undoing of categories of difference sociologist Stefan Hirschauer elaborates that “cultural phenomena—as opposed to naturally given differences—consist of contingent symbolic *differentiations* which are shaped by specific historical and geographical contexts” (170, my translation).<sup>1</sup> I see age as such a cultural phenomenon which—like race, class, and gender—is defined through human differentiations that are made important in a given society through historical and cultural contexts. Age then, may have different meaning to different people in different temporal, social, and cultural contexts. But what exactly is age and what is aging? Numerous scholars from a wide range of academic fields have asked these questions. The discipline of classic gerontology deals with the biological components of age, inquiring what processes within a human’s body lead to the phenomenon of aging. These biological studies aim at slowing down the aging process with some researchers even trying to eradicate it altogether. In that connection, ‘old’<sup>2</sup> age is

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<sup>1</sup> The original German version reads: “kulturelle Pänomene – anders als naturhaft gegebene Unterschiede – aus kontingenten sinnhaften *Unterscheidungen* bestehen, die von historisch und geographisch spezifischen Kontexten geprägt sind.”

<sup>2</sup> I use the word ‘old’ in quotation marks throughout this paper because ‘old’ as a category is completely arbitrary. There is no consensus on what ‘old’ is. Rather there are cultural images that are associated with

often regarded as an illness that needs to be cured. Biomedical gerontologist Aubrey de Grey, for instance, has established the research foundation SENS, in order to “repair the damage underlying the diseases of aging” (SENS Research Foundation n. pag.). This medicalization of the aging body leads to a focus on its decreasing abilities which, in turn, suggest that ‘old’ age is a realm that solely consists of illness and misery. In that sense, these biological approaches to age support a cultural context that fosters an imagery of ‘old’ age as purely negative.

Besides this biological component, however, there are social and cultural aspects with an undeniable effect on the way we age, the way we structure our life course, and the way we perceive ourselves and are perceived by others. These approaches to age as a cultural construct try to identify the mechanisms behind the processes of aging that are influenced by biology, culture, and society. In that connection, Margaret Gullette argues that “[i]n age, as in gendered and racialized constructs, relations of difference depend on the dim of representations, unseen internalizations, unthinking practice, economic structures of dominance and subordination” (27). As well as gender and race, age is thus a construct that is shaped by cultural imaginaries and ideologies. In her book of the same title Gullette thus argues that we are *Aged by Culture*. She suggests the formation of the culturally determined field of age studies, to undo “the erasure of the cultural in the sphere of age and aging” (102). Her argument thus critiques approaches such as de Grey’s of underestimating the power of cultural contexts in which the aging body emerges and calls for approaches to the aging process that take into account the structures behind its construction.

In this paper, I explore the cultural construction of age through an extraordinary case of ‘old’ age. The 2014 HBO documentary *Life According to Sam*, which serves as the basis for my argument, depicts Sam Berns, a teenager with Hutchinson-Gilford progeria syndrome (short progeria). Progeria is a rare aging disorder that lets the human body age at a tremendously accelerated speed.<sup>3</sup> This rare condition then offers insights into cultural constructions of age

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the status of being ‘old’ and a person who fits those images is considered to be ‘old.’

<sup>3</sup> To describe the condition as a mere acceleration of the aging process is a simplification of its biological complexities. While children with progeria develop wrinkled skin, arthritis, and heart disease, other diseases that are a common medical issue among aged populations, such as cancer, are not common amongst these children. Further, children with progeria are, in the very beginning of their lives,

by juxtaposing its cultural, social, and biological dimensions. Sam Berns takes up the social role as a student in junior high school, which dictates the way his stage in life is culturally imagined. At the same time, his body is ‘old,’ linking him to cultural imaginaries of physical ‘old’ age. In their discussion of the discourses surrounding age in Western societies, Mita Banerjee and Norbert Paul suggest that “[i]n order to overcome the established rhetorics of aging, we are in need of ‘wake-up calls’” (271). In other words, it is necessary to look at cases that deviate from normative expectations of the aging process. Just as gerontologists interrogate ‘extreme forms of aging’ to reveal its biological secrets, I thus argue that the same can be done for the cultural construction of ‘old’ age by looking at these ‘wake-up calls.’ By considering an example that stretches the boundaries of age and aging culturally as well as medically, I will explore how age is culturally constructed through various subcategories. Ultimately, I argue, a discussion of progeria, as an ‘extreme form of aging’ can contribute to the field of age studies in general by making visible numerous aspects that work together to form a cultural understanding of what age is. Through this visibility, in turn, the condition allows a closer look at the contexts in which a certain category of age becomes important for the definition of age as a whole.

### **The Subcategories of Age**

In order to understand age as a cultural phenomenon it is important untangle its several subcategories. In this context, Sinikka Aapola defines age as a “multidimensional social and cultural phenomenon” (330) and thus divides age into four different aspects. She connects (1) chronological age—the number of years lived, (2) physical age—the aging body, (3) experiential age—one’s personal age experience, and (4) symbolic age—the social connotations attached to a person’s stage within the life course. In this article, I will lay the emphasis on the second and third point: physical and experiential age. Symbolic age, however, will inevitably be a part of the discussion since the effects images of age have on a person’s role within society are inextricably linked to all other categories Aapola describes. To focus on only three subcategories allows for a shift of attention away from the number of years a

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categorized as younger as their peers because of a decelerated growth of the body. This paradox, which is certainly part of the overall discussion of progeria in general, is never in the focus of the narrative I am discussing in this particular paper and therefore, for now, left out of my discussion.

person has lived. This last aspect usually acts as the most authoritative feature of age in Western societies, as chronological age is inscribed into everyday lives through institutions and laws. Current scholarship on age and aging has begun to criticize the obsession with chronological age as a signifier for the 'old.' For instance, Silke van Dyk asks: "Why is it . . . that a 70-year-old marathon runner should have more in common with a 90-year-old demented person than with a 50-year-old manager?" (99). What van Dyk implies here is that the way a person acts should have more to say about his or her stage in life than the mere number of years he or she has lived. However, the cultural connotations connected to chronological age, albeit irrelevant in determining the way a person acts, have the power to categorize that same person as 'old' or 'young.' Considering the arbitrariness of chronological age, it becomes questionable if it should be given the power to determine a person's social role within the life course at all. By shifting the focus away from the arbitrary measurement of chronology, other features of age and the part they play in constructing a life course can be seen more clearly. Nevertheless, as chronology is deeply rooted in the mindset of Western culture, it is impossible to discuss age regardless of its connotations. It is a part of the discussion, at least to the point that the readers of this article—and I as the writer am in the same position—will often tend to think about the issues at hand from the perspective of chronology. Yet, I am trying to consciously neglect it in order to focus on other aspects of age. I am thus interested in the way the narrative of Sam Berns' life challenges what Aapola calls physical and experiential age.

Physical age, according to Aapola is "a person's bodily condition, his/her ability to function and outer appearance" (304). Usually, the visual features of age are the first thing people recognize when encountering other individuals: the way a person dresses and moves, the smoothness of skin, and the color of hair. All these features make implications about age based on the cultural assumption that 'young' people are beautiful, independent and agile whereas 'old' people are unattractive, immobile and fragile. In that connection, Kathleen Woodward criticizes "the virtual obsession of western culture with youth and with the appearance of the body" which leads to a "binary between beauty and the so-called ravages of time [and] between health and disability, figured as old age" (xvi-xvii). As the concept of physical age, thus, leads to a cultural image of 'old' age as undesirable and connected to disease, it is closely related to the biological approaches to later life as pursued by Aubrey de

Grey, leading to the perception of the aging body as a problem that needs to be fixed. However, regarding the aging body as such, influences cultural assumptions about 'old' age as being socially, and economically worthless. In turn, the imaginary of 'old' age of social and economic uselessness increase the expectations of illness and disability in later life. Thus, physical age is closely linked to the cultural image of decline, describing the aging body as dependent and increasingly useless. Gullette argues that "[o]nce [decline] has tinged our expectations of the future . . . with peril, it tends to stain our experiences, our views of others, our explanatory systems, and then our retrospective judgement" (11). Physical age can thus be described as the pure biological approach to age, leading to cultural imaginaries of 'old' age as purely negative.

As opposed to physical age, experiential age as Aapola defines it is "the age a person subjectively attributes to him/herself" (306). In other words, this is the age one feels. To broaden the context, I would like to extend the definition of experiential age. If the concept of experiential age refers to the way a person feels, it also refers to the way a person behaves in terms of these feelings. A person who feels 'young,' acts 'young,' a person who feels 'old,' acts 'old.' Experiential age thus refers to the age of the mind or to a maturity level, which ultimately determines the way people think and behave as well as the activities they engage in and the interests they have. Accordingly, certain actions (e.g. learning) are culturally imagined belonging to the 'young' mind whereas other actions (e.g. playing bingo) are attributed to the 'old' mind. This aspect of experiential age thus works with the cultural imaginaries of what a person at a certain age can or cannot do. These widely recognized assumptions are closely linked to another aspect of experiential age which Aapola calls embodied age. This subcategory "refers to the experiential dimension of a person's embodiment, his/her feelings and emotions. The focus is on how a person feels in relation to his/her body and its appearance and capabilities" (307). This aspect indicates how strongly experiential and physical aspects of age are intertwined. The way a person feels about his or her age is presumably linked to the state of the aging body. In other words, conditions that are associated to the aging process, such as weak bones or low energy levels influence the way a person feels in terms of her or his age. On the other hand, this further division of experiential age presents difficulties in terms of the terminologies used in this article. If experiential age is related to physical aspects, how can it be distinct from physical age? I argue, in the

following, that it is this assumption of the body as a determining factor of a person's feelings in terms of age that fosters cultural images of 'old' age as decline and is challenged through Sam Berns' narrative. This becomes visible because his age performance is non-normative in the way that it juxtaposes physical age, as the age of the body, and experiential age, as the age of the mind.<sup>4</sup>

Dividing the construct of age into subcategories can thus contribute to the way age is perceived in terms of the interplay or juxtaposition of body and mind, as well as to an understanding of how this construct evolves and which parts of it are emphasized in certain settings. To refer back to Hirschauer's quote, by looking at these subcategories, it is not only possible to look at the contexts in which age as a difference becomes an important cultural classification but also what part of the overall construct is the defining measure of a person's age in a given context. In that connection, Hirschauer argues that differences are being "drawn *or* withdrawn, maintained *or* undermined, and through the encounter with other differences enhanced *or* displaced" (181, my translation).<sup>5</sup> Accordingly, the crucial question in the study of any difference should be "*Which* difference is effective *where* and *when*?" (182, my translation).<sup>6</sup> As they are combined or regarded separately, the various categories influence the way differences are perceived according to their cultural surroundings. I argue that understanding in which context the subcategories of age influence each other make visible the mechanisms that define age as a culturally constructed category in a particular point in time in a given society.

In order to discuss the influences these subcategories have on each other, it is crucial to look at cases where they are made extremely visible and that serve as what Banerjee and Paul call 'wake-up calls.' Progeria serves as an example of these calls as it presents an 'extreme form of aging' by strongly deviating from normative assumptions of aging. I will look at the documentary *Life According to Sam* through the lenses of each subcategory of age in order

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<sup>4</sup> When I refer to the age of the mind in this paper, I do so with regard to the above given definition. Although, the terminology, when it comes to 'old' age might easily be associated with dementia, I am not using the terminology in this way because these are no issues that are touched by progeria.

<sup>5</sup> The original German version reads: "gezogen *oder* zurückgezogen, aufrechterhalten *oder* unterlaufen, und bei der Begegnung mit anderen Unterscheidungen verstärkt *oder* verdrängt"

<sup>6</sup> The original German version reads: "*Welche* Differenz ist *wo* und *wann* in Kraft?"

to reveal how their interplay in various settings provides different perspectives on the way age is culturally constructed.

### **'Extreme Age' In *Life According to Sam***

Sam Berns's condition stretches normative assumptions about the aging process by juxtaposing the aspects of physical age and experiential age. With regard to the aging process Cheryl Laz points out that "[a]lthough age often feels like something we simply are, it feels this way because we enact age in all interactions. Since we usually act our age in predictable ways—predictable given a particular context—we make age invisible. We make it seem natural" (100). In that sense, in order to seem 'natural,' age needs to be performed in a certain way. Due to disease, Berns's body and his outward appearance make it impossible for him to act out age in a 'natural' way and thus it becomes visible to the outside world. It is not only age in general that is made visible through progeria but also its different sub-categories. Because physical age and experiential age do not align, the case of Sam Berns serves as a point of inquiry for the observation of the interplay of different age categories to explore which category has the power to determine a person's age in different situations. *Life According to Sam* portrays Berns's everyday life and the way he copes with his condition in various different settings. I argue that by challenging the way age is 'naturalized' his story questions the way age, and especially 'old' age, is culturally constructed in Western society. It is important to note that I am interested in these constructions, meaning the imaginaries of 'old' age, as they evolve through cultural discourses. In that sense, for instance, chronology is tied to expectations about the aging body. Yet, the connection between the two, as van Dyk points out, is completely arbitrary. By saying that progeria speeds up the physical aging process, I thus mean that the condition inflicts individuals with attributes that would be expected to occur only in later life.<sup>7</sup>

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<sup>7</sup> The progeria body, one could rightly argue, is not identical with the aging body. In fact, children with progeria only show some signs of the aging body. I am therefore not arguing that the aging experience for children with progeria is the same as it is for the elderly, especially, because the aging process in itself is an individual experience, that makes it difficult to compare and contrast in all discussions about it. Nevertheless, numerous problems connected to these processes are also faced by many elderly. As the problems in terms of the body are similar to these of children with progeria, I argue that studying exactly these norm-challenging cases may serve as a starting point for a new perspective on aging.

According to Hirschauer “there apparently is a cultural need for order which demands the up-keeping of categories to give orientations and a certainty of action” (173, my translation).<sup>8</sup> Therefore, the initial encounter with a person leads to their instant categorization by others. The first impression the audience gets of Sam Berns is, as it often is in every-day encounters, a visual one. Berns’s portrait is featured on the documentary’s DVD cover where he appears frail, has wrinkles, is bald, and wears glasses. All these attributes taken together are visual indicators usually associated with the ‘old’ body. It is the outward appearance that causes the viewers to make initial assumptions about Berns’s age on the basis of his physicality. Without any further information, the spectator relies on the information given through his outward appearance. Consequently, because wrinkles and frailty are associated with ‘old’ age, he would most likely be categorized as such or, at least not as ‘young.’

Although these outward features are caused by progeria, the film clarifies in its first minutes that “What is aging in Sam, is aging in all of us” (00:03:07). His disease does not only give him the visible features of a physically ‘old’ man but also weak bones, arthritis, and the cardiovascular system that would rather be assigned to a person that has reached the chronological age of eighty. This connection between progeria and the conditions associated to the ‘old’ body appears to be deliberately placed as it serves the purpose of promoting progeria research. Berns’s parents, both pediatricians and the founders of the Progeria Research Foundation, use the film as a platform to elaborate on their quest for a cure. The emphasis on the similarities between the progeria body and the aging body then serve as an appropriation for their research as it promises to help the aging population in general. On the one hand, the comparison thus serves the purpose of generating support for progeria research. On the other hand, the fact that there are undeniable physical similarities between the ‘normal’ aging process and progeria leads to the question whether there are also similarities in the process of how these children are aged by culture. With Hirschauer’s assumption about the fluidity of human differentiation in varying contexts in mind, the question, I am thus asking is: Can progeria, as an extraordinary process of aging, shed light on the way the subcategories of age interact in a given situation in order to form a cultural construct of age?

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<sup>8</sup> The original German version reads: “Es gibt offenbar einen kulturellen Ordnungsbedarf, der nach Aufrechterhaltung von Kategorien verlangt um Orientierungs- und Handlungssicherheiten zu gewährleisten” (173).

Sam Berns's body is put into the foreground again in the very first scene of the film where his aged hand is shown in a close-up shot as he plays with Legos. This shot can be read in two different ways. First, it can be seen as a juxtaposition of the aged body and the 'young' mind. His wrinkled hand would be assumed to belong to an 'old' person, whereas playing with Legos is generally regarded as a children's activity. In that sense, the action of engaging in a children's activity would question the initial categorization of Berns as 'old' according to his physical age. Hence, reading the scene in terms of the juxtaposition of subcategories shows how different environments can emphasize different aspects of the constructions of age, questioning Berns's initial appearance as 'old.'

The second possible reading derives from the fact that playing with Legos could also be a therapeutic method to keep the arthritis-affected joints mobile. In that sense, the image of a hand that looks wrinkled and therefore 'old' could also be read as a promotion of the prevalent cultural imaginary of 'old' age as a phase of 'second childhood.' This phase of the human lifespan, according to Andrew W. Achenbaum, "signifies diminishing physical and intellectual faculties with advancing years" (301). In that sense, then, an 'old' person playing with Legos would attribute to the assumption that the very early and the very late stages of life are comparable in terms of physical abilities as well as mental capacities. According to this reading of the scene, it would still be the Berns's physicality that determines the way his age is constructed. To the audience, at that moment, he appears 'old' to the extent that he is unable to remain part of an adult life-sphere and has to return to his social role as a child. Here it becomes clear how physical age determines social roles through cultural imaginaries. Aapola's 'symbolic age' is thus implicitly present in all other age categories.

The latter reading of the scene, however, is deemed inappropriate by a voiceover in which Berns explains: "I didn't put myself in front of you to have you feel bad for me. I put myself in front of you to let you know that you don't need to feel bad for me because this is how... I want you to get to know me. This is my life and this... progeria is part of it. It's not a major part of it, but it is part of it" (00:01:49-00:02:10). The audience learns the reason for his rapidly aging body, which stands against his 'young' mind. In that sense, the action of playing with Legos is a juxtaposition to Berns's aging body and not a way of coping with it through therapy. Consequently, in this initial scene, the audience is presented with the struggle of

two subcategories of age: on the one hand, Berns would be considered to be 'old' through his physical age, represented by the appearance of his arthritis struck hand.<sup>9</sup> On the other hand, he would be considered 'young' according to his experiential age as he plays with children's toys. The documentary thus emphasizes the 'otherness' *and* the 'sameness' of Berns's persona. By saying that what is aging in him is aging in everybody, it establishes him as part of a society that is worried by aging demographics and the prospect of decline. As opposed to that, it encourages its audience to see the differences between his aging body and his social role as a child and thereby suggests an approach to his story that is not overshadowed by the stereotypes surrounding the aging body. In that sense, all cultural connotations belonging to the aging body, such as immobility, decline, death, etc. are negated by the action of playing with Legos. At the same time, all connotations belonging to the action of playing with Legos, childhood and primarily health, are negated by the aging body.

Berns's experiential age, adds yet another nuance to the image of his age through the self-description of his condition. He describes progeria as a part of his life, yet not a major one. He, himself thus actively takes up a position toward his life that leads away from the overwhelming associations going along with the aging body. His statement therefore counters all assumptions people could make about his life and his abilities due to his physical age by foregrounding his experiential age. It works against the cultural imaginary of 'old' age and questions the power the aging body should have in this construct.

By questioning the role physical abilities should have in the construction of the self, Berns's narrative thus asks us to see the value in the aging body. Connected to that demand for a value-centered view on the body, Sally Chivers makes an argument for the convergence of disability studies and aging studies. She claims that

[t]o practitioners and scholars studying age, disability is most often a negative category, and one that older people risk falling into. By contrast, the field of disability studies aims to recognize the full critical and cultural potential of a disability perspective; that is, scholars studying disability see that different ways of being in

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<sup>9</sup> The condition of arthritis is in medical terms not restricted to the later life. Yet, it is associated with it. Even though there is juvenile arthritis, cultural imaginaries connect the disease in general to the aged body which links the image of Berns's hand directly to 'old' age.

the world can be sources of knowledge, satisfaction, creativity, and happiness.  
(*Silvering Screen* 9)

Accordingly, the field of disability studies, so it could be argued, is one step ahead of age studies in acknowledging the value and meaning in the disabled body. Age studies, as well as gerontology are likely to fall into the trap of reproducing discourses of progress and decline and as such reproducing the binaries of the aging process. Seeing disability in later life as decline and therefore as something negative denies the “knowledge, satisfaction, creativity, and happiness” which according to Chivers are assigned to the disabled body. Berns’s narrative serves as an interesting starting point into the exploration of ‘old’ age through the lens of disability studies, since his aging body is the product of a disease and he, himself, thus represents this intersection of research fields. In the sense of disability studies, then, the simple act of playing with Legos and being hopeful despite his aging body can be read as an attempt to view the aging body in exactly the way Chivers proposes. Berns’s narrative and the juxtaposition of the negativity of the aging body to the positivity of the ‘young’ mind challenge Western society’s derogatory assumptions of the aging body. Ultimately, to see the binary of ‘young’ and ‘old’ within one individual makes the audience understand that this binary is a mere social construction and that, in turn, the negative image of the aging body could be redefined along the lines of value and knowledge. To reinforce Berns’s initial statement, he is often shown in environments that are generally associated with youth throughout the film. He appears in class with his friends, talking about homework assignments and projects or, he is shown at a rock concert. Thus, the film underlines that, in everyday life, his physical age is not given the power to majorly interfere with his experiential age. It is suggested that in the cultural connotations of the aging body are objected by his social status as a student. In those instances, the physical state of his body does not seem too important. It is through this focus that the age of his body is undermined whereas his experiential age is maintained and even enhanced.

As opposed to the images of the initial scenes provided, the film also shows situations where Berns’s physical age is placed at the center of attention. A large portion of the documentary deals with Sam’s mother, Leslie Berns, and her quest to find a cure for progeria and,

ultimately, a medication that slows down the aging process in all people.<sup>10</sup> To do so, the documentary accompanies Sam Berns through his required hospital visits, showing the processes of examinations and attempts at treatments. These scenes foreground the age of his body. During his treatments, he is separated from his life, which foreshadows the social isolation that the later part of life supposedly brings with itself. About his experiences in the hospital Berns says: “When I’m in the hospital, I’m isolated from friends, I’m isolated from television, I’m isolated from my home, I’m isolated from my cats. It’s like I lose all of the things that make me me, except for progeria” (00:52:48-00:53:34). What Sam describes here is disengagement, something that is popularly believed to be a typical effect of the aging body. As they are discussing several approaches to age and aging, Heike Hartung and Rüdiger Kunow elaborate that according to disengagement theories, “the aging body makes necessary a gradual removal from participation in social activities” (17-18). Disengagement theory, initially established by Elaine Cumming and William Earl Henry in their book *Growing Old: The Process of Disengagement*, is described by them as a “common-sense theory” (13). They argue that “aging is an inevitable mutual withdrawal or disengagement, resulting in decreased interaction between the aging person and others in the social systems he belongs to” (14). Accordingly, theories of disengagement claim that it is natural for the elderly to stop interacting with the rest of the world. Regarding this process as the natural course of life then suggests that being disengaged would be inevitable and acceptable for the elderly. Even though Cummings and Henry have been criticized for overgeneralizations in their work, this theory appears to be still regarded as ‘common-sense’ in terms of the assumption that disengagement in later life is a natural process. Hence, Hartung and Kunow state that “[o]ld people are perceived (and often wrongfully so) as either having or being withdrawn from the overall interactional processes of society and culture” (16). While it is well known in the academic world that disengagement is generally not a process that is to be welcomed, cultural imaginaries of ‘old’ age are still driven by this very belief. This cultural imaginary of

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<sup>10</sup> This is again the assumption that studying ‘extreme forms of aging’ medically might help to gain insight to the general process of aging. It is stated on the HBO homepage, promoting the documentary that “gaining a better understanding of how the disease works could lead to breakthroughs in treating heart disease and aging in the general population” (n. pag.). Researching progeria thus is not only the starting point of my research, it is also used as a promotional tool, toying with societies wish to undo aging and to find eternal youth.

disengagement and isolation is then taken up in the documentary as his aging body forces him to spend time in the hospital where he has to deal with nothing but the signs of 'old' age. The progeria body, thus, has a similar effect on Berns as the aging body has on the elderly. It is in these moments in the hospital that physical age becomes Sam's defining feature and he is, like the elderly population, associated with decline. He thus falls victim to disengagement, yet, a disengagement that is specific to time and place. The audience knows that his state of isolation is only prevalent in the specific context he finds himself in. Here, again, it becomes obvious how certain social and cultural contexts influence the significance of a given category of difference. That is, the context of the hospital enhances the prevalence of Berns's physical age, while withdrawing the determining power of his experiential age. In that sense, depicting him in the hospital adds to the argument of embodied age being at the intersection of physical and experiential age which changes according to specific setting. The way Berns feels in relation to his aged body differs from situations in the hospital to situations in school, for instance.

The 'wake-up calls' asking the audience to rethink their assumptions about the aging body become even more prominent in a later scene when he tries out for his school's marching band (01:06:30-01:10:50, 01:28:47-01:30:48). Here again his youthful behavior, the wish to play in a marching band and the drive to do everything humanly possible to achieve that goal, is juxtaposed to the restrictions his bodily condition lays upon him in terms of marching in sync with the band and playing or even carrying the drum. Nevertheless, he is determined to make his dream come true and his parents find a way to design a lighter harness for the drum, giving him the chance to participate in the band.<sup>11</sup> In that instance, his performance shows that it is not necessarily the body itself that keeps individuals from participating in certain activities. Rather, it is the way these activities are designed within a given society. In pursuing this argument, Chivers suggests that "[a] person in a wheelchair may not be able to navigate stairs, but that is a challenge only in a society that builds stairs, rather than ramps" (*Old Woman xxix*). Accordingly, being weak is only a problem for Berns because he lives in a

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<sup>11</sup> The efforts of parents and teachers as Sam's support system also show that it needs dedicated caregivers to overcome the limitations of the aging body. It would thus be a fruitful topic for further research to compare the support system of children with progeria to that of elderly people who deal with the limitations of an aging body.

society that builds heavy harnesses in the first place. His efforts and the efforts made on his behalf are then attempts to encourage society to become more inclusive for all kinds of different bodies, including the 'old' one. Further, it again becomes obvious that, in certain environments, Berns's aging body is not a victim to disengagement from society of which he is an active part of. Conversely, the narrative of Sam Berns shows that the aging body alone cannot keep him from participating in social activities. The lesson the documentary teaches then is that there are means to keep the negative connotations of the aging body and their impacts on later life at bay. This possibility should be transferable to the elderly, as well. When it is possible for a child with progeria to overcome the boundaries of the aged body, why should the elderly not be able to do the same?

Reading Berns's statements and actions against the grain could suggest, however, that he is simply in denial about his aging body and therefore about his condition in general. Hartung and Kunow explain that "denial frequently takes the form of an internalized strategy of the self, which exiles old age from a meaningful self-conception by a continuous temporal displacement" (16). In that sense, by claiming that progeria is not a major part of his life, Berns could be displacing the fact that his lifespan is very limited. He would accordingly not cope with his condition by choosing not to be defined by it but rather denying the fact that it is there. I would argue, however, that, trying to go about a life that is as normal as possible is not a sign of denial but a sign of coping. However, whether what the audience is presented with is denial or coping is a question that ultimately is not to be answered by discussing the documentary, as it is a deeply psychological and private matter. Berns and the makers of documentary certainly are intent on letting the audience see him deal with his condition by living out his social role as a 'young' person and therefore showing that a life with an aged body is worthwhile. He is aware that carrying the marching band equipment is not possible for his body and yet, with the help of his surroundings, he finds a way to work around it. In connection to Chivers's argument, Berns would then be searching for meaning and knowledge in his life with a disability.

It is, in turn, only because the documentary shows Berns's life in that particular light, that the call for a treatment for progeria is legitimate. His quest for meaning and happiness emphasize the need to help children with progeria. This medical argument then brings back the

notion of 'old' age as a disease and it is important to bear in mind that, in this special case, 'old' age truly is a disease. Regarding it as such calls for a cure and thus the documentary can ultimately be read in two different ways. Besides the positive aspects of suggesting that the aging body can lose the burden of its cultural connotations through the emphasis of other aspects in life, it also implies that an attempt to 'cure' aging would be an idea to be welcomed. Accordingly, the flipside of the narrative reveals that focusing on the Berns's experiential age, serves the purpose of supporting his request for a longer life. In other words, only because he is acting and feeling 'young,' the spectator is inclined to believe that it is necessary to search for a cure in the first place. This, in turn, shows that, to use Hirschauer's terminology, drawing one category of difference while withdrawing another, when done deliberately, always serves a purpose, in this case the purpose of promoting the efforts to find a cure for progeria and to ultimately prolong the human life-span.<sup>12</sup>

Despite the two very different possible approaches to the documentary, the narrative works toward a deeper understanding of the aging body and does imply that there lies the possibility in meaning and value in life, even towards the end of it. This is why it is important to reveal that Berns's experiential age is used in many instances to overwrite his physical age. In this very context then, Berns serves as an example for a progress narrative, which Margaret Gullette defines as "stories in which implicit meanings of aging run from survival, resilience, recovery, and development, all the way up to collective resistance to decline forces" (17). Sam Berns fights decline by highlighting his possibilities. Additionally, his example shows that aging is not a matter of black and white. Having an aged body might restrict a person from engaging in certain activities but it does not restrict that person from being happy and leading a meaningful later life.

## Conclusion

Using the HBO documentary *Life According to Sam* as a case in point, I have shown how progeria as an 'extreme form of aging' can contribute to the discussion of the cultural construction of age. As Sam Berns's condition puts him between being 'old' and being 'young' by

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<sup>12</sup> Looking at the bigger picture of the studies of difference, it would thus be interesting not only to investigate the explicit situation in which a difference is made important but also what mechanisms work toward this interplay and what purposes are served by it.

juxtaposing physical and experiential age, his story shows how age itself is a fluid construct that is constantly redefined through the environments it is situated in. Moreover, discussing ‘extreme forms of aging’ cannot only contribute to the study of age but also to the dialogue between the medical and the social and, in the case of Sam Berns in particular, it can spark a dialogue between the fields of disability studies and age studies. On the one hand, Sam’s story leaves us with the question whether an aging body can be seen as an illness and whether we should attempt to cure it at all. On the other hand, reading the narrative through the lens of disability studies indicates how the aging body is culturally constructed by focusing on decline and disengagement.

Ultimately, it is Berns’s experiential age, made possible through supporters who are willing to work against the constraints in his environment, which determines how he is perceived, and perceives himself, through his age. The situations in which his body and his physical age are the center of attention are restricted to the hospital, where he is isolated and fragile which leads to an understanding of the aging body as a challenge—which it undoubtedly is for everybody experiencing it—but one that does not have to be the defining aspect of a person’s life.

## Works Cited

- Aapola, Sinikka. "Exploring Dimensions of Age in Young People's Lives: A Discourse Analytical Approach." *Time and Society*, vol. 11, no. 2-3, 2010, pp. 295-314. *Sage Journals*, <http://journals.sagepub.com/doi/abs/10.1177/0961463X02011002007>.
- Achenbaum, W. Andrew. "Delineating Old Age: From Functional Status to Bureaucratic Criteria." *Age in America: The Colonial Era to the Present*, edited by Corinne T. Field and Nicholas L. Syrett, New York UP, 2015, pp. 301-319.
- Banerjee, Mita, and Norbert Paul. "Aging Beyond the Rhetoric of Aging." *Serializing Age: Aging and Old Age in TV Series*, edited by Marciel Oró-Piqueras and Anita Wohlmann, Transcript, 2016, pp. 269-272.
- Chivers, Sally. *The Silvering Screen*. U of Toronto P, 2011.
- . *From Old Woman, To Older Women: Contemporary Culture and Women's Narratives*. Ohio State UP, 2003.
- Cumming, Elaine, and William Earl Henry. *Growing Old: The Process of Disengagement*. Basic Books, 1961.
- Gullette, Margaret Morganroth. *Aged by Culture*. U of Chicago P, 2004.
- Hartung, Heike, and Rüdiger Kunow. "Introduction: Age Studies." *Amerikastudien / American Studies*, vol. 56, no. 1, 2011, pp. 15-22. *JSTOR*, <http://www.jstor.org/stable/23317636>.
- HBO. "Synopsis." *HBO Documentaries: Life According to Sam*, 2017, <http://www.hbo.com/documentaries/life-according-to-sam/synopsis.html>.
- Laz, Cheryl. "Act Your Age." *Sociological Forum*, vol. 13, no.1, 1998, pp. 85-113. *JSTOR*, <http://www.jstor.org/stable/684926>.
- Life According to Sam*. Directed by Sean Fine and Andrea Nix Fine, HBO Documentary Films, 2014.
- Overall, Christine. *Aging, Death, and Human Longevity: A Philosophical Inquiry*. U of California P, 2005.
- SENS Research Foundation. "About SENS Research Foundation." *SENS Research Foundation: Reimagine Aging*, 2016, <http://www.sens.org/about>.
- Van Dyk, Silke. "The Appraisal of Difference: Critical Gerontology and the Active-Aging-Paradigm." *Journal of Aging Studies*, vol. 31, 2014, pp. 93-103. *Science Direct*, <http://www.sciencedirect.com/science/article/pii/S0890406514000504>.
- Woodward, Kathleen. "Introduction." *Figuring Age: Women, Bodies, Generations*, edited by Kathleen Woodward, Indiana UP, 1999, pp. ix-xxix.