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FINDING THE GALAXY OF DISABILITY MARIA REIMANN'S LIFE WRITING

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Maria Reimann; disability studies; disability life writing; disability identity; coming out as disabled; disability community

Literary and cultural disability studies, or, more broadly, what Rosemarie Garland-Thomson calls new (critical) disability studies in the humanities (Garland-Thomson, Ojrzyńska 2020), is a research area that is slowly but steadily gaining momentum in the Polish academia. Offering new perspectives on disability, it helps us rethink certain basic, seemingly transparent and neutral, categories that have widely been used to divide the broad spectrum of human diversity into those that fit in the “norm” and those labelled as abnormal, deviant, lacking, broken, and in need of fixing. What serves as one of its most crucial and prolific areas of research and intervention is cultural representation. As has been argued by a number of scholars and activists, one of the reasons for the prevalence of negative stereotypes of disability is the fact that for centuries most images and other depictions of disability were created by non-disabled people. Hence the contemporary disability studies’ interest in representation which, as Michael Bérubé puts it, “has a double valence for disability studies” (Bérubé 2015: 428). This is largely because, as he further notes,

“[r]epresentation” speaks to both political and aesthetic concerns; it suggests an image that stands in for and points toward a thing [...], or a mechanism by which one

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person or group of people is empowered to stand in for and express the wishes of another person or group (Bérubé 2015: 428).

In other words, the slogan “nothing about us without us”,¹ which was widely adopted by British and American disability activists as early as in the late 1960s and the 1970s, remains politically relevant for disability studies both in legal and aesthetic terms.

As regards cultural representation, the change from the dominant medical and charity models, which define disability as an individual problem that needs to be solved or overcome, towards a more nuanced way of interpreting disability as a multidimensional, alternative way of being in the world has been significantly facilitated by works created by people with disabilities. These works frequently examine the author’s personal experience of disability as a complex phenomenon which is shaped not only by biological and medical factors, but also social and cultural ones. Borrowing the term from postcolonial studies and, in particular, from Salman Rushdie’s famous 1982 article *The Empire Writes Back with a Vengeance*, a number of disability scholars have called the strategy that is nowadays commonly used in such works and that sheds new light on disability “writing back to the able-bodied centre”.² The strategy involves a change of perspective that helps challenge and revise certain established, reactionary beliefs and representational strategies from the point of view of underprivileged and marginalized social actors. In other words, writing back to the centre, be it male, white, heterosexual, or non-disabled, gives rise to new, alternative narratives, which, as the example of Maria Reimann’s recent autoethnographic work *Nie przywitam się z państwem na ulicy: szkic o doświadczeniu niepełnosprawności* (*I Won’t Greet You in the Street: A Sketch about the Experience of Disability*, 2019) shows, complicate and add new dimensions to the understanding of key concepts in disability studies, such as: disability identity, disability community, or coming out as disabled.

As Dan Goodley notes, “[c]rucial facets of writing back are to be found in relation to the re/storying of self” (Goodley 2011: 164). For people with disabilities, telling their story anew can be a way to rewrite their identity along more positive, non-ableist lines. Therefore, a lot of critical attention in contemporary disability studies has been given to what Thomas G. Couser calls disability life

¹ Interestingly, the slogan has Polish roots and it dates back to the early sixteenth century when a law was introduced according to which the king could not pass new legal acts without consent of the nobles.

² Cf. Goodley 2011: 163–164 and Ojrzyńska 2017: 163–165. The term has also been used in the context of disability studies by David T. Mitchell and Sharon L. Snyder, who created the documentary *Vital Signs: Crip Culture Talks Back* (1995).

writing which, more often than not, serves as an emancipatory literary tool of empowerment. And yet, his analyses of various “first person non-fictional narratives” written by individuals with different impairments show that autobiographical life writing may also reinforce some negative stereotypes, especially when it relies on certain popular literary devices, such as the plot of overcoming (Couser 2018: 203–204), which is closely connected to the fact that

[l]ike other minorities historically represented largely by members of dominant groups, disabled people come to literary production from within the same culture that marginalized them [and thus] they are vulnerable to infection with the very prejudices that oppress them (Couser 2018: 200).

Nevertheless, contemporary disability life writing has developed a number of representational strategies and patterns that successfully question and counter the medical and charity discourses of disability and show it as a complex and multidimensional phenomenon.

Maria Reimann's *Nie przywitam się z państwem na ulicy* serves as an important, valuable, and informed contribution to Polish disability life writing. The book has reached wide readership, among other things, thanks to the fact that it was published by Wydawnictwo Czarne, a publishing house founded in 1996, which since then has been supplying the Polish book market with high-quality non-fiction by award-winning Polish writers and such international authors as: Patti Smith, Thomas Bernhard, or Liao Yiwu. In the year preceding the publication of Reimann's book, Wydawnictwo Czarne also released a collection of five personal stories of Polish mothers of children with the so-called “severe” disabilities, gathered and edited by Jacek Hołub. The title of the collection *Żeby umarło przede mną* (*I Hope that the Child Will Die before Me*, 2018) accentuates the desperation of the women who lack proper support from the state, health professionals, and sometimes partners. They live in a world that does not welcome their children, a world in which their children would not survive without their constant help and assistance.

In general, Polish disability life writing, which – with few notable exceptions, such as Sławomir Mrożek *Baltazar. Autobiografia* (2006), discussed by Klaudia Muca in her article – is still largely a niche genre that has been developing more vibrantly in the social media than in the book market where disability narratives are often framed as:

– self-therapy, as in the case of the above-mentioned memoir written by Mrożek who experienced aphasia after a stroke;

– stories of overcoming which often fit in the idea of “inspiration porn”,³ as in the case of the twelve autobiographical narratives collected in the volume with a telling title *Moje Kilimandżaro* (*My Kilimanjaro*, 2008). The volume opens with a short introduction written by the Polish psychologist Irena Obuchowska, who states:

This book is a dialogue between the weakness of the body and the power of one’s will. We find in it the beauty of life in spite of pain, disability and despair. [...] The book offers a pretext to look at one’s own life, reflect on one’s own hardships and the way one deals with them. Such a reflection may be beneficial for the reassessment of one’s own life and the reconsideration of one’s own hierarchy of values (*Moje Kilimandżaro* 2008: 5);

– personal tragedies (often happening by God’s will⁴) as in the case of the collection *Cierpieniem pisane. Pamiętniki kobiet niepełnosprawnych* (*Written with Pain. Memoirs of Disabled Women*, 1991), which offers a selection of personal stories that point to the problems of a number of (Catholic) women of different ages who are depicted as a group that was (and still is) particularly prone to social exclusion and discrimination in the post-socialist (post-1989) Poland.

Maria Reimann, whose critically acclaimed book does not fit in these conventional, often ableist, frames of representation, is a visually impaired academic with first-hand experience of disability who has been researching the lives of women with the Turner syndrome, a genetic condition that affects only women who may have a wide variety of symptoms, ranging from short stature and webbed neck to ovarian failure and heart problems. *Nie przywitam się z państwem na ulicy* takes an autoethnographic perspective which, as Carolyn Ellis, Tony E. Adams, and Arthur P. Bochner note, “seeks to describe and systematically analyze (*graphy*) personal experience (*auto*) in order to understand cultural experience (*ethno*)” (Ellis, Adams, Bochner 2011). Laura L. Ellingson and Carolyn Ellis further define it as “a [critical] response to the alienating effects on both researchers and audiences of impersonal, passionless, abstract claims of truth generated by such research practices and clothed in exclusionary scientific discourse” (Ellingson, Ellis 2008: 450).

Therefore, autoethnography seems to be a particularly valuable emancipatory tool for people with disabilities as well as representatives of other marginalized

³ The concept of “inspiration porn” has most succinctly been explained by Stella Young in her TED talk “I’m not your inspiration. Thank you very much” (available at: https://www.ted.com/talks/stella_young_i_m_not_your_inspiration_thank_you_very_much/transcript).

⁴ E.g. the volume *Cierpieniem pisane* opens with the quote from the Gospel of John: “Neither this man nor his parents sinned,” said Jesus, “but this happened so that the works of God might be displayed in him” (John 9:3).

groups who have often been denied their own voice. It responds to the need to rethink the traditional unequal relationship between a non-disabled researcher and a disabled object of the research, which has been questioned since the very beginning of contemporary disability activism and disability studies.⁵ As Ellingson and Ellis put it, autoethnography “attempts to disrupt and breach taken-for-granted norms of scientific discourse” by blurring the lines between such binaries as: “researcher-researched, objectivity-subjectivity, process-product, [...] and personal-political” (Ellingson, Ellis 2008: 450) and thus serves as a tool of empowerment and emancipation.

Reimann's work intertwines three distinct threads: academic theory, academic research on the experiences of women with the Turner syndrome, and – most importantly – a critical examination of the author's own experience of disability. The last thread is most plainly visible in the book describing the authors' journey towards developing a more adequate sense of identity which goes beyond the binary disabled/non-disabled opposition. In this journey, Reimann does not shy away from probing into her own internalized prejudices and biases and critically examining the legacy of contemporary disability studies and activism through the prism of her own experience. As will be shown, *Nie przywitam się z państwem na ulicy* fits in with Alison Kafer's perception of disability as political, which “entails departing from the social model's assumption that «disabled» and «nondisabled» are discrete, self-evident categories, choosing instead to explore the creation of such categories and the moments in which they fail to hold” (Kafer 2013: 10). Both for Kafer and Reimann disability is “a site of questions rather than firm definitions” (Kafer 2013: 11), a site of critical engagement and inquiry. *Nie przywitam się z państwem na ulicy* highlights the diversity of the experiences of disability. To use Reimann's metaphor, the book shows a galaxy – a constellation of unique individuals who variously respond to their different impairments and disabilities. To become part of the galaxy, the author undergoes the process of “claiming cripp”, which does not simply reverse the binary oppositions and what Joan Scott calls the “politics of dichotomy” (qtd. in Michalko 2002: 23) or uncritically adopt a “cripp pride” stance. Reimann's claiming cripp, in line with Kafer's arguments, involves “deconstructing the binary between disabled and able-bodied/able-minded” (Kafer 2013: 13) as well as various uneasy identifications available across the disability community and single diagnostic groups, and

⁵ As the Union of the Physically Impaired against Segregation (UPIAS) famously put it in their 1974 policy statement, “[w]e reject also the whole idea of ‘experts’ and professionals holding forth on how we should accept our disabilities, or giving learned lectures about the ‘psychology’ of disablement. We already know what it feels like to be poor, isolated, segregated, done good to, stared at, and talked down to – far better than any able-bodied expert” (UPIAS 2006: 446).

promoting increased attentiveness “to how different bodies/minds are treated differently” (Kafer 2013: 13). Her attentiveness to differences between various bodily and social experiences does not yet neglect or deny the commonality of some experiences, such as that of social stigma.

A strong allusion to the stigma attached to disability can be found in the very title of Reimann’s *Nie przywitam się z państwem na ulicy: szkic o doświadczeniu niepełnosprawności* (*I Won’t Greet You in the Street: A Sketch about the Experience of Disability*). One of the possible reasons for the speaker’s unwillingness to greet the addressee may be a desire to avoid any contact with a person with discrediting features and in this way escape what Goffman calls “courtesy stigma” (Goffman 1986: 31), in other words a situation in which the speaker would “share some of the discredit of the stigmatized person to whom they are related” (Goffman 1986: 30). Yet, Reimann skilfully challenges the expectations that the title inspires. As we learn from the book, the title is her own statement addressed to a non-disabled reader who may be unaware of the nature of her disability. As a person with an impairment that is rather inconspicuous and often goes unnoticed by people around her, Reimann feels the need to remind her interlocutors that she has limited vision and thus often does not recognize people in the street. In this way, she wants to reduce the risk of being accused of impoliteness, should she fail to greet a familiar passer-by. This suggests that on numerous occasions the author might have passed as non-disabled at the price of being labelled as rude. In order to avoid further possible misinterpretations of her behaviour, Reimann starts with a voluntary disclosure – an act of coming out in which she openly explains how her impairment affects the way she interacts with people in public space. Yet, her coming out and becoming part of “the galaxy of disability” were, in fact, a much longer process.

The book explores Reimann’s difficult personal and academic strife to find a common ground with her interviewees – women with the Turner syndrome, which leads to the (re-)discovery and exploration her own disability identity. The task seems demanding as there are a number of different factors that have been shaping individual experiences of each woman described in the book, including social and material background, (in)fertility, education, or appearance. Reimann thus highlights a need for a more nuanced, intersectional, context-specific approach to disability research.

One of the things that the author shares with many of her interviewees is the fact that her condition makes it impossible to easily classify her according to the binary system which divides people into disabled and able-bodied. Alluding to the Polish scholar Małgorzata Melchior, Reimann states that people with a visual impairment like hers “have a complex identity – they belong both to

the world of the sighted and that of the blind” (Reimann 2019: 26). And yet her personal experience suggests that, more often than not, this form of liminality precludes a sense of belonging to either world. Thus, in her adult life, Reimann finds it difficult to step into the ready-made disabled and non-disabled identities. She positions herself in-between these social constructs which are too narrow to accommodate her complex experience.

The binary thinking about disability that the book questions completely ignores the fact that many impairments differ in terms of intensity and are often unfixed and changing. These misconceptions lead to the frequent lack of accommodations for people who do not occupy the far end of the disability spectrum. Reimann, for instance, is considered to be too impaired to adopt an ordinary dog. Yet, when she asks if she could have a trained guide dog, she is informed that it would not be possible to train a dog for her since

[a] human being needs to be predictable for the dog. [...] The person should always behave in the same way; a visually impaired [but non-blind] person sometimes sees something and sometimes doesn't and thus won't always follow the dog (Reimann 2019: 66).

Eventually, Reimann is encouraged to take in a dog that has dropped out of the training. Although she quickly develops a strong bond with the animal, she still doubts her own skills and abilities since her competence in dog walking has once been questioned.

The fluid, spectral nature of disability and the inadequacy of the binary approach also come into play when Reimann researches the Turner syndrome. As the word “syndrome” (*zespół* in Polish) suggests, the genetic condition comprises a number of symptoms which differ in intensity and quality. One of the most common traits that can be observed among women with the Turner syndrome is the loss of ovarian function and consequent infertility. Perceived by all of Reimann's interviewees as a matter of necessity, rather than choice, childlessness prevents them from fulfilling their socially prescribed gender roles. This may be a reason why many participants in the summer camps for young women with the Turner syndrome, which were also attended by Reimann, have easily internalized a number of stereotypes. The young women are typically seen as caring, docile, and not causing any trouble. Reimann, who often finds it difficult to identify with her interviewees and understand their experience, also underscores the stereotype that she considers most objectionable – that of eternal children, which is closely connected with the women's physical appearance and the overprotective attitude of their families and carers. Strongly suggested but never clearly verbalized in the book, one of the reasons why this stereotype has

been internalized by the women is that it serves a form of escapism. One can hardly avoid the impression that, clinging to their childhood, the women avoid facing the problems and stigma related to the common social perceptions of their femininity as incomplete, deficient, broken, and lacking.

Reimann admits that she often felt frustrated and angry at the way in which her interviewees conformed to the stereotype of eternal children. At first glance, it may seem that while the women persistently avoid the potentially traumatic confrontation of their non-standard femininity with conventional social expectations, the author uses her impairment to challenge certain gendered bodily norms. Reimann states:

[i]f I really wanted, I would learn to do makeup. [...] But I use my visual impairment to avoid conforming to certain requirements related to femininity (Reimann 2019: 108).

Yet, the situation which she describes just a few lines earlier and which led to her giving up on makeup undercuts the subversive and rebellious potential of her choice. Reimann recalls one of her first – and probably last – attempt at makeup. She gave it up after she realized that her face looked clownish, having been told by her boyfriend that he found her very attractive and that she should not wear makeup in the future. Her excessive makeup evidently breached the non-disabled rules of propriety and moderation, for which she was subtly yet effectively reprimanded. Although the author declares that she is not concerned with the demands of socially-constructed femininity, she occasionally ponders if her “lack of makeup is something that attracts others’ attention” (Reimann 2019: 109). This shows that the Reimann’s behaviour, much like that of her interviewees, cannot be easily categorized as either subversive or complacent. The author refuses to pass easy judgements and sheds light of the complex and often ambiguous motivations that inform the individual choices made by the women depicted in the book.

Historically, the binary approach whose social construction *Nie przywitam się z państwem na ulicy* criticizes was reinforced by the medical discourse which conceptualized disability as a form of deficiency, deviation, and abnormality. This concept is closely connected with the mechanics of Foucauldian “clinical gaze,” which, as Rosemarie Garland-Thomson explains, “defines the norm by picturing the deviant” and which is accurately illustrated by clinical photographs (Garland-Thomson 2001: 336). As she notes elsewhere, “[t]he medical subject would have been posed with slumping and resigned posture and a black rectangle covering the eyes” (Garland-Thomson 2009: 156). The clinical gaze focuses on

the departure from the medical “norm”, rather than on the individual, who is objectified, degraded, and reduced to a medical specimen. As Foucault puts it,

the doctor's gaze is directed initially not towards that concrete body, that visible whole, that positive plenitude that faces him – the patient – but towards intervals in nature, lacunae, distances, in which there appear, like negatives, the signs that differentiate one disease from another, the true from the false, the legitimate from the bastard, the malign from the benign (Foucault 2003: 7–8).

The women with the Turner syndrome whom Reimann interviews as part of her research are often perceived through clinical lens. Following Magdalena Radkowska-Walkowicz (cf. Radkowska-Walkowicz 2019: 117), Reimann goes even further to argue that the medical discourse often “monsterizes” her interviewees. Both scholarly and popular descriptions of the syndrome – including the one found in Wikipedia – abound in various “abnormal” bodily features which shape and reinforce exaggerated depictions and negative perceptions of the genetic condition (Reimann 2009: 105–106). Ignoring the fact that many, if not most, women with the Turner syndrome do not display all the symptoms, these representations are not only misleading, but also harmful in that they stimulate the women's desire to “pass” as non-disabled and reinforce the atmosphere of secrecy around the genetic impairment.

“To Pass or Not to Pass” (Siebers 2008: 96) – with these words Tobin Siebers opens his seminal text on *Disability as Masquerade*. As he argues, the strategy of passing as non-disabled has one major advantage – it makes it possible to avoid the stigma attached to the Goffmanesque “spoilt identity” of a person who has been labelled as disabled. As Siebers explains,

[t]emporary passing is empowering, producing brief moments of freedom from the prejudice and morbid curiosity often found to surround disability. Pretending to be able-bodied is one way of performing normalcy, of inserting oneself in society and escaping the alienating experience of being disabled (Siebers 2008: 118).

On the other hand, passing may cause the feeling of guilt, resulting from the fact that the person in question is aware of the fact that he or she is accepted only because he or she is pretending to be non-disabled. As Siebers further notes, this may lead to the internalization of ableist prejudices, a need for “overcompensation that exacerbates already existing conditions”, and loneliness, as passing requires secrecy (Siebers 2008: 118). Most of these experiences are strongly present in the stories shared by Reimann's interviewees.

The Turner syndrome is largely shrouded in a veil of taboo and secrecy, while hiding its symptoms has become easier than before thanks to such medical

procedures as human growth hormone therapy. Although most of Reimann's interviewees successfully pass as non-disabled, they evidently find the burden of secrecy heavy and emotionally draining. That is why many of them feel very comfortable when they attend a summer camp for young women who all have the same medical condition, even if this involves participating in evidently infantilizing activities. Although they are pressured to conform to a stereotype of docile and obedient children, they are also given a unique opportunity to spend some time in a place where they not treated as the other. As Reimann puts it, "the Turner syndrome becomes invisible. [...] Paradoxically the camp is a place where TS disappears for a moment" (Reimann 2019: 73). The women find themselves in an alternative micro-world where their condition is no longer a shameful secret, but the "norm".

For some of the women, the interview is a form of "coming-out" and reclaiming their disabled identity by constructing and voicing their self-narratives. This is how Reimann describes the final part of one such conversation:

When we bid farewell and I thank her for the conversation, Zuzanna also says "thank you". She "probably needed to open up to someone; she wanted to tell me her story", but because of the fact that she had not told it too many times before, in a sense it was a narrative that was created in the process of telling the story. I keep thinking about the women who have not told their stories to anyone before. I keep thinking about the women who agreed to talk to me but in their statements there was more silence than words (Reimann 2019: 112–113).

Coming out can be a liberating experience. Yet, as Reimann indicates, it does not happen overnight, but is rather a long process of finding one's voice that will make self-redefinition possible. As Tobin Siebers puts it, "[c]oming out of the closet is not as simple as opening it" (Siebers 2008: 99). Therefore, most of the conversations that Reimann had with her interviewees only served as the first step towards self-discovery and self-acceptance.

In a sense, the book also presents Reimann's own journey towards self-acceptance and self-discovery. Raised to be "normal", the author, when she was a child, claimed to see things that could not see due to her impairment – an impairment which did not stop her from developing such skills as cycling, even though her first bike trip ended up in an emergency room (Reimann 2019: 39). She presents herself as a strong and independent individual who fulfils a number of roles in society. She is a mother and a scholar who perfectly fits in the contemporary model of a self-sufficient, productive, and successful citizen. It seems that Reimann never fully identified as disabled. She recalls:

Whenever I crossed the threshold of the Polish Association of the Blind, I felt somewhat awkward. As if I didn't belong there, as if I was too abled or too healthy. Every year I asked them to pass the Christmas parcel that they would prepare for me to someone else who needed it more than I did and I felt intimidated by the very fact that the parcel was waiting there for me (Reimann 2019: 55).

This was one of many occasions when Reimann rejected the "disability label".

Reimann admits to having been pressured by her parents to use certain strategies of managing stigma described by Goffman. One of such strategies consists in compensating for the alleged deficiencies. As Goffman puts it,

[t]he stigmatized individual can also attempt to correct his condition indirectly by devoting much private effort to the mastery of areas of activity ordinarily felt to be closed on incidental and physical grounds to one with his shortcoming. This is illustrated by the lame person who learns or re-learns to swim, ride, play tennis, or fly an airplane, or the blind person who becomes expert at skiing and mountain climbing (Goffman 1986: 10).

Reimann recalls being frustrated and angry at her parents who forced her to compensate for her impairment by making her participate in activities that in some ways exceeded her abilities, such as tennis classes or winter ski camps.

She also admits that, as a young person, she did not know any other visually impaired people. The author even suspects that her parents did not wish her to make such acquaintances. When she was a teenager, Reimann met a girl with a hearing impairment, and they instantly developed a close friendship. Although they do not see each other too often, the author feels that they share "a secret that is incomprehensible to others [...] a sort of loneliness in experiencing disability" (Reimann 2019: 56). In other words, what has been defining her experience of disability is the largely successful, and yet acutely solitary struggle to fit in the "normal" world through overcompensation. Michalko calls this "the interactional battlefield of passing" (2002: 9) in which the non-disabled public self tries to suppress the disabled self whom "the ideology of compulsory able-bodiedness" (McRuer 2006: 2) seeks to confine to the private sphere (see Michalko 2002: 21). And yet, at the same time, Reimann admits that she also occasionally "use[d] her stigma for 'secondary gains'" (Goffman 1986: 10), such as being granted automatic admission to a state secondary school of her own choice or extended time during exams (Reimann 2019: 18).

Although both the author and many of her interviewees experience a sense of connection and mutual understanding with other people with disabilities, *Nie przywitam się z państwem na ulicy* accentuates that the fact of having a disability does not automatically lead to social or personal bonding. One of the women

with the Turner syndrome, Barbara, recalls that when she was a child, her mother pressured her to befriend another girl with the same condition whom she accidentally met in the street. Reimann concludes that she has heard several similar stories from her interviewees which only prove that “the belief that a person with TS should befriend another person with TS is rather naïve” (Reimann 2019: 75).

In the opening chapter, Reimann poses a number of disability-related questions, the most important of which concern her own identity:

I have written that many girls and women with TS [...] do not consider themselves disabled, but do I define myself as disabled? Visually impaired – yes, but disabled? Although I have a disability certificate and I am entitled to disability pension, disability is not part of my identity – or perhaps it only sometimes is. When I feel that I lack something or something is difficult for me (Reimann 2019: 18).

Yet, the way disability is presented in Reimann’s book as a fluid and unfixed identification goes beyond the interactional model, according to which disability is a result of an interaction between an individual and their social and physical environment. Disability is not exclusively a negative experience resulting from social barriers, the lack of accommodations, or the limitations related to ableist stereotypes and preconceptions. It is a much more complex and often conflicted experience.

In a conversation with a non-disabled female writer who seeks to verify her own stereotypical views on visual impairment, Reimann feels the need to “defend” her unique way of experiencing the world. She explains that the reason why she does not wear glasses is that they do not improve her vision. Reimann admits that they sharpen her sight, but instantly adds: “I do not find this particularly pleasant. I live in a world without sharp lines. Without sharp edges” (Reimann 2019: 81). And yet, in one of the next chapters, she presents her earlier experience of wearing sunglasses that improve contrast in a somewhat different light. She recalls:

When I tried them on at a medical centre and for a moment went outside, I felt wonderful because they protect against the sun and, at the same time, improve my vision. However, I decided not to buy them, knowing that I wouldn’t wear glasses that make my disability conspicuous. I would never go out wearing special glasses for the visually impaired (Reimann 2019: 148).

On another occasion, she also mentions the discomfort that she felt when she first saw a photo of herself reading a book and holding it very close to her face. Reimann openly admits that while she is not ashamed of informing a waitress that she has problems with her vision, she is embarrassed by the way she reads a menu. Accentuating the author’s desire not so much for “nondisability and normalcy but

ordinariness” (Michalko 2002: 152), this story thus fits in what Michalko calls an “adaptive narrative” (2002: 152) which accentuates the need to neutralize the difference and specificity of disabled ways of functioning in the world.

Reimann’s attitude to her own impairment seems in many ways contradictory and conflicted. Thus, her psychological journey depicted in the book involves not only embracing the positive dimension of her atypical way of being in the world, but also its negative aspects resulting from both ableist social perceptions of disability and certain possible limitations related to her impairment, such as the fact that she will probably never drive a car. It involves accepting the legitimacy of her wishes to be, on the one hand, “ordinary” and unique, on the other, which both connect to the desire to be in control of the way she is perceived by other members of society.

Reimann’s research on the lives of women with the Turner syndrome helps her realize and accept the complexity of her own experience and embrace the long-repressed aspects of her own self. As she states towards the end of the book, “[d]isability is an identity that I have tried to escape in a number of ways because I found it unattractive. [...] Now [...] I can see it in a different light” as something interesting and worth exploring (Reimann 2019: 153). Most importantly, Reimann learns to admit her own fear and weakness. In the earlier-mentioned conversation with the female writer, she explains that she often feels insecure:

[y]ou are never completely sure who is approaching or where you are [...] But perhaps this also teaches you to trust the world and other people. I’m, for instance, deeply convinced that many people help me a lot. [...] I receive a lot of help from others and I find it somehow touching (Reimann 2019: 81).⁶

Reiman thus accepts her insecurity and fragility and appreciates the value of human empathy and interdependence.

In a sense, Reimann’s process of change reflects the transformation that disability studies has been undergoing in recent decades. It is by no accident that this transformation started at the intersection of disability and women’s studies. It involved the re-assessment of such communal values as empathy, mutual support, and interdependence, and challenging the model of a productive, self-sufficient, and independent individual that played a prominent role both in disability activism and disability studies. This idea strongly resonates in the works of: Rosemarie Garland-Thomson, who states that “disability, like any challenge or limitation, is fundamental to being human – a part of every life” (Garland-Thomson 2019: 6), the philosopher Eva Feder Kittay, who has

⁶ Also cf. Reimann 2019: 85–86.

written extensively on the significance of dependency for disability studies (see e.g. Kittay 2011; 2015), Alison Kafer, who argues that “[t]o eliminate disability is to eliminate the possibility of discovering alternative ways of being in the world, to foreclose the possibility of recognizing and valuing our interdependence” (Kafer 2013: 83), and David T. Mitchell and Sharon L. Snyder, who in their book on the biopolitics of disability argue that

[w]hat is often lost in relations of neoliberal normalcy are ways in which disabled people’s openly interdependent lives and crip/queer forms of embodiment provide alternatives maps for living together in the deterritorialized, yet highly regulated spaces of biopolitics (Mitchell, Snyder 2015: 3).

This new way of thinking about disability also paved the way for Lennard J. Davis’s dismodernist ideal which “aims to create a new category based on the partial, incomplete subject whose realization is not autonomy and independence but dependency and interdependence” (Davis 2002: 30). This ideal helps us rethink what makes us human along new lines and embrace our fragility and dependency.

The final chapter of Reimann’s book has a telling title *Patrzenie w bok* (*Looking to the Side*), which alludes to the game that she played with other children and her parents’ friend Roman, who taught them how to find the Andromeda Galaxy in the sky. Finding it is only possible if you do not look directly at the group of stars, but focus your sight right next to it. Reimann compares her interviewees to a galaxy that she has been trying to discover and understand by creating a space for the women to share parts of their stories which, however different from one another, form a coherent constellation. In order to join the galaxy, the author needs to re-embrace her own fragility and dependency and come to terms with her conflicting emotions connected with her own disability which she eventually accepts “as worthy of choice” (Michalko 2002: 14).

The author’s psychological journey does not necessitate a choice between the binary identity labels. In other words, Reimann finds a solution to the problem with which the visually impaired scholar Rod Michalko struggled for many years and which he describes in the following manner: “Sightedness and blindness could not cohabit my identity. I was one or the other but not both” (Michalko 2002: 10). Her memoir largely deconstructs the disabled/non-disabled dichotomy, following Alison Kafer’s advice that such a deconstruction “requires more attention to how different bodies/minds are treated differently” (Kafer 2013: 23) as well as to the ways in which they serve as sources of unique personal experience. Reimann’s book and her research on the lives of women with the

Turner syndrome serve as evidence of her learning to exercise the so-defined attentiveness.

The metaphor of finding one's galaxy that is introduced in the final chapter seeks to communicate the idea of relating to other people and, at the same time, retaining one's unique position in the universe. A struggle to fit in narrowly-defined social identities frequently involves a repression of a part of one's self. Thus, examining her personal experiences, Reimann goes beyond the limited, ill-fitted (both disabled and able-bodied) communal identities, positioning herself in the space in-between them. It is only from this unfixed, liminal position that she may successfully relate to herself and to her interviewees with whom she shares the experiences of stigma and solitude but who, at the same time, remain in a number of ways distant and unique. As Michalko posits, "Coming out as disabled implies the necessity of reconnecting disability and identity" (Michalko 2002: 70). This reconnection is not synonymous with the identification with a fixed socially-constructed identity, but consists in realizing both the shared and the unique aspects of one's bodily and social experience.

In a sense, Reimann envisages disability in a similar manner as the dyslectic scholar Tanya Titchkosky, who sees it as "a teacher that makes us rethink the meaning of identity formed in relation to a body that both violates and resists assumptions regarding the stability of the self" (Titchkosky 2006: 208). Writing about her life with Rod Michalko, Titchkosky states: "Our life is spent in these mixtures of disabilities, which also position us differently in the social worlds of which we are a part and from which we are often separated" (Titchkosky 2006: 230). Exactly the same can be said about Reimann and her interviewees whom the Polish author presents as stars in the galaxy of disability, which may at first glance seem distant, but when seen through proper lens become close and relatable and yet still unique.

BIBLIOGRAPHY

Bérubé Michael. 2015. *Representation*. In: *Keywords for Disability Studies*. Ed. Rachel Adams, Benjamin Reiss, David Serlin. New York–London: New York University Press. ISBN: 978-14-7983-952-0. Pp. 428–436.

Cierpieniem pisane. Pamiętniki kobiet niepełnosprawnych. 1991. Ed. Adam Wieczorek. Olsztyn: Polskie Forum Chrześcijańsko-Demokratyczne Rada do Spraw Rodziny Stowarzyszenia PAX.

Couser Thomas G. 2018. *Signifying Selves. Disability and Life Writing*. In: *The Cambridge Companion to Literature and Disability*. Ed. Claire Barker, Stuart Murray. Cambridge: Cambridge University Press. ISBN: 978-11-0745-813-0. Pp. 199–211.

Davis Lennard J. 2002. *Bending over Backwards: Disability, Dismodernism, and Other Difficult Positons*. London–New York: New York University Press. ISBN: 0-8147-1950-3.

Ellingson Laura L., Ellis Carolyn. 2008. *Autoethnography as Constructionist Project*. In: *Handbook of Constructionist Research*. Ed. James A. Holstein, Jaber F. Gubrium. New York: Guilford. ISBN: 978-15-9385-305-1. Pp. 445–465.

Ellis Carolyn, Adams Tony E., Bochner Arthur P. 2011. *Autoethnography: An Overview*. “Forum Qualitative Sozialforschung / Forum: Qualitative Social Research” [online], no. 12.1. ISSN: 1438-5627. <http://www.qualitative-research.net/index.php/fqs/article/view/1589/3095> [13.03.2020].

Foucault Michel. 2003. *The Birth of the Clinic: An Archaeology of Medical Perception*. Trans. Allan M. Sheridan. London–New York: Routledge. ISBN: 978-04-1530-772-7.

Garland-Thomson Rosemarie. 2001. *Seeing the Disabled: Visual Rhetorics of Disability in Popular Photography*. In: *The New Disability History: American Perspectives*. Ed. Paul K. Longmore, Lauri Umansky. London–New York: New York University Press. ISBN: 0-8147-8564-6. Pp. 335–374.

Garland-Thomson Rosemarie. 2009. *Staring: How We Look*. Oxford: Oxford University Press. ISBN: 978-01-9532-680-2.

Garland-Thomson Rosemarie. 2019. *Becoming Disabled*. In: *About Us: Essays from the Disability Series of the New York Times*. Ed. Peter Catapano, Rosemarie Garland-Thomson. New York: Liveright. ISBN: 978-16-3149-585-4. Pp. 3–8.

Garland-Thomson Rosemarie, Ojrzyńska Katarzyna. 2020. *Critical Disability Studies in the Humanities*. In: *Disability and Dissensus: Strategies of Disability Representation and Inclusion in Contemporary Culture*. Ed. Katarzyna Ojrzyńska, Maciej Wieczorek. Leiden: Brill. ISBN: 978-90-0442-467-8. Pp. 17–34.

Goodley Dan. 2011. *Disability Studies: An Interdisciplinary Introduction*. Los Angeles: Sage. ISBN: 978-18-4787-558-7.

Goffman Erving. 1986. *Stigma: Notes on the Management of Spoilt Identity*. New York–London–Toronto: Simon and Schuster. ISBN: 0-6716-2244-7.

Hołub Jacek. 2018. *Żeby umarło przede mną. Opowieści matek niepełnosprawnych dzieci*. Wołowiec: Wydawnictwo Czarne. ISBN: 978-83-8049-715-3.

Kafer Alison. 2013. *Feminist, Queer, Crip*. Bloomington–Indianapolis: Indiana University Press. ISBN: 0-8020-8437-0.

Kittay Eva Feder. 2011. *The Ethics of Care, Dependence, and Disability*. “Ratio Juris”, no. 1. ISSN: 0952-1917. Pp. 49–58.

Kittay Eva Feder. 2015. *Dependency*. In: *Keywords for Disability Studies*. Ed. Rachel Adams, Benjamin Reiss, David Serlin. New York–London: New York University Press. ISBN: 978-14-7983-952-0. Pp. 163–173.

McRuer Robert. 2006. *Crip Theory: Cultural Signs of Queerness and Disability*. New York–London: New York University Press. ISBN: 978-08-1475-713-0.

Michalko Rod. 2002. *The Difference that Disability Makes*. Philadelphia: Temple University Press. ISBN: 1-5663-9934-3.

Mitchell David T., Snyder Sharon L. 2015. *The Biopolitics of Disability: Neoliberalism, Ablenationalism, and Peripheral Embodiment*. Ann Arbor: University of Michigan Press. ISBN: 978-04-7205-271-4.

Moje Kilimandżaro. Losy niepełnosprawnych – wspomnienia. 2008. Ed. Błażej Kuszelski. Poznań: Fundacja Filantrop. ISBN: 978-83-9269-410-6.

Mrozek Sławomir. 2006. *Baltazar. Autobiografia*. Warszawa: Noir sur Blanc. ISBN: 8-3739-2138-9.

Ojrzynska Katarzyna. 2017. *Nabila Shabana dialog z kulturą sprawną*. "Tekstualia", no. 4. ISSN: 1734-6029. Pp. 163–176.

Radkowska-Walkowicz Magdalena. 2019. *Nikt nie rodzi się kobietą? Zespół Turnera i zwierciadła kobiecości*. In: *Zespół Turnera. Głosy i doświadczenia*. Ed. Ewa Maciejewska-Mroczek, Magdalena Radkowska-Walkowicz, Maria Reimann. Warszawa: Oficyna Naukowa. ISBN: 978-83-6605-605-3. Pp. 113–140.

Reimann Maria. 2019. *Nie przywitam się z państwem na ulicy: szkic o doświadczeniu niepełnosprawności*. Wołowiec: Wydawnictwo Czarne. ISBN: 978-83-8049-914-0.

Siebers Tobin. 2008. *Disability Theory*. Ann Arbor: The University of Michigan Press. ISBN: 978-04-7205-039-0.

Titchkosky Tanya. 2006. *Disability, Self and Society*. Toronto–Buffalo–London: University of Toronto Press. ISBN: 0-8020-8437-0.

UPIAS. 2006. *Union of the Physically Impaired against Segregation [Policy Statement, Aims, 1974]*. In: *Encyclopedia of Disability: A History in Primary Source Documents*. Vol. 5. Ed. Gary L. Albrecht, Sharon L. Snyder, David T. Mitchell. Thousand Oaks–London–New Delhi: Sage. ISBN: 0-7619-2565-1. Pp. 444–446.

Katarzyna Ojrzynska

FINDING THE GALAXY OF DISABILITY MARIA REIMANN'S LIFE WRITING

(abstract)

The article examines how Maria Reimann's autoethnographic book *Nie przywitam się z państwem na ulicy: szkic o doświadczeniu niepełnosprawności* (*I Won't Greet You in the Street: A Sketch about the Experience of Disability*, 2019) addresses and problematizes such essential concepts for contemporary disability studies as: disability identity, coming out as disabled and, most importantly, disability community. It focuses on the way in which the

book seeks to reconcile the seemingly contradictory and conflicting ideas about disability. It also argues that by deconstructing the disabled/non-disabled dichotomy, Reimann reinvents the idea of disability community, imagining it as a galaxy of individuals who can only find a sense of connection by recognizing the uniqueness and distinctiveness of another's bodily and social experiences.

SŁOWA KLUCZOWE

Maria Reimann; studia o niepełnosprawności; niepełnosprawność i życiopisanie; niepełnosprawność jako tożsamość; niepełnosprawność i *coming out*; społeczność osób z niepełnosprawnościami