

**A few words about dignity:
An introspective study of
a person with disability**

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*Received 19.04.2022,
received in revised form 22.12.2022
accepted 22.12.2022.*

Abstract

In the article, I present issues of presence, existential absence, and the sense of dignity of a person with a disability. I present these issues for the first time and attempt to show disability “from within”, a perspective to which I am no stranger as I myself am disabled.

The issues of presence, absence and human dignity have always fascinated me. Hence, in this text, they are “filtered” through my dramatic and sometimes even traumatic personal experiences. In conveying these experiences, I never forget what human existence should be – the fact that there should be dignity, presence and being. Is my human experience marked by this? At some point in the text I make a “moral accusation” in connection with this issue. Additionally, I have never forgotten (and will never forget) the person who helped me to “reborn” for myself, people and the world. “The significant person and her achievement in relation to the author” is my modest expression of gratitude to someone because of whom I LIVE. However, the central points of reference in this text are questions of *human dignity* and *presence*. They form its axis and are its guiding categories of analysis. I conclude by stating that these are important, even essential issues

in order to understand the phenomenon of what it is to be human. And to be unique in that humanity.

The main research question which I pose is the following: **Does society see that people with disabilities have dignity? Furthermore, the thesis I propose and which I believe arises from this question is: society has little recognition of the dignity of people with disabilities.** More specific research questions will be quoted below in the text which, in terms of methodology, has been written using an auto-ethnographic approach (Wolcott 2004, Kacperczyk 2014, Urbańska 2012). The choice of this highly qualitative methodology was guided by the assumption that autoethnography allows a subjective presentation of specific fragments of those events inscribed in the category of *human dignity* described here. This will be an analytical autoethnography, after Canagarajah (2012), because through writing I analyze the emotional, mental and situational states that I have had to face in the past, while some of the experiences that generated these states resonate with me to the present. Last but not least, it is my hope that my openly described states of mind will contribute to some betterment of this particular area of human existence in its extremely important, social and cultural dimensions.

Keywords

disability syndrome, presence, absence, dignity, moral accusation, autopoiesis, paradoxes, deed, Deus.

O godności słów kilka: Introspektywne studium osoby z niepełnosprawnością

Abstrakt

W artykule przedstawiam zagadnienia obecności, egzystencjalnej nieobecności oraz poczucia godności osoby niepełnosprawnej. Przedstawiam te zagadnienia po raz pierwszy i staram się pokazać niepełnosprawność "od wewnątrz", perspektywę, która nie jest mi obca, ponieważ sama jestem niepełnosprawna.

Kwestie obecności, nieobecności i godności ludzkiej zawsze mnie fascynowały. Stąd w tym tekście są one "filtrowane" przez moje dramatyczne, a czasem wręcz traumatyczne osobiste przeżycia. Przekazując te doświadczenia, nigdy nie zapominam, jaka powinna być ludzka egzystencja – o tym, że powinna istnieć godność, obecność i istnienie. Czy moje ludzkie doświadczenie jest tym naznaczone? W pewnym momencie tekstu wysuwam "moralne oskarżenie" w związku z tą kwestią. Ponadto nigdy nie zapomniałam (i nigdy nie zapomnę) osoby, która pomogła mi "odrodzić się" dla siebie, ludzi i świata. "Znacząca osoba i jej osiągnięcie w stosunku do autorki" to mój skromny wyraz wdzięczności dla kogoś, dzięki komu ŻYJĘ. Jednak centralnymi punktami odniesienia w tym tekście są kwestie *ludzkiej godności* i *obecności*. Tworzą one jego oś i są jego przewodnimi kategoriami analizy. Na zakończenie stwierdzam, że są to ważne, a nawet istotne kwestie, aby zrozumieć fenomen tego, co to znaczy być człowiekiem. I być wyjątkowym w tym człowieczeństwie.

Główne pytanie badawcze, które stawiam, jest następujące: **Czy społeczeństwo widzi, że osoby niepełnosprawne mają godność? Co więcej, teza, którą proponuję i która, jak sądzę, wynika z tego pytania, brzmi: społeczeństwo w niewielkim stopniu uznaje godność osób niepełnosprawnych.** Bardziej szczegółowe pytania badawcze zostaną przytoczone poniżej w tekście, który pod względem metodologicznym został napisany w ujęciu autoetnograficznym (Wolcott 2004, Kacperczyk 2014, Urbańska 2012). Przy wyborze tej wysoce jakościowej metodologii przyświecało mi założenie, że autoetnografia pozwala na subiektywne przedstawienie konkretnych fragmentów tych wydarzeń wpisanych w opisywaną tu *kategorię godności ludzkiej*. Będzie to autoetnografia analityczna, po Canagarajah (2012), ponieważ poprzez pisanie analizuję stany emocjonalne, mentalne i sytuacyjne, z którymi musiałam się zmierzyć w przeszłości. Niektóre doświadczenia, które wygenerowały te stany, rezonują ze mną do chwili obecnej. Wreszcie, co nie mniej ważne, mam nadzieję, że otwarcie opisane przeze mnie stany umysłu przyczynią się do poprawy tego szczególnego obszaru ludzkiej egzystencji w jego niezwykle ważnym wymiarze społecznym i kulturowym.

Słowa kluczowe

syndrom niepełnosprawności, obecność, nieobecność, godność, oskarżenie moralne, autopoiesis, paradoksy, czyn, Deus

1. Introduction

“Does the world need such weak and disabled people and why?” As a person with a severe physical disability, my answer is obvious and unambiguous. The answer is yes, they are needed. Weak and disabled people are needed to sensitize others, to teach humility and distance to what is difficult, to what hurts and to what is painful in a disability. They are also needed to show what or who a person with a disability can become, and they can become a hero / a superhero in an unequal fight with regression and limitations from the very beginning. It is a struggle for existential normality, as if *in spite of being abnormal*. Weak people are needed by the world and people to show and make manifest a person’s humanity from the point of view of the authentic principles, rules and truths that underlie humanism, gone astray and even lost in the zeal of a contemporary desire for consumer ownership. People with disabilities are needed by the modern world more than ever, because they constitute a kind of bridge between the earthly world and the world of transcendence. There was a reason why these people were called “God’s children.” Wait though ... is it a better or worse God? This question is extremely intriguing and a provocation to engage with this issue intellectually from a critical perspective and then submit oneself to its conclusions. At the same time, it definitely inspires to enter deeply and more broadly into the axiological problem under discussion, which is difficult to unravel much like a Gordian knot. Reflection on it becomes entwined in the entangled portrait of the Creator: on the one hand, a “supposedly” very clear message of unconditional love for man, and on the other hand, the deafness of the same Absolute being, blinded to human evil, lawlessness, and harm. Hence we can be

“children of a better God” or “children of a worse God.” Everything depends on reflection and what can be inferred from it. Therefore, I am needed so that I can testify to myself and at the same time show that my existence, unworthy in the eyes of people and the world, is noticed, appreciated, “distinguished” and especially valuable in the eyes of the Creator. This testimony is also needed to give other People, like me, a new perspective on what is, as far as possible, a normal, independent and completely free existence. It is a true revolution in connection with how the issue of human disability is viewed which, in the case of being able to function within society, is an important factor that can cause tensions or conflicts of interest. The world also needs me for a completely different and prosaically obvious reason: as proof that I am (?) a human being, be it one clothed in the armour of a disabled body. It is strange to admit the connection. Hybrid? I reflect on these thoughts in the presented text, hoping that it shows the essential reality and drama of human dignity and humanity which, because it is innocent, forms one of the most strongly felt and irreversible of existential crises.

2. Are they present on the same and equal terms?

At this point, perhaps a completely different, more specific question should be asked, as if from the opposite perspective: **Is the postmodern world and culture inscribed in contemporary civilization ready to accept mentally, on fair and equal terms, and in all existential areas, people classified as weak and disabled?** For me, this question opens up the possibility of interpretation and the opportunity to reveal my own opinion and position, which may significantly differ from the interpretations accepted by and presented in the scientific literature. I will make observations and formulate conclusions based on examples taken from my own perception and the reception of experiences that have affected me personally. This will include reflection resulting from my own perspective of disability in terms of the question I posed above.

With regard to my own attitude to the above question, I have formulated the thesis that the contemporary world, so firmly fixed in the postmodern culture of modern technologies, ubiquitous consumerism, the culture of success, mental well-being and an adherence to the values of individualism, is not able to accept a weak or disabled person on fair and equal terms within the social and cultural parameters it now operates. The world would never do that. Such an approach would require a completely different philosophy in terms of looking at a person who is weak: not to see her in the context of a patient, a ward, a dependent or someone that is submissive, but as someone on equal terms. Such a view would depend on openness and a sense of partnership, on being equal and involving equality. However, it would take a change in attitude, courage and an enlightened, critical mind to be able to understand, or at least try to understand, the individual diversity of a weak or a disabled individual. Few can afford the great effort needed to change their attitude towards such a person, who is often completely socially and physically absent from the social sphere of life. And even then, when the disabled person herself tries to signal her presence, she encounters indifference and ignorance on the part of society.

Weak and disabled people, although they are actually physically present, are in fact mostly absent from the social sphere. And, more often even, they are absent from the cultural sphere: in the area of artistic expression, where it is possible to fully reveal one's inner world, often closed in for fear of being ridiculed in an external world full of egocentrism and criticism. The external world of the able-bodied and the strong rejects what is difficult, that which causes suffering and pain. From my personal perception and experience – it shies away from taking any responsibility for the weak, disabled person. To assume responsibility for another human being requires superhuman courage to undertake the challenge of showing the disabled person an expression of empathy, acceptance or support in her existential drama, which she has been involved in from the beginning of her life. This is inherent to the drama until the very end. For the

disabled person, the present is mostly existence within the four walls of their own apartment or just a room – they are absent. Nobody will ask disabled people for their presence, nobody cares about them, nobody even asks for their purely human empathy. The unproductive, the inactive, the closed-in, and not only within four walls, but locked into weakness and disability, suffer terribly physically. However, they feel their spiritual and mental suffering much more strongly and more powerfully than their physical suffering. They suffer alone and in solitude, locked inside deformed bodies, unable to do anything on their own. This is the everyday situation that affects them. Sometimes they are even unable to express the pain and suffering they experience on their own, because they cannot speak. At this point, the drama deepens, it becomes even more difficult and painful. The eyes, which are the mirror of the soul, reveal this tragedy. **This is why I put forward another thesis, however subjective, that the modern world is not ready to accept on fair and equal terms a person with a disability – she is present, but in fact she is absent.** Absent from the social and cultural spheres. Non-disabled people will never be able to “fully understand”, even minimally, a disabled Weak person, until they have felt the effects of exclusion for themselves, have touched it ... The Present, who should also be known as the Absent, are silent heroes in the unequal fight in the war caused by their disability, which totally enslaves them, drastically limits and poignantly degrades them socially and culturally. Unless... they meet a significant Person or Persons and get helped to become recognised publicly, like it was in the case of my own painting exhibition.

3. A war to regain human dignity

In the context of the topic of human dignity that has been taken up here, fundamental questions should be asked from the very beginning. Does a disabled person feel their own dignity? Does she experience and feel self-esteem? Does she feel respect for herself/towards herself? Disability is always and inextricably connected with the feeling of being inferior, uglier, unnecessary.

It irreversibly discriminates, marginalizes, excludes and stigmatizes. It causes pain and suffering. It intensifies isolation and feelings of being closed in. The mere fact of being present, but in fact absent on the existential plane as a whole, does not contribute to the building of self-esteem, which in the case of a disabled person is relatively low. Self-esteem in a person with a congenital disability, as in my case, is formed in the family environment. For as long as I can remember, I've had relatively low self-esteem, "always". It was only by being with Mum that it grew in some way. Perhaps it was because in her eyes I was a "normal" child, who was required to do many things, often on my own. Perhaps this increase in self-esteem in relation to Mum resulted from a strong emotional bond in terms of the parent – child relationship. Building human dignity – self-esteem and self-respect – are like the trials of Sisyphus: never ending work on oneself.

What is dignity to me? It is freedom. The freedom that I have gained after experiencing decades of existential bondage. My self-esteem is strengthened by a significant person and the small successes connected with living that bring me closer to greater existential independence as well as independence in all areas of everyday life. The two most important components that build and shape personal dignity are self-esteem and self-respect. Being present and absent at the same time, with a sense of guilt for being there at all, and the feeling of inferiority generated by a disability, are existential factors that were and, indirectly, are still present in me. One must undertake a never-ending total war on them, one which is waged on all existential fronts. Disability is associated with limitations, loneliness, fear, suffering, and inequality. From my point of view, the most overwhelming feeling currently felt – apart from the ones mentioned above – is the feeling of loneliness – both in the physical sense and in the area of transcendence. Loneliness in disability is perhaps a new dimension of existential reality that I have to face in this never-ending war to regain human dignity. The disabled person's own humanity trampled on by the arrogance of those who are strong and able-bodied, who consider themselves

almost *Homo Deus*. Over the course of modern history, such an attitude has led to an unimaginable genocide, while weak and disabled people were the testing ground for this genocide: economically too expensive, socially unnecessary, a disruption to the beautiful image of the Aryan ideal of the human being – to be healthy, beautiful and fit. Will the modern *Homo Deus* play God and strip mankind of his inalienable right to human dignity? The question I pose here echoes the one asked by a generation at the crossroads of uncertain and unclear historical events. Entangled in the incoherent and mysterious future of some yet unknown human being. The feeling of loneliness strikes with redoubled strength and power – as in the case of a disability that robs the individual of the ability to recognize and feel a sense of dignity – self-esteem and self-respect. Let it sound out incessantly: *Homo sacra res homini*.

4. Human dignity in the dignity of God

The idea of human dignity is internally justified only in Christian philosophy: for dignity to come from an inner source that source must exist. Every man is worthy of respect because he was created in the image of God. (Filińska et al. 2010: 35)

In the modern world, the image of Deus, the portrait of God, is presented from the position of His non-existence, negation, and exclusion. This phenomenon can be compared indirectly to the present situation and that of the weak person, but as one who is actually absent on the existential plane. The exclusion of Deus, who is the highest axiological dignity, from social and humanistic narratives, results in the exclusion of the weak, disabled person from the holistic, social and existential plane. If we do not show respect for Deus, why should we show respect towards a disabled person? This question pushes, even “forces” you to confront it intellectually, to have your own ideas about the issue of dignity. Human dignity that is threatened with being trampled on, depravation and diminishment. This in turn leads

to a diminishment of the highest axiological dignity of Deus – the dignity of God himself.

Why do this? Why Show Respect? Why this dignity? This one-of-a-kind and unrepeatable belonging to Him – to Deus – makes man more sensitive, more sensitive to suffering – not his own, but the suffering of others through the experience of the “spiritual encounter”. I felt this “inner source” personally, perhaps it is truer to write that I felt the majesty of God, powerful in otherworldly sensations and feelings. I come to the limit of meaning through words – writing after Bakhtin – the Absolute surrounded me and, apart from fantastic and beautiful divine love, He showed me respect and for a few seconds noticed my trampled, violated transcendence devoid of self-esteem and human dignity. In the eyes of the Creator, I was a human being, someone “worthy” of dignity, especially respect and LOVE. A fantastically unearthly, beautiful love. I refer to this love of Deus constantly and I miss it very much. It is – both the love and the dignity of the Absolute – indescribable. Divine dignity enclosed in the experience of the “spiritual encounter” is an amazing testimony to the power of the majesty of Deus. The Creator's show of respect for me is amazing. It is a beautiful gesture of the Creator towards the absent, weak and disabled person.

Touching the “inner source”, just touching and meeting the power and majesty of the Creator allowed me to verify everything, change it, turn it around one hundred and eighty degrees. My previous axiological order was overturned. Dignity is no longer only freedom. From the experience of the “spiritual encounter”, it is also related to the Absolute, whom I could “know”. In the end, it allowed me to reach for a different thought, a different view of the category of Deus, as well as the category of that which is simultaneously Present and Absent. This fresh, invigorating “breath”, which belongs to the future, will become the nucleus of successive changes in all existential areas of my life.

Human dignity is not only revealed through the Christian image of the “inner source” of the figure of God. Dignity as a superior category of the highest value is inscribed in all religious and

spiritual systems of the world, but also in atheistic ethics. Buddhism, Islam, Judaism and Christianity follow their own paths to the achievement and respect of human dignity. The category of human dignity remains a universal and inalienable one. At this point in time, I have come to the conclusion that the “inner source”, the figure of God, is the same for the four major religious systems of the world. DEUS IS ONE. The hallmarks of the One Deus are: goodness, love, and the dignity bestowed upon man. I have also come to a second conclusion: in the eyes of God, the good done to another human being is the only true measure of that which is human and positive.

5. Loss and the sense of dignity

It should be emphasized that man does not lose his dignity, even if he has lost everything else – which implies, against all expectations, the constancy of a person’s ability to remain convinced of the need for dignity. One could say that dignity manifests itself more, not in the sense that it exists more, but that it is more evident in a man who has lost all his other qualities. (Filińska et al. 2010: 38)

The feeling of being weak implies a lack – a lack of that which would increase self-esteem, which would raise a low sense of human dignity from almost zero level. Disability is connected to a feeling of some sort of loss. This loss will never be recovered by anyone. Nobody can verify or repair it. It is the kind of loss that affects your entire existence, and it is an irreparable loss. With this “unfair” loss, resulting from being affected by a disability, which is a form of stigmatization, the human being does not lose the dignity assigned to her. She never loses it, even if she has lost everything else – even self-respect. She feels wronged by fate. On the one hand, she feels anxious, and on the other, she would like to do something. She would like to rid herself of the pain and existential hatred of bodily garments, shout out to the world about her own anger at the existing state of affairs, and very often she cannot. Sometimes she does not even know how. She often feels angry but does not take it out on

others. Very rarely I direct this anger towards myself. An accumulated anger for the existing state of affairs, one which has built up over time and which erupts with the force of a deadly volcano. It is hard to visualize. All self-respect has gone. At this point, everything has gone. Combined with negative self-esteem, it leads me to an existential drama. It leads to an “assassination attempt”, which I write more about below. It is a borderline event. The axiological distortion that affects me does not even allow me to have a minimal feeling of dignity towards myself! This axiological bias, the result of evaluation undertaken after an “attack on myself”, leans towards closure and isolation, and a subjective sense of dignity towards myself disappears. It simply does not exist. Dignity has “died”. By committing an act ethically and morally axiologically unworthy and inconsistent with all the professed norms, I made the most difficult and extreme choice. At that point, I lost everything, but I did not lose dignity in the gaze of Deus, which is worth discovering and taking note of. Dug and excavated from under the rubble of shattered dreams that will never come back, this Dignity ultimately triumphs along the lines of the existential drama that has unfolded. To lose all this, “to die” while still alive. So, although I have lost everything in an ethical and moral sense, I still call myself a hero, a hero who has gained existential freedom. And the dignity bestowed by Deus.

The feeling of human dignity with regard to my own example carries an important message for me, about which I must write and I do write below. This message is hope and the birth of self-esteem, essential components of a humanity grounded in limitations and disabilities. I do not give in to disability, but face up to it, going beyond all the limitations that have been designated as impossible for human beings to overcome. A dignity by your side that gives you wings.

6. (Un)banal paradoxes

I am an endless string of existential tragedies entwined in the (un)banal paradoxes that I face. Second by second, minute by

minute, hour by hour, day by day, week by week, month by month, year by year, decade by decade. The tragic aporia of existential contradiction, inconsistency, and illogicality is noticeable from the very beginning of our earthly life. It is my hallmark. The contradiction of being and non-being is the field of action of the first paradox: that which should die lives, against logic, against all the signs, both earthly and other-worldly. In this paradox, existence won. In this particular portrayal, (un)banal life triumphed. For me, at the moment, non-being is losing to being in this fight. Lack of any coherence or logic are characteristic elements of existence and they belong to me. My life is in the paradoxes.

Another paradox is the disproportion between the physical and intellectual spheres. The physical sphere remains in significant regression, while the intellectual sphere works at a high level. In this contradiction, which is a tragic example of aporia, I see a tremendous tension resulting from my inability to physically do anything that would allow complete physical independence. The paradox of this situation generates negative emotions, feelings and mental states. Existence in this developmental paradox is difficult. It requires intellectual flexibility and unearthly patience to deal with all the elements of existential dependence and a great level of self-awareness. Such a high level of intellectual development also creates another developmental paradox, in the area of education. This paradox begins with the legal and statutory requirement of a child to be involved in compulsory education. In terms of physical development, I did not qualify for compulsory education at all. In terms of intellect, I was eligible for the normal system of public education. From the very beginning, this developmental paradox was associated with a struggle at institutional level for the right to a normal and universal education. At this point, I would like to introduce another research question posed by this article: **How do institutions established to care, support and protect people with disabilities, carry out these tasks when people with disabilities find themselves in a state of existential crisis?** I will try

to explore this issue below, from the perspective of challenges posed by school as well as in other areas of life.

Facing up to all these paradoxes helped, however, build a sense of dignity. It broke up and reduced the tragic aporia. It reduced a feeling of loneliness in a world unfavorable to those who are present, but who "do not fit" into the picture of what it is to be present as a whole. I still hold this statement to be true: I am present, but in fact I am absent from the existential space of human action. Absence does not "hurt" physically. It only hurts psychologically – it stigmatizes, excludes, definitely marginalizes, strongly and effectively. As (not) present I am permanently faced with an eternal existential dilemma: to fight or to surrender to this strange presence with no prospects. From this perspective, without a future, the most important existential ingredient has been forgotten – the ingredient of dignity. More precisely, to actually establish it (institutionally?) has been forgotten. In this moral and ethical paradox of presence and absence, dignity and lack of dignity, I am trying to find it, have found it, bravely facing the challenge of an existence marked by the onerous stigma of disability – difficult, tiring, sometimes even brutally dramatic. To face this challenge is to enter into a losing battle and win it. To be a moral winner in this battle in which one side is "destined" to lose from the beginning. To face it is to take up challenges and, above all, to take up the challenge of being in the world. When this modern world mocks authority, the ideal, values, the Absolute, it is extremely difficult.

Dignity cannot be limited, diminished or neglected in any way. It is the most important value given to the human being. Self-esteem, which is a component of dignity, is difficult to attain. To have it, however, guarantees an easier and more effective existence. It is impossible to explain the coherence and logic of this tragic aporia which is inscribed from the very beginning. Everything, all these personal – subjective tragedies and dramas take place somewhere in between. Between something known and unknown. Between the possible and the impossible. Between being present and absent in the world. Between that which is known to reason and that which is unknown to reason.

It is this *between* which allows for a new perspective on issues relating to the existential when it comes to a person with disability. Except it stands in the way of gaining a sense of dignity – an integration of the self and being. You are “here and now”, you are personally present. For example, at school, in classes. But is it being present? I pose this question as a provocation. I pose it to make the reader think, in order to trigger a discussion on the change that needs to take place in the paradigm that, overall, views the person with a disability as helpless, unhappy, completely dependent, suffering, and so on. I can confirm that I suffer, but I also love, I am happy, joyful, open to new things, as well as resourceful – all, of course, to the extent that is possible. I am also independent as much as is possible and to the extent that is physically possible. I am completely independent in the sphere of transcendence and the sphere of the written word. These two spheres give total existential freedom. The road to this was and, in part, still is rough, winding and uneven. However, it has become a challenge. A challenge that can lead me to gain self-esteem and to retrieve an unknown human dignity. As a consequence, it may lead to the emergence or development of a completely new paradigm for the disabled person – loving, happy, joyful, helpful and resourceful, very independent and existentially self-sufficient. No, it does not have to be a utopia. It can come true. In part, it has happened, and it has happened to me.

People with disabilities not only can become authors of themselves, in a certain sense, they must become authors of themselves. Autopoiesis for them is not something they can get as a handout, as a fortuitous gift, or as an unexpected privilege. Autopoiesis for them is a hard-won necessity, a ruthless challenge, a heroic destiny. The tragedy and, at the same time, the heroism of this situation consists of the fact that surrendering to the challenges of autopoiesis – that is, rejecting the model of the “man of a particular role” and the “man of learning”, contrary to expectations, pressure and “humanitarian laws” – is the only way to maintain a sense of personal, human dignity. (Filińska, Momot, Wojciechowski 2010: 96)

How incredibly hard and how incredibly difficult it has been/is, to become the author of myself, struggling with a stigmatizing disability that takes away almost everything from me. However, I became the author of myself when I got the opportunity to “transfer” my thoughts, feelings and emotions through the written word: first poetry and later prose, which gives greater possibilities. Autopoiesis is a never-ending process – a process of becoming oneself, a human being – from absence to presence. Being the author of yourself is one of the greatest feats for an “actor”, a long, hard, and at times, even painful process. This play, before which destiny set me, turned out to be a hellishly difficult one, a brutally painful and dangerous one to perform. While creating myself, I was not, could not be totally alone. The stigma of my disability shaped the psychological portrait of the character that I have had to play in this drama, along with the countless unpredictable twists and turns I have experienced in my life. There was no prospect for the self-esteem which is a major component of human dignity. Dignity was trampled on, ignored, diminished, and even killed. There was no consent whatsoever for me to have dignity or to be able to experience it – especially in this performance, where I am subjected to violence of various kinds. By creating myself, being the author of myself, I do not consent to pigeonholing, isolation, exclusion, or marginalization. Such an attitude makes me a lone gun, a person on a quest, who in this existential drama constantly fights for herself with all her power and strength. I fight for the creation of myself with the feeling of a minimum of elementary dignity. “Self-assassination” has become the calling card of this dignity – a dignity, however, that is still absent – in this art of looking for myself.

7. Moral accusation

My will TO BE from the very beginning was enormous. As someone present, I was condemned to medical malpractice from the beginning of my earthly existence, and from maturity, to the “mental destruction” resulting from acts of violence of various

kinds. However, I had the force of will to break free from the destructive forces that pushed me towards the abyss of complete annihilation and non-existence. How strong this will was, and I think it still is, can be shown by the fact that I was triumphant twice when confronted with a terrible death. I outsmarted death and thereby showed its existential inferiority. My willpower allowed me to rise above the terrible destiny of the existential death that stalked me right next to a cold hospital cot among alien faces, and alien voices and hands. I was not yet fully aware that the will to live had won this clash with death at the earliest moment of my life. The force that was liberated at that time could not have come from earthly time and space. After all, the strength of death was much greater in those circumstances than the energy of life. And yet ... against all odds, life won. Life was granted to this BEING, who was not completely aware of what she would have to face in the future. **This is why I dare to put forward a third and a fourth thesis: The world needs people with disabilities for reasons that nobody can yet imagine. It also needs them because they remind us that institutions can often neglect their moral duties or distort them.**

And I would have to face disability, developmental regression, loneliness, acts of violence, as well as various other traumas, including an “assassination attempt” and an attempted suicide. In addition to mis-understanding me as Different. I would have to face INDIFFERENCE, CALLOUSNESS towards the tragedy and drama of the acts of violence that affected me, assisted by the silent consent of others. At this point, I bring the heaviest moral accusation to bear upon those who could have stopped this spiral of violence [the high ranking employee of the care institution, as well as its management]. They didn’t stop it. Nobody tried to stop it. Apart from a significant Person, whose words broke through the concrete walls of institutional indifference and the cynical disregard of the dramatic situation of a client: *nota bene* a care institution and one which was supposed to prevent violence. All these moral perpetrators were against me: the victim of acts of violence. As a result of their

attitude, moral permission was given to the perpetrators of violence to use it. According to these officials and their reasoning, the victim is the guilty one. She provokes by her behaviour [non-acceptance of acts of violence] and needs to be brought to “order” by the perpetrator of acts of violence. I rebelled against such cruelty – mental and emotional violence which left no visible traces. A cruelty meted out by a perpetrator who was always right, although he was not right at all. By this moral accusation, which is the main form of my opposition to institutional hypocrisy and ignorance, I want to communicate to everyone that lack of reaction, indifference and callousness, puts perpetrators of moral violence on an equal footing with perpetrators of real violence. I will repeat: ON AN EQUAL FOOTING! It places them all in the worst possible light. The morality and professed values of such people are debased. Their attitude led me to the suicide attempt I mentioned above. If at that most dramatic of moments someone from the senior staff of the institution had believed me and shown the smallest amount of understanding or supported me, if only slightly, in the fight for my own human dignity, there would have been no dramatic choices, decisions, or events. I know that with the “assassination attempt” that was carried out on me, I reached an existential abyss. With this dramatic deed I showed that there is a border that no one can ever CROSS in relation to any person. This border is that person’s sense of human dignity. Violation of human dignity in an extremely traumatic and violent form led me to make FINAL decisions and choices which, in turn, led to the events which occurred.

How strong one becomes in the context of moral accusation, of the will to show the perpetrators of violence, that being in the worst possible position, completely lost, I am able to come back from the existential abyss and reach the highest point possible with regard to my regressive development. I have tried to prove this each day from the moment I first made the accusation. Standing as one with the significant person who has supported me I WOULD SURVIVE AND I WOULD BE. Destiny, as if in spite of these moral perpetrators of violence, has shown great generosity towards me. It has given me the will to make spectacular

changes. It has taken me to the very height of my own developmental capabilities. It has been discovered slowly and then revealed to the world by the significant person. At this point, the significant person is an unquestionable SYMBOL of a human approach to the issue of attitudes towards acts of violence and towards the victims of such acts. He shows disinterested interest and concern. He supports me, as much as he can and is able, in my existential tragedy and the drama of my situation. It is a symbol of pure humanity in a world of indifference, heartlessness and mental cruelty, as well as desensitization to the harm, pain and suffering that have become part of my life. The significant person as a symbol becomes a positive, characteristic, charismatic figure. By standing as one with the victim, he exposes herself clearly to all – the moral perpetrators of violence and the real perpetrators of such violence. He is, like the victim, misunderstood, accused, sometimes even despised by those moral perpetrators.

Indifference and heartlessness KILLS. Efficiently. And helplessness is terrifying. The existential drama described above marked the beginning of a long-term recovery. It initiated perhaps, a most difficult process, because it is a process of “rebirth” from a position of “transcendent death”. From the lowest and most difficult position in the case of a human being affected by a disability. Without this support, commitment and work from the significant Person, I would not be here at all. This significant Person is the most important figure in my entire recovery process. Steadfast determination and the will to achieve the greatest possible existential independence and self-reliance with the support of a significant person and in all areas, after so many years, has such an effect that no one could ever have believed it. The effect of the possibility of an independent, and as far as possible, self-sufficient existence.

Willpower conquered everything. In the beginning, this willpower overcame a terrible death, and in an already mature existence, the same willpower overcame acts of violence, “psychic destruction” and “self-assault”, in order to reshape me. Absent,

but slowly emerging from the dark abyss of existence marked by disability – Present. Human. Persons. Identities.

8. Being human by doing

I cannot exercise my freedom by violating my dignity. I have to respect my body as well as the bodies of others. I must respect the ideal of humanity that I carry within me. I am setting an example for future generations through the actions I do in my daily life. (Fil-ńska, Momot, Wojciechowski 2010: 113)

There is never freedom without self-determination. Without freedom, there is no sense of one's own personal dignity. As long as I can remember, I have had a big problem with self-determination, freedom and dignity. Disability effectively prevented me from having respect for my own body, which greatly limited me, stigmatized me and made me dependent on others. How can I accept my own body over which I have no control and have never had any control? I pose this question because no answer will ever resolve the moral dilemma of such a conflict of interest. After several decades of existential being, I am of the conviction, have come to the conclusion, that the acceptance of one's own imperfect, uncontrollable body is possible only when one has matured to this extremely difficult psychological process within oneself. Becoming mature enough to accept one's own body is a process that should also end with the acceptance of oneself as a valuable human being, someone that is needed by people and the world. To let future generations see me as someone who has attained the most wide-ranging of existential freedoms. This maturation can be viewed in terms of perpetual action. In connection with this, I believe the underlying reason for my existence is to set an example for others, for society, for those who are similar to me and those who are different from me.

I present myself to future generations through creation, a deed that I have to struggle with every day. This form of action, in the broadest sense of the word, is familiar to me. In Karol Wojtyła's Christian personalism, I have encountered the state-

ment that a person only ever becomes fully human when he acts, is active. Man realizes himself, becomes present through deeds, actions, cooperation, not only in relation to himself, but especially in relation to a weaker person, one who requires support, help and understanding. Through the act of creating successive cultural texts (?), I show future generations, as well as the present one, what my deeds and actions can lead to. And this is from a person who is physically able to do very little. In contrast to this, in writing and the intellectual field, I do spectacular things that should be completely impossible. I reveal disability from the inside, with regard to the most difficult issues and problems that I constantly have to deal with, and which are existentially important both for people today and for the generations to come. I became aware of this while reading Peter Sloterdijk. This philosopher has coined the term “action creates the thing that is done” (Sloterdijk 2014: 442), with which he himself identifies. Sloterdijk’s statement fully reflects the mainstream of existential being. With regard to writing a text, I reveal to people and the world little-known and still insufficiently understood aspects of a person with a disability. Sometimes it evokes contradictory feelings, from simple disagreement to basic human anger towards the things that a person wants to limit, exclude and stigmatize. However, over decades of a limited existence, I have developed my own system of coping with negative feelings and mental states. This is important in order to maintain the relative balance of my inner existential world. Obtaining this inner balance or, putting it another way, gaining spiritual peace, has given me a greater willingness to act not only in the fields of writing and science, but also in the wider existential field. Following Sloterdijk’s “action creates the thing that is done,” has allowed me to cross the sometimes artificially established borders of those things which are (im)possible for human beings, borders which I constantly cross. And all of them. It is a kind of challenge or a call to radically and definitively change how people see and perceive disability in the currently functioning paradigm, which puts the person with a disability in a totally inferior position both for the person and for the world that

surrounds her. Now is the time to change this. Changes occur very slowly. This paradigm shift should take place, not with the unilateral participation of a person in the traditional sense, of the able-bodied person, but with the involvement and active participation of people with disabilities. This should include all its forms, ranges and types. Without such a perspective, the anticipated change in the perception and understanding of a person with a disability will never take place. This proposition is a call for discussion within the entire community of people with disabilities. It is a very varied, diverse community with a variety of needs, challenges and problems to face up to and overcome. On the one hand, this diversity may have a destructive effect on the processes of consolidation that need to take place. On the other hand, an overall rapprochement may be possible within the whole of the disabled community, in order to establish a shared front for action aimed at a positive change in the current paradigm. It will be a difficult task, but not impossible. Everything is possible. After all, it is “the deed creates that which is done” / “action creates the thing that is done,” and Peter Sloterdijk’s categorical imperative “you must change your life” calls for this.

9. The significant person and his achievement in relation to the author

I became present, first of all under the influence of my mother, and after her death, that of a significant Person. Disability effectively prevents presence. As an individual, I was not able to become present by myself, to show myself to people and the world. Having such a limited existence, I was not able to mark my presence. Because how was it possible for me to distance myself from the person I was, to become an independent person, to present myself? This question gives an idea of the range of often extreme difficulties that had to be solved and overcome. It involved a change in approach, not on the basis of a mental dictate, but on the basis of an equal partner relationship with another person who fully accepted me as a person. All these

elements were connected by a significant Person, someone who became the main instigator of the internal changes that took place within me. Full acceptance and an approach based on partnership with the significant Person caused me to open up to Him as a partner, to become involved in what was a regular conversation between two People. With this Person, it was the first time that I had entered into a discussion, and one that was equal. For the first time in a relationship with someone from the outside, I voiced my own observations, conclusions and thoughts. For the first time I started to talk about my feelings, emotions, doubts and fears. The significant Person put in considerable work, commitment and patience to draw me out of myself and to help me break free of the blockade of mental fear of talking to someone from the outside, someone alien. The significant Person created an atmosphere that was extremely friendly and full of emotional warmth enabling me to open up to him, to other people and the world itself. It was a long-term process. The significant Person was close, the closest he could be including transcendentally, as a person in relation to another person. However, at the same time, he not only gave me a great sense of mental and emotional security, emotional stability and emotional support, but he also shaped my sense of personal separateness and individuality. He led me from complete closure, he brought me back from the dark abyss of verbal silence. A silence which was meaningful, painful, tragic and even dramatic in its portrayal of a human identity. The significant Person brought to presence the (non) present me; a person wanting to free herself from internal despair, suffering, pain and loneliness. This making-present shows that you CAN pull an individual back from the abyss of being closed in on herself and lead that person towards a spectacular, beautifully transcendent openness which includes another person and the surrounding world. This became possible thanks to the selfless commitment of the significant Person who undoubtedly believed in my capabilities and saw a great, natural but deeply hidden potential for development. The significant Person has contributed and continues to contribute to my success – being able to

achieve the best I can in terms of my development as a human being. This is an unquestionable and irrefutable fact.

10. In way of an ending

From what I can see and what I have experienced on an individual level, Polish society does not yet fully recognize and accept people with disabilities, despite the adoption of an increasing amount of normative legislation in all types of institutions. The reality in contemporary Poland, at the beginning of the twenty-first century, is that a person with a disability still feels a great deal of humiliation, pain, intolerance and dissatisfaction. The dignity of people with disabilities is violated, as was the case in the famous spring protest in 2018. From an axiological point of view, the attitude of political decision-makers was morally the worst one possible. Society was shown the place of people with disabilities or rather, it was shown that there is simply no place for them on the ladder of social coexistence. Indeed, as far as society is concerned, people with disabilities should be barred from the possibility of any form of social coexistence. The truth, however, is just the opposite; people with disabilities contribute to the development of moral empathy, social networks of institutional support, and inclusive practices which should become the norm of a humanistic society. The challenge to return to a humanistic concept of civil society is of the utmost importance. The call for such social insurgency runs along the fault line that prevents man from doing evil. It is a line that has become dangerously thin, even transparent. A hidden evil shines through it, dormant, but now given the opportunity to wake up. Such an awakened evil may turn out to be more destructive in reality than it actually looks. Hence the idea of humanism is so extremely necessary and important on the threshold of the twenty-first century. That and the fact that the dignity of the human being, as a value superior to all existing values, becomes a fundamental prerequisite of humanity.

Translated by Martin Blaszk

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