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A History of the Exclusion of the Mentally Handicapped

Abstract The article corresponds to the problems of terms describing people as mentally disabled vs. intellectually disabled, compared to those with an intellectual disability. The application of each of those notions is justified by the premises of an axiological and worldview nature. Political correctness encourages us to replace stigmatizing terms with more neutral ones. However, the question arises: from where did the terms of a discriminating character appear in the language?

The article presents examples of the application of segregation policy since the 1970s, as a result of which the intellectually disabled remained in residential care centers, separated from the rest of society. Based on the literature of the 1970s, a dramatic picture of the fate of people deprived of human dignity is painted. This situation meant that the terms applied to intellectually disabled people condemned them to the worst position in society. It began to change when the policy of social integration and inclusion was implemented in the West.

The second part of the article includes deliberations over the understanding of the words "disability" and "intelligence" (a word present in the term intellectual disability). Two contrasting ways of comprehending the term intelligence are presented: one derived from ancient times and the other introduced by the modern system of psychological measures. I demonstrate what consequences the application of those two understandings of the term intelligence bring for the understanding of the human condition entangled in the modern world.

The summary presents the conclusion that mental retardation does not need to be treated as a deficiency or a dysfunction, but it may be – according to the idea of variety – treated as an equal way of being a human, different from the statistical majority of the population, however, still demonstrating a unique specificity and beauty.

Keywords mental handicap, intellectual disability, segregative policy, integration, inclusion, diversity, humanity

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A notion that appears increasingly often in the literature of sociology related to the people discussed in the paper is the notion of variety. I am not willing to name the terms, as any that I would use would not be philosophically or axiologically innocent. Each suggests a certain philosophy, a specific manner of thinking about the world. The notion of variety appears increasingly more often in speaking about those people, and there are even some attempts made to determine those individuals not in categories of disability but in categories of "queer" (McRuer 2006). This term is synonymous to disquieting, eccentric, odd. McRuer introduces a theory he calls "compulsory able-bodiedness" and argues that the term "disability" is produced by the system of compulsory able-bodiedness, just as the system of compulsory heterosexuality produces queerness (2006:2).

It would seem that deliberations over these problems are only of a linguistic nature, seemingly referring to the comprehension of words. However, words are not the object of attention and reflection by people. The exploitation of certain terms hides the intention to introduce the mentioned people into a specific social context. This process of naming encompasses the beautiful concept called political correctness. But, praising the concept of political correctness can lead us on a wild goose chase. Because if we were to succeed in coming up with an axiologically neutral notion, not stigmatized, the ruthless colloquial language would take over the term almost immediately, transforming it into a stigma. That was the case with the idea of "mental handicap", which was anti-stigmatizing towards the notion "mental defective". When that became stigmatizing, a new term was developed, "disabled persons", and from that "persons with disabilities".

Modern Rationality of 20th Century

The pursuit for non-stigmatized terminology has not been around for long in Europe. In Scandinavian countries, which were the first in Europe, and in the world, to begin the process of integration and normalization, disabled individuals growing up in the 1970s and 1980s were called "the first generation of integration" (Gustavsson 1996:232). Since then, there have been numerous attempts made to "bring back into society" those who had lived in closed institutions, fulfilling the segregation policy, which was mandatory at that time. The Norwegian researcher, Jan Tøssebro, writes about it a little misguidedly: "[...] the three decades after WWII, that is, between 1945 and 1975, were called the "Golden Age" of the welfare state. This description is of an international character, but it is also related to Scandinavian countries. The first fifteen years of that time may also be called the "Golden Age" of the segregation policy towards the intellectually handicapped. This refers both to centers of permanent stay, as well as to the interconnected system of special education" (Tøssebro 1996:47).

At the beginning of the 1970s, numerous publications were issued where authors made every attempt to describe "the creation of living conditions" for people staying in total institutions. Many of those publications were available in the USA, where the process of deinstitutionalization began relatively early. Here, such articles as "Construction of living spaces in an institution" (Risley, Favell 1979:

3-24) or "Planning a system of services in a residential center" (Swenson, Seekings, Anderson 1979:25-26). The contents of those publications suggest that it was a time when the movement of the humanization of previously completely dehumanized people, deprived of any feelings of a worthy existence, started. However, the idea to simply close the institutions that isolated those wretched individuals from the society and send them home still hadn't come about. Western societies needed to wait for almost a whole decade.

Erving Goffman, who between 1955 and 1956 conducted some research in a psychiatric hospital in Washington, describes the degradation processes which were experienced by 700 patients of that huge total institution (Goffman 1961:7). To deprive the patients of the feeling of self-esteem and self-respect – to crack the whip and control them completely – there were some procedures applied that caused loss of the feeling of personal security: "Beatings, shock therapy, or, in mental hospitals, surgery – whatever the intent of staff in providing these services for some inmates – may lead many inmates to feel that they are in an environment that does not guarantee their physical integrity" (1961:21). Goffman also writes about numerous humiliations and torments which the patients were exposed to. "Medical and security examinations often expose the inmate physically, sometimes to persons of both sexes; a similar exposure follows from collective sleeping arrangements and doorless toilets. An extreme here, perhaps, is the situation of a self-destructive mental patient who is stripped naked for what is felt to be his own protection and placed in a constantly lit seclusion room, into whose Judas window any person passing on the ward can peer" (1961:24).

A conceptual network, developed as a result of analyses and numerous other, even more drastic actions taken against the patients, led Goffman to come up with the category of "total institution", and put forward a theory of the operation of such institutions. According to that theory, which employs ideally typical structures, five categories of total institutions may be distinguished. One of them is posed by centers for persons who require care and control, because they may be "a threat to the community, albeit an unintended one" (1961:15). Rational thinking related to the effectiveness of keeping people – closed in a single place, isolated from the world – whose biography is a homogeneous degradative "career" of a patient giving away his fate in the hands of an institution, is expressed in the creation of anti-TB centers, hospitals for the mentally sick and leprosariums. The remaining four categories of total institutions embrace a wide spectrum of persons, who for certain reasons, and for some purpose, have been placed together in an isolated space. Goffman claims that "to learn about one of these institutions we would be well advised to look at the others" (Goffman 1961:14).

Therefore, it may be assumed that sometimes spectacular differences in the operation of particular institutions are not so significant as to make it impossible to provide them with a common name. The fate that the societies of the West had for their handicapped and mentally ill (this differentiation, currently obvious, was not complete in the first half of the 20th century) is a mirror that reflects the attitudes and arising actions in an exaggerated and condensed manner which we take as members of a society towards ourselves. A psychiatric hospital from the 1950s is a grim metaphor of 20th century rationality. As claimed by Goffman, this so called "mental illness" cannot be regarded as the "reason" for placing an individual in a psychiatric hospital: "in the degree that the 'mentally ill' outside hospitals numerically approach or surpass those inside hospitals, one could say that mental patients distinctively suffer not from mental illness, but from contingencies." (Goffman 1961:126). Speaking graphically, an inevitable condition for placing someone in a psychiatric hospital is that someone needs to diagnose a mental illness, that is, to denounce the wretched individual. In the case of people labeled mentally handicapped, there needs to be someone, who would "give away" such a person.

An example of the description of the fate of the intellectually handicapped and mentally ill individuals, kept together in centers of isolation, is an album of black and white photos with the significant and terrifying title: "Christmas in Purgatory. A Photographic Essay on Mental Retardation" (Blatt, Kaplan 1974). The first part of this album was published as a separate publication in 1966. Family and friends of the mentally retarded distributed thousands of copies of this shocking document, sending it to representatives of governmental agencies, members of health commission, academic professors and leaders of parents' movements. They showed pictures of adults and children – naked or dressed in inappropriate clothes of the cheapest quality; closed in isolated rooms without handles, in empty spaces with walls dirty with excrement, in locked solitaries or bedrooms for dozens of people. The photographs are accompanied by commentaries of a commission that inspected the institution. For example: "we were amazed by the over-crowdedness, by the disrepair of older buildings, by the excessive use of locks and heavy doors, and by the enormity of buildings and numbers of patients assigned to dormitories"; "Beds are so arranged—side by side and head to head—that it is impossible, in some dormitories, to cross parts of the rooms without actually walking over beds. Often the beds are without pillows"; "Six States spent less than $2.50 a day per patient, while only seven States spent over $5.50 per day. Nationally, the average is $4.55 per day, less than one-sixth of the amounts spent for general hospital care"; "The population of State residential facilities runs the gamut from a few hundred to more than 5,000; but on the average, each institution is caring for 350 patients over stated capacity and has a waiting list of better than 300." Each chapter opens with a motto, which is a quotation from a literary classic. Notions that pose metaphors for human fate in literature adopt an amazing character in the descriptions of the total institution and the inhumane conditions for their "patients". The motto opening the first chapter is Dante's "Abandon all hope, ye who enter here". Another dramatic quotation opening one of subsequent chapters comes from the Phila Henrietta Case: "Oh! Why does the wind blow upon me so wild? Is it because I'm nobody's child?"

All of this happened more than fifty years ago, during a century declared the age of knowledge and science, in a country claiming to be the cradle of democracy.

Reaction to this message, which was sent to prominent people around the USA, was beyond the expectations of many. Social policy towards the handicapped changed so radically that the second part of the album, published together with the first part in a new edition in 1974, presents enthusiastic pictures of children and adults lives, residing in closed institutions, images full of "life space", surrounded by toys and aesthetic equipment. However, the photos still present bedrooms filled with many people, child residents surrounded by their peers and educators. It is still an institutionalized life. The disabled are still on the margins.

Another shocking picture is painted by Vittorino Andreoli, an Italian psychiatrist-reformer, in his book published in 2004. The author describes his first visit to a psychiatric center, which took place when he was a high school student. There were various "weirdos", who had one thing in common – they were incurably dangerous to themselves and to society, and – following the regulations decided on in 1904 – "they were the cause of social umbrage" (Andreoli 2007:11). The mentioned act of 1904 was the only Italian act regarding the sick, so the need – so common in the 20th century – for the bureaucratization of different areas of social life had at the beginning of the century its precursors who needed to be urgently isolated and strictly controlled. In 1959, when Andreoli visited the San Giacomo della Tomba psychiatric center in Verona, Italy, "[...] it was a real fortress. The walls were so high that at the top of them there were pieces of broken glass bottles attached, to discourage any potential escapees" (Andreoli 2007:12). The walls surrounded ten, symmetrically arranged buildings, inhabited by men and women separately. "Each building had two floors: the ground floor was occupied during the day, the first floor included bedrooms. For the night, everyone went upstairs, to go to sleep, during the day they came down to a huge room on the ground floor. One hundred and twenty people – the number of patients in each building – existed together all the time. The only place of relaxation during summer weather was a little garden surrounded with wire netting. A patient could enter the park only when accompanied by a nurse" (Andreoli 2007:12). Residents of separate pavilions were divided according to the severity of their mental illness: the least sick were placed in the first pavilion, male and female respectively, those with the most intense symptoms were located in the fifth pavilion. The higher the pavilion number, the more radical the tools of enslavement: "In the fifth pavilion, the situation of women was the most dramatic. An abomination. The women were left with no dignity, naked on a cold floor, chained to walls and smeared with excrement – truly Dantesque" (Andreoli 2007:12).

The everyday routine was not very complicated. All patients did the same things every day, that is, they slept or sat motionless. "The paramedics worked in three shifts. The first one tied the patients up, which was not an easy task, as they often rebelled, therefore the task was ascribed to strong and well-built persons; the second shift needed to untie them, wash them and tie them up again; the third undressed the patients from caftans and placed them in beds. If someone was tied at six in the morning, and soiled himself at half past six, they were not washed before two in the afternoon" (2007:12). Isolation from the external world was complete, and the walls were totally impenetrable. "A psychiatric center had to be a self-sufficient unit, autarkic, where contact with the external world was kept to a minimum. Bread was baked there, laundry done and underwear darned. [...] Nothing was permitted to go outside the psychiatric center, as everything there was poisoned and dangerous for the city which surrounded the walls" (2007:13-14).

In subsequent years, together with development of treatment methods, the patients were not left to their miserable fate. Instead, attempts were made to implement therapies that would bring them back, maybe not to society – as they were still strictly isolated – but to rationality or the functioning of a regular man. The most widespread treatments, regarding their alleged effectiveness, were shock treatments and therapy with insulin. The shock treatment was introduced in 1938 by Ugo Cerletti, inspired by a procedure applied in slaughterhouses, which consisted in knocking out the pigs before killing them, so their meat was as tasty and delicate as possible. Since then, shock treatment has become a routine procedure of psychiatric therapy. "I, myself," writes Andreoli, "for many years, while working in a psychiatric center, applied this method to my patients. What is more, it became a kind of liturgical celebration" (Andreoli 2007:17). Similarly, the therapy with insulin was a procedure thanks to which the psychiatrists could control the unpredictable and aggressive behaviors of the 'nuts' in an easier way. "The patient was provided with such a dose of insulin which caused coma, maintained for a specific time; each patient had an individual dose [...], which was determined experimentally, not following any scientific knowledge, but first of all considering the level of danger that a given patient produced" (2007:18). After a certain time had passed, the patients were woken up with sugared water, introduced into the body through a tube. "It sometimes happened that the patient did not wake up, and then rescue actions were undertaken quickly, such as stimulation of heart and circulation or respiratory tract. Some of them woke up only after several hours. Some of them did not wake up at all" (2007:18).

Andreoli, while describing the dramatic scenes taking place in psychiatric hospitals at the beginning of the second half of 20th century, summarizes them very bitterly: "In recent years, and even today, when I recall the past, I ask myself a tormenting question: how was it possible that when I crossed the psychiatric center's gate for the first time, and I was not even 21 years old at that time, I did not wonder about the indecency, perversion and inhumanity that prevailed? [...] How could it happen that not only me, but also men of great moral character accepted all of that? What is more, they were absolute rulers of the mad men in those places! [...] How could a boy like me, passionate about Greek culture, knowing Euripides and adoring philosophy, not rebel against such a striking degradation of humanity? [...] How can you explain this human callousness in the face of the suffering of others? [...] I am still tormented by these questions. I see them as no less dramatic than those related to the atrocities of concentration camps. It is not an inadequate comparison, I am not exaggerating" (Andreoli 2007:23-24).

A Stereotype as a Summary of Social Knowledge

It is not surprising that the people who remained in isolation up to the second half of the 1970s were not ascribed with labels proving their participation in social life. Their unenviable fate was reflected by the words which described them, usually insults. Only from the end of 1970s in numerous European countries, and in Poland even later – estimations say from the end of the 1980s – did a process of changes in attitudes of the general population towards disabled citizens start, especially towards the mentally disabled (Shevlin, O'Moore 2000:207). On the other hand, it needs to be highlighted that Poland, together with other countries of the "Eastern bloc", isolated from the West by the "iron curtain" from the second half of 1940s, did not adopt the Western patterns too strictly, and did not readily lock up its handicapped citizens in gigantic total institutions, something which was highly popular in more advanced countries. The figure of the "village fool", slightly old-fashioned and backward, was still present as an exemplification of the fate of a "free" handicapped person, not institutionalized, living life in a society which ascribed them a social role which maybe was not glorious but at least was socially sanctioned. The tradition of Polish special pedagogy, related to the works of Maria Grzegorzewska, cannot be overvalued, as even in 1920s she spread the idea which can be found in the motto of APS (Academy of Special Pedagogy – Maria Grzegorzewska University) - "there is no cripple, there is a human". Nowadays, such an approach could be seen as a precursor of today's trends. However between 1945 and 1960, in the "Golden Age" of total institutions, such declarations sounded highly anachronistic.

To this day, terminology related to the disabled resembles recent isolation. These are stereotypes of an unequivocally negative tone, "such persons are perceived as a burden for others, an object of taunts, violence, but also a threat for the rest of society, an unfortunate and pitiful entity" (Chodkowska, Szabała 2012:90). The authors claim that among the disabled the most hurtful terms are ascribed to the mentally handicapped, and the stereotypes pertaining to this group are often derogatory (Chodkowska, Szabała 2012:90).

This could be exemplified by stereotypes connected with sexuality. There are two extreme and mutually exclusive opinions, treating the mentally handicapped as hypersexual or asexual (Szabała 2010:62). The first stereotype arises from the end of 19th century, when it was thought that "as it is impossible to control sexual drive, such individuals may be threatening to the environment" (2010:62-63). 'Even now', such beliefs mean that any symptoms of sexuality by the mentally handicapped are controlled and attenuated, sometimes drastically. This results in their sexual education often being accidental, vulgar and incomprehensible (2010:63). This, in turn, leads to a "self-fulfilling prophecy" – the mentally handicapped actually give the impression that they are also handicapped in that sphere of life. The stereotype of asexuality is connected with thinking about the mentally handicapped as being "eternal children". This view, extremely different from the previously listed, results in similar consequences: no sexual education, a striking negligence of actions leading to sex identification, et cetera. Therefore, it can be stated that strict control and suppression of sexuality – regardless of whether it is undertaken in relation to the first or the second belief – leads to a decrease in life quality of those people whose social functioning is determined as distorted, handicapped, or deviating from standards of regularity.

Of course, we need to give such people a name somehow. The current terminology is as follows: An intellectually disabled person, or – even more contemporary – a person with an intellectual disability. I do not oppose those formulations, as we need to use terms that other people can comprehend. However, I believe that describing those people one way or the other is of a metaphorical character, not a literal one. Hence, the fight over words makes no sense. Academic discourse deliberating the terminology may lose sight of the problem's essence – it is not the manner of terminology, but the drama of the existence of those people who were treated in an inhumane manner by Western societies taught by 20th century traditions.

Lack of Intelligence as a Disability

It is worth considering the issue, why the previous term "mental handicap" was replaced by "disability" and why this disability is related to intelligence. What does the word "intelligence" mean, after all? According to the words of one of the greatest philosophers of the 20th century, Hans-Georg Gadamer, the word "inteligentia" has ancient roots. However, this term meant something completely different to the ancient Greeks to what it means now. For the Greeks, "inteligentia" meant a deep insight, even deeper and fuller than "ratio", that is, mind. Inteligentia meant familiarity with the highest principles of life, actions and thinking (Gadamer 2008:181-182). But, there are no traces of this in our terminology. Our contemporary understanding of the word "intelligence", that is, from the end of 19th century, when the word appeared in today's sense, and us understood by Western societies, is completely different than in the case of Greeks. Therefore, it is a temporal and geographic meaning.

In our society, intelligence is a certain measure, bringing a metrical understanding of a certain feature. What is more, this feature is of quantitative character, which means that we all have it, to a greater or lesser extent. In these terms, the differences between people are of a quantitative character. A genius possesses great amounts of this feature, and an intellectually disabled person very small amounts, but it still is the same feature. And these are the foundations which one of the most reductionist measurements is built upon, which we inherited from the 20th century, that is, the intelligence quotient. People's intelligence can of course be measured, but we need to ask: what for? Reductionism consists in the fact that developmental age is divided by life age. And in order to do this, we need to know what is absolutely normal for the average person at a given age. I would like to congratulate people who possess such knowledge. If the developmental age is lower than the life age, the IQ level of an individual is lower than 100. It means that, as psychologists say, a person "solves tasks" at a level lower than their life age. But, what does

it mean to "solve tasks"? How often does an average man go to a psychologist's office and solve any tasks? In their everyday lives, people do not solve any tasks, they just live. We need to use that measurement for school, administration and official purposes. Bureaucracy demands it. But, we should bear in mind that this measure is of a statistical character. It says nothing about the man, because the feature itself says nothing about the man. One of the leading contemporary intelligence scholars, Ian Deary, in the recently published book entitled "Integracja" [Integration], writes about various problems connected with measuring intelligence. However, he does not doubt that, first of all, intelligence means a person's intellectual fitness, and second of all, it is a feature, or as thought by some contemporary researchers, a collection of features (Deary 2012:18).

Gadamer, who undertook philosophical deliberations over intelligence, said that speaking about the intelligence of animals is not an anthropomorphism, as we frequently believe. The great philosopher reckons that it is on the contrary: speaking about the intelligence of people is unconscious theriomorphism, that is, ascribing animal characteristics to people (Gadamer 2008:195). I might not be as radical as he is, but those deliberations made me aware that the measurement that we apply in relation to our disabled fellow human beings tells us less about them and more about ourselves. We developed the measurement for ourselves, so we measure ourselves with that measurement. It is not funny to be human with an average level of intelligence in our society. It does not sound impressive.

Therefore, I do not oppose the term "a person with an intellectual disability", because we simply need to use a term. However, I am not a fan of this term, because it suggests that disability clings like a limpet to a person. The beauty of their humanity remains intact, and the disability, this limpet, is something only standing nearby. I do not believe it is true. Since we think that disability is a certain lifestyle, it also is one of the strings that attaches us to the world. Nobody is a free spirit, we are all attached to Earth with various strings: sex, race, children, weights and everything else. If someone travels around the world, they know that being a Pole does not sound especially impressive in numerous countries. Disability is another such string. I do not see any reasons why we should be ashamed of it.

One of the greatest philosophers of the 20th century, Martin Heidegger, once said such an aphorism: "A human does not have its being, as the human being is being" (Heidegger 1994:67). The being of a human is not a feature, it is a process. The essence of humanity of those people consists in being disabled individuals, with all the reservations about the comprehension of the word "disability". They are like this.

Putting them in categories of variety, instead of dysfunctions, leads to the activation of public discourse. Communion with intellectually disabled persons starts being symmetrical, which means that it enriches ourselves. For numerous years, relations with our disabled fellow human beings took the form of charitable actions: We will give, we will stroke their heads, we will take care of them, we will create proper conditions for them, we will take care of their humanity. But, what can they do? Then, we said: "I am not interested in what you can give me, because you can give me nothing." It changes. We do not need to defend their humanity anymore, because they are able to take care of it themselves.

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Upośledzenie umysłowe jako niepełnosprawność i jako sposób bycia człowiekiem

Abstrakt: Artykuł dotyczy problematyki używania pojęć określających osoby upośledzone umysłowo versus niepełnosprawne intelektualnie versus z niepełnosprawnością intelektualną. Za używaniem każdego z tych pojęć kryją się przesłanki o charakterze aksjologicznym i światopoglądowym. Poprawność polityczna skłania do zastępowania wyrażeń piętnujących bardziej neutralnymi. Pojawia się jednak pytanie: skąd w języku pojawiły się określenia mające charakter dyskryminacyjny.

W artykule ukazane są przykłady stosowania do lat siedemdziesiątych dwudziestego wieku polityki segregacyjnej, w wyniku której osoby niepełnosprawne intelektualnie przebywały w zamkniętych zakładach całodobowej opieki, oddalone od głównego nurtu życia społecznego. Ukazany został przerażający obraz losu osób pozbawionych podstaw godności ludzkiej, na podstawie amerykańskiej publikacji z tamtego okresu. Sytuacja ta spowodowała, że stosowane wobec osób niepełnosprawnych intelektualnie określenia sankcjonowały ich gorszą pozycję w społeczeństwie. Zaczęło się to zmieniać po wprowadzeniu w krajach zachodniego kręgu cywilizacyjnego polityki integracji i inkluzji społecznej.

W drugiej części artykułu podjęto rozważania dotyczące rozumienia słów „niepełnosprawność” oraz „inteligencja” (słowa obecnego w pojęciu niepełnosprawność intelektualna). Ukazano dwa sprzeczne rozumienia terminu inteligencja: wywodzące się ze starożytności oraz wprowadzone przez nowoczesne systemy miar psychologicznych. Ukazano jakie konsekwencje dla rozumienia kondycji człowieka uwikłanego we współczesny świat ma posługiwanie się tymi dwoma rozumieniami terminu inteligencja.

W konkluzji stwierdzono, że upośledzenie umysłowe nie musi być traktowane jako brak czy dysfunkcja, lecz może być – zgodnie z polityką różnorodności – traktowane jako równoprawny sposób bycia człowiekiem, różny od sposobu manifestowania się człowieczeństwa wśród statystycznej większości obywateli, niemniej odznaczający się swoistą specyfiką i pięknem.

Słowa kluczowe: upośledzenie umysłowe, niepełnosprawność intelektualna, polityka segregacyjna, integracja, inkluzja, różnorodność, człowieczeństwo