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**Moral Outrage and the Fight for the Reputation of Children with Intellectual Disabilities**

**Qualitative Content Analysis of Posts Below an Interview with Parents of a Woman with Down Syndrome**

*Abstract:* The aim of the paper is to identify the causes of moral outrage expressed in the comments published below the interview with parents of an adult woman with Down syndrome who are also co-founders and co-runners of a “Bardziej Kochani” (“Loved more”) Association for parents of persons with Down syndrome. A qualitative analysis of the content of posts was carried out due to the status of the author of the comment (person related to the environment of people with disabilities or not). The article analyses status of emotions in sociology and discusses the perceived roles of the interviewees, especially their assumed responsibility as role models. Main causes of moral outrage emerging from the comments are presented: the way of talking about disability and people with disabilities, issues related to integration in education. Linguistic differences resulting from the status of comments’ authors were also indicated.

*Keywords:* internet forum, intellectual disability, qualitative content analysis, moral outrage, emotions and sociology

**Introduction**

Current social sciences are more and more interested in the situation of persons with intellectual disability. They have not been present in social space until the mid-twentieth century. Norwegian researchers describe the three decades after World War II, 1945–1975, as the “Golden Age” of the welfare state: “The first 15 years of this period were also the ‘Golden Age’ of segregated services for intellectually disabled people. This goes both for long-stay residential facilities and special education” (Tossebro, Aalto, Brusen 1996: 47).

Over the past few decades, situation of persons with disabilities and their families has changed radically. However, the way of speaking remains conservative. Sophie Mitra writes about this: “The notion of disability is enigmatic, even confusing. The term itself ‘disability’ has negative connotations, which is no surprise given the prefix ‘dis’ meaning ‘absence’ or ‘negation.’ Beyond the everyday semantic muddle around the term ‘disability,’ how it is conceptually defined is also challenging” (Mitra 2018: 8–9). Sociologists writing about...
persons with intellectual disability have to take this challenge and taking this challenge is what we do in this paper.

Western societies are at present in the process of appreciating the role of persons with disabilities in the social life. “Disability may be considered a minority issue. After all, only about 15 per cent of the population—one in seven—is disabled. But there are at least a billion people with disability on the planet, plus all their relatives and friends. So, most lives are touched by disability in some way, and it’s about time we understood it better” (Shakespeare 2018: 1). Besides many very good solutions, there is still much to change. “Data from around the world show that a large number of disabled people remind unemployed or economically inactive, more than 80 per cent in some countries […]. Unequal access to education and training, negative attitudes of employers and colleagues, inaccessible transport systems and workplaces and a lack of flexible work practices and employment support schemes present significant barriers to equality of opportunity in the labour market for disabled people” (Waddington, Priestley, Yalcin 2017: 73). Writing about linguistic, emotional, mental and factual issues connected with the presence of persons with disabilities in our surroundings could reduce the social distance.

In recent years, Polish sociologists have been dealing with disability issues relatively often. Recently, several significant works have been published thanks to which disability is the topic not only of pedagogical and psychological, but also sociological considerations (Gąciarz, Rudnicki 2014; Koperski 2018; Ostrowska 2015). What is more, disability has become the interest of interdisciplinary oriented researchers (see Natalia Pamuła, Magdalena Szarota, Marta Usiekniewicz 2018; Godlewska-Byliniak, Lipko-Konieczna 2018; Maciejewska-Mroczek, Radkowska-Walkowicz, Reimann 2019). In our paper, we are adding a voice to the discussion about sociological contexts of disability by analyzing the content of posts published on the internet below the interview with parents of a woman with Down syndrome.

The interview entitled “Co by było, gdybyśmy wiedzieli, że nasze dzieci będą miały zespół Downa? To nieuprawniony eksperyment logiczny” (“What if we knew that our children would have Down syndrome? It’s an illegitimate thought experiment”1] was published in March 2018 in the weekend edition of the gazeta.pl portal. Ewa Wołkanowska-Kołodziej spoke with Ewa and Andrzej Suchcicki about people with Down syndrome1. The interview was published on the eve of the World Down Syndrome Day’s celebration (March 21st). It was published on the Internet and thus could be commented on by the readers on the forum. Like most online publications, it also found an echo on other Web portals and forums, where users commented on both its content and its form. The interview concentrated on the everyday life of family with a person with Down syndrome. It presented mostly the parents’ perspective.

1 Unless indicated otherwise, all notes in square brackets “[“]” are by the translator, Wojciech Figiel.
2 The interview, in Polish, can be found at http://weekend.gazeta.pl/weekend/1.152121.23107217,coby-by-bylo-gby-were-knowledged-zeze-children-beda-mialy.html. Ewa and Andrzej Suchcicki are parents of a woman with Down syndrome. They are also co-founders and co-runners of a “Bardziej Kochani” (“Loved more”) Association for parents of persons with Down syndrome.
Methodology and Analytical Procedures

This paper focuses on the analysis of posts that appeared directly below the interview, within two months of its publication. During this time, 346 comments were submitted to the forum. Qualitative content analysis was conducted with the support of Atlas.ti. After first overview of selected material, main analytical categories were established. Further readings driven by these categories resulted in developing codes that are more detailed. The qualitative analysis of the content of these posts is carried out against the backdrop of the concept of moral outrage caused by the remarks of the Suchcicki family. We reflect on what is the subject of this outrage. What provoked such intense emotions? Was it the form or the content of the interview? Who expresses the outrage—authors personally or professionally associated with disability or normates.

Only those posts that directly referred to the interview were subject to analysis. The people who posted their comments on the forum did not engage in a discussion, but rather present their opinion about the article, without referring to contributions made by other forum users. When analysing forum posts, one should take into account the features of the Internet forum as such. Forums, especially those that are publicly available, as is the case with the forum at gazeta.pl, are anonymous spaces. The sender of the post is not required to reveal his or her personal information (this is optional, and some contributors did so). Moreover, forums are usually characterised by quick comments, sometimes posted under the influence of emotions, sometimes in a careless, chaotic and ill-considered way. We are dealing only with the text and what we can read in it and in between its lines (see Markham 2011). We cannot determine the tone of voice, gestures, body language and intentions of the utterance (unless it is clearly expressed in the post). Therefore, the set of posts which constitutes the corpus for this analysis is characterised by utterances that are long, thought through and sometimes written in the form of a letter addressed directly to the person or persons giving the interview. These posts are examples of polemics with opinions expressed by the interviewees. Such polemics are written by people associated with the community of people with disabilities and are often signed by name and surname of their author. Whereas, comments posted by the normates are usually shorter and are not linked to professional or personal experience. Differences in the language used by authors are also observed.

Sociology and Emotions

During the “empirical” period of sociology, the concept of moral outrage was not employed often. For several decades of the twentieth century, the so-called “classical period”, sociology was an empirical social science which, rather than being focused on the study of living human beings made of flesh and bones, concentrated on the analysis of rules and relationships. Bourdieu describes this specific reductionism and “professionalism” of academic sociology projects in the following way: “At one level, the sociological landscape has not changed much over the past quarter century. [The book from which this quotation comes first appeared in 1992—EZM] On the one side, the brunt of empirical research continues to address questions that are more frequently the product of “scholarly common sense”
than of serious scientific thinking. And such research often justifies itself by “methodology” too often conceived as a specialty in itself consisting of a collection of recipes and technical precepts that one must respect, not to know the object, but to be seen as knowing how to know the object. On the other side, you have the return of a form of Grand Theory severed from any research practice. Positivist research and theoreticist theory go hand in hand, complement and compliment one another” (Bourdieu 1992: 175). This ironic description of research practices decorated with speculations made by armchair theoreticians devoid of any real-life references reflects in a slightly exaggerated, but in fact accurate way, the climate in which empirical sociology, as a recognised paradigm of science, was practiced.

From the beginning of 21st century a new sub-discipline of sociology has been initiated, namely the sociology of emotions. “Sociology of emotions as consciously separate sub-discipline maintains that emotions have a social dimension, that means they are created, lived and expressed in close connection with what is cultural and social” (Binder, Palka, Pawlik 2009: 8). Emotions are not only a topic of sociological considerations but can also permeate to the research workshop. Sociologists are living people and they have the right to express emotions freely if their considerations concern difficult and painful matters. Then “engaged science” is created which gains credibility just by revealing emotions (Wejbert-Wąsiewicz 2009: 211–212). This is also our case. We also engage in emotions to make our argument credible.

It seems that the sources of inspiration for the analysis of emotions, especially extreme ones that trump the rules of discourse of rational social actors, can be found in the works of sociologists of the “pre-classical” epoch. At that stage, sociology was only striving at an empirical paradigm, but had not yet reached it, and was dominated by the “pre-scientific” descriptions of disordered and non-categorised everydayness. William Graham Sumner was one of the early sociologists who wrote about everyday life practices and the moral codes that are constructed in their context. Marian Kempny and Krystyna Romaniszyn, authors of “Introduction to the Polish edition” to the Sumner’s most famous book, write that he played a special role in American sociology, representing ”a transitional phase in the move from the canons of nineteen-century social science to the model of empirical sociology” (Kempny, Romaniszyn 1995: XLIV). Thus, he dealt with ”residual” topics, which were abandoned by 20th century sociology.

Several important concepts introduced by Sumner into sociological writings may be useful for the analysis of emotions. These include “we-group”, “others-group” and “ethnocentrism” (XXXIII). In particular, the latter concept, understood in a specific way, can be employed to made an attempt at interpretation of the phenomena that a group of people treats as rational and as “objectively” describing reality, whereas for another group, the presence of the same phenomena provokes moral outrage. Sumner suggests that we should conceive “‘ethnocentrism’ as a technical name for such a view of things in which one’s own group is a center of everything and all others are scaled and rated with reference to it. Folkways correspond to it to cover both the inner and the outer relation. Each group nourishes its own pride and vanity, boasts itself superior, exalts its own divinities, and looks with contempt on outsiders. Each group thinks its own folkways the only right ones, and if it observes that other groups have other folkways, these excite its scorn” (Sumner 2008: 13).
Sumner’s writings concern ethnically diverse groups, but nowadays, when deep, spectacular dividing lines cut across the criteria other than ethnicity, his concepts can be transposed onto social differentiations based on non-ethnic criteria. The criterion that we take into account in our analyses causes profound differences in viewpoints. This criterion is the fact of having a child with Down syndrome. Families in which a young child with Down syndrome is raised are in the modern society, for the most part, an enclave of strictly separated, and principled, views. It is of secondary nature to define the content of these views, as shall be discussed later. The most important thing is that the necessity to cope with Down syndrome triggers an intransigent attitude in parents and requires them to take a stance. In contemporary epoch, the times of “moral permissiveness”, such attitudes are rare.

Sumner attributes a special role in the process of we-group consolidation to the use of epithets expressing contempt and abomination for others-groups, who regard as correct other ways of doing things. “Opprobrious epithets are derived from these differences. “‘Pig-eater,’ ‘cow-eater,’ ‘uncircumcised,’ ‘jabberers’” (Sumner 2008: 13) are examples of such epithets presented by Sumner.

The Down beside Me

The question of abusive epithets is one of the main reasons for the rise of a subculture of families bringing up a child with Down syndrome, a subculture that emphasises the distinctiveness and uniqueness of the group that presents the syndrome of the “besieged fortress.” The latter manifests itself by the fact that members of the group, guided by noble motives, must constantly fight against the ignorant and people with bad intentions, who want to continuously humiliate their children, demonstrate contempt for them and total lack of understanding for their uniqueness. The use of epithets is one of the main reasons for attacks on people outside of the group. In fact, it is all about one epithet: “the Down.” The use of the word “Down” in an interview, but also in many other contexts related to the problems of people with Down syndrome, acquires apocalyptic dimensions and becomes a question of insult and humiliation. The peculiarity of the relation to this word reveals fundamental differences between the way of thinking of subculture of families with a child with Down syndrome and that of “the rest of humanity.” In the social perception, the word “Down” is a well-understood and linguistically functional mental shortcut that works as such in everyday language.

The following is an example of the use of this word in the interview: “I take my Down and we go on a trip.” The authors of many comments posted on portals for representatives of the subculture of families express their outrage. They drag the name of the author of these words through mire, they attribute to her the worst intentions. What is more, they claim that using this word causes irreparable damage to the social perception of people with Down syndrome, because it controls people’s thinking. They thus attribute to the person

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3 This is the title of a literary competition for primary, junior high and high school students that has been organised for several years by the “Bardziej kochani” [“Loved more”] Association.
employing this word the powers of a demiurge who can change the way the world works. Of course, this impact is destructive, making the besieged fortress the only bulwark for the defence of the dignity of persons with Down syndrome.

To this “dum,” i.e. unemotional, colloquial expression, these people attribute the power of depriving life of its meaning, disintegrating of family ties, exclusion of people from the society. The causative power of this one word seems to be unlimited. Hence the moral outrage that results from the use of it is omnipotent. How to substitute, then, a word used in everyday language which, because it is intelligible to conversational partners, enables a smooth flow of everyday conversations? Instead of saying “I’m taking my Down on a trip,” one SHOULD say “I’m taking my adult daughter Natalia, who is a person with Down syndrome, and we’re going on a trip.” Indeed, this phrase sounds ‘better,’ provided it is a short, “official” message, not a simple phrase taken out of the context of a longer conversation, during which such “official” phrases would have to appear many times, effectively preventing understanding in everyday conversations.

The second issue related to the “exegesis” of the alleged epithet has a much deeper dimension. It is noteworthy that moral outrage is directed not towards what “opponents” do, but towards what they say. Even more precisely: not towards what they say they are doing, but towards how they talk about it. Moral principles expressed through moral outrage have a purely formal dimension, they refer to the “methodology of speaking” and not to the philosophy of living together with a loved one with Down syndrome. Not a single comment to the interview raised the question of what kind of trip the mother took her Down on. What is the value of this trip, what cognitive, emotional, social, interactive, or God knows what other benefits the Down will have from this trip. Is going on trips a regular part of the Down’s life? In addition to going on trips together, does the mother take her Down to other places? What do they do together? What does the Down like to do and does the mother respect these preferences? All these questions are left unanswered. For those expressing their outrage, correct words are synonymous with treating people in a dignified way. It is easy to be indignant about linguistic incompetence, and it is also very easy to avoid outrage by making minor changes to the vocabulary. That’s it, problem solved.

Perversely, one could ask the indignant, which sentence causes their greater moral outrage: “I take my Down and we go on a trip” or “I take my son Wojciech, who is a person with Down syndrome, and I lock him in my shed, because I believe that this guarantees safety and promotes happiness of persons with Down syndrome.” Perhaps the latter sentence would cause polemics instead of outrage?

It is no coincidence that Sumner stresses the role of abusive epithets as one of the strongest elements uniting the group. The attitude towards the epithet is ‘beyond discussion,’ i.e. its only function is to allow emotions to explode, rather than the discussion of the correctness of anything. Things that can be discussed may be the subject of fierce criticism, but not outrage. On the other hand, outrage is not a criticism in the sense that there is no room for any discussion. I therefore argue that the content of the viewpoint of those expressing their outrage is secondary to the primary role of the attitude of the intransigent, morally pure preacher of human dignity of (some) people.
**Intellectual Disability and Social Interactions**

Another bout of moral outrage is caused by the following remark made by the interviewee: “The integration of people with intellectual disabilities is inherently impossible. This is due to the logic of interpersonal relationships. Mentally retarded people do not have much to offer to their peers, so there cannot be equal relationships between these two. The only possible relationship is that between caregiver and caretaker.”

In this case, the role of epithets is different, but also extremely expressive. The outrage is expressed by means of epithets. As in the previously analysed case, there is no reasoning whatsoever. The only purpose of the reaction to the words spoken by the interviewee is to show one’s own moral superiority and the humiliation of the “adversary.” This is evidenced by the use of such characterisations as: “typical, little, selfish Pole,” “you Down” (sic!), “to the psychiatrist with him” or “you have turned the course of history back to the times of European fascism and exclusion, negating the value of the individual, negating the needs of a person with Down syndrome.” Again, the role of the demiurge, attributed to the author of the sentence that is commented upon, makes one wonder: how on Earth a remark from an interview printed in a newspaper would make the world turn upside down? “With this single interview, you have destroyed what I have been building for the last 23 years”—it seems bizarre to compare 23 years of work on the rehabilitation of the child and raising social awareness against a single sentence taken out from one interview. This calls into question the belief of a person who expresses such opinion that their efforts bring lasting effects, since it is so easy to erase them. “As you know, I was the only Pole, aside from the Ambassador of Poland to the United Nations, Mr. Witold Sobków, who took part in the recognition and declaration of 21st March as the World Down Syndrome Day at the United Nations.” This is great news. What is it supposed to tell us? That the author of these words is, by definition, right and stands on a much higher moral ground than a person who thinks that social interactions with a person with an intellectual disability are asymmetrical.

In general, it can be posited that moral outrage is caused by the claim that a person with intellectual disability is disabled intellectually. One can agree with those expressing their outrage that it is cruel, especially when that intellectually disabled person is one’s child. Perhaps things should not look like that, perhaps people with intellectual disabilities should not be in a worse social position where they “do not have achievements,” “do not have friends,” “do not have much to offer to their peers.” But the world is as it is and not as it should be. Sitting in their “besieged fortress,” those who express outrage are practicing enchantment of reality. They very much want the reality to be different than it is. Reminding them how things are, is an act of simple callousness. Outrage is a reaction to callousness. Unwrapping the candy of intellectual disability from the paper of sentimentalism and grandiloquence is regarded as cynicism.

Significantly, as in the case analysed above, moral outrage does not concern actions taken by “adversaries,” but words that they say. These words relate to the philosophy of humanity and not to the pragmatics of everyday life. Moral outrage therefore leaves no place for the use of arguments, since it does not refer at all to any empirically ascertainable states of affairs. The use of the word “adversaries” (enclosed in quotation marks) in this paper should also be commented on. Sumner noted that in order to con-
solidate a we-group we need an others-group, and the most important law of social life

is not the principle of sympathy, but the principle of competition […] nature in this way selects the best individuals in a given society. According to him, choosing this option means the development of society and the well-being of its best members, while opting for the principle of sympathy leads to social regression and favours the worst individuals (Kempny, Romaniszyn 1995: XXXIX).

In the context of the present analysis, the “worst individuals” are those who, according to those who express outrage, do not keep up with the spirit of modernity, show regrettable pessimism and backwardness, reversing the course of history, and as such are not worthy of being called partners in the conversation. Competition in this context can mean a struggle for the primacy of one’s own philosophy of life. A philosophy that posits that human nature is so plastic that it can be freely shaped by means of rehabilitation, stimulation and supplementation. However, it must be noted that such an attitude is not “very modern,” its origin can be traced back to the 18th century optimism of the Enlightenment. Moreover, the word “backwardness” is not a descriptive one, but just another epithet. The lessons we learn from history can be much more instructive than clinging to our own optimistic imaginations.

Sociologists have rarely analysed the social role of people with intellectual disabilities. Sumner addresses the issue of how these people function in the society in a book that was published in the first decade of the 20th century, i.e. in a period when the rationality of Western societies striving to maximise the economic potential of families had not yet led to the introduction of a policy of segregation. People with intellectual disabilities lived in society and occupied specific positions in the social structure. Following the period of several decades of the 20th century rationality, which demanded that intellectually disabled citizens be handed over to the specialists who managed them and isolated them from the society, in the 21st century we witnessed the “naturalisation” of the intellectually disabled as citizens and the return to their traditional roles that they had occupied until the early 20th century. It may thus be valuable to look at how early sociologists described the social structure in which there was a place for people occupying low positions in the hierarchy because of their low social value (Sumner 2008: 40–42), and to look for analogies with the present situation.

Can enlisting sociological texts written more than a hundred years ago to interpret modernity be called backwardness? Analysing a theatre play, Piotr Morawski writes that disability constructed in the 19th century, both in the social reality of the industrial era, as well as in circuses and theatres showing various ‘peculiarities,’ has now been presented in Clowns, a play that in addition ostentatiously refers to this tradition by its title. […] Disability is deconstructed, it appears on stage as a social construct, and not, as in the 19th century shows, as a confirmation of ideas about the norms of ‘visibility.’ (Morawski 2017: 356).

This famous director does not cut himself off from the past, but rather treats it as a cultural resource upon which he superimposes contemporary interpretations.

The Down and the Rest of the World

The subject of the analysis in this part is what constituted the reason for outrage of those among posts written mainly by people from the outside of the enclave of intellectual dis-
ability or disability in general. Therefore, only those posts are analysed where one can infer that the author is not personally or professionally linked to the community of persons with disabilities. Sometimes a perspective of non-normates is presented to underline the difference. These posts are usually anonymous and do not refer to the experience of being either a professional, or a person in any other way related to disability. What, then, causes the outrage of normates?

It must be pointed out that the language of posts submitted by the normates differs from the language of professionals or those related to the community of people with disabilities. Phrases such as “a person with disabilities” appear less often, while words such as “crip” or “handicapped,” i.e. terms that have disappeared from the dictionary of political correctness some time ago, do find their way into those posts:

Finally, it must be said loudly, against this holy correctness: “a man without legs—is a crip”. “a man who is in a wheelchair for other reasons—is a crip,” “a deafmute man”—is handicapped, a man who is mentally handicapped for various reasons—is abnormal. Groaning and incanting the reality will not help it. (...) There are no people who are differently normal, differently healthy or differently abled.

The post expresses the support of its author for stating things clearly and for setting clear limits. Down syndrome is Down syndrome, a zero-one variable—either you have it or not. The use of increasingly blurred terms for different types of disabilities means that these labels tell us less and less about the reality.

In contrast, it is worth looking at posts written from the perspective of professionals, people with disabilities or others who have some relation with them:

How can one say such things about one’s child? How can one boast that “I was walking with a beer can in hand, there wasn’t yet a ban on outdoor drinking, and with the Down in a carriage”? 

(...) I do not fully agree with their approach to the life with their little daughter who has Down Syndrome, with these terms, with this lack of humility, of reflection, that maybe they can offend somebody who has equally ill child [this “little daughter” is an adult woman—MS].

On the other hand, the posts of the normates also display negative comments on the way that a person with Down syndrome is referred to:

The interview is very biased. The terminology in the interview regarding the persons with Down syndrome is unacceptable to me;

How can one say in this way, “Down,” about anyone. I don’t understand it. I recently have read an interview with a young, pretty woman, who was working, studying, doing a driving licence, having “normal” friends and dealing with everyone on equal terms, who... has Down syndrome. Only that she has been rehabilitated very intensely since her childhood. And now go and tell her “You Down,” please... Really, no comments. After all, everyone wants the child to function as best as possible and to be treated normally, nobody wants to hear things like “me with my Down,” “These Downs,” it ought to be obvious. Apparently, it’s not for everyone...

In their recent play entitled “The Revolution that wasn’t,” the actors of Teatr 21 shout and sing on stage “And I’m the Down!”. This is a perfect illustration for another post:

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4 The forum posts were originally written in Polish and are presented here in English translation. All typos, spelling and punctuation mistakes reflect those made by the authors of original posts.
5 Teatr 21 [Theatre 21] is the first theatre company in Poland with the majority of actors with Down syndrome. More information about their activities, in English, can be found at http://www.polishtheatrejournal.com/index.php/ptj/article/view/85/348—WF.
Of course, the way specific groups refer to themselves in their community is their own business.

And this seems to be a key issue when it comes to the way of naming disabilities. As a matter of fact, the interview also touches upon this aspect. The way a group talks about itself, what terms they use to name themselves is a matter for those belonging to this group. No one has a monopoly on the one and only correct term. And so we have “Mummins,” Downs, etc. There are also new, more political terms such as people with disabilities, people with learning disabilities, etc.

What causes outrage insofar as terminology is concerned is not so much the fact that the interviewees refer to persons with Down syndrome simply as “the Downs,” but rather the fact that the interviewees are themselves parents of a woman with Down syndrome and run an association for people with intellectual disabilities. As emphasised above, the interviewees are credited with enormous power. As if one interview could ruin someone’s achievements, squander all the advocacy in favour of people with intellectual disabilities. The author of one comment (non-normate) writes:

What worries me, however, is that our Polish society listens to it, a society of people who are not involved, people without knowledge of Ds, people without respect for persons with disabilities. So how do such articles prepare our world, what respect for disability [do they foster]?

In some posts, the public role of the interviewees is emphasised. They are seen through the prism of their involvement in the activities of the association. They are the conveyors of a mission and the way in which this mission is carried out is subject to evaluation. The Suchcicki family is not seen as parents of a woman with Down syndrome, but as activists. The evaluation of their words contradicts the evaluation of the activities carried out by their association:

I value the books you publish. I read the “Bardziej kochani” magazine. I’m glad that you run supported housing. However, I object to this approach to people with Down syndrome, which can be seen in the interview. No person with Down syndrome is defective. As representatives of such a large organisation, which has the ears of so many people, you should take care of good PR for our children. You want people with Down syndrome to be treated well by society. This will only be possible if we, the parents, talk about people with Down syndrome with respect;

By setting up the association, you, Andrew, have assumed certain obligations. You have an extra responsibility for your actions and words, because they go out to the world. People are listening to you. Parents of children with Down syndrome listen, politicians who decide about the fate of our children listen, the average Mr. Kowalski listens and he will pass his conclusions on to his son, who, in turn, will share these with his friends at school.

A single interview is supposed to have a causative power, to change attitudes and squander all the work that has so far been done by the community of people with disabilities. One interview cannot be attributed with such powers. All the more so because it is full of irony and distance from reality and people with Down syndrome. And who, if not parents, can afford such irony and distance? Following the performance of “The Revolution that wasn’t,” the play that has been mentioned before, there were comments that people laughed when the actress with Down syndrome, who cannot speak, was performing on stage. She could only make some sounds and communicated differently. It was said that the audience made fun of her and her way of communication. However, I am convinced that it was the therapeuticisation and pedagogisation of intellectual disability that were made fun of: in the play,
the actress with Down syndrome received instructions on what sounds had to be produced in order to express laughter. Is it possible, then, to laugh in a different way? Why can we be accused of laughing at a person with disabilities when we laugh at what that person does? Why do we treat this laughter and this behaviour differently from laughter caused by the behaviour of other, non-disabled people? We promote terms that separate disability from a person (like a person with disabilities instead of a disabled person), but are we not able to look at such a person in a different way than through the prism of their disability? Because it is not right to laugh at these poor disabled, impaired people? Or maybe by expressing our concern for their well-being, non-discrimination and equal treatment we, in fact, treat them differently? Or is it all rather about the well-being of the normates?

The interview also triggered many posts on the integration of people with disabilities with the non-disabled. Andrzej Suchcicki said:

_The integration of people with intellectual disabilities is inherently impossible. This is due to the logic of interpersonal relationships. Mentally retarded people do not have much to offer to their peers, so there cannot be equal relationships between these two. The only possible relationship is that between caregiver and caretaker. Our daughter Natalia is 28 years old and the volunteers in our association are younger than her, so the relationship between them is opposite to the one that is dictated by the calendar. No friendship or even acquaintance will result out of this. Retarded people feel best among themselves and we are trying to convince about it various inspired reformers, without success._

On the one hand, the posts stress that someone finally said the truth about integration as such. On the other hand, there is criticism of this way of looking at the relationship between the intellectually disabled and non-disabled. One person goes as far as to say:

_YOU HAVE TO BE A REDNECK TO SAY THAT CHILDREN WITH DOWN SYNDROME HAVE 'LITTLE TO OFFER' THINGS ARE THE VERY OPPOSITE.—THEY HAVE MUCH MORE TO OFFER THAN AN ORDINARY CHILD..._

Leaving aside the fact that a person who holds different views is called a “redneck,” the above quotation illustrates the main thread that appears in the posts that relate to integration. The very idea of integration and its benefits are described, defined and interpreted in all ways. The authors of posts often ask the key question: who benefits from integration? For whom is this integration more beneficial? For whom or for what is it? To counter what Andrzej Suchcicki said, the benefits for the normates resulting from their relations with persons with Down syndrome are emphasised, for example:

_People with Down syndrome or other disabled people, e.g. those who are only physically disabled, are needed so that others learn empathy, support, to see a man and not only the money, profit, benefit, to learn to live without egoism and to be able to spend their time with others;_

_I am in favour of integration, if only to make healthy children and their parents aware that such children (people) are among us, that they also want to feel accepted by society. And it is only on this point that I disagree with Natalia’s father...;_

_firstly, I do not agree that people with Down syndrome have nothing to offer to healthy people. Neither will they be their intellectual partner nor will they equal in sports, but their presence in the classroom teaches healthy children that not everyone in the world must be beautiful and brilliant, but they can still be cool and worthy of respect;_

_I will go nuts in this country! How can you write in the headline that disabled people have nothing to offer? This is not true! Such persons by their very existence and presence TEACH others at school, on the street, in the society_
the TOLERANCE and the ACCEPTANCE of otherness. And that’s a lot. Every society should learn that there are people living next to us who are different in appearance, psyche, talents, tastes, skin colour, views, etc.;

The point of integrated schools is not so much the integration of people with disabilities and the “normal” ones. In my opinion, the most important element of these schools is “to familiarise” children with the fact that there are a lot of disabled people around us (physically and mentally) and they are not a threat.

Perhaps comments highlighting the benefits that people with Down syndrome bring to the relationship were provoked by the idea that they have nothing to offer. Nonetheless, it is striking that there is not a single word in the posts about the benefits of the relationship, benefits of integration for the people with Down syndrome. Is the integration that is advocated for, thus, bringing equality? Under whose conditions the integration that is praised in some posts is to take place? And for whom is it? Who should feel good about it? Perhaps integration for the benefit of the normates is intended to calm their conscience: after all, we support inclusive education, we send our non-disabled children to these schools to learn empathy, respect and tolerance for diversity, and we are so open. But what do the normates, the non-disabled people contribute to this relationship? What are the benefits for people with Down syndrome? This topic is absent from the comments.

Instead, the question of the systemic implementation of the idea of integration is present. Integration as such is perceived positively, but some pathologies in its implementation are pinpointed to:

Yes but these educational professionals have nothing to offer and are sloganeering and after some time it turns out that it is a bluff but they are either retired or the responsibility has become time-barred and so they do not take any responsibility. Usually it’s about money and working hours in education [sector] everyone wants to do this for bonuses and limits on working time or to do scams in general and not for the GOOD of these children;

Integration, as every idea, is a signpost, not a solution to the problem Solutions that we have are for the rich countries and we are poor and therefore the integration is stuttering Maybe its greatest value is that the society will see this problem at all;

It does not make sense to “organise” such classes under the same conditions as regular classes. The maximum number of students per teacher is about 10–12. Students without “limitations” should also be carefully chosen (taking into consideration their parents as well), there must be full understanding and acceptance of being in such a class. Finally: there must be proper technical conditions in the classroom. Otherwise all depends…;

(…) I wouldn’t deny the [value of] integration classes—all in all it’s a good idea… but let’s start from the basics the normal class should not have 30 people but 15 max. outstanding individuals should be provided with profiled classes or additional classes, … and integration classes, which would be even less numerous, in which there would be additional teachers, which would have the appropriate support of specialists, logistic (e.g. appropriate teaching aids but also a minibus), of course in Polish conditions this idea does not work, but it is not that there is something wrong with this idea, it is this country that is f… up.

One can also posit a question about the limits of integration: where can the integration take place and who can participate in it, who can integrate and where? Here, again, the question of language arises: Down syndrome is not the only kind of disability, the latter represents a wide range of phenomena, including autistic spectrum disorders, mobility, vision, hearing and other impairments, e.g.:

Integration schools are for the “healthy,” for people with MOBILITY impairments (which is NOT synonymous with intellectual disabilities, e.g. there are children who had traffic accidents) and children with e.g. a mild hearing
loss (who cope perfectly, with hearing aids), with minor speech impairments (which can be easily dealt with by several years of speech therapy and you will not notice that they have any problems, who apart from it are equally healthy and smart—or even smarter), etc., which are able to integrate perfectly. Yes, there are children who should not be there and yet they are there, they should go to more adapted schools but it is the fault of people who do not do everything well, and not the fault of this idea.

The interview also provoked comments on sincerity or openness and lack of political correctness in Suchcicki's contribution. Many posts showed a very positive tone, which results from the perception of their ideas as honest, true and authentic, e.g.:

*Thank you for this piece. It is bringing the unknown closer;*

*I am glad that finally someone honestly said what people think about the intellectually disabled. No one wants to hurt them, but on the other hand they are not partners for conversation, etc.;*

*Thank you very much for this interview. I know very little about the lives of parents of disabled children. And you are a part, and not a small one, of human society. I wish you a lot of health and cheerfulness;*

*A normal person, what a relief and support. He knows that it is the intention and not the words that makes an insult. He lives with a child (albeit an adult one) as it is…;*

*Finally, the voice of reason…;*

*A very wise article. It shows a sober reality. Showing a several-month-old child with Down syndrome in advertisements is a deception. A tiny child still looks delightful but then. Unfortunately, it is left to its own company and a good one [in this case]. A very reasonable man…;*

*The father's great wisdom, but is it politically correct ? Nowadays even the lame have the right to dance in a ballet.***

The posts express relief that someone openly said, in common-man’s language, without the use of all these correct and sophisticated formulations, how does the life of a person with Down syndrome and their parents or caregivers look. There is no place for saying that people with disabilities are “the same,” because one must honestly admit that they are not.

The honesty and political incorrectness of the interview is not only an object of admiration and respect, but also a cause of criticism addressed not to the Suchcicki family, but to all those who express their admiration and appreciation for the interview:

*You are all happy that finally someone has released you from remorse and political correctness. Thanks to this "great interview" with this "wise man" you can finally say "these Downs" and openly criticise the integration education that stops your wonderful healthy children from enjoying NORMAL education away from minorities, otherness and real life. At last you can feel BETTER, right? You pathetic, little people.***
The outrage expressed in the posts is caused by the way of talking about intellectual disability. People from the Down syndrome community go as far as to demonise the interview itself, pointing to its almost irreversible and devastating impact on the situation of people with Down syndrome and their relatives. They stress the public role of the Suchcickis and monopolise the way in which we should speak about disability. The outrage is caused by terminology, absent is the question of actions, i.e. what (and how) do the parents do with their (adult) children with Down syndrome. Posts that come from the outside of the community of people with intellectual disabilities use rather colloquial and therefore not always politically correct vocabulary. In fact, these politically correct terms are not always intelligible for the average reader: intellectual disability in the social perception can be close to mental illness, whereas mental retardation is already a familiar and intelligible concept.

The outrage is also built around the axis of integration (in education), especially the opinion that people with Down syndrome have little to offer to their non-disabled peers. The posts show that integration is the right way to take, because it somehow “forces” to see the otherness in the form of a person with Down syndrome or a person with other disability. Therefore, the normates are to draw benefits from integration. Few posts refer to the benefits for the persons with Down syndrome.

References


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