SOCIOLOGY OF DISABILITY

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Managing Stigma—the Experiences of Parents of Children with Intellectual Disability

Abstract: In this paper I analyze the phenomenon of parents' managing the stigma of their child's disability. Using Erving Goffman's concept of stigma, I point to its usefulness in understanding the management of stigma by parents of children with intellectual disability. I also stress the usefulness of the category of stigma in the context of how the parents work on their identity. The results of research indicate that the parents of children with a disability live with a sense of stigma in regard to their children. Parents adopt various ways of managing this stigma in connection with whether their child's disability is visible or not. Managing stigma may involve revealing or concealing a child's disability. In the research, qualitative techniques were used, with special emphasis on an unstructured interview. Data analysis was performed in accordance with the procedures of grounded theory.

Keywords: parents, child, identity, disability, stigma management

Introduction

The issue of families with a child with an intellectual disability has been addressed in the literature many times (see, among others, Hodapp 2007; Hodapp et al. 2005; Phyllis, Draine 1995). Studies prove that the arrival of a child with a disability determines family life, providing each member with new duties, functions, and tasks, and very often destroying the previous order. The presence of an intellectually disabled person in a family means that the family situation is difficult and unique. In the case of a family with a disabled child, family functions are generally distorted; having more important roles requires a serious amount of work, which involves a great deal of psychological stress for family members (Niedbalski 2020). As a result of experiencing an increasing number of difficulties in family life—often exceeding the possibilities and mental resilience of family members—certain members, especially the parents, may experience a role crisis and identity disintegration (Carey 2013). In the case of families with a disabled child, the large effort required to raise the child often lead to burnout syndrome. Whether a disabled child's development adversely impacts the child's family and the behavior of the parents is largely determined by the parents' personalities, their emotional attitude toward the child, and also their views on child-rearing (Phyllis, Draine 1995).

Studies have paid considerable attention to the issues of parenthood and the role of mothers (Docherty, Reid 2009) and fathers in regard to their children (Heller, Arnold 2010), or the problems of the motherhood or fatherhood of adults with disabilities (Hodapp 2007;

Hodapp et al., 2005). There is also research into the challenges of parenthood roles in the context of long-term care and support in multi-generation families (Miltiades, Pruchno 2001). Researchers have also been interested in the aging parents of disabled adults (as well as the aging of the disabled people themselves), their challenges in everyday life, and the position, roles, and features of siblings of disabled adults (Orsmond, Seltzer 2007). Seltzer et al. (2005) analyzed the connection between the lifelong disability of a child and the health of the child's parents. They state that parents with a child that has been disabled for its whole life face atypical caring challenges, which may cause stress and thus impact their physical and mental health.

Studies show that one of the effects of intellectual disability in a child may be the lowered self-esteem of the parents. Parents raising mentally impaired children often lose their sense of value, which in turn leads to social exclusion (cf. Orsmond et al. 2003). Society avoids contact with disabled individuals and their families, as people are afraid of encountering differences, problems, and sometimes incomprehensible behaviors. This, in turn, leads to so-called apparent integration, that is, we are in favor of it unless it concerns us personally, for instance, we support integration, but we do not want our child to be a part of an integrated class (see Barnes, Mercer 1997).

The family with an intellectually disabled child fulfills the same functions as a family with a healthy child. However, the difference is in the conditions in which particular tasks are conducted and in the intensity of their influence. A family that raises a child with a mental disability functions in conditions of permanent overload. However, the mere presence of a child with limited mental capabilities within a family system does not immediately make it dysfunctional. It is only the way families deal with crises connected to the child's disability, in different situations and periods, that determines the family's functionality or dysfunction.

This paper analyzes various categories of disability (covert/overt and visible/invisible) in the context of how the parents of a child with an intellectual disability create and articulate their identity. Special attention is paid to the consequences of the label "not fully able." In this work, I have sought to learn how the parents of a child with a disability perceive the world around them, make sense of certain elements, and in turn have a basis from which to shape their life space. In order to embed the analysis, I present the ideas in this paper in a broader theoretical perspective and refer to key assumptions from Erving Goffman's concept of stigma (1963) for the study of social life. In regard to stigmatized persons, Goffman addressed issues of social identity (based on a stereotypical assignment of individuals to social categories in connection with their personal and structural characteristics), personal identity (distinguishing one individual from others through positive characteristic features and identifiers with a unique combination of facts about them), and ego identity (the subjective meaning of one's own situation and continuity, and one's character, which is acquired through experience). Equally essential for me is how Goffman separates the bearers of stigma into "discredited" and "discreditable" people. I do not intend to address the issue of a child's disability from the perspective of a personal family tragedy but to analyze how parents manage openness in regard to a dysfunction that—according to parents—has a dimension that leads to social stigma. In the present paper, I attempt to demonstrate that parents use various strategies to try to counteract social

stigmatization. At the same time, I was interested in how parents (mothers in particular) deal with the—often inevitable—progressing "visibility" of the dysfunction as their child matures and develops physically. I see the phenomenon of disability as a social construct which—taking on an embodied character—becomes a source of stigma for parents of disabled children. For this reason, my subject of interest and main research problem is the process by which the parents of a child with a disability reconstruct their identity and redefine the situation. I refer to their personal experiences, as revealed in in-depth case studies.

Theoretical Inspirations and Definition Issues

The literature describing the situation of families with disabled children usually discusses the attitudes of the parents, the values of married life, the atmosphere of coexistence in the family, the family's social structure, and sometimes the personality features of the parents. It is assumed that the greater the disruptions in the scope of these qualities of family life, the greater the disorders in the processes of raising and caring for a disabled child. Such an analysis model fails to explain the complexity of the situation in some families. Moreover, such a model assumes in advance that there is a close causative relationship between the child's disability and disorders in the social adjustment of the parents. It has not been sufficiently explained how families raising a child with a disability form dysfunctional behaviors or behaviors that allow for effective social roles, that is, behaviors that enable the parents to function properly in the context of the changes occurring at the level of their identity.

In response to criticism of the analysis models for the functioning of families with a child with a disability, an interactive approach to research was proposed. In this perspective, the social roles of the parents are being constantly produced in a reflective process of interpretation, and their implementation is not so much a simple application of the rules that society suggests as creative in nature and associated with active co-development in the processes of interpretation, creation, and modification (Hałas 1987: 164 and further). According to the premises of the interactive approach, identity is also created within a continuous process of relationships between individuals and their surroundings. In defining themselves, individuals compare themselves with the world and in particular with other people, noticing the similarities and differences. They also want to stress their individuality and distinctness. In this perspective, the human sense of identity is mainly related to a person's own existence, feeling of distinctiveness from their surroundings, internal cohesion, own value, autonomy, and independence (Piotrowski 1998).

The interpretative orientation, which makes use of qualitative methods of data gathering and analysis, shapes the research perspective and provides numerous possibilities for discovering what constitutes disability (Blumer 1969). Therefore, in this paper, I will treat disability as one of an individual's attributes that becomes meaningful in different social situations. Disability, like ability, is a social construct, and as such, it depends on the social context, the course of interactions, or the response of "normals" (see Goffman 1963). Therefore, I look at disability through the prism of its contextuality, interactivity,

and emergence, as well as its multifactoriality and diversity. In my analysis, the varieties of disability (such as overt or covert disabilities, and visible or invisible disabilities) are important.

For this article, I identify disability in its dimension of covertness or overtness as an activity undertaken within the framework of particular social interactions. In contrast, disability in its dimension of visibility or invisibility is defined as a person's characteristic (property). However, regardless of which is mentioned, both dimensions of the phenomenon construct the dramatic performance—to use Goffman's (1963) terminology—of people with a disability. People with either a covert or invisible disability can thus be described as "discreditable," in contrast to those who have a visible stigma, and thus the term "overtness management" can be used (again, in Goffman's terminology). Importantly, in the case of "discreditable" people, their main problem in interacting with "normals" is the tension created in social contacts, while in the case of "discredited" people, it is the appropriate management of information about their disability (Goffman 1963).

Taking into account the above references to the category of disability and the notions of stigma, the interpretative approach, with its whole theoretical and methodological background, is particularly appropriate when we want to give voice to those who live on the social margins on a daily basis. Emphasizing that the reality we live in—and thus the reality of disabled individuals and their families—is shaped by people in a particular community allows us to discover the multiplicity, diversity, and complexity of perspectives construing the phenomenon of disability in our cultural circle.

It is worth stressing that interactionism in relation to disability research is not just another way of researching; it is a perspective that allows us to see the previously underestimated contextuality of our knowledge and beliefs. This can have a significant impact on the social status of people with disabilities and the place they are provided in the social space (Ferguson et al. 1992). Furthermore, such an approach allows a more systematic perspective to be adopted when looking at the whole family, because it is clearly visible that there are mutual dependencies between the behaviors and feelings of family members; the emergence of changes in the behavior of one person in the family (e.g., due to a disabled or sick child) impacts the situation of all other members, that is, the functioning of the family system as a coherent whole, and moreover, the functioning of such families is also affected by the social environment in which they live.

Therefore, the research models we adopted not only enabled us to look at the stigmatization issue analyzed here but also indicate a broader perspective on the whole life and functioning of families with a disabled child.

Research Methodology

The research material adopted in this study is information obtained from parents who have experienced significant transformations in their lives in connection with raising and caring for an intellectually disabled child. The information was obtained through non-structured free interviews. In total, forty interviews were conducted between 2017 and 2019 among parents who had a child with an intellectual disability.

The reasons for selecting the above-mentioned technique derive from accepted onto-logical premises (human experiences, interpretations, knowledge, evaluations, and inter-actions are perceived as significant interdependencies of the social reality) and epistemo-logical premises (the legal manner of data generation based on those ontological premises comprises interaction, conversations with people, listening to stories, and gaining access to individuals' knowledge, evaluations, and impressions). The data acquired is of a whole and in-depth character, in accord with Rubin and Rubin's (2012) thesis that qualitative re-search should be applied in relation to notions whose deeper understanding is best served by detailed examples and expanded narratives.

The interviews were conducted in natural conditions, mostly at an interviewee's place of residence, due largely to the interviewee's need to provide permanent care to a disabled family member. A small number of the interviews were conducted outside the place of residence, as a result of various restrictions connected with the dwelling and the interviewee's inability to talk there. In every such case, the interviewee had to ensure that the disabled child would be cared for by other people (usually other family members).

All participants in the study were informed about the purpose and nature of the research, as well as about the terms and scope of use of the data collected during the interviews. The research subjects could have their doubts clarified and ask questions in order to understand the essence of the research in full.

Before analysis, the interviews were transcribed word for word, with the details of the in-terviewees' utterances being preserved as faithfully as possible. All the data was anonymized through the permanent deletion of all information concerning first, last, proper names, etc., or their replacement by other data which makes it impossible to identify the respondents.

Analysis and interpretation of the research material was conducted in compliance with the principles of grounded theory methodology (GTM) (Glaser 1978; Glaser, Strauss 1967; Strauss, Corbin 1990). Hence, the selection of subsequent cases for the study was theoretical (theoretical sampling), based on the constant comparative method. Thanks to theoretical sampling, a researcher, while collecting, encoding, and analyzing materials, makes simultaneous decisions about what data to collect and from where (Glaser 1978; Strauss, Corbin 1990). While applying the constant comparative method in my search for other data, I attempted to choose cases that were similar in some regards yet highly different in other respects in order to grasp the maximum number of conditions that differentiate the presence of categories and their mutual correlations (Charmaz 2006; Glaser 1978). The selection of cases lasted until theoretical saturation was achieved, that is, until subsequent cases had confirmed the previous analytical findings (Glaser 1978).

The usefulness of GTM in this research largely resulted from the specificity of the environment we were exploring. GTM makes it possible to reach the perspective of the social actors and grasp the processual dimension of the phenomena (Glaser 1978). Thanks to a flexible approach to the data sources, the researcher can draw on all kinds of information. This ability proves to be especially important in regard to phenomena for which the collection and analysis of empirical data is difficult, for instance, when it comes to spheres of social life, and notions such as disability.

Data analysis was supported by CAQDAS—Computer Assisted/Aided Qualitative Data Analysis Software. The analytical and conceptual work was performed with NVivo

software. The data was then analyzed by adopting the functions implemented in this program in a way that corresponds to the requirements of the research methods. The software also made it possible to modify all elements of the project continuously as new information appeared.

Ways of Managing Disability Stigma

In regard to how the parent-interviewees manage stigmatization, we can make a fundamental distinction between those actions aimed at disclosing a child's disability and those aimed at concealing it. At the same time, while considering both of the above-mentioned strategy categories, we need to take into account whether we are dealing with a visible or invisible disability. The group of parents under study included those who had an "openness policy," which involved revealing the child's disability even though they could potentially have hidden it (revealing was thus a purposeful and conscious action by the parents). These actions could be more or less expressive and can thus be placed on a scale. At one end, there were participants whose attitudes can be described as defensive or withdrawn. They use techniques that lead to the blurring of the disability, but they also try to take advantage of "natural" situations and circumstances that increase the probability that their child will not attract attention ("stand out"). At the other end of the scale were the parents who take a belligerent stance based on the principle that "the best defense is a good offense" (and so, in a way, they stun others with the disability).

However, other types of strategies were undertaken by those parents who could not hide their children's disabilities, even though they wanted to (thus their actions resulted not from choice but from the situation). On the one hand, these were cases where the type and nature of the dysfunction made it impossible to hide the child's dysfunction in any way. On the other hand, they were cases where the inability to conceal a child's disability was the consequence of changes in the child's body at adolescence.

Nevertheless, concealment was used when the disability was both visible and invisible. When the disability was easily visible, the parents needed to work harder at concealing it, but there was also a growing concern that it would be discovered by the "normals."

Concealment and Protection from the Disclosure of a Disability

Hiding a disability requires careful consideration and then the implementation of a specific strategy (cf. Frable et al. 1990). Such activities often carry the risk that a hidden disability will be discovered. This may lead not only to the stigmatization the parents were trying to avoid but also to exclusion and marginalization due to a loss of credibility. The disclosure of a disability may expose parents to constant attention and trigger excessive curiosity in third parties, combined with the crossing of privacy boundaries in formal situations. For this reason, parents of disabled children need to think carefully about how they will engage in active identity manipulation (Carey 2013): whether they will try to conceal the disability and work to have their children consider themselves fully functional, or vice versa, whether

they will apply a policy of openness and transparency. Alternatively, they may combine both strategies and use them depending on the context. The dilemmas faced by parents of children with disabilities are well illustrated by the following fragment of a conversation with one of my interviewees.

It's not so obvious, because I've already experienced a lot of different situations. I've tried hard and felt it inside. I'll put it this way. There is no single good practice that is always effective, because a lot depends on people, on other people and their attitudes. There are situations where it is better to pretend and situations where you can be more direct and open. I'd say there's no rule in this regard. (i.01.19) [1]

Despite those concerns, parents of children with a covert disability often try to control information about the condition. This is connected with the negative connotation of disability in a broader social context, but it may also result from an unclear status because not all ailments are generally recognized as credible health problems that entitle a person to the status of a disabled individual (Kroll-Smith, Floyd 1997). Therefore, while children with a visible disability are labeled by the environment in advance, children with a covert disability are labeled as a result of actions and decisions made by their parents in terms of concealing or disclosing the stigmatized disability.

Like everything else, those things regarding our situation (as parents of children with disability—note by JN) *also have their consequences. I'm talking about such a sensitive issue as the fact that sometimes it's better to have it written on your face than to pretend that everything is okay. Because you see, when you have a disabled child, and this disability is visible, then at least nobody will question it, but when your child looks "normal," we encounter disbelief and ignorance. Both are tiring, but which is more (…) I'll leave without comment. (i.06.18)*

When dealing with the immediate environment, activities that are aimed at concealing a child's disability often take the form of a performance. If a parent is to be effective, he or she must suppress and conceal anything that might conflict with the more general values of a socially adequate "norm." This means controlling the child's expressions and regulating his or her behavior in such a way that there is no incompatibility between the behavior and the definition created for the situation. The behavior could disrupt the interaction and cause it to collapse. Therefore, the purpose of the parents' construction of the performance is to conceal or distract attention from the child's disability and the visible effects. The more visible the effects, the more camouflaging actions are undertaken. An attempt by parents to conceal stigmatizing characteristics (Goffman 1963) and reduce the interpersonal distance may, for example, involve dressing their child in a way that adequately camouflages dysfunctions and potentially noticeable developmental irregularities. For example, this could mean dressing the child in clothes that conceal characteristics that could cause other people to depreciate the appearance of the child.

When Miłosz [2] *was little, he was a pretty boy. Look* (the interviewee shows a picture in an album—note by JN)*; you wouldn't have said that this was a child with a problem. And since the stroller was also a regular one—because when the child was little, it wasn't necessary to buy a special stroller—and you could wear completely ordinary clothes like this, you couldn't see anything. And you know, when something is "ordinary," it doesn't arouse any interest. (i.02.19)*

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[1] Through the article, I cite fragments of my respondents' statements: the letter 'I' means interview, the first figure indicates the consecutive number of the interview, and the last figure is the year when the interview was conducted. For example, i.01.19 means that it was the first interview conducted in 2019.

[2] All names in the text have been changed.

In constructing the performance, the parents seek to gain acceptance of the interaction partner, but if the disability is visible (despite attempts to hide it), a kind of game of appearances may take place. An able-bodied person can avoid paying attention to a child's disability (ignoring the stigmatizing element) by "kindly neglecting" it (Goffman 1966). However, persons who are unable to accept the parents' attempts to conceal the stigmatizing characteristic may ignore the parents, withdraw from the relationship, or condemn both the child and the child's parents to "invisiblity." This is how parents experience social exclusion when dealing with others, especially strangers. At the same time, parents often point out that non-disabled people behave this way because they feel embarrassed and do not know how to behave when they "discover" the child's disability (cf. Belzyt 2005).

Unfortunately, it's often true that people aren't so good when you get to know them (…). I say this because I've experienced it more than once. When somebody doesn't know me, our situation, or my child, they treat us differently. I've unfortunately experienced the way people treat us when they find out about the disability. Either there's this artificial compassion, which I just don't like, or this gentle avoidance, because they don't know how to behave. Anyway, it's just so unnatural and sad at the same time. (i.09.18)

Parents point to behaviors that are intended to divert attention from the disability, trying to "pretend to be someone else" or hiding the stigmatizing characteristic. While adopting the strategy of "pretending," parents must be aware of all those elements of social interaction that others treat as natural and about which they do not need to think (Goffman 1963). However, if these attempts have no effect, the parents may use provocation, which, according to them, involves showing themselves "on their own terms." This means that the parents of a disabled child, as bearers of the stigma, try to arrange the situation so that—through their behavior, choice of environment, or use of props—they can use the element of surprise and thus gain an "interactive advantage" over the "normals." The key to success is then to anticipate others' reactions and to provoke reactions for which the parent is prepared, in order to maintain and control a sense of security during an interaction (cf. Belzyt 2005).

It can happen that you have no choice but to do something instead of burying your head in the sand. You need to take the wheel. Therefore, in order for me to function quite normally, and for my child to have normal conditions in this world, I try not only to think for us two but also to anticipate how others will behave. (i.05.18)

The stigmatized characteristic, which both parties of an interaction are aware of, interferes with the course of the interaction because it creates mutual expectations between them. On the one hand, a "normal" person is equipped with the belief, based on a stereotype, that people with a stigmatized characteristic have a certain set of traits. Thus, the stigmatized characteristic involves a particular social identity (Biernat, Dovidio 2007). On the other hand, the stigmatized are also convinced—both on the basis of internalized norms and previous interactive experiences—that they are perceived in a particular, negative way (Goffman 1963). This view can be reconstructed from the conversations and interviews with the respondents. Thus, in the linguistic sphere, there is a visible distancing and delineation between the world of the subjects ("us") and the "normals" ("them"—in the interviews, they were described as "people," "society," "someone," and "everyone"). It is worth noting that parents of fully able children are also included in the category of "them," that is, those who do not understand the parents of children with disabilities and reduce their identity to

the dimension of the stigmatized characteristic. Thus, the mechanism of the reflected self can result in avoiding interactions with "normals" (Goffman 1963).

We, the parents of disabled children, know how difficult it is to live when your child is sick; you cannot help the child as you would like to, and there is no greater happiness for us than even the slightest sign of improvement in their health. Unfortunately, people don't understand it. I have such a sad feeling that society doesn't really accept us. At every step, you can see how someone negatively evaluates us, looking at us with suspicion or pity. (i.09.17)

The actions undertaken by parents of children with a disability involved excluding their child and themselves from the general category of stigma bearers and presenting themselves as individuals who meet the criteria of a social standard. In order to do so, the interviewees distanced themselves from components of this stereotype, which they believed was a reference point for "normals." An element that was of great importance for parents of children with a disability was explaining the reasons for arranging a performance. It is worth noting that this thread appeared spontaneously in most of the interviews and took the form of "explaining" and "apologizing" (Goffman 1961). Perhaps the interviewees got involved in constructing the "performance" due to a kind of interactive compulsion, a fulfillment of the social expectations of "normal" people that the bearers of stigma should explain their motives. The interviewees gave objective and rational reasons for engaging in the performance (e.g., a fear of negative opinions from other people) or compulsion from the external situation (e.g., lack of other measures to prevent the immediate environment from marginalizing the child and its family).

It's unfortunate, but the situation forces me to do so, because how am I supposed to function differently when I encounter various unfavorable deviations at almost every step. In order to deal with this, you have to take various measures, which sometimes means that you just have to pretend to be someone else in front of others. But how else can you deal with it? (i.07.19)

Such statements were an externalization of the subjects' meta-reflections about who they are in the eyes of others (who were identified as "normals"), and what they think about themselves. As Goffman points out, stigmatized people are often uncertain as to how they are perceived by "normals," and during an interaction, they remain "in a state of constant readiness" to assess the impression they make (Goffman 1963). Also, the "normals" may not feel comfortable in these interactions, finding many unintended meanings in the other party's behavior. The "normals" may weigh words, and fear that their actions will not be properly understood (Goffman 1961). At the same time, a bearer of stigma may question the approval with which they are treated by the "normals," find shortcomings in their behavior, and constantly observe actions and words in order to detect even small signs that the acceptance of the "normals" is only for show (Goffman 1963).

Revealing and Managing the "Label" of Disability

Among the parents of children with a disability were people who consciously decided to reveal their status despite the risk of stigmatization. Such a decision was supported by the idea of achieving "authenticity" and becoming a "true and valuable" person, which, according to Goffman (1963), is one of the reasons for not concealing a stigmatizing

characteristic. On the other hand, not showing weakness can be a culturally legitimate way to present oneself as a valuable and culturally competent person (Fitzgerald, Paterson 1995). Even in the case of recognized disabilities, in certain cultural contexts it is not appropriate to complain or show pain or suffering, and the person who hides the pain and suffering is seen as brave and is valued for this.

Moreover, the principles of adapting to the role of a character who bears the stigma the "normals" attach to the stigmatized person make it possible, as Goffman claims (1963), for the whole of society not to notice the injustice and suffering that result from bearing the stigma. All of this makes revealing a disability extremely difficult and complex—not only because of the question of whether to do so, but also because of the question of how to do it. As Clair et al. write (2005), disclosing a disability that is invisible or covert can take various forms and involve various tactics. The two most common are "normalizing," that is, presenting the situation as normal (e.g., pointing at common features between members of the stigmatized group and the "normals"), and "differentiating," that is, emphasizing one's distinctiveness (e.g., by pointing out that one has different needs). Whichever option is adopted by the parents, they usually stress that their identity is as worthy (as valuable) as the dominant identity, and they engage in activities aimed at abolishing stigma and discrimination. This might involve, among other things, relevant social rules or legislation (Clair et al. 2005). In other words, parents who use these tactics try to change the way they are perceived, as is illustrated by the following quote.

I must say that I couldn't imagine a situation in which I had to hide the fact that my child is disabled. I had different thoughts but never something like this. I would probably do him more harm if I were to pretend in front of others that it is different than it actually is (…). Marek is different, but he has the same rights as everyone else, and he has the right to be treated the same way, because he is a human, a member of our community, and he's just like everyone else. (i.06.19)

Nevertheless, the motives for revealing a disability (or not concealing it) are varied, and they do not need to be limited to the willingness to cause a change in how "normals" perceive parents and their disabled children. The motive may also be a desire to be genuinely oneself, especially when the concealment leads to stress, but also in regard to building and maintaining bonds with "normals," or the motive might be connected with wanting to take advantage of available facilities, or sometimes even with wanting to act to bring about social change (Clair et al. 2005). Therefore, in the case of a covert disability, questions arise: How should the disability be revealed? Should the revealing be done at all if the "person with a disability" status might hinder rather than promote the building of bonds? Calculating the benefits and drawbacks may sometimes lead to the parent choosing not to make the disclosure (Racław, Szawarska 2018).

So, I'm going to say it's not easy when you're alone. You feel alone. Because the parent of a child with disability— even if they had a whole group of people—they experience everything inside themselves. And every decision, every way of doing things, is an attempt that must be faced. That's why you sometimes need to choose what is more important, better. Whether to fight openly with the world or play a part and stay hidden. I'm not judging which is more appropriate, because it's always difficult, and many factors determine whether or not you play an open hand. (i.02.19)

On the other hand, we also encounter situations where disclosure is not the result of desire, courage, or calculation, but is related to the inevitable physical changes that occur

as the child grows older and that make it difficult or even impossible to hide the disability. Lacking an alternative other than total isolation, the parents decide to make their son or daughter's disability public. In this context, it is crucial in which space the disclosure occurs, both in the literal sense, that is, the physical space, and in the sense of social perception. This is because overtness management is highly dependent on the space in which there is contact with the "normals." While in the private space, among people close to them, the respondents can (to a large extent) "control" the course of an interaction, in the public space they have to take into account that not everything can be predicted and that a multitude of unexpected situations may make them feel fearful—not so much of revealing the "otherness" of their child, but of the reactions of people they do not know.

I don't have any problems with accepting my child, or I should say, his disability. I've done this many times, and I've done my homework—I think I could get an A. But it sickens and repels me when I see so many pupils being made to sit in the corner, if I can put it this way. What I mean is, if I can't change how others see us and treat us, I just move aside. Why should I be frustrated or afraid of how others will take me and my child? (i.09.18)

It is also interesting how some parents view the public space in the context of the choice of ways they can "appear" in it while maintaining their desired sense of "anonymity." In this way, they manage not so much the overtness as the "degree of visibility" of the stigmatized condition. In this sense, the strategies undertaken by the parents can be viewed as attempts to maintain a certain order of interaction, the disruption of which could lead to interpretative confusion (cf. Garfinkel 1967). In this way, parents try to take symbolic control of certain parts of the space by conducting the interaction on "their own rules of the game." This is often achieved by using the capital that they have at their disposal for such circumstances (e.g., the ability to cope with stress or having adequate resources of "life" experience).

Since I cannot, unfortunately, limit the scale of misunderstanding, or sometimes simply human ignorance, I try, wherever possible, to manage a situation in such a way that I can be perceived, as the mother of a disabled child, as well as possible. You have to know how to anticipate others and be one step ahead of them, but this is only possible when you are careful and attentive, based on knowing what others don't need to know and having had experiences that others may lack. (i.01.19)

This type of revealing was conducted primarily within trusted interaction circles. In this sense, the above-mentioned essence of establishing and maintaining acquaintance with "normals" seems to gain not only confirmation but also additional meaningful context.

It should be noted that one of the most important factors in decisions regarding disclosure is the support the parents receive from their closest circles and, therefore, (in most cases) their family of origin. At the same time, a lack of such support often determines whether the parents will refrain from, or at least postpone, an openness-management policy. It is also worth mentioning that all the respondents chose a kind of a coming-out circle before deciding to go beyond their closest family and friends. Thus their situation was largely dependent on the support they received from their family of origin, which draws attention to the respondents' sense of pro-activity in regard to protecting their child, which they achieved primarily through "visibility management."

I know from experience that without the help of my family—without the involvement of someone who can support you when you need it, and without being aware that you can simply count on someone—it is extremely difficult. It

is invaluable to have loved ones who are ready to help and support you when it's really bad. This not only helps in times of crisis, but it's also an injection of positive energy, which turns out to be extremely necessary in the struggle with everyday life. (i.03.19)

In experiencing the acceptance of relatives, the parents of children with disabilities were able to anchor a sense of "normality" in the common space of their immediate surroundings, and this was then reflected in the shape of their identity narrative within the public space. On the one hand, it meant that the parent felt more confident, and they gained some additional attributes when confronting "normals" in the public space. On the other hand, the acceptance of relatives was a security buffer (or defensive mechanism) against negative emotions and fear of contact with the environment, which in turn could help the parents to avoid disappointment (and also injury) as a result of the intolerant and stigmatizing behaviors, reactions, and actions of "normals." By contributing to the symbolic "visibility" of the role and status of a mother or father of a child with a disability in the framework of interactions within an institutionalized (public) space, the meaningful consequences of these activities were not without impact on the shape of the parent's identity narrative. Furthermore, when such interactions are read in terms of success, they make it possible to project certain patterns of behavior into other areas of everyday life.

I admit that I didn't manage to go out to people right away, both literally and mentally. Not only did I myself struggle with the trauma of my child's disability all the time, but I also felt other people were looking at me. It was a horrifying feeling that paralyzed me even further. I felt I couldn't function in this world. I wanted to shut myself in at home and not leave. And I don't know where I would have landed and what would have happened to me and my child if it hadn't been for the help of my closest friends and family (…). I drew from their strength, and it was from them that I had this energy to face the "demons" in my head and those "ghostly" looks of the passers-by on the street. (i.05.19)

"Revealing" was, therefore, all the more critical for parents. Based on the legitimacy of such a (self-) presentation, the respondents gained external confirmation of their (socially questioned) "normality," which, in the long run, could allow them to "more boldly" go into the "unknown waters" of (the constantly discovered) public space. Acting within different dimensions of the social space, the parents constructed and (gave meaning) to specific strategies in the wider category of "openness management."

The Feeling of Otherness and Its Influence on the Identity of Parents of a Disabled Child

One of the biggest dilemmas indicated by the narratives of the parents in the study is identity work in the context of defining themselves in the world in relation to their role—which is "(co)shaped" on various levels of meaning—as the mother or father of a child with a disability. Therefore, in order to understand the narrative situation of the respondents in negotiating their image of their Self, it is worth considering how the status of a parent is socially "decoded" on the basis of interactively drawn models of parenting within a wider cultural context.

In this context, the study suggests that one of the dominant experiences related to being the parent of a disabled child is the sense of difference. In Goffman's view of

stigma (Goffman 1963), depending on the child's type of disability and its visibility, the mother or father quickly notices that they are treated in a special way. And "special" has no positive dimension here. The child's intellectual disability makes the parents feel different in a pejorative sense. It is, therefore, a sense of distinctiveness that often does not guarantee the development of an identity based on self-esteem and the awareness of one's competences. In the case of parents of disabled children, "other" means "different" in the sense of "worse." It is often the case—particularly in small local communities—that the mother and father of a disabled child are not referred to simply as "parents" but are stigmatized with terms such as the "mother of a retarded child," that "poor father," or those "pitiful parents." These kinds of labels not only destroy the image of the mother/father but also make them feel disappointed with their parenthood.

It has happened to me more than once that someone looked at me in an unpleasant way or said something unwelcome (…). Anyway, I can say that I encounter such situations, and it's painful. It's unfortunate, but they make me feel like I am worse because I have an unusual child, and I feel worse, then. I should be used to it by now, and I try not to pay too much attention, but emotions tend to be stronger than common sense. In any case, it's not me who lacks common sense; it's the others (…). (i.09.17)

The parents of children with disabilities often assume the identity of a disabled person, which they are not themselves. The consequence of this is that they feel an aversion to themselves, depreciating their value in various spheres, which makes them vulnerable to negative emotions and even depressive states (cf. Popielecki, Zeman 2000). This is particularly evident and is intensified in two stages of the life of their disabled children, that is, in early childhood, when the parents have to accept the "otherness" of their offspring, and in adolescence, when there are deep and visible changes in the body of an adolescent child. This usually leads to an even greater "alienation" of the parents, since there is a growing gap between social expectations for adolescents and the psychosocial capabilities of the disabled person.

I can't hide that my child is disabled, unfortunately. But as time goes by, it becomes more and more evident. When Jaś was little, he didn't stand out so much. Actually, hardly anyone could say something was wrong with him. But when the time for nursery school came, it turned out that there were already some serious hurdles. That is, he couldn't cope; he could not adapt to the new situation in a group of children. And then, well, with age, when he should theoretically have reached a higher level of development, as it is nicely called, there was a growing gap between him and his peers. (i.02.18)

The child's disability had a direct impact on how they interacted with others. At the same time, the nature of the disability stigma differed depending on whether the child had a more or less visible (or at least concealed) dysfunction. In this context, it is worth emphasizing once again that Goffman's distinction (1963) between discredited and discreditable people applies. In the case of parents of a disabled child, the difference is that one group has some "control" over perceptions of their child's dysfunction, as they can conceal it from the world. (cf. Goffman 1963).

Whenever I'm somewhere, I try to stay out of sight. But it's getting worse as time goes by because the older Jaś is, the more difficult it is for us to move him. He is getting heavier and heavier, and as we get older, we're running out of strength. And although we are lucky because his illness does not give such clear signs—because it's not visible physically—he still has some problems moving independently, and you know, as he grows, he just arouses the curiosity of other people by being in a stroller. (i.03.17)

The "discredited" are not capable of effectively hiding the dysfunction and disability of their children, and this deprives them of the possibility of manipulating impressions. As a result, they believe their child's dysfunction is not only immediately visible, but also that it fails to provide a chance to adjust to societal requirements by concealing it. This means the only effective means of limiting "difficult" situations is to avoid any circumstances and places that would threaten to expose the existence of a disability (cf. Goffman 1963).

Everything was terrifying for me (…) I didn't want to see anyone or show myself to anyone at all. I thought I was…Mmm, how can I say it?—"maladjusted"—that I would feel out of place among people, especially since I wasn't comfortable that I would be seen as someone different. (i.04.17)

As Kowal (2012) stresses though, regardless of whether we are dealing with a family with a visibly or non-visibly dysfunctional child (at least according to the parents), a disabled individual, through their "otherness," loses the embodied schemes of morality that are rooted in the social awareness. This is how a child's disability is permanently present not only in the life of the child but also in the life of their loved ones, not only in a strictly physical sense but also in the metaphysical dimension as the above-mentioned awareness of "otherness." Disability violates socio-cultural standards on "normality." Therefore, a child's disability remains a source of stigma for the respondents, especially in those social relationships where it becomes a reason for discrimination.

Unfortunately, I have to admit it with regret, but I've already experienced various types of unpleasantness many times because of my child's disability. And I'm not even talking about such mundane things as staring on the street or on a bus, or the odd comments of passers-by. But even in such places as clinics or health care centers, where you would expect greater understanding, I also had situations that you know, what can I say (…) I wish people didn't see me and my child through the prism of disability, and as not a human being (…) (i.02.18)

One of the reasons for hiding a disability is shame. The emotions involve the lack of cohesion between the manifested "I" of the parents and the response of others to the perceived picture of their child. Consequently, as Jakubowska states (2009), the most important field when considering emotions becomes ego verification. Emotions are an element of social control here. Particular stress is placed on emotions such as fear of sanctions or being tagged a "weirdo" (Turner, Stets 2005). As Thomas Scheff highlights, individuals are in a state of continual self-awareness, especially in relation to such feelings as pride and shame (Scheff 1990). Therefore, human beings monitor their egos on an ongoing basis; they evaluate themselves even when they are alone.

What can I say (…)? I was ashamed that my child was disabled. I mean, I thought that when others found out, I would be seen as the father of "that retard." I know it's sad, but I just felt worse than those parents who had healthy children. I simply felt miserable that I would be seen as someone who is raising an unusual child, because this is how I perceived it. And I wasn't wrong, because when it came out, it was like that, I mean they made me feel it at work and in my family. (i.09.17)

Therefore, the dysfunction of a disabled child may affect the entire self-definition of the parents regarding various social roles and contexts, such as the family, work, or simply relationships with other people. According to Becker (2009), a negative feature attributed to a person is generalized, and in the course of further negative markings, an individual tends to identify themselves with the assigned role. Therefore, work on the body is frequently

related to social "coercion," which determines the individual's efforts to adhere as closely as possible to an acceptable pattern in a given community. In the case of parents of children with a disability these efforts often involve extensive rehabilitation and revalidation actions intended to produce a state where the child can reach a certain level of psycho-physical development. This is particularly visible in the period of early childhood, when the parent has recovered from the shock of their child's disability, but at the same time, they have not accepted their child's inevitable and undeniable condition. Many parents stressed that this was a period of intensified work but also of progress, which was manifested by achievements in terms of development, especially the growing physical and motor skills of the child. At the same time, numerous interviewees stressed that when adolescence begins, the previous rehabilitation achievements start slowly to deteriorate. As a result, the parents were not only disappointed with the "elusiveness" of the previous "achievements," but they were also accompanied by a feeling of resignation, sometimes of apathy and withdrawal.

I did everything I could. I just said to myself that I would put Tomek on his feet, and I did. It was a very difficult period, physically, for me and for Tomek, of course, because he had this physiotherapy three times a week in a health care center, and I exercised intensively with him at home on the other days. (i.01.18)

Parents' struggles, efforts, and labor to improve the condition of their offspring, and then the fact that the child manages to overcome its limitations, achieve an appropriate level of fitness, or take part in family and social life (as far as it can), mean that the identity of its mother and father becomes closer to the identity of parents of a "normal child." This is why parents of a disabled child may abandon many of their needs and often act at the expense of other family members; they do everything to make their child similar to other healthy children. At the same time, adolescence, when the situation is often reversed and slowly regresses, is not only painful for the parents but also leads to a renewed lowering of their self-confidence and abilities, and the disavowal of their sense of identity.

Conclusions

In reference to Goffman (1963), we can say that stigma is a relationship between an attribute and a stereotype. It is also processual and assumes the existence of two roles that everyone plays in certain relationships and in some phases of life. Attributes that stigmatize an individual do not condition the nature of the roles of the "normals" and the stigma bearers but the frequency of playing those roles. In an era of new technological and medical advances (including diagnostics), when the boundaries of health and illness are blurring, the prevalence of various disabilities or their temporal nature may contribute to the reclassification of people with disabilities, especially those with invisible dysfunctions that can be concealed from "normals."

The prevalence of a trait or a social change in definition means that a particular health or fitness trait ceases to be a stigma and loses its ability to trigger the stigmatization process. The common nature of a given phenomenon and its being treated as an everyday experience trivializes it in the social perception, especially in the historical context—as in the case of the mass phenomenon of people with crutches or amputated limbs just after World War II

(Gniazdowska 2016). In this way, the scope and forms of different behaviors of people with an invisible/covert stigmatized characteristic may be redefined as an equal lifestyle or mode of functioning in the world (cf. Davis, Braun 2010).

In this context, an important difference between visible and implicit disability seems to be the role of medical diagnosis in determining the place, identity, or significance of disability in a wider social context. While parents of children with visible disabilities try to "transfer the burden" of the disability away from their "medical" status to their environment, making the environment responsible for the barriers or difficulties encountered, for the parents of children with an invisible disability, an expert diagnosis is essential to obtaining legitimate disability status (Fox, Kim 2004). This status is supposed to explain situations that may otherwise be treated as manifestations of negligence, laziness, or other moral "blemishes." Paradoxically, it seems that parents of children with a visible disability—through the distance they are able to create between themselves and their son or daughter's disability—may be less subject to identification with the dysfunction than are the parents of children with a hidden disability (Racław, Szawarska 2018).

All this means that for parents managing the stigma of the bearer (the child), the primary concern is not the tension between their social and personal identity. Their main problem is usually controlling information in order to conceal the stigmatized condition, or, as mentioned above, to make real problems seem credible (i.e., the discovery of the stigmatized condition). In the first case, as "discreditable" people, the parents of a child with an invisible/covert disability have to "face a situation where people unaware of their child's condition will accept it, even though they have prejudices against people like them" (Goffman 1963). This also applies to the bearers of the invisible stigma. In the latter case, when the dysfunction of the child is visible, the parents may try to hide it (which is usually not only difficult but often ends in failure and exposes the parents to even greater marginalization and ostracism on the part of the "normals"), or they may apply a strategy of openness in regard to the stigmatized condition.

The efforts of parents of children with intellectual disability to control the symbols of stigma, prestige, or "badges" are particularly important in public life, although, as Goffman (1963) rightly points out, intimacy with others does not protect the stigmatized from human contempt. For example, a "badge"—in the form of a lack of visible disability in the child—can be extremely burdensome for parents who aspire to join a group of the "discredited" in order to be able to adopt a different code of conduct than the "normals" (i.e., the general public). In this sense, the strategies undertaken by parents can be seen in the context of the metaphor of family self-defense tactics, which are adopted as part of a wider process of dealing with the stigma.

Parents of children with intellectual disability, who function on a daily basis within a world of meaning—in regard both to their own experiences and those of people in similar situations—anticipate the possibility of encountering some manifestation of their symbolic social marginalization. For this reason, when planning strategies for the daily functioning (and thus presentation) of the family in a space beyond the safety of their private area, they take great care both in managing the visibility (or openness) of the disability and in building "justifications" for taking particular steps to conceal it. This situation, which reflects the nature of their everyday activities as events occurring within a context of fear, seems to

explain, in part, the great caution with which parents approach the normals whom they encounter in the public space.

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