

Social Exclusion of Mothers of Children on the Autism Spectrum as Presented in Popular Publications

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Abstract

The text provides an introduction to analyses of the social exclusion of mothers of children with autism spectrum disorders. The aim is to highlight and discuss several stories from the increasing number of printed accounts by mothers describing their daily struggles with disability and social judgment. The discourses of exclusion concerning this social group are a highly interesting research topic due to its multidimensionality and stereotypes ingrained in society.

Keywords: autism spectrum disorder, difficult motherhood, transference stigma, mothers' biographies, popular publications

1. Introduction

Nowadays, special pedagogy strongly emphasises the need to support persons with autism spectrum disorders in the context of education, revalidation and social inclusion. An important element building the effectiveness of the methods applied is the child's environment, including above all a family that accepts and embraces disability. Social exclusion has accompanied disability since the dawn of time. In the context of exclusion and stigmatisation of persons with autism spectrum disorders, it is an extremely interesting issue from the cognitive point of view due to theories emerging in recent years concerning factors influencing the development of the disorder itself. The examination of the topic should begin with the first theoretical publications (from the 1940s), as at that time the causes of autism were considered to be completely different from those recognized today. The aim of this text is to provide an insight into the

issue, based on the accounts of mothers of people with autism spectrum disorders. The accounts presented are a slice of content taken from popular publications (biographical and autobiographical) written by parents, resulting from their need to talk about their experiences, including frustrations. The main objective is to identify and cite those aspects of the reality of families affected by social misunderstanding and consequently transferred stigma. The overarching aim is to highlight and draw the society's attention to the multidimensionality of the needs of parents and families of persons with autism spectrum disorders. The analysis is made on the basis of statements by mothers who face exclusion and stigma on a daily basis due to the autism spectrum diagnosed in their children. The history of the theoretical approaches to the issue—the causes of autism spectrum and stigma—is also presented.

2. The mother as the source of autism—historical overview

The “discovery” of autism is attributed to Leo Kanner, although there had already been publications that spoke of “autistic behaviour” (for example, in the work of Grunia Sukhareva in 1925). Kanner, in a 1943 publication entitled “Autistic disorders of affective contact,” described the disorders of the children as “congenital.” At the same time, he paid a lot of attention to the description of the parents, whom he portrayed as intellectual, cold and rigid; consequently, researchers from the psychoanalytic school established a link between the parents' characteristics and autism.¹ Kanner explained his words by misinterpretation, even going so far as to say to the parents “I acquit you.”² However, the machine of stigmatisation of mothers of children on the autism spectrum took off in earnest. They were called “Frigid mothers.” In a text that appeared in *The Time* magazine of 26 April 1948, entitled “Medicine: Frosted Children,” the authors described those who “wear schizoid nappies” and who “are happiest left to themselves.” The entire text maintains an accusatory tone and ends with a rhetorical question: “Is it the frigid parents who are defiling their children?”. The text concludes with a reference to the words of an expert who presented the parents as cold and flawed. This expert used a metaphor in which children were “carefully stored in a refrigerator that was not defrosted.” Consequently, for many years the name of “fridges” was attached to the mothers of autistic children, turning compassion into contempt (Donvan & Zucker, 2017, p. 89).

¹ The researchers include Melanie Klein, author of the separation-individualisation disorder theory, where autistic behaviour is the result of abnormal and “cold” parental care, particularly the mother; Tustin Francis, author of a theory of the cause of autism in the premature loss of the symbiotic relationship with the mother; and Tinbergen Niko, author of the theory that autistic behaviour occurs as a reaction to the severe anxiety felt by the child as a result of insecurity in the relationship with the mother (Pietras & Witusik, 2010, p.102).

² At the First Congress of the National Association for Autistic Children in San Francisco on 17 July 1969, Leo Kanner said: “I would like to state here that I acquit you as parents. I have been quoted falsely many times” (Kanner quoted in Brauner & Brauner, 1988, p. 218).

The most frequently cited researcher, a strong supporter of the theory that mothers are to blame for the emergence of autism in their children, was Bruno Bettelheim. Interestingly, he was neither a psychologist nor an educationalist by training (he held a doctorate in art history). Accidentally, he became an authority on autism, not least through a book he wrote in 1967 entitled *The Empty Fortress. Infantile Autism and the Birth of the Self*. The text was written as a guide to the strange world of autism. Bettelheim detailed the cases of the children in his care at the Orthogenic School. He described the children's behaviour as clues to help the reader understand why these children choose to escape reality. This publication became a key position to prompt readers to negatively label mothers as the cause of the "empty fortress" in the child.

In the spirit of negative connotations, social campaigns have been organised by foundations and associations that bring together parents and that are dedicated to finding the causes and treatments for the autism spectrum. One campaign was accompanied by the text: "Autism is the enemy. Autism takes children away from their parents. Autism destroys society. Autism causes families to break up."³ Such campaigns aimed to draw public attention to the problem of diagnosing autism, but there is a risk that many people who do not deal with the spectrum on a daily basis may treat their slogans literally, that is, misunderstand the message of the campaign authors. Thus, an image of a family with autism is built on the basis of a few words, or, as in the case of Hollywood films, a few scenes created to enrich the storyline, which have little to do with the "real" life on the spectrum. In this case, the saying that it does not matter whether people speak well or badly—it is important that they speak, is a threat to the true face of the spectrum for autistic persons but also their immediate family.

Unfortunately, the myth of the mother being responsible for the child's autism also operates today. A 2004 study by Katarzyna Markiewicz on psychology students' knowledge of the causes of autism indicates that among the respondents as many as 34% believe that the cause of autism is lack of parental love, especially from mothers. As many as 32.8% suspect the presence of personality disorders in the parents themselves, while 16.4% of the respondents believe that the cause of autism are poor parenting attitudes. Thus, although the concept of frigid mother guilt was debunked as early as the 1960s and 1970s, it still finds its promoters and people who relate to it in a sympathetic manner.

³ "I am Autism, Autism Speaks" campaign in 2008 (Drzyzga-Lech, Kleczek & Ir, 2021); a similar event was the 2007 campaign of the Children's Research Center at New York University: "We have your son. We're going to make sure he can't take care of himself or interact socially for the rest of his life. This is just the beginning. Autism." The campaign was accompanied by billboards with, among other things, the above text, which was entitled "A letter from the kid-nappers" (Donvan & Zucker, 2017, pp. 504-505).

3. The mother of a person with autism spectrum disorders in everyday life— the perspective of the mother and the society

Motherhood in the context of a child's disability is called “difficult motherhood” in the disability literature. The disability of the new-born child can, to a certain extent, slow down or even in some cases stop the process of self-realization as a mother and provoke a lack of acceptance of the child and the new situation. The lack of acceptance and the rejection of the thought of the diagnosis, and at the same time the emerging sense of injustice, can cause a crisis or even a shock, and these feelings can sometimes last for several years and have a destructive and traumatic effect on the woman (Kościelska, 1998). In addition, the mother often has to give up her ambitions, plans for her life and her dreams for her child's future. Thus, for her it means a change of perspective regarding her whole life situation. According to Anna Zalewska (1999) and Małgorzata Kościelska (1998), women affected by “difficult motherhood” feel as if a part of their “self” has been destroyed and they cannot find their new identity. Instead of becoming mothers and enjoying their new role, they assume the position of disability experts. As Aleksandra Maciarz (2004) points out, the assessment of motherhood itself “is usually made through the prism of the health and development of her children, their academic and behavioural achievements” (p. 16). Thus, in this context, the child's disability becomes the basis for an often negative social evaluation of both the child and the mother. In a similar vein, Ewa Pisula (1998) writes that “[w]hile in the case of physical illness or death, compassion and help from those around is a matter of course, in the case of a mentally handicapped child people are unable to talk openly about the problem and support the parents” (p. 25).

The texts analysed in this article were selected on the basis of literature search available on the Polish publishing market. Nowadays, disorders from the autism spectrum are described not only in the literature on the subject but they increasingly appear in books aimed at a wider audience. Initially, 11 books were examined, of which 5 were used for this particular analysis. The selection was dictated by the emerging keywords: autism spectrum, mother, social exclusion, everyday life and the date of publication, i.e. the last 3 years. One publication is from 2012 and was included due to its reportage nature. The publications selected for analysis present the quintessential struggles of a modern mother of a child with an autism spectrum disorder; these are stories that are true, unvarnished and aimed at readers who do not deal daily with the spectrum but also those at the beginning of their journey due to the arrival of a child with a disorder in the family.

The publications analysed in the context of the public perception of the mother of a child with autism spectrum disorders, in the narratives of these mothers, often sound as follows:

Let this mother not deviate too much from the image, and if she dares to break the elaborate portrayal of an angel in a skirt with the face of a sufferer and the seriousness of a blessing, we will judge her. Society is entitled to give an opinion: such children should go only to the institution. But she, as a mother, does not have the right to say that—because of what kind of mother she would be. (Zalewski, 2012, p. 115)

In addition to the image attributed to the mother of a child with a disability, there are still opinions in the society about mothers' guilt: "Another visit to the neurologist and the doctor's statement: 'She is fine. It's all because of you, you're an over-theorised teacher'" (Niklewska, 2020, p. 29).

Constantly under pressure from society's perception of their children's disabilities, mothers struggle with many aspects of exclusion. The disability of children with autism spectrum disorders is often described as invisible: due to the lack of changes in outward appearance, the child's disability cannot be seen "at first sight." The phenomenon of "invisible disability" can be extremely oppressive for parents. It often causes exclusion, to which the parents themselves lead, anticipating, as it were, the social reactions when the person standing next to them nevertheless realises that they are dealing with a child with autism. The mothers themselves say: "Children and young people with visible disabilities evoke empathy in us. Fit and healthy but behaving atypically arouse surprise, mockery and often anger and indignation" (Hołub, 2022, p. 221), or: "I kept hearing: you can't see anything from him, he'll grow out of it, you'll see. This is the perception in Poland—a disabled person is a person in a wheelchair, with obvious physical defects. And if you can't see it, there's no problem" (Zalewski, 2012, p. 127); "Disabled—then let him be in a wheelchair, at least let him look weird!" (Zalewski, 2012, p. 77), while when "[p]eople on the street see a boy fluttering his arms[, they] automatically take a step back" (Zalewski, 2012, p. 107). "The invisibility of autism" is also a stigma of supposed responsibility for disability. There is

a certain "problem," which is the invisibility of autism. It is a fact, autism is invisible, without physical dysfunction. Parents therefore do not elicit pity, while they are indeed exposed to many comments. Here, in small towns, I think their background is more often faith and religion. I refer to opinions like "She's so smart, he's so smart, and they have THIS child. Well, God doesn't choose..." (Zalewski, 2012, p. 107)

Due to such a difficult definition and perception of disability, and society's perception of the child's "naughtiness," most mothers often succumb to the accepted image and take on the stigma of "the guilty one." Almost every mother describing her situation in the publications analysed experienced a moment of blaming herself for her child's disability: "I wanted to determine the causes of what happened. I started by completely unjustifiably blaming myself as co-responsible for Ola's autism. Since this was the case, I must have 'failed' something" (Niklewska, 2020, p. 31). In another case, the narrative is even more

blunt: “I was cruel and ruthless to myself, I burdened my psyche with a monstrous sense of guilt” (Niklewska, 2020, p. 32). Unfortunately, in none of the cases described did the mothers receive adequate specialist support.

Importantly, the mothers themselves often reach the point where they are able to gain distance from their own role—that of the mother of a child with autism:

I learned to relax. I started to “allow” myself time for myself and my own pleasures. Before, I also relaxed sometimes but only theoretically. Sitting in the cinema, I thought I had no right to be there because I should be helping Ola. I realised for the first time how much I was “pasting” myself. It came to my consciousness that you cannot truly love anyone if you treat yourself so cruelly. (Niklewska, 2020, p. 93)

The mothers need a lot support and understanding, but they often have to come to a point in their lives completely on their own where they can coexist with autism, while being aware of their family’s “otherness.” Urszula Klajmon-Lech points out that

[t]he sense of otherness does not only affect the affected persons themselves, but also (and sometimes even more so) their loved ones. They feel cheated (by fate, by God, by themselves), they experience a sense of guilt, they painfully experience the lack of acceptance of their own child, but also of their own family by society. (2017, p. 268)

Numerous scientific publications have been written on the topic of stigma in the context of intellectual disability and the autism spectrum. In contrast, the phenomenon of transference stigma has not been discussed extensively and is a relatively neglected area of special education. It is a complex and multidimensional phenomenon; therefore, it is difficult to capture precisely and unambiguously. Transferred stigmatisation involves the extension of the stigma from the individual directly affected to the associated environment or person. According to Erving Goffman, “when an individual is associated in the social structure with a stigmatised person, the environment may treat him or her in the same way as the stigmatised person” (2007, p. 33). Thus, those who care for a sick, disabled or disturbed person—a spouse, siblings or extended family—are exposed to transferred stigma. Transferred stigma is most often analysed in relation to the broader family/caregiver of a person with disability or chronic illness, without identifying specific family members. It is then referred to as “family stigma.” This stigma is usually defined through the lens of three dimensions: carer stigma, structural stigma and social stigma, which reflect the intrapersonal, interpersonal and social aspects of stigma. The above dimensions are characterised by three main elements: cognitive attributions (related, for example, to the appearance or severity of the illness), emotional reactions (positive and negative emotions) and behavioural responses (i.e. reducing direct involvement in care and hiding it). These elements reflect a process where ste-

reotypes or cognitive attributes lead to emotional reactions and later to behavioural consequences. Families raising children with explicit or less explicit disabilities repeatedly experience family stigma. Transferred stigma, according to Stanisława Byra and Monika Parchomiuk (2014), is observed in individual family members in three contexts: 1. the very relationship to the person stigmatised because of the disability or illness experienced; 2. the care exercised in relation to a family member burdened with a discreditable attribute; 3. the conscious choice of a partner possessing socially stigmatised attributes. (2014, p. 33). These contexts are part of the difficult everyday life of families of persons on the autism spectrum: “‘Autism is a thousand-fold challenge,’ ‘One child, and it’s like having four,’ ‘Maybe you need a psychologist?’, ‘As much work as with twins’—how many times have I heard sentences like this... Interestingly, mostly from doctors” (Pyszny, 2023, p. 79). It is therefore possible to move beyond the stigma by recognising the mother’s hardship. However, such a way out is only partial, because apart from sympathy and enigmatic words of support, the mother is still left alone with her daily struggles. Her transferred stigma is a huge challenge not only to her psyche, but also to her mundane physical endurance.

4. Diagnosis of autism spectrum disorders as anti-exclusion: through the eyes of the mother

The moment of receiving a diagnosis is socially associated with a disintegration of the previous life, defeat and despair, because the family receiving the diagnosis faces many difficult decisions and dilemmas. Above all, it has to cope with accepting the otherness of its new member and the changes that are and will be taking place in the existing functioning of the whole family. In fact, in many cases the situation at the beginning of the life with a child with a disability is often critical, but usually with time one comes to terms with this state and accepts a specific model of life, creates one’s own model of upbringing, recognizing the capabilities and limitations of one’s child (Minczakiewicz, 2010, p. 81).⁴ On the other hand, analysing the narratives of mothers of children on the spectrum, a different, optimistic tendency can be discerned: “We went there (the counselling centre) to get this diagnosis, not to hear that our son does not have autism. We went to find out what we could do” (Zalewski, 2012, p. 19). Another mother states: “This may sound strange, but when I found out it was autism, I was happy. It was like a stone had fallen from my heart. Finally I knew what was wrong with my child, I could try to help him” (Hołub, 2022, p. 26) and yet

⁴ Twardowski (1995), among others, has written about the moment in the life of parents when they find out about their child’s disability, dividing this period into different phases of parental adaptation to disability: the phase of shock (emotional shock), emotional crisis (despair, depression), apparent adaptation (use of various defence mechanisms), and constructive adaptation.

another writes: “I finally knew for sure what was wrong with Ola—she has autism. I felt relieved and somehow reassured, I was beginning to understand something” (Niklewska, 2020, p. 44). The diagnosis itself, therefore, became a point in life that was not bad or depressing, but a pivotal moment in a positive sense—it gave the parents the knowledge what to do next. One mother even wrote that:

When we got the diagnosis, I felt like my heart was breaking into a thousand pieces. [...] I had never felt such pain. I understood that for 16 years, without realising that my son had Asperger’s syndrome, I had tried to force things on him that were beyond his strength. (Hołub, 2022, p. 179)

Others wrote that “The diagnosis was a magic paper, a pass to let you go” (Michalczak, 2023, p. 44), and that “Relief that what is happening has a name, fits into some kind of framework” (Zalewski, 2012, p. 43).

However, when news of receiving a diagnosis reach outside the immediate circle, some unwarranted and erroneous stereotypes continue to operate in social groups not directly related to the disorder:

Autism. Six letters lumped together in one word that don't tell me anything. They are so random... I cry all night. A colleague asks in the morning at work what happened. An avalanche of stories follows. “And do you know what psychologists do when a child with autism comes to them?” she asks. “They congratulate the parents because, after all, these children are often little geniuses.” (Pyszny, 2023, p. 28)

People with autism are often thought to have some kind of exceptional ability or at least a high intelligence quotient. This is one of the most common misconceptions about the autism spectrum. Another is the belief that it is a problem of parental inefficiency and therefore the child’s “naughtiness.” It should definitely be noted that autism is not a parenting problem or the result of inconsistent parenting attitudes, and such opinions strongly discredit and build misconceptions about everyday life with autism.

5. Conclusions

The discourses of exclusion in the case of mothers of people with autism spectrum disorders can concern multiple aspects, from social exclusion in a broad sense to individual exclusion, but also self-exclusion. Mothers struggle with reacting to other people’s opinions but also have to face their own emotions and unfulfilled expectations of their children, for example: “I had the belief that if you give someone everything you have that person responds in exactly the spirit we expect. It was an expectation full of hubris. It had nothing to do with what I, as a mother, got” (Michalczak, 2023, p. 50). The contemporary world is not yet quite open to understanding the everyday life of families of people with disabilities. Although it is increasingly common to find popular books that talk

about autism “from the inside,” the audience for these texts is quite limited, and the stereotypes and beliefs regarding disability and autism are built on rather superficial knowledge. The publications in question, however, give hope that, through their truthfulness of the narrative, they will make “ordinary” people want to talk to each other, cause amazement but also a desire for appreciation on the part of mothers/parents because the more acceptance, understanding and praise they receive, the more strength and energy they have for their children.

Autistics and their mothers do not need pity and sympathy—they need a space without exclusion because, as Temple Grandin said, “If I could stop being an autistic person, I wouldn’t choose to, because then I wouldn’t be myself” (Grandin in Sacks, 1999, pp. 210-211). Homplewicz writes that “[a] mother’s love and a father’s love are to a child as the sun and the earth are to a plant: it is impossible to exist without either of them—the plant then dies and the child falls into internal disability” (2000, p. 70). It is therefore worthwhile, in line with the spirit of autism self-advocates, to abandon the medical model, in which autism is “what you have,” in favour of an identity model, in which autism is understood “as what you are” (McGuire & Michalko, 2011). Such a transition will definitely benefit autistics themselves, as well as their immediate families and, consequently, society as a whole. On the other hand, talking out loud about everyday life, analysing and pointing out paths that have already been discovered and blazed by other parents, is an extremely important element of support for families where a child is born on the spectrum. And pointing to publications that describe real-life situations and events becomes all the more credible. Perhaps it is worthwhile to reach for biographies and autobiographies, in addition to using scientific publications, when teaching the public about autism to understand the disorder “from the inside.” The very title of the book by autism self-advocate Naoki Higashida, *The Reason I Jump*, prompts the search for answers.

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