


The Experiences of the Families of Individuals on the Autism Spectrum During the Pandemic: A Study of Neurodiverse Individuals and Their Caregivers in the Context of Anomie Caused by the Global Health Crisis¹

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Abstract: The health crisis triggered by the COVID-19 pandemic temporarily suspended many of the existing rules and principles of the social order. This crisis can be described as social anomie. In this article, we explore the coping strategies of persons with disabilities in this state using the example of the families of individuals on the autism spectrum. While the neurodiversity of people on the spectrum is associated with adaptation difficulties and a low tolerance of change, the outbreak of the pandemic introduced abrupt changes in the functioning of institutions, the trajectories of daily life, and existing routines. The analysis of in-depth interviews conducted among parents of children on the autism spectrum shows how, in the face of radical changes in their external conditions, caregivers adapted the available measures to the developmental needs of their children and other family members. In the face of an anomic social order, innovation turned out to be the dominant coping strategy.

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Introduction

Although three years have passed since the outbreak of the greatest health crisis in modern world history, the issue of the COVID-19 pandemic is still widely discussed in both the media and scientific literature. This is because the political, economic, and psychosocial consequences related to the pandemic have led to numerous crises, not only in terms of public health protection (Bloom, Cadarette, 2019), but, more importantly, they have taken a toll on the physical and mental health of many people around the world (WHO, 2022). The experience of everyday life in the early stages of the pandemic in the spring of 2020 is associated with a sense of anxiety, danger, and a loss of control. The restrictions and requirements implemented – together with the temporary lockdowns and reinforced by fear-inspiring media reports on the dynamics of the spread of the SARS-Cov-2 virus – escalated feelings of dread and helplessness. A disease on a hitherto unknown global scale, one affecting people in all countries around the world and uncontrollable by any available medical means, entailed the destabilisation and disorganisation of social life. The most common restrictions during the first wave of the pandemic included the closure of workplaces and cultural and educational institutions until further notice, as well as restrictions on tourism and compulsory isolation. Such widespread limitations on a large scale, as well as the fear of the possibility of becoming ill and dying, or the spectre of a post-pandemic economic crisis and an uncertain future, engendered a range of different attitudes

(Motyka, Al-Imam, Aljarshawi, 2020). The repercussions of the experiences of that period can still be seen in everyday life, perpetuated as a cultural and collective trauma (Długosz, 2021). The outbreak of the pandemic disrupted the existing order of everyday life and introduced sudden changes, making it impossible to maintain previous routines. We can therefore assume that the pandemic contributed to anomie, understood as the disintegration of the social order, when “learned habits and routines [...] lost their sense” (Bauman, 2007). While such a state caused difficulties for everyone, individuals on the autism spectrum and their families felt it more acutely (Genova, Scavarda, Świątkiewicz-Mośny, 2023). In this article, we show the anomic reality from the perspective of the families of people on the autism spectrum and attempt to identify what strategies were employed in adapting to the challenges of everyday life during this period.

The pandemic as a trigger for anomie

In world history, epidemics and wars have frequently changed the fate of humanity, each time leaving devastation in their wake. They were often documented by artists who tried to sensitively convey the consequences and scale of the chaos caused by the crisis they provoked. Pieter Bruegel, in his painting titled *Triumph of Death*, depicted the medieval struggle of people plunged into absolute destruction (Friedlaender, Friedlaender, 2020). This work is still one of the most recognisable thanatology depictions in the history of painting. The first great European epidemic served as the background for Giovanni Boccaccio's *Decameron*, considered one of the greatest works of literature. The motif of smallpox devouring societies also appeared in other books, such as *A Journal of the Plague Year* by Daniel Defoe, or in Albert Camus' famous work *Plague*, which literally and symbolically charts the drama of the plague understood as a time of social turmoil (Abram, 1973). The scale of events related to the COVID-19 pandemic that swept the globe at the beginning of 2020 is different from that in the works mentioned above, but the chaos it caused in the world at the dawn of the 21st century allows us to analyze this period through the prism of anomie, understood as the incoherence of the axionormative system.

The etymology of the word ‘anomia’ derives from Greek, where *a-* means “without” and *nomos* “law”. Thus, anomia, read literally, means ‘normlessness’. The pandemic called into question the existing legal order, forcing suspensions, modifications, and amendments. The previous rules could not always be implemented during such a health crisis. This sparked a sense of uncertainty, instability, and a breakdown of the social order, with hitherto prevailing norms incompatible with the new reality (Garfield, 1987).

Anomie and social disorganisation, according to Emil Durkheim, is a natural consequence of rapid social change (both progress and regression). The spread of the SARS-Cov-2 virus evoked and forced adaptations to new conditions. Changes occurred with unusual speed, challenging the normative stability (Durkheim, 2011). According to Emil Durkheim, anomie can be regarded as either a disruption of harmony and social integration in a given population, or as a lack of norms in the sociocultural structure. At the same time, the author noted that the intense changes affecting society produce

a series of new problems. The effect of these changes is the loss of control over individuals. This is because anomie frees them from normative obligations and creates space for the realization of their individual aspirations. In the long term, this results in the atrophy of social bonds and threatens to make individual social actors more selfish, as the individuals gradually lose the ability to realize the expectations placed upon them (Durkheim, 2012). The reality of the pandemic corresponds perfectly to this characteristic, building a tension between the social and the individual, between the public and the private (Zdun, 2020).

The answers to the turmoil of the pandemic can be found in the theory of Robert K. Merton, who insisted that the so-called deviant behaviours, resulting from anomie, should not be subject to evaluation. This primarily refers to situations where “culturally defined goals” are no longer matched with “the institutionally appropriate modes of attaining these goals” (Merton, 1982). This unleashes adaptation strategies that can take the form of conformity, ritualism, innovation, retreatism, and rebellion (Merton, 1938). Mertonian deviancy is not necessarily pathological, but often leads to positive outcomes. This can be seen in the context of the COVID-19 pandemic, which became an accelerator for change in many areas of society. Some of these have proved to be positive, making everyday life easier or more efficient.

Since the beginning of the pandemic, messages on public health and COVID-19 have been aimed at modifying the lifestyle choices of individuals in order to flatten the disease curve. New rules emerged that simultaneously became institutionally-accepted norms. During the pandemic, previously known personal hygiene practices took on a new form, resembling a ritual of purification and control. These redefined practices were often at odds with those from before the pandemic, e.g. pre-pandemic face covering meant hiding and aroused suspicion, where forced face covering during a pandemic meant being responsible. Similarly, the pre-pandemic norm of maintaining social relationships and the values behind them was replaced by the need to isolate and retain social distance during the pandemic. As the pandemic continued and restrictions persisted, parts of the population challenged the newly-established rules and accepted norms (Powell et al., 2021), finding new adaptation strategies.

The analysis of the three months following the detection of the first case of COVID-19 infection in Poland makes it possible to understand the scale of the social disorder entailed by the chain of successively announced, introduced, reviewed, and ultimately lifted restrictions (Appendix 1). First, there was the closure of educational institutions and the introduction of distance learning, followed by the gradual closure of other places (sports facilities, cultural and entertainment centers, shopping malls, mega stores), which forced a reconstruction of the existing social norms and practices. Organized forms of activity outside the place of residence determining the daily life of individuals and their social interactions in all age ranges in public were reduced, suspended, or closed.

Functioning in most areas of life, including work, care, and educational institutions, required redefinition, as previous settings and approaches were inaccessible or, due to the new conditions, beyond reach. The legal framework of the pandemic recommended that, where possible, the implementation

of professional roles should take place at home. For some, the resulting changes in family life or in the labor market led to a loss of stability in their roles (Frąckowiak-Sochańska, Mroczkowska, Kubacka, 2022). According to the Public Opinion Research Center surveys from this period, one in four people or someone in their household lost their job due to the epidemic (24%) or worked fewer hours (24%). Women (27%) were more often affected by such changes than men (21%) (CBOS, 2020d).

The implementation of compulsory education according to the scenario known to date was impossible, and being a teacher, pupils, or parents, and interacting in this triad, required a complete reorganization in the new virtual reality. While bell-regulated time management in classrooms was impossible, in the pandemic school, the computer – until then used mainly in computer science classes – became an indispensable asset in teaching and learning. However, as indicated by one in three parents surveyed by the Librus Rodzina portal ($N = 20,989$ parents of pupils from more than 6,500 schools using the Librus electronic gradebook), the devices necessary for distance learning were shared by several users at home. In addition, limited space at home was often shared between those attending school and those carrying out professional duties. At the same time, the responses of nearly half of the surveyed parents, collected at the beginning of April 2020 (1st–6th), suggested that none of their child's teachers had delivered lessons by video-meetings. Almost one in four parents (17%) responded that at least half of their child's teachers delivered lessons remotely in this way. Other teachers used worksheets (72%), videos (63%) or e-books (47%). The shift of teaching from school to home entailed a reorganization of parental time. Almost one in four spent four hours or more in April 2020 supporting their youngest child with remote learning (Librus Portal, 2020). The cited data illustrates the disorganization of the lives of Polish pupils and their parents in the first months of the pandemic. The experience of such changes was associated by many with a deterioration of their health, including mental well-being (Pyżalski, 2021). The effects of the crisis were discernible in all social groups (CBOS, 2020d). However, for neurodiverse people with adaptive difficulties, with their low tolerance of change, need for repetitive situational conditions for feelings of safety, and lack of institutional support for their carers during this period, the pandemic meant addressing further challenges (Prokop-Dorner, Ożegalska-Łukasik, Świątkiewicz-Mośny, 2023).

Autism and family life

Autism spectrum disorder is classified under the category of neurodevelopmental disorders (DSM-V, ICD-11). They manifest themselves as difficulties in areas related to social communication (e.g. limitations in understanding, interest, responding to incoming messages), social interaction (e.g. problems in establishing social relationships, verbalizing emotional states), and age-inappropriate behavioral or interest patterns (e.g. inability to adapt to new circumstances, excessive compliance with rules or hypersensitivity to sensory stimuli). Autism spectrum disorder is usually observed in early childhood and its symptoms of varying severity define individuals' daily lives in many areas, i.e. education, work, family life, and social engagement. The functioning of families with children with autism spectrum disorders is sometimes subordinated to the need for therapy and revalidation. Despite the

increasing number of individuals being diagnosed with autism spectrum disorder and the growing availability of informational campaigns and educational initiatives about autism, families still struggle with a lack of understanding (Pawlikowska, Maciejewska, 2018). These families must face criticism of the child's non-standard behavior and their child being treated as a misfit, seek social acceptance and, eventually, cope with loneliness (Tsirigotis, Lewik-Tsirigotis, Dydyna, 2012). The experiences of families raising a child with autism spectrum disorder are frequently linked to anxiety, stress, confusion (Komender, Bryńska, Jagielska, 2009). Autism is recognized as one of the more difficult developmental disorders for families (Tsirigotis, Lewik-Tsirigotis, Dydyna, 2012). Children on spectrum look similar to their peers, but their behavior differs significantly from what is considered typical. They develop all the difficulties that are associated with discreditable stigma (Goffman, 2005; Świątkiewicz-Mośny, 2010; Mitter, Ali, Scior, 2019) and courtesy stigma (Prokop-Dorner, Flis, 2021).

Parents and carers of children on the autism spectrum often experience difficulties in meeting their needs. These needs concern both the basic level (e.g. those related to ensuring safety) and the higher ones related to self-realization (parents often give up their passions or careers) (Tsirigoti, Lewik-Tsirigotis, Dydyna, 2012). The emotional and social difficulties accompanying families on a daily basis compel the search for solutions and adaptation strategies. The solution-seeking process in the case of those on the autism spectrum is dynamic and stretched over time. Families learn to stay ready for change and show great flexibility. This is necessary, because the spectrum characteristics change with age, some disappearing and new ones appearing (Łukowska, Urbanowicz, 2020). Uta Firth notes a relation between characteristics resulting from the autism spectrum and processes connected to individual's development, so it can be concluded that autism affects development and development affects autism (Firth, 2008). The diversity of individuals on the spectrum also presents challenges to adaptation – everyone is different, so adaptation strategies also need to be individualized (Popek et al., 2015; Attwood, Garnett, 2020).

Research on families with children on the autism spectrum during the COVID-19 pandemic has been conducted by numerous research teams worldwide. For the most part, these are small-sample studies focused on particular aspects of the functioning of individuals on the spectrum and their relatives, carried out under specific conditions related to pandemic constraints and within a specific time discipline. The available systematic reviews of studies on this subject (Alonso-Esteban et al., 2021; Dal Pai et al., 2022) show that, although the findings differ due to variables such as the age of individuals on the spectrum, the family type, and the intensity of spectrum characteristics, most of them emphasize that the consequences of the pandemic were an experience of crisis for many families.

The functioning of families of individuals on autism spectrum has been correlated with impaired child functioning (Tokatly Latzer, Leitner, Karnieli-Miller, 2021) and higher levels of parental stress (Isensee et al., 2022). The results of a comparative study suggest that pandemic-induced habit change was more frustrating for children on the spectrum than for typically developing children (Hosokawa et al., 2021). Data collected in different cultural contexts indicate an increase in the frequency of difficult situations for children on the spectrum during the pandemic. Their parents reported more

aggressive and stereotypical behaviors during this time, as well as hyperactivity and the impaired communicative competence of their children (Mutluer, Doenyas, Genç, 2020). This had an impact on difficulties in organizing their leisure time (Colizzi et al., 2020). The study by Cristina Mumbardó-Adam, Silvia Barnet-López and Giulia Balboni (2021) also speaks of “quality” time. The authors mention that, in addition to the difficulties in adapting to the changed habits, the surveyed Spanish families perceived benefits from learning new abilities such as autonomy- and house-care-related skills. They also valued the time spent together and more frequent interactions (Mumbardó-Adam, Barnet-López, Balboni, 2021). In turn, reports from Germany and Austria show an increase in the psychopharmacological medication of children (Isensee et al., 2022). The tension and anxiety of carers was largely due to unexpected changes in the availability of educational and therapeutic services, as well as the parental sense of incompetence in having professionals take over in these areas. A study of Israeli families demonstrates carers’ sense of powerlessness in the face of the numerous adverse health consequences that the pandemic restrictions entailed and difficult emotions related to their inability to maintain previously typical patterns of functioning (Tokatly Latzer, Leitner, Karnieli-Miller, 2021). It is also worth mentioning that the dynamics of family life changed, with some studies highlighting an escalation of intra-family conflicts (Isensee et al., 2022).

Methodology

The aim of the study was to describe the experiences of families of individuals on the autism spectrum and to explore the challenges they faced during the COVID-19 pandemic. Exploring the experiences of these Polish families, we focused on understanding their perception of the multidimensional changes, the adaptation process, and the ways in which roles and internal relationships between family members and external contacts were reorganized (Flick, 2010). The description of the adaptation to the sudden change in living conditions resulting from the pandemic was intended to help us to categorize the ways of reacting to the collapse of the axionormative order using Mertonian types of coping with anomic reality.

We conducted individual in-depth interviews (Kvale, 2010) to explore the experiences of the families of individuals on the spectrum. We contacted representatives of pre-identified NGOs and diagnostic, rehabilitation, or educational institutions working for people on the autism spectrum and their families in southern Poland by e-mail. In addition, we used the snowball sampling technique. In this way, we recruited individuals who, due to their role as family carers and/or professional work, accompanied young persons on the spectrum during the pandemic. In order to obtain an as accurate view as possible on the situation of families, we used a triangulation of interviewees (Denzin, 2006) – parents of children on the autism spectrum and professionals working with families of people on the spectrum. Based on the criterion of expertise and professional and/or personal experience, we intentionally selected a sample of experts associated with different types of institutions: psychological-educational counseling centers, therapy centers, schools, and NGOs dedicated to autism. Several of the interviewees combined the experience of caring for their own child on the spectrum with being

a professional or an activist in NGOs. A total of 9 women and 1 man participated in the study (Table 1). This sample, although imbalanced by gender, reflects a much larger share of women than men taking care of their child on a daily basis (Główny Urząd Statystyczny, 2016; CBOS, 2018).

Table 1. Description of the study sample

ID.	Characteristics of the Interviewees
1	Mother of a teenager with Asperger's Syndrome; facilitator of activities for children on the spectrum and their families
2	Mother of several children, one of whom is on the autism spectrum
3	Mother of an adult with Asperger's Syndrome; facilitator of national activities for people on the spectrum
4	Mother of a child with Asperger's Syndrome; teacher supporting pupils on the spectrum
5	Mother of a teenager with Asperger's Syndrome; member of an organization for people with autism
6	Mother of two teenagers, one of whom is on the autism spectrum; member of an organization for people with autism
7	Father of a child on the autism spectrum
8	Psychologist specializing in the functional diagnosis of children and teenagers, working with children on the spectrum for 10 years
9	Psychotherapist working with children on the spectrum in state and private settings for 8 years
10	Support teacher; head of an inclusive school

Source: own elaboration.

We conducted the interviews either face-to-face or remotely, depending on the interviewees' preferences. They were carried out from December 2021 to February 2022, during the fourth wave of COVID-19. The interviews were conducted based on interview guides (for professionals and family carers). The interview guides focused on the experience of everyday life in the pandemic, the caring challenges arising from the implemented restrictions or their consequences observed in family life (family carers) or in the operation of an NGO (activists) or a diagnostic, rehabilitation, or education facility (professionals), and coping strategies.

The interviews were conducted by experienced qualitative researchers and their duration ranged from 30 to 140 minutes. All interviews were recorded and transcribed in the form of structured and detailed notes enriched with verbatim quotes of relevant passages. The data was coded deductively and then put into an analytical grid that helped organize the concepts discussed by the interviewees and foster comparisons between study participants (Miles, Huberman, 1994). By analyzing the experiences of the interviewees, we were able to identify patterns, which we then categorized

using the theoretical typology of strategies of adaptation to anomie. In this way, we developed an image of coping with anomie. We discuss it in detail below and provide illustrative quotes from the study participants.

Due to the social commitment of several of the interviewees, and to ensure their full confidentiality, we have limited the descriptions presented in Table 1 solely to information that is necessary to understand their situation.

Between ritualism and retreatism – study outcomes and their interpretation

The findings from the study allow us to conclude that the outbreak of the pandemic was a liminal moment for many families of people on the autism spectrum. This new and anomic reality required the use of different ways for carers and teachers of children on the autism spectrum to manage resources and goals.

The map of families of children with disabilities is defined by three main points: home, school, and therapy site (counseling centers, clinics). Parents asked about the pre-pandemic daily routine shared that, in order to provide optimum conditions for children on the spectrum, they had worked out schedules with rehabilitative, therapeutic, or sports activities over the years and sought to ensure their unwavering repetition. Resulting from the pandemic, the disruption of previous patterns of education and therapeutic activities, crucial to the well-being of children on the spectrum, eroded their sense of security. According to parents and professionals, the prolonged disruption of established “home – therapy – extracurricular activities” patterns contributed to the cessation of therapeutic progress or even its regression. Daily trajectories were suspended and required the development of new solutions. In the subsections below, we present the key components of the new maps of families of people on the spectrum, although the urgency of their sketching would rather suggest calling them “strategic survival drawings”.

“The biggest problem”

In the collected material, the statement “the biggest problem was remote learning” is repeated like a refrain. The implementation of online education in Poland took place under atypical conditions and neither schools and teachers nor pupils and their families were prepared for such a huge change (Ślusarczyk, Świątkiewicz-Mośny, 2023). The problem was not only a lack of computer equipment, but also a shortage of digital competences and distance learning methodologies. A common claim is that remote education had many negative side effects. The characteristic features of the autism spectrum (particularly those related to cognitive processes) posed an additional challenge that both pupils and teachers had to contend with. Teachers working with pupils with autism spectrum disorders indicated that the key obstacles included learning new material and dealing with peer relationships (Buchnat, Wojciechowska, 2020).

The study participants indicate that pupils on the autism spectrum reacted to the changing school realities in different ways, and that the diversity of their attitudes seems to correspond with the multitude of individual conditions of each person. Among the interviewees, there were some positive statements about the online classes, although negative experiences outweighed them. They reported that the remote learning environment was beneficial to children with auditory hypersensitivity. Isolated from the stimulating setting of the classroom, they had a greater capacity to focus and began to work better at home. A different experience was those of children and teenagers on the spectrum who found it difficult to focus their attention on lessons mediated by remote platforms. Most participating parents saw negatives in the first two months of online schooling. They observed a lack of adequacy of measures to meet the needs of their children. One of the mothers shared her belief that, like her son, the other pupils were only logged on and doing their best not to study (Interviewee_1). Similar observations on the effects of distance learning were provided by Marzena Buchnat and Aneta Wojciechowska (2020), noting the difficulty in focusing on the lesson and remembering new material. Also, the research by Joalanta I. Wiśniewska and Patrycja Jurkiewicz (2022) shows that remote education did not yield positive results for children on the autism spectrum. Difficulties in maintaining focus during lessons stemmed from numerous distractors. The need to control attention distractors triggered extreme emotions and caused fatigue.

Difficulties in remote education for children on the spectrum translated into new challenges for parents, who took it upon themselves to mediate between their child's abilities and an inadequate learning medium. The following is the experience from the first two months of the pandemic shared by Interviewee_2:

I couldn't work because I had to just sit with [child's name – authors], hold his hands, because he learnt all the keyboard shortcuts on the first day and was able to switch that lesson to something else that interested him more. He was so excited. And he also didn't really understand what was going on, so those first two months were exhausting for us, especially physically [...] (Interviewee_2).

Interviewee_6 highlighted the long-term consequences of the remote learning experience: "My son fell to pieces. I mean, we have a year and a half to catch up on". This view was reported by many parents but, in the case of children on the autism spectrum, "falling to pieces" is much more difficult to "fix". A break in therapy is usually regarded as regression, meaning that the pupil does not just pick up from where the pandemic and remote education began, but often loses skills and competences which they had already acquired.

Particularly important for people with autism spectrum disorders are consistent routines involving activities in fixed places. Outdoor recreation is an important mental-health-building element that the parents can use. For some of the families included in our study, the closure of green spaces and/or sports clubs became a major obstacle. Along with school and therapy, these were part of their children's regular schedule.

According to the analysis of the interviews with parents and professionals, changes in the implementation of compulsory education caused frustration and adaptation difficulties for children on the autism spectrum. However, some of the new practices regulated by the anti-COVID-19 policy met with their approval. Some interviewees emphasized their children's conformist adaptation to the new restrictions, e.g. wearing masks, disinfecting their hands or limiting the use of public transport. One mother explained that "persons on the autism spectrum like such rigid rules. Top-down prohibitions were good for [my son – authors]" (Interviewee_4).

Solitude in the pandemic

One loss from the pandemic which was highlighted by the parents and professionals was the lack of opportunities to strengthen the social skills of children and teenagers on the spectrum with their peers. Virtual contact was not an appropriate way to initiate or sustain interactions, and those pupils on the spectrum who changed schools during the pandemic were in a particularly difficult situation. Faced with remote education, they were less able to establish relationships that would have been challenging enough in even a traditional setting. The mother of a boy changing schools from middle to high school in 2019/20 spoke of the effects of two years of education fluctuating between remote and face-to-face classes:

[My son – authors] is now repeating "I don't need other people. I don't need them for anything. I'm not interested in them." He actually refuses any interaction with the class... I don't think it's depression, but maybe he adapted to such isolation. It's much more difficult for us at the moment to get him out of this state. The class has changed over the time, and he has dropped out of the company, functioning on the margins now (Interviewee_6).

The lockdown and dropping out of the active pre-pandemic routine fostered tendencies matching the typical person on the spectrum of social communication and interaction abnormalities. One of the interviewed mothers, who co-ordinates integrative classes for people with autism, observed less interest in the provided workshops. Her classes were the only ones available for some time in the area. She could see from her son that: "he was very comfortable sitting at home and studying remotely. Going out was already a problem. And so were other children of a similar age – they were not very keen to go out either" (Interviewee_1).

The initial phase of the pandemic was particularly hard on the families of individuals on the spectrum, not only because of the sudden suspension of the existing routines, but also due to the lack of any support. This experience was shared by others, particularly by those caring for dependants (children, sick people, people with disabilities). One mother recalled: "we were left on our own in that hardest moment – those first two months when restrictions were so strong that we couldn't see anyone" (Interviewee_2). Similar observations are made by Jolanta I. Wiśniewska and Patrycja Jurkiewicz (2022). The interviewed parents of children on the spectrum from the Mazowieckie Voivodeship emphasized that their situation was very difficult. Such families experienced isolation

and loneliness, in some cases consequently leading to emotional crises or depression. Some of the participating parents in our study, due to the caregiving burden, had to resign from work or social activities. The interviewed father referred to the period of illness as the most challenging moment in pandemic family life. The necessary hospitalization of one of the parents, in addition to the stress resulting from the crisis in the healthcare system, entailed the need for the other parent to take over all of the round-the-clock care of the children for an extended period. When describing the burden of the challenges of the period, he spoke of actions aimed at *surviving*.

Some parents regretted that there was no psychological support available to them. Taking on the numerous and varied roles of teacher, therapist, round-the-clock carer, and often full-time worker, plus facing illness and/or hospitalization, led to physical and emotional burnout. One interviewee said:

In this pandemic situation, we redirected our energy into making sure our children didn't break down, not thinking about ourselves at all. We didn't get any support, apart from what we had built up for ourselves over the years – for example, the opportunity to talk to another mum and find solace in the fact that she was in the same situation. We didn't get any psychological support, no one even asked us about it at all. I think we, as parents, got hit very hard too, it's just that maybe none of us thought about it, because the children are the most important thing for us. On the other hand, I definitely came out of it weakened and I can see from the mums I've made friends that they also came out of it more wounded. That psychological support for parents would have been useful (Interviewee _5).

Suspended rituals

Carers faced a multitude of pandemic difficulties alone, with previously developed social and institutional support networks having been suspended. The lack of face-to-face meetings proved to be very challenging. Gatherings with close relatives and friends were put on hold, as well as those within broader networks of acquaintances, neighbors, or support groups. A study conducted at the beginning of the pandemic on one of the largest Polish online communities for mothers suggests that virtual interactions became an important element for many parents seeking help with new challenges (Piłat-Kobla, Prokop-Dorner, Studencka Grupa Badawcza, 2022). The pandemic period also showed that the implementation of social practices that bring solace, e.g. participation in cultural or religious practices, is possible on communication platforms.

The first month of the COVID-19 outbreak was a time which saw the closure of diagnostic offices, as well as therapy and revalidation centers. As time passed and solutions were worked out, some of the facilities returned to operation but under a sanitary regime. This involved a significant rearrangement of many procedures (e.g. parents could not accompany their children to practice as before; child could not bring their own toys; the length of the consultation was reduced) and consultation rooms (e.g. removal of soft carpets, elimination of soft toys), which the children were familiar with and whose repetition gave them a sense of security. The virtual interventions introduced in some institutions

did not prove effective for young children and children at lower levels of intellectual functioning, causing difficulties in establishing contact or limited ability to concentrate on a tablet or computer screen. The professionals we interviewed reformulated their previous methods of working individually in their offices to working with the family in the home setting. One of them said this about her pandemic role: “In working with children and with people on the spectrum, it is important to support the environment, but at the time when this work was exclusively online, these proportions shifted to more time spent with the environment” (Interviewee_8).

A breakthrough in adapting to the pandemic reality was the regulation allowing children with a disability to attend school. This restored the possibility of pupils on the autism spectrum of returning to school and having direct contact with a support or particular subject teacher. However, it was a return to a deserted and quiet school building, with the space having had completely different functions before. It is worth noting that schools are usually clearly defined in educational terms – teaching and implementation the curriculum – rather than in social terms, e.g. building relationships with peers. The practice of opening schools to children with disabilities was common in many European countries, but some researchers detected the risk of pupils segregation (Genova, Scavarda, Świątkiewicz-Mośny, 2023). The interviewees in the study we conducted saw the advantages of such a solution.

Although in some cases the return to school was only on certain days of the week, the benefits perceived by parents were significant. One of the study participants mentioned with satisfaction that her son had one-to-one tuition with a support teacher. It turned out that returning to school for individual sessions was a good solution for him. The return of contact with the teacher was helpful in calming emotions: “everything was fine, better. He felt calmer when there were no children in school, just a few people coming there. There was no crowd. And he was somehow much calmer” (Interviewee_2). This contact also contributed to better learning outcomes: “he mastered the material from a 45-minute group lesson in 15 minutes” (Interviewee_2). Another study participant also emphasized that: “it was the best thing that could have happened to my [child’s name – authors] for that time, because he really didn’t lose those precious months, years, and I appreciate it very much” (Interviewee_4).

Summary

For Pieter Bruegel, the setting of a late medieval epidemic served to represent the more general issue of humanity in chaos. For us, the COVID-19 pandemic has become a picture depicting the experiences of the families of individuals on the autism spectrum. The disruption of the axionormative order in the reality of the pandemic disorganized educational and therapeutic institutions. This, in turn, translated into a breakdown of predictability and order, one particularly needed by children and teenagers on the autism spectrum. The sudden closure of educational and therapeutic institutions entailed the need for carers of people with disabilities to develop new strategies. The transition from pre-March 2020 working patterns to an imposed pandemic model, followed by a return to earlier practices, has left children and teenagers frustrated. Their difficulties in adapting to new conditions and limited

institutional support required parents to normalize the destabilized dailyness at the expense of their increased involvement. The taming of the pandemic threat, including the introduction of legal regulations and institutional measures, has primarily resulted in confinement of individuals with disabilities in their family homes and the delegation of additional work to their carers. The burden of round-the-clock childcare, including therapy or revalidation tasks, fell on parents.

In interpreting the experiences of families of people on the autism spectrum, we find Merton's theory of categorizing ways of responding to axionormative chaos to be particularly useful. Each of Merton's proposed responses to anomie allows us to reconstruct possible scenarios for families' adaptation to the pandemic reality. For example, ritualism could be the situation in which families who are attached to specific institutionalized measures invariably rely on them, disregarding the fact that their goals are not effectively met with their use – e.g. staying in remote therapy, which does not bring the expected benefits. Another type of reaction – namely retreatism – might occur when relatives withdraw from caring for a family member with a disability or from social life by remaining isolated and inactive. Rebellion could materialize, for example, in protests organized by caregivers who fought for a better regulation of the situation of their loved ones. As shown in our analysis, the change in the pre-pandemic order and the lack of support from external institutions led the interviewed parents to seek innovative solutions. Merton's innovative strategies for dealing with anomie are based on finding new means to achieve important goals. The data collected demonstrates that during the pandemic, not only caregiving, affective, and nurturing tasks, but also a significant part of therapeutic duties and dealing with manifestation of child's frustration alone constituted the parental role. The carers worked as instructed by the professionals, taking over their tasks. This situation was partially mirrored by the situation in schools. The pandemic forced a reformulation of the scope of the rights and responsibilities of education providers (Ślusarczyk, Świątkiewicz-Mośny, 2023). Parents joined in organizing pandemic schooling, which worked with hitherto "banned" media. Pupils could, or rather had to, use phones, tablets or computers, and parents took control of the school worlds (both the teacher's and the child's). Therapy-related innovations involved engaging parents, who were not always suitably qualified, to carry out such tasks.

The range of new challenges faced by the families of individuals on the spectrum during the epidemic also contributed to a revision of the previous perception of their material environment. Their home, which beyond its primary function became a space for the educational, therapeutic, and professional tasks of the whole family at once, often required rearrangement. Most interviewees spoke of changes allowing the use of necessary therapeutic devices, e.g. for sensory integration, or a new division of space between family members. Families with more than one house, in addition to their primary flat, benefited from the opportunity to move to a greener space, limited in the town area, or from the creation of spaces to stimulate new activities for their children.

The COVID-19 pandemic and its rapid course in its first few months caused emotional turmoil, which, along with consecutive epidemical waves was expressed more loudly and publicly. Expert knowledge, with its reassuring potential, became uncertain and volatile. Carers of children and teenagers on the

autism spectrum experienced a double blockage of a pandemic support mechanism: the closure of schools and therapeutic institutions compelled an even more individualistic orientation toward their children. Consequently, in the long term, it undermined the parents' ability to meet their children's educational and developmental needs in a high-quality way, including the development of their children's social competences and their own psychological well-being. However, the anomic reality also had a mobilizing power. In some cases, it "forced" the necessity to find the best strategy to manage the resources at hand in order to ensure the best possible functioning of the family. It is also important that the families of children on the autism spectrum, from an early stage of their development have to confront additional challenges. When seeking for the best educational and therapeutic solutions for their children and for the functioning of their family, parents face the necessity of being flexible and open-minded. The involvement of parents in the behind-the-scenes of therapeutic work during the pandemic will require greater transparency in the process.

A significant conclusion is to emphasize the importance of the resources held by the interviewees when confronted with the experience of the pandemic. Access to different types of resources turned out to be the main determinant of coping well with the anomie. The collected data enabled us to describe the patterns of the experiences of families living in big cities, associated with NGOs or using the educational and therapeutic services of state and private institutions. To fully understand the challenges of the families of individuals on the autism spectrum, further research is needed, taking into account the experiences of families with less social, economic, and cultural capital, and families in smaller centers. Finally, future research in this area should attempt to deepen the understanding of the challenges of caregiving and engagement in the therapeutic process from the perspective of fathers.

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Cytowanie

Anna Prokop-Dorner, Natalia Ożegalska-Łukasik, Maria Świątkiewicz-Mośny (2023), *The Experiences of the Families of Individuals on the Autism Spectrum During the Pandemic: A Study of Neurodiverse Individuals and Their Caregivers in the Context of Anomie Caused by the Global Health Crisis*, „Przegląd Socjologii Jakościowej”, t. XIX, nr 3, s. 96–115.
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Obrazy pandemii szkicowane doświadczeniem rodzin osób rozwijających się w spektrum autyzmu – badanie wyzwań dla osób neuro różnorodnych i ich opiekunów w kontekście anomii wywołanej globalnym kryzysem zdrowotnym

Abstrakt: Kryzys zdrowotny wywołany przez pandemię COVID-19 spowodował czasowe zawieszenie wielu obowiązujących zasad i reguł porządku społecznego. Kryzys ten można określić mianem anomii społecznej, czyli stanu zachwiania ładu społecznego oraz systemu wartości i norm, a także erozji więzi społecznych. W artykule opisano doświadczenia osób z niepełnosprawnościami w sytuacji anomii na przykładzie rodzin osób rozwijających się w spektrum autyzmu. Neuro różnicowanie osób w spektrum autyzmu jest związane z trudnościami adaptacyjnymi i niską tolerancją na zmiany, a wybuch pandemii wprowadził nagłą zmianę w funkcjonowaniu instytucji, zaburzył dotychczasowe trajektorie życia codziennego oraz uniemożliwił utrzymanie dotychczasowej rutyny. Analiza wywiadów pogłębionych przeprowadzonych wśród opiekunów dzieci w spektrum autyzmu pokazała, jak wobec diametralnych zmian warunków funkcjonowania opiekunowie dostosowali dostępne sposoby działania do potrzeb rozwojowych dzieci i pozostałych członków rodziny. Wobec anomijnego porządku społecznego dominującą strategią radzenia sobie okazała się innowacja.

Słowa kluczowe: anomia, pandemia, spektrum autyzmu

Appendix 1

Dynamics of the COVID-19 outbreak in Poland: restriction policy and public opinion on these events in Poland between 4 March and 2 June (split into 13 weeks).

Week I 4.03–10.03	Week II 11.03–17.03		Week III 18.03–24.03		Week IV 25.03–31.03	Week V 1.04–7.04	Week VI 8.04–14.04
4/03/2020 first person diagnosed with COVID-19 10/03/2020 ban on public events	11/03/2020 WHO declares a state of pandemic 12/03/2020 first death due to COVID-19 12/03/2020 suspension of schools, kindergartens and nurseries 25/03/2020 implementation of distance learning in all educational institutions 13/03/2020 introduction of the first restrictions: – ban on gatherings of more than 50 people – restriction of shopping malls – closure of gyms, swimming pools, museums, libraries and cinemas – limitation of the operation of restaurants to takeaway services		20/03/2020 declaration of an epidemic in Poland 24/03/2020 introducing further restrictions: – restriction of mobility to a minimum – restriction of the number of seats on public transport – participation in religious ceremonies up to 5 persons – ban on gathering in playgrounds and parks – recommendation of remote working “wherever possible” – increasing criticism of those who go outside		31/03/2020 introducing restrictions: – limiting the number of customers in shops to three per cash desk – introducing a “senior citizens’ hour” – closure of hotels – closure of hairdressing and beauty shops	2/04/2020 banning access to parks and forests	8/04/2020 the number of COVID-19 infections reached 5,000 8/04/2020 introducing compulsory wearing of masks in public places
Survey by the Public Opinion Research Center conducted between 5–15/03/2020: – 46% of Poles agree that the COVID-19 outbreak was something unprecedented; 48% think it was a seasonal illness, it was not something special, just blown out of proportion by the media, and 6% of interviewees had no opinion on the matter; – more than 60% were afraid of contracting coronavirus – a little (45%) or a lot (17%); nearly one in four were not afraid of contracting it at all (10%) or rather not afraid (27%). Of those fearful are women (66%); fear of infection was inversely proportional to education level; – 42% anticipate that an epidemic, mass coronavirus outbreak in Poland was only a matter of time; – 51% of Poles were convinced that the public health service in Poland was sufficiently prepared for a possible outbreak of COVID-19 coronavirus, not sufficiently prepared; 17% had no opinion; – due to the infectious nature of SARS-CoV-2, 57% of Poles had not made any changes to their daily practices at that time, while 43% had done so. Almost half of women had made changes (48%) (CBOS, 2020a).							
Week VII 15.04–21.04	Week VIII 22.04–28.04	Week IX 29.04–5.05	Week X 6.05–12.05	Week XI 13.05–19.05	Week XII 20.05–26.05	Week XIII 27.05–2.06	
20/04/2020 first stage of restriction lifting: – lifting the ban on access to parks and forests – minors under the age of 13 may travel without parents – increasing the limit of people who can shop at the same time – introducing the STOP COVID ProteGOSafe app that can “reduce the rate and range of the spread of the coronavirus”		4/05/2020 second phase of the lifting of restrictions: – reopening of libraries, hotels, shops and malls under sanitary regime		18/05/2020 third stage of the lifting of restrictions: – reopening of hairdressing salons, restaurants and cafés under strict sanitary regime – limited reopening of schools		30/05/2020 fourth phase of the lifting of restrictions: – removing the obligation to wear masks in open spaces – waiving limits on the number of customers in shops and restaurants	
	Survey by the Public Opinion Research Center conducted between 23–27.04.2020: – 59% of Poles agree that “the current coronavirus pandemic is something exceptional”. 32% of Poles agree that there have always been seasonal illnesses, influenza and other virus illnesses and the current pandemic is nothing special and is being inflated by the media; 9% answered that it is difficult to say (CBOS, 2020b).				Survey by the Public Opinion Research Center conducted between 22/05-4/06/2020: – 62% of adult Poles are afraid of contracting coronavirus, while 37% are not afraid of the infection. The proportion of people considering the current outbreak as “something exceptional” has increased, with more than half of those surveyed (52%) seeing the disease as something that current generations have not yet experienced, while more than two-fifths see it as one of many diseases (42%). – more than half say they are up to date and familiar with the current state of the law regarding restrictions and regulations related to the epidemic (54%), a further 40% estimate that they are more or less familiar with these regulations, 5% indicated that they are lost in the regulations. The vast majority of interviewees estimate that Poles comply with epidemic restrictions (79%). However, of these, only more than a quarter of interviewees (27%) believe that almost everyone complies with the restrictions, while more than half (52%) are of the opinion that the majority do so, i.e. not everyone complies with these regulations and applies them in practice. A further 17% of interviewees are even more critical and believe that many or even most do not adhere to the restrictions associated with the epidemic state (CBOS, 2020c)		