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A child's otherness resulting from disability. A phenomenographic study of adoptive and foster parents

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A certain percentage of disabled children are not raised in their biological families. It happens more and more often that the place of residence of such a child is not an institution but the adoptive or foster family. Increased prevalence of this type of families makes the study of this area of functioning of children with disabilities more and more important. The paper covers the issue of dealing with a child's difference by their adoptive/foster parents. The difference has its source e. g. in a disability. The empirical part of the article is the result of qualitative research conducted with parents from 20 adoptive/foster families that raise a child with a disability (this is a part of a broader research project conducted by the authors with these families). The analysis of the interviews shows the ways to discover the otherness, the difference of the child, the ways to accept this otherness, and the importance they ascribe to the otherness of the child.

KEY WORDS: adoptive / foster family, disabled child, difference, otherness

Facing the otherness of one's child can be a task both of biological, as well as of adoptive and foster parents. In this regard, one can find between them many common components, indeed, it can be assumed that most parents are party to certain experiences and events from the realm of parenting. In both cases, situations in which the financial situation (or the general living conditions) worsens, can arise, as every child within a family requires additional financial resources, and a disabled child even more so, in particular due to its special needs¹. The emergence of a disabled child in the family can lead not only to the reduction of its financial resources, but it can also impact its psychological resources and bring about social isolation². This situation is further exacerbated by the effects of the political transformation related to the feeling of loss of security, financial stabilisation, and the abandonment of institutional forms of social support³. As a result, families have to cope with various types of problems, e. g. financial, educational, changes to the power balance between the various members, negative attitudes of the environment, and others⁴.

¹ E. Muszyńska, *Ogólne problemy wychowania w rodzinie dzieci niepełnosprawnych*, [in:] *Dziecko niepełnosprawne w rodzinie*, ed. by I. Obuchowska, WSiP, Warszawa 1999, pp. 101–164; G. Kwaśniewska, *Rodzina dziecka z przepukliną oponowo-rdzeniową*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2005; A. Sakowicz-Boboryko, *Rodzina jako realizator potrzeb rehabilitacyjnych dzieci niepełnosprawnych*, Trans Humana, Białystok 2005.

² M. Parchomiuk, *Rodzice dzieci z mózgowym porażeniem dziecięcym wobec sytuacji trudnych*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2007; B. Górnicka, „Rodzicielski świat” matek i ojców wychowujących dziecko z niepełnosprawnością, [in:] *Rodzicielstwo w kontekście wychowania i edukacji*, ed. by J. Brągiel, P.E. Kaniok, A. Kurcz, Wydawnictwo UP, Opole 2013; J. Lipińska-Lokś, B. Skwarek, *Rodzice w obliczu niepełnosprawności dziecka*, [in:] *Rodzicielstwo w kontekście wychowania i edukacji*, ed. by J. Brągiel, P.E. Kaniok, A. Kurcz, Wydawnictwo UP, Opole 2013.

³ Conf. A. Krause, *Człowiek niepełnosprawny wobec przeobrażeń społecznych*, Oficyna Wydawnicza „Impuls”, Kraków 2005.

⁴ Conf. Z. Kazanowski, *Przemiany pokoleniowe postaw wobec osób upośledzonych umysłowo*, Wydawnictwo Uniwersytetu Marii Curie-Skłodowskiej, Lublin 2011.

Edyta Chajda⁵ indicates that despite the public opinion being aware of the difficulties encountered by families raising disabled children, in the opinion of the decisive majority of Poles (94%), the care for and the support of disabled people is primarily the duty of the family. Commonly, the rehabilitation of the disabled child is assigned to the role of the parents. The mother is perceived as the animator of life of the disabled child. Beata Antoszevska⁶ notes that the mother becomes the direct animator, when she takes care for the child basing herself on her innate intuition and the need to help, and the indirect animator, when she seeks specialist help and makes use of it. The mother also becomes the entity implementing the recommendations of specialists. The child spends most of its time in the area of the family, and it is in most instances that this is where it is expected that the recommendations of therapists/ rehabilitation specialists are implemented by the next of kin, which might multiply the probability of an ultimate therapeutic success. The uptake by an even larger fraction of the population of the new, partnership-based model of the family, assuming a more balanced distribution of power and obligations between the individual members of the family causes fathers to be party to ever more tasks related to the raising of the child, caring for them and rehabilitating them⁷. Irrespective, however, of whether we are considering the situation of biological, adoptive or foster mothers or fathers raising disabled children, it can be assumed that they have to cope with an higher number of difficult situations than the parents of children without disabilities. Difficulties related to the differences in the

⁵ E. Chajda, *Postawy wobec osób niepełnosprawnych, Komunikat z badań*. CBOS, Warszawa 2007, p. 8.

⁶ B. Antoszevska, *Matka jako animator w życiu dziecka niepełnosprawnego*, [in:] *Współczesne problemy pedagogiki specjalnej*, ed. by U. Bartnikowska, Cz. Kosakowski, A. Krause, Olsztyn 2008, pp. 186–191.

⁷ K. Ćwirynkało, *Ojciec w wychowaniu i rehabilitacji dziecka z niepełnosprawnością*, [in:] *Edukacja i socjalizacja w życiu osoby niepełnosprawnej*, ed. by A. Klinik, D. Prysak, Oficyna Wydawnicza Humanitas. Wyższa Szkoła Humanitas, Sosnowiec 2011, pp. 133–147.

functioning of a child, and social expectations, make the parents' stress greater⁸.

Beside the similarities in the situation of biological as well as adoptive and foster families of a disabled child, noticed should be also their special characteristics, for a few reasons at least. First of all, noticeable is the high frequency of prevalence of various kinds of disorders within foster or adoptive care⁹. This phenomenon is also noticed in Polish literature¹⁰. For instance, Jacek Bleszyński¹¹, having analysed 97 adoptive families, indicates that among 41 children adopted by these, no symptoms of various diseases and/ or developmental disorders were registered. The report of the Polish Central Statistical Office in turn, 'Social assistance and care for the

⁸ Conf. E. Pisula, *Psychologiczne problemy rodziców dzieci z zaburzeniami rozwoju*, Wydawnictwa Uniwersytetu Warszawskiego, Warszawa 1998; Pisula E., *Rodzice i rodzeństwo dzieci z zaburzeniami rozwoju*, Wydawnictwa Uniwersytetu Warszawskiego, Warszawa 2007; K. McGlone, L. Santos, L. Kazama, R. Fong, Ch. Mueller, *Psychological Stress in Adoptive Parents of Special-Needs Children*, "Child Welfare" 2002, LXXXI, 2, pp. 151-171; A. Borowicz, *Stres rodziców wychowujących dzieci z niepełnosprawnością słuchową*, "Niepełnosprawność – zagadnienia, problemy, rozwiązania" 2012, 2, pp. 55–80.

⁹ J.A. Rosenthal, V. Groze, A.G. Aguilar, *Adoption Outcomes for Children with Handicaps*, "Child Welfare" 1991, LXX, 6, pp. 623–636; H. Minnis, K. Everett, A.J. Pelosi, J. Dunn, M. Knapp, *Children in Foster Care: Mental Health, Service Use and Costs*, "European Child & Adolescent Psychiatry" 2006, 15, 2, pp. 63–70.

¹⁰ U. Bartnikowska, K. Ćwirynkało, *Rodziny adopcyjne i zastępcze dziecka z niepełnosprawnością*, Oficyna Wydawnicza "Impuls", Kraków, 2013; Bartnikowska U., Ćwirynkało K., *Dziecko z niepełnosprawnością w rodzinie adopcyjnej i zastępczej. Część I – zetknięcie się z niepełnosprawnością dziecka, analiza decyzji*, Kwartalnik „Szkice Humanistyczne” 2012a, XII, 2(28), pp. 197–216; Bartnikowska U., Ćwirynkało K., *Dziecko z niepełnosprawnością w rodzinie adopcyjnej i zastępczej. Część II – jakość funkcjonowania rodzin*, Kwartalnik „Szkice Humanistyczne” 2012b, XII, 4(30), pp. 199–216; U. Bartnikowska, *Dziecko z uszkodzonym słuchem w rodzinie zastępczej – studium przypadku*, „Wychowanie na co Dzień” 2013, 1–2, pp. 3–8; K. Ćwirynkało, *Rodzina zastępcza z dziećmi z niepełnosprawnością intelektualną. Studium przypadku*, „Wychowanie na co Dzień” 2013, 1–2, pp. 9–16.

¹¹ J.J. Bleszyński, *Kluczowe zagadnienia przysposobienia i funkcjonowania rodzin adopcyjnych*, Oficyna Wydawnicza „Impuls”, Kraków 2010.

child and family in the year 2015' ("Pomoc społeczna i opieka nad dzieckiem i rodziną w 2015 roku")¹² indicates that for the end of the year 2015, in the realm of family foster care in Poland, 10.5% of all those under care had a statement of disability. However, information about how many of the other children would have other, 'minor' dysfunctions, such as difficulties in learning, emotional disorders and behavioural disorders. It can be speculated, based on studies from the United States and Great Britain¹³ that these are more numerous than children with statements of disability.

A further issue concerns the character of relations between the adoptive/ foster parent and the child. On the one hand, it can be speculated that the lack of a biological bond between the parents and children can strip parents of a major source of mobilisation to provide the child with the best possible care. On the other hand, however, these parents are very often very determined and have at their disposal various methods thanks to which they are able to provide the child with optimum conditions for development. Available research suggests that e. g. adoptive and foster mothers raising intellectually-disabled children suffer from depressions comparatively to a lesser extent than biological mothers of such children¹⁴, and the level of satisfaction of adoptive and foster parents from raising a disabled child can be judged as high¹⁵. Not insignificant is also the issue of the ability to receive additional financial support as

¹² *Pomoc społeczna i opieka nad dzieckiem i rodziną w 2015 roku* (2016), Warszawa: Polish Central Statistical Office, [pomoc_spoleczna_i_opieka_nad_dzieckiem_i_rodzina_w_2015.pdf](#) [access: 8.07.2017].

¹³ J.A. Rosenthal, V. Groze, G.D. Aguilar, *Adoption Outcomes for Children with Handicaps*, "Child Welfare" 1991, LXX, 6, pp. 623–636;

¹⁴ L.M. Glidden, V.L. Valliere, S.L. Herbert, *Adopted Children With Mental Retardation: Positive Family Impact*, "Mental Retardation" 1998, 26, 3, pp. 119–125.

¹⁵ N. Gallant, *What works in special needs adoption*, [in:] *What works in child welfare, Child Welfare League of America*, ed. by M. Kluger, G. Alexander, P. Curtis, Child Welfare League of America, Washington, DC, 2000, pp. 227–234; A. Gath, *Mentally Retarded Children in Substitute and Natural Families*, "Adoption and Fostering" 1983, 7, pp. 35–40; J.A. Rosenthal, *Outcomes of adoptions of children with special needs*, "The Future of Children" 1993, 3, 1, pp. 77–88.

well as with respect to specialist aid by foster families (both related as well as professional), in particular these having the status of specialised foster families that by definition are there to provide care to children with developmental disorders.

Utilised methodological procedure

The subject of the undertaken studies was the experience of adoptive/ foster parenthood over a disabled child, with specific focus on the parental reception of the otherness of the child. It was the purpose of the research to show the methods of comprehension of the otherness of a disabled child by its adoptive/ foster parents. The research problems were formulated as follows: In what categories do the adoptive/ foster parents describe the otherness of the disabled child accepted into the family? What does the otherness of the child mean in their view? What is the meaning ascribed by those under research to their experience of the otherness of the child?

In order to respond to the specified questions, a qualitative research strategy was chosen within the interpretative paradigm. The assumption of this research route stems from the specifics of the analysed group, the uniqueness and difficult accessibility of the analysed group. The selected paradigm permitted the assumption of the presence of intersubjectivity. According to Edmund Husserl¹⁶ it yields the basis to state that subjectively experienced worlds have a common intersubjective part that may, through science, gain the name of an objectively existing reality.

Phenomenography was chosen as the method utilised to find the answers to the questions posted above; it “deals with qualitatively varied methods utilised by people to experience phenomena and consider them, and to think of the mutual relations between

¹⁶ E. Husserl, *Nastawienie nauk przyrodniczych i humanistycznych. Naturalizm, dualizm i psychologia psychofizyczna* (translated by Z. Krasnodębski) [in:] *Fenomenologia i socjologia*, ed. by Z. Krasnodębski, Wydawnictwo PWN, Warszawa 1989, pp. 54–74.

people and the world"¹⁷. For data collection, deep interviews were utilised that, after transcriptions, were encoded based on the inductive approach¹⁸ and components of grounded theory of Katy Charmaz¹⁹.

The presented results constitute a fragment of a broader research project concerning the situation of disabled children in adoptive and foster families conducted in the years 2010–2012²⁰. The research group was composed of 20 families (in each case one or both of the parents took part in the study), who had adopted or taken in to a foster family a disabled child. There were eleven adoptive families in the study, and nine foster families, of which three were related and six were unrelated foster families (in this group only one family had the status of a specialised foster family). The age of the children varied between two and 27 years, and the disabilities they suffered were e. g. damage to hearing, intellectual disability, grave chronic illness, FAS, cerebral palsy and autism. The studied used an original proprietary questionnaire used to conduct the interview. The study was executed using the qualitative procedure. Interviews were conducted that were later transcribed and subjected to qualitative analyses.

Results of own research

Descriptions of parents pertaining to their first experienced related to the child's otherness divide all the analysed parents into

¹⁷ R.G. Paulston, *Pedagogika porównawcza jako pole nakreślania konceptualnych map teorii paradygmatów*, [in:] *Spory o edukację. Dylematy i kontrowersje we współczesnych pedagogiach*, ed. by Z. Kwieciński, L. Witkowski, IBE, Edytor, Warszawa – Toruń 1993, p. 41.

¹⁸ M. Hammersley, P. Atkinson, *Metody badań terenowych*, Poznań 2000.

¹⁹ K. Charmaz, *Teoria ugruntowana. Praktyczny przewodnik po analizie jakościowej*, Warszawa 2009, pp. 59–124.

²⁰ U. Bartnikowska, K. Ćwirynkało, *Rodziny adopcyjne i zastępcze dziecka z niepełnosprawnościami*, Oficyna Wydawnicza „Impuls”, Kraków 2013.

two main groups: 1. those who discovered the developmental disorders in their children only after accepting them into the families, 2. those who from the beginning knew that the child has developmental problems.

Parents unaware of the child's otherness

The discovery of disorders – as it seems – should rest in the competences of specialists deciding on the transfer of a child to a specific family. The parents should fully consciously, knowing their abilities and skills, decide to take a child with certain limitations into their care. In actuality, in several cases, the matters were different.

The unawareness of the parents concerning the presence of disorders in children was caused by two factors. In some of these cases, it was the age of the child that prevented the statement of a broad diagnosis concerning further e. g. mental or motor development. In younger children (in particular newborns, but toddlers as well), it is difficult to describe an ultimate diagnosis concerning developmental abilities due to the large variations in individual development, and also due to the difficulty in differentiating symptoms of negative influences of external factors from the arising of a child's actual (limited) potential, as well as due to the flexibility of the child and its abilities to surmount developmental difficulties under favourable conditions. In other cases, the lack of knowledge of the parents was caused by the employees not disclosing to them the known diagnoses of the children.

The first cause (the child's age at the time of acceptance into the family) resulted in the disability being discovered with a delay of several years. The following example statements prove such experiences of some of those questioned:

“Frانيا's problems became apparent only in grade zero of primary school. I was made aware of the emergence of difficulties in terms of her

acquiring knowledge and skills. Many contraindications against commencing primary school were indicated [...] We did not want to accept the fact that our only child has problems in school, that she has limited cognitive abilities. We did, after all, care for her, and had not noticed anything worrying earlier [...] We thought that once she would start school, these difficulties would disappear by themselves and that everything would be all right, so we sent her as normal to the first grade of primary school. That's when the problems started..." (Felicja, adoptive mother of an eleven-year-old girl with an intellectual disability)

"Kamil developed normally, until the age of three it was normal, a cheerful child, running around... When he was a year and three months old – we did away with nappies. [...] There were only problems with speaking, because he spoke very little, and then he ceased to altogether. He went to preschool only for a month, because the teachers already noticed that Kamil behaves differently when among children [...] started those visits at psychologists, various doctors, where we found out more and more that he was autistic" (Krystyna, related foster mother of a fourteen-year-old girl with autism).

In both cases, the diagnosis of the disability was a surprising discovery for the interviewees. In the narrations, there appears a gradation of experiences in life, and the moment of the diagnosis is placed among those most difficult. This is not a phase of shock as seen in parents, to whom a disabled child is born, but it is an experience that can be compared to the experiences of biological parents, the children of whom are diagnosed later than just after birth. The children of the interviewed people already have behind themselves several years of history at the family, hence both statements include the diagnosed problems set against the children's prior successes (quick adaptation to using the potty for physiological needs, observing an emotional balance and a lack of tendency towards aggression in a child). They form the context for the changing family situation. Both of the interviewees relate stories about the child venturing outside of the family circle, going to preschool, and, accordingly,

the possibility of confrontation of the child's functioning with the functioning of their peers. The statements also exhibit a category of waiting for an improvement, which, however, does not come about in the extent expected by the parents.

The force of experiences of the interviewees is noticeable through those parts of the narrations that apply to the defence mechanisms used against them²¹: denial (*"We did not want to accept the fact"*), the illusion of the temporary nature of the problems (*"once she would start school, these difficulties would disappear by themselves"*) and undertaking not necessarily rational activities that were to remove them (*"we sent her as normal to the first grade"*), seeking out the guilty and self-accusation (*"We did not send the child to preschool [...] perhaps this was a mistake"*), the need to confirm the diagnosis, maybe even seeking a different, more advantageous one (*"those visits at psychologists, various doctors, where we found out more and more that he was autistic"*). The information about the defence mechanisms utilised by the parents, included in the stories of the emergence of disability diagnoses in the child confirm that these were difficult emotional experiences.

Parents to whom the fact of a disability already persisting in a child include, among others, Regina and Ryszard. This is their dialogue showing the unawareness of the difficulties of the intellectually-disabled children accepted into the foster family:

"We knew nothing. We were told he wets the bed at night [...] It is a fact that the children's home did not notify about any disturbances at all" (Regina)

"We received all the documents only when the case in court was officially closed [...] Among them was the medical statement of the disability" (Ryszard)

"Yes, but even this statement in reality told us nothing [...] when Rafał came, then my husband told him already on the second day: "You

²¹ Conf. E. Pisula, *Psychologiczne problemy rodziców dzieci z zaburzeniami rozwoju*, Wydawnictwa Uniwersytetu Warszawskiego, Warszawa 1998.

know, son, when I was your age I was already reading «The Deluge» and we gave Rafał a thick book [...] on the next day, we asked: "Sweet Rafał, did you already read something in the evening?" He replied, not really [...] Then we said – we need to visit the eye doctor [...] We only realised later that it's not the eyesight that's causing the problems [...] nobody warned us about it" (Regina)

"We have met people as people, you know, not as their problems, but people as people. Had we not met people as people, but just knew the documents, the decision might have been different" (Ryszard)

The discovery of the disability, of which the parents were not informed, happens quite quickly. The statements of interviewees representing this kind of family show several characteristic components. The first one is getting to know the child as they are, but – as the interviewees stress – getting to know them through the lens of humanity and not developmental shortcomings. The description of the parents usually spans the meeting of one person with another, and the force of the "first impression" without the burden of negative information. The second component is lack of information on the development of children. They do not come to families labelled and marked with their limitations. The parents can personally discover their potentials (including the specifics of their functioning along with certain limitations). Parents stress as well that the decision to accept a child due to lack of access to diagnoses was based upon getting to know the child(ren) and not their flaws. The third component is the process of discovering the children's shortcomings itself. This discovery covers two paths: documents and own observations. Documents are a natural path of getting to know children that should precede accepting them into the family, and for the interviewees, it was "disclosed" quite late. The interviewees, however, ascribe a particular significance to having discovered the diagnosis later, as an important fact contributing to the reaching of a positive decision concerning the commencement of care of the children. They ascribe the cause of emergence of negative attitudes

towards children and their rejection to the early information of the diagnoses and the training materials.

With this element, interwoven is the process of entering parent roles, the formation of the identity of the parent and the identity of the child (expressed by the words "*You know, son, when I was your age...*"). Identical means "the same". Ryszard shows identification of the child's abilities with his own abilities presented at a given age, ascribes to him similar interests. This leads to the discovery of (unidentified as of yet) differences in a child, and initiates the process of looking for causes. The parents accept two possibilities: sight problems and neglect. Intellectual disability is more difficult to accept. Defective sight can be corrected, neglect was halted by the child being accepted into the family, and may be compensated. However, intellectual disability is disability that – as shown by the research of Antonina Ostrowska²² – gives in most cases in the environment rise to an attitude not only of rejection, but distance. It can be speculated that for this reason, the interviewees had it easier thinking of limited abilities of children as being the result of neglect or eye damage. In addition, the interviewees confess that in their case intellectual disability is something not seen earlier. Both state that earlier they had no contact with people below the intellectual norm, quite the opposite – they revolved around educated people.

The ultimate element distinguished in the process of discovering the children's disability is the fear of one's competences as a parent. The parents are intuitively aware that specific needs of disabled children also require specialist knowledge and skills.

Parents aware of the child's disability from the very beginning

Two subgroups may be differentiated between among the interviewees: Persons fully aware, and those partially aware. Persons

²² A. Ostrowska, *Niepełnosprawni w społeczeństwie 1993–2013*, IFiS PAN, Warszawa 2015.

partially aware, which include the foster mother quoted below, had received the information that the children they plan to accept into the foster family have certain limitations or health problems. However, as they went about getting to know the child, other developmental limitations came to light.

"I knew she went to a special school, but I was told that this disability borders on the norm, later it emerged that the disability is moderate, despite mine and Celinka's enormous work" (Czesława, unrelated foster mother of an eleven-year-old girl with an intellectual disability).

The other interviewees were from the very beginning aware of the child's disability, which does not mean that all were fully at home with it. Some of the interviewees had formerly contact with people with such disabilities as the child accepted by them (e. g. Monika with deaf children, and Wanda with her own child fed parenterally).

"The illness is unforeseeable. [...] For seven years we had [a parenterally fed daughter – author's note] before Witek made his way to us, we learned to live with it" (Wanda, unrelated foster mother of a five-year-old boy with a grave chronic disease).

Wanda focuses first of all on the otherness related to the necessity of parenteral feeding for Witek. This is a disease that she could already "live with", because here biological daughter is fighting the same disability. She thus knows that it cannot be foreseen, that it requires frequent medical consultations and this knowledge allows their family to calmly accept the boy's otherness. The interviewee, after her daughter was diagnosed with the disability, most probably went through all phases of adaptation: shock, emotional crisis, apparent adaptation and constructive adaptation²³. The acceptance of

²³ A. Twardowski, *Sytuacja rodzin dzieci niepełnosprawnych*, [in:] *Dziecko niepełnosprawne w rodzinie*, ed. by I. Obuchowska, WSiP, Warszawa 1999, pp. 18-54.

the daughter's otherness let her naturally accept such a disease in others. The interviewee, when speaking of the first period of the presence of Witek in their family, completely omits his other difficulties: hearing difficulties, hospitalism, intellectual difficulties. It is possible that even opening up to otherness of a single type caused also openness to the differences of others in general.

Monika is in a similar situation – she knows other children with deficient hearing that go to the same school as the girl she had taken in.

“Marysia was already nine years old, and she went to a school for the deaf for two years already, she was stuck in zero grade, she couldn't budge from there [...] she did not know how to eat. She was so thin and little. But when I took her in, it was one of the most frightening things” (Monika, former unrelated foster mother of a currently 27-year-old deaf daughter).

Monika is also at ease with Marysia's main disability – the hearing deficiency. Work at a school for the deaf caused her to become, using the terms of Erving Goffman²⁴, “oriented” or “informed” in the specifics of the functioning of the people with such a trait. She thus had no trouble with accepting her and welcoming even as normal and obvious. Moreover, she had met Marysia with her personal limitations, she knew her position in the school and in the class (the fact that other children have contempt for her due to the death of her mum), she knew about the other problems (related for instance to her mental development), she knew her past at least fragmentarily (stay at the children's home). The skills and basic limitations of Marysia are thus known and accepted. However, it comes to light that a certain difference of the girl causes much disconcert to her mother – eating problems. Monika discovers not only her disability, but a certain difference in behaviour. She describes this in quite a lot of detail, because she ascribes to this a great signif-

²⁴ E. Goffman, *Piętno. Rozważania o zranionej tożsamości*, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2007.

icance. The ability and the will to eat is one of the basic activities supporting life. The inability and dislike by Marysia to eat is like "defending herself against life" or life with her needs minimised. This is behaviour that is completely unknown and strange in her mother's view, who undertakes various efforts to understand them, uncover the causes and change them. So, in Monika, there arises the additional question of getting to know THAT particular person, her specific mode of functioning different from other deaf children.

The troubles of other people began with getting to know the specific child, its abilities and limitations, and the specifics of the disability. If we would consider signs related to a child's otherness that was included by the interviewees in their statements, then it emerges that not all of these were related to the disability itself. Some of them applied to the appearance and form of the body of the child, the (not always proper) medical diagnoses, others indicated otherness stemming from the experiences of the child with the biological family or care facility.

"FAS was suspected, and that disease – hepatitis C, as it turned out, it wasn't there [...]. It turned out later that there are still other flaws" (Lidia, adoptive mother of a six-year-old girl).

"She was frighteningly small [...] born in the 33rd week of pregnancy, she weighed 1300 grams, she should weigh over 2 kg, she had microcephaly, she did not have the bodily proportions of a newborn" (Judyta, adoptive mother of a seven-year-old girl).

The statements quoted above show a part of the diagnoses quoted by the interviewed parents. These span mainly medical statements. Others pertained to the behaviour of children. This was described in detail in the narrations of Anna and Antoni, who had adopted three-year-old Agnieszka:

"There were various suspicions, that she was sexually abused, she feared men. She was very withdrawn, scared. When she was told to stand, she could stand motionless all day. She was not trusting, par-

ticularly of men [...] Whatever one gave her, she hid it under her pillow [...] The beginnings were very difficult, she was a very inaccessible child. She always wanted things her way. She did things to spite me. [...] She was negative towards everything” (Anna).

“She was very scared. She was frighteningly distrustful, distanced” (Antoni).

Anna and Antoni describe specific behaviour of their daughter. Their statements clearly show the meeting of people from two different worlds: friendly-minded adults and a child that has a lot of negative experiences behind her. Beside symptoms of disability, a child accepted as an older one bears in itself the stigma of experiences from the former period of life. This might be some form of sexual abuse, physical or psychological violence. It is the cause of behaviour that in the described case (in the subjective view of the interviewees) manifested itself with negativism, timidity, withdrawing, motionlessness, “spitefulness”, persistence, the child’s “deceitfulness”. The interaction of the parent with the child in such a case is a grand challenge, as seen in the memory of the mother’s own powerlessness. The meeting between these two worlds (of the parents and the child who was hurt) causes an incongruence in their cooperation to emerge. Both sides try to “survive” and impose their “rules of the game”, whereby both parties use strategies they had known up to that point. The parents use their knowledge on raising children, the child uses old mechanisms aiding survival (e. g. resists or shuts down, which enabled it to survive difficult situations until then).

The experience of a child’s otherness brings about with itself correcting certain own and others’ views of the child and its future, as told by one of the adoptive mothers – Judyta:

“But as I sat there in intensive care, my sister called, asking: how are things? Any progress? I told her: it’s just that – no. And then my sister said: listen, when Justynka will already have your last name, I will get her an account and every month I will transfer a little something

for her. And when she'll be 18–19 years old, going to university, she will have some money of her own [...] ... And I got terrified, I said to my sister: listen, but I don't even know if she'll even be able to graduate from primary school. Nobody knows that, and the probability is high... maybe she'll just be able to grow a field of carrots. And my sister said: then she'll get a field of carrots (laughs)" (Judyta).

This statement includes the characteristic component of assigning Justynka a place in the family. Belonging to the family, being part of its system, means using its support, including financial support. Both sisters ponder the future of the little girl, and both would want the best for her, so they think about securing her future. In the discussion, however, a clash appears between the knowledge of Judyta on her daughter's difficulties, and the visions of her sister. In this briefly described dialogue, articulated is the possibility of emergence of intellectual difficulties of the child, with a simultaneous declaration of their acceptance and the reorganisation of the future "planned" for the child.

A further category placed by the parents in their statements were the causes for the observed signs of otherness in children. As it turns out, they seek the reasons for a part of these not only in the disability, but also in the environment, from which the child originates. This is partly even medically justifiable (as was in the case of Lidia and Judyta – their daughters suffered from FAS, being a result of the mother consuming alcohol during pregnancy), partly the parents may barely speculate that certain disorders are due to negative emotional, social, psychological experiences that the children had suffered in their biological families or at institutions. The environment of origin is not only held for the cause of disability, but of the different behaviour of the child as well:

"This was her way. It's not that she's bad, but she must have taken a lot from the environment she was raised in. She was in a group of children who would constantly argue and shout, and it was not possible that she would be positive towards you from the very beginning,

react to your questions or orders [...] In general, she did not want to go anywhere. She was afraid of everyone around her, because she was not certain of her footing, whether she's with us to stay [...] What ever did she have to go through as a child... When you raise one from a very young age, it's completely different" (Anna).

The interviewee is referring to (un)known history of a child, and she speculates that some of her behaviour is the result of past experiences. She's experiencing the otherness of behaviour of her adopted daughter even comparing her to children adopted just after birth. Fears, withdrawing or negativism are assigned to the feeling of uncertainty. The mother – what's important – is convinced that the child isn't "bad". She's not looking for sources in flawed genes, tendencies inherited from biological parents, but in experiences. Her 'speculations' were confirmed in the last decade in the thoughts of Alan Schore analysing the research of other scientists on the influence of neglect and violence aged up to the second year of age²⁵.

A further category of descriptions that is used by the parents in relating their first parenting steps in coping with the child's otherness are methods of dealing with emerging difficulties.

When it comes to the effects of unfavourable experiences in life, there regrettably are parents who only mention "home" coping methods. Here, professional support is missing. When in turn speaking of the effects of disabilities, some of the interviewees (in particular those who had little children) describe quite precisely the therapeutic and rehabilitation schemes. Lidia and Judyta describe a very intense period of rehabilitation right after taking the children in. They both met their adopted daughters soon after birth, and – as Judyta recalls – "it was about getting as much from her as possible". Lidia also stresses the purpose of the work: "this was work to get her to develop faster, for certain things to subside faster, so that she could start

²⁵ A. Schore, *The Effects of Early Relational Trauma on Right Brain Development, Affect Regulation, and Infant Mental Health*, "Infant Mental Health Journal" 2001, 22, pp. 201–269.

talking faster, so that she could start turning over faster, so that she could start walking faster [...] I wanted to do everything not to lose these first moments, because I knew they are very important to improve her functioning”.

At this stage, what matters most is the intensity of effort, contact with many specialists that are able to guide the rehabilitation process, orientation towards specific minor goals, engagement of other members of the family. In both cases, the roles of the parent and the rehabilitation specialist intertwine. It's an intense, yet not stormy time – as opposed to families, in which disabled children are born. The interviewees accept the child, are joyous with it, are focused on it and not on their own feelings that also differ from those presented in the first stage by biological parents. Emotions are usually positive here, related to the initial euphoria of having “found” a child, and not to the shock related to the diagnosis of disability. Disability is an important component of the first interaction between mother and child, but it does not burden it negatively. The child does not lose its value if it has certain limitations.

The final category in descriptions that emerges in narrations concerning the first struggles with a child's disability/ otherness are the observed effects.

“I remember that the psychologist told me (laughs) to let go of these fears of the child's development already, because she was really already developing well” (Lidia).

“Justynka was really developing then. Then she turned cute, some people were appalled that a single person can get a child to raise, and such a cute one at that” (Judyta).

Successes (a veritable metamorphosis of the child) are confirmed by the environment. In both cases, from the very beginning, the child with their limitations is accepted in full, and this acceptance is not tied with passivity. In both families there is mobilisation, the faith in the possibility of improvement, and a crowning of efforts with success.

Summary

The beginnings of handling a child's disability were described by the interviewees in the following categories: discovering otherness based on experiencing daily life with the child, getting to know the symptoms present in children (medical, psychological and other diagnoses, reaching existing documents or obtaining the results of specialist tests), familiarising oneself with this particular case of difference, attempts at describing the reasons and initial methods of handling the difficulties, and obtaining and using specialist aid.

The research suggests some closing thoughts. A prior diagnosis of the child is important, because the improved awareness of the parents allows them to reach a responsible decision that will be free of negative emotions related to the uncovering of impediments. Such actions shall also permit the determination of the direction of the parents' actions, saving the parents "running around in circles" and destroying the chances for a child's better development – allowing the usage of all abilities and the entire potential of the child, the resources within it, and the resources of the parents and of the environment.

Examples of interviewees who had known the child earlier show just how this permission of mutual, spontaneous learning about one another of orphaned disabled children and people who may not necessarily be planning on being foster/ adoptive parents can be important and how it can open up the way for disabled children to adoptive/ foster families. The parents get to know the child as it is, and knowing its difficulties, may undertake the role of parents for it.

"A civilised world of people and values makes attempts at discovering various dimensions of humanity. It is keen to accept the unique that every one carries in them"²⁶. In case of the described

²⁶ Frąckowiak T., *Tożsamość człowieka upośledzonego umysłowo: niezrozumiała odmiennność, kryzys identyfikacyjny i edukacyjny dylemat*, [in:] *Spółczesność wobec autonomii osób niepełnosprawnych*, ed. by W. Dykcik, Eruditus, Poznań 1996, p. 76.

families, this is an attempt at discovering uniqueness that is carried within by the doubly-burdened children: by abandonment and disability, and also an attempt at making them valuable, needed, loved... The interviewees undertake the effort to handle the child's otherness, spanning on the one hand a specific disability, and on the other hand – abandonment, neglect or violence.

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