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## The crisis of parents of a child with a disability in the perspective of new normalisation tools

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Social and cultural transformations determine the functioning of a disabled child's family. The Internet, support groups or associations are the new normalisation tools parents can use. They can affect both the structure of his or her parenting as well as the process of coping in difficult situations. The author analyses the social and emotional situation of parents of children with disabilities, based on her research. They describe the significant categories and areas important for further scientific exploration.

**KEY WORDS:** family system, child with disability

### Introduction

Learning about the specifics of functioning of the family of a child burdened by a disability constitutes a topic that is important both in the perspective of holistic support of child development, as well as in areas of analysis of the integration of disabled people and the normalisation of the social environment. The societal and cultural changes taking place, as well as transformations of paradigms

in special-needs education<sup>1</sup> cause the family, as the environment closest to the disabled person, to also fall under specific influences. Through changes and transformations, it thus creates new areas of scientific exploration. The disability of a child influences the formation of a new quality of family functioning. Hence, learning about the process of coping with the emotional crisis caused by the child's disability, as well as the formation of the identity of the parent, is key both from the standpoint of the support offered to the family, as well as the meanings societally bestowed upon the family of a disabled child. Long years of practice in the area of work with parents, as well as analyses of subject literature and the scientific research conducted by me on the functioning of the family of the disabled child had made me aware of exactly just how important is exactly the parent's coping with the emotional crisis for the relation of the parent with the child, the therapist, and the societal environment.

## Own research

I would like to develop my thoughts on the crisis of the parents, after they had received the disability diagnosis of a child, based on two of my studies:

- a netnographic study concerning the societal functioning of the family of an intellectually-disabled child, conducted as part of a problem reconstruction of the research of H. Borzyszkowska;
- a pilot study concerning the coping by parents with the emotional crisis constituting the aftermath of a child's disability diagnosis - in the form of interviews with 20 parents of disabled children, who are covered with early development support;

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<sup>1</sup>Conf.: A. Krause, *Współczesne paradygmaty pedagogiki specjalnej*, Oficyna Wydawnicza „Impuls”, Kraków 2011.

The first of these studies, concerning the societal functioning of the family of a disabled child, was an inspiration to develop the indicated topic. This study constituted a vital component of the problem reconstruction of the study by H. Borzyszkowska, concerning the societal isolation of the families of intellectually-disabled children.<sup>2</sup> The study made use of netnography and an analysis of visual material. The study group was composed of a forum and six blogs written by parents of children with intellectual disabilities. The study had a qualitative character, and the analysis was conducted within the constructivist paradigm. Conclusions stemming from it thus do not have the properties of generalisations. They indicate, however, certain tendencies and possibilities that may mark the functioning of contemporary families of disabled children. An important category that came up during the analysis of the research material were specifically new normalisation tools. I consider this term to encompass the possibilities utilised by those under study in the coping strategies they had developed. These are, among others, making use of the Internet, cooperation with associations and foundations, general access to psychological and therapeutic help. Being aware that the described study concerns a specific group – parents that are active on-line – I conclude that the indicated possibilities constitute normalisation tools influencing the societal and emotional situation of families of disabled children, of which these parents can make use.

The societal and emotional situation of the family seems to be, in the perspective of my studies and analysis, the aftermath of coping with stress and difficulties (crises) implied (generally speaking) by the child's disability. Specifically in this area, the meaning of new normalisation tools that can be of importance to the coping strategies developed by the parents increases. For instance, the Internet as a source of knowledge makes it easier for parents to seek and find information both on difficulties, diseases, as well as on the

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<sup>2</sup>Conf.: H. Borzyszkowska, *Izolacja społeczna rodzin mających dziecko upośledzone umysłowo w stopniu lekkim*, Wydawnictwo Uniwersytetu Gdańskiego, Gdańsk 1997.

possibilities of searching for support. This is important in the area of the parents countering problems, and makes them feel more competent e. g. in the relations with medical personnel or therapists. At the same time, through forums and blogs, the internet forms for parents the place of formation of social relations and where they receive emotional support from, even contributing to the formation of the identity of a parent of a disabled child.<sup>3</sup>

The main constituent components of analyses of the situation of the parent of a disabled child are the emotional crisis of the parents of children with disabilities, and the stress they feel.

*"A crisis within the family is a transitional state of system disarrangement, requiring the implementation of changes in order to restore internal stability and balance. These changes pertain to rules, patterns of interaction, the roles taken and the family structure. A family in crisis is characterised by a particular set of properties that, from the societal point of view, are unwanted, and it does not fulfil its functions."*<sup>4</sup> In this perspective, the crisis appears as a process of adaptation of the family to the new situation caused by factors of change. The force of the child's disability, as the factor determining the crisis, is dependent on other aspects of functioning of the family – its socio-economic situation, the characteristics of the parents, their bonds as well as abilities to adapt and fit in. The crisis of the parents is described in most cases of musings in this topical area. Changes taking place in our society seem, however, important in the perspective of coping with the crisis, as does – as I have already indicated – the possibility of usage of new normalisation tools in the coping strategies developed by the parents.

In literature on the subject, in characterising the situation of the family of a child suffering from a disability, the authors frequently refer to the descriptions of emotional experiences after they receive

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<sup>3</sup> Conf.: J. Doroszuk, *Sytuacja społeczna rodzin dzieci z niepełnosprawnością. Rekonstrukcja problemowa badań H. Borzyszkowskiej*, Uniwersytet Gdański, 2015, unpublished thesis, pp. 233–270.

<sup>4</sup> B. Matyjas, *Dzieciństwo w kryzysie: etiologia zjawiska*, Wydawnictwo Akademickie „Żak”, Warszawa 2008, p. 107.

news of their child's disability, by A. Twardowski. He indicated the following periods: of emotional shock or distress, also referred to as the critical period, of emotional crisis, of apparent adaptation, and the period of constructive adaptation.<sup>5</sup> The description of the process of the family adapting itself to the disability of the child by A. Twardowski emerged based on a reference of the author to research conducted in the 1970s by J.C. Ewert, M.M. Green and L. Rosen. The indicated emotional states, experiences or tendencies may for the most part be universal and timeless in character. Very important in the indicated description is also e. g. the presentation of the shaping of the acceptance of the parent with respect to the disabled child as a process, as well as the indication of the possibility of existence of a dichotomy between the behaviour of the parent and their emotions (e. g. in the period of the so-called apparent adaptation).

Worth considering, however, seems the fact that the strategies of coping by the parents with a crisis situation were at the time (1970s) not determined by such factors as e. g. support groups, on-line forums or training seminars and courses for parents of children with disabilities. In addition, due to the societal and cultural changes, the domination of the humanist direction over the medical direction, as well as the increase of individualistic tendencies (yielding a positive meaning to being different), questions emerge on the current influence of external factors on the situation of parents of disabled children. Meaningful in this perspective seem also changes in the structural and functional arrangement of the family.<sup>6</sup> In addition, contemporaneously, even A. Twardowski indicates a systemic foundation of relations within the family.<sup>7</sup> As a consequence, new areas emerge that are worth scientific study, e. g. strategies implemented

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<sup>5</sup>A. Twardowski, *Sytuacja rodzin dzieci niepełnosprawnych*, [in:] *Dziecko niepełnosprawne w rodzinie*, ed. by I. Obuchowska, WSiP, Warszawa 1991, pp. 21-27.

<sup>6</sup>Conf.: F. Adamski, *Rodzina. Wymiar społeczno-kulturowy*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków 2002, p. 145.

<sup>7</sup>Conf.: A. Twardowski, *Wczesne wspomaganie rozwoju dzieci z niepełnosprawnościami w środowisku rodzinnym*, Wydawnictwo Naukowe UAM, Poznań 2012.

by the parents for obtaining help or the sphere of communication of the parents with medical personnel or with other specialists working with the child, as well as the roles taken on by the parents and their influence on the level of acceptance of the disability of the child.

Understanding the acceptance of a child's disability by the parent as a linear process characterised by specific stages is confronted in literature of the subject with the presentation of the acceptance of the child by the parent as a cyclical process dependent on external factors.<sup>8</sup> Developmental progress of the child or the support received may contribute to positive changes in the psycho-social situation of the parent and the meanings assigned by them thereto. Specific issues and challenges, in turn, which the parent stumbles upon, seem to be akin to distracting factors, negatively burdening the situation of the parent and causing the stress they experience to increase.

The stress of parents is described as one of the consequences of a child's disability.<sup>9</sup> It applies to the fact of the disability or illness of the child itself, and is also a consequence of the difficulties (related for instance to the functioning of the child, reactions of the environment or additional obligations) that the parents have to face every day. The type of impediment to the functioning of the child is indicated as a factor of importance for the level of stress experienced by parents.<sup>10</sup> As those most susceptible to experiencing stress are indicated the mothers of children with disorders from the autism spectrum, which may be conditioned, among others, both by the impaired possibility of forming the mother-child relation (due to the spectrum of disorders of the autistic child), as well as by reactions from the social environment (the disability of the child is in

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<sup>8</sup> Conf.: D. Poston, A.P. Turnbull, J. Park, H. Mannan, J. Marquis, M. Wang, *Family quality of life: a qualitative inquiry*. "Mental Retardation" 2003, no. 41, pp. 313-328.

<sup>9</sup> Conf.: E. Pisula, *Psychologiczne problemy rodziców dzieci z zaburzeniami rozwoju*, Wydawnictwo Uniwersytetu Warszawskiego, Warszawa 1998, pp. 48-94.

<sup>10</sup> Conf.: R.M. Hodapp, R.C. Urbano, *Adult siblings of individuals with Down syndrome versus with autism. Findings from large scale US survey*, "Journal of Intellectual Disability Research" 2007, no. 51, pp. 118-129.

many cases not clear, whereas their behaviour differs from socially acceptable norms).<sup>11</sup> The stress experienced by mothers – in particular in the perspective of the research of M. Sekułowicz – is even indicated as one of the factors – besides hopelessness, frustration or isolation – influencing the exhaustion of strength of parents of children with disabilities.<sup>12</sup>

Understanding the situation of the parent of a child with a disability as marked by the experienced stress and the coping with the crisis (or crises) against the backdrop of the changes in the functioning of the family as indicated above makes me inclined to perform a problem reconstruction of the phenomenon of the crisis of a parent of a disabled child. For this purpose, I have conducted a pilot study, the main aim of which was to get to know the socio-emotional situation of parents of children with disabilities in the first years of life of the child. Aiming to perform an analysis of the experiences and trials of parents, I have oriented the studies towards quality.<sup>13</sup> The main problem was for me the question of the perception by the parents of their socio-emotional situation against the backdrop of their child's disability. I have arranged the specific detailed issues around such phenomena as: obtaining the diagnosis of disability, defining the disability by the parent, support received by the parent, roles taken by the parents as well as the support of the child's development.

M. Łobocki points out that *“understanding the phenomenon means as much as seeing it from the perspective of people that it applies to, meaning, recreating the subjective traits of significance assigned to it [...]”*.<sup>14</sup>

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<sup>11</sup> Conf.: Cunningham C.C., *Families of children with Down syndrome, “Down Syndrome Research and Practice”* 1996, no. 4, pp. 87-95.

<sup>12</sup> Conf.: M. Sekułowicz, *Wypalanie się sił rodziców dzieci z niepełnosprawnością*, Wydawnictwo Naukowe Dolnośląskiej Szkoły Wyższej, Wrocław 2013.

<sup>13</sup> Conf. M. Szymański, *O znaczeniu badań jakościowych nad wartościami*, [in:] *Z badań nad wartościami w pedagogice*, ed. by W. Furmanek, Zakład Dydaktyki, Techniki i Informatyki Uniwersytetu Rzeszowskiego, Rzeszów 2006, p. 51.

<sup>14</sup> M. Łobocki, *Wprowadzenie do metodologii badań pedagogicznych*, Oficyna Wydawnicza „Impuls”, Kraków 1999, p. 87.

Considering the singular and unique dimension of experiences within the field of parenthood marked by disability, the qualitative interview seemed to me to be the effective route towards getting to know the perspective of the parent, with the purpose of this interview being – as S. Kvale points out – “[...] *achieving an interpretation of the description of the world of experiences of the interviewed person*”.<sup>15</sup>

The interviews were conducted by female students of the IInd year of master’s complementary studies in the field of special education – early child development support, at the University of Gdańsk, within the framework of the course I teach – working with the family of a little child. Before commencing the interviews, I determined together with the students the key issues in the area of methodology of the study and the questions aimed at appropriately guiding and steering the interview towards learning the answers to the set research problems. I analysed the interviews personally. I did, however, also discuss them with the students as part of the university lectures, thanks to which I was able to learn the interpretations by the special education guides beginning their professional careers and, also, their work with parents.

The research sample was composed of 20 parents (19 mothers and one father), the children of which make use of early development support. Each of the studied persons has a child (or children) with a mobility disability (five parents), an intellectual disability (two), a sensory disability (two) or with multiple disabilities (four), or experiencing disorders from the autism spectrum (seven). The interviews varied in size and level of detail due to the different modes of narration by the parents, as well as due to the amount of time that they were able to devote to me to provide the interviews. The research material in total covers several dozens of pages of transcriptions.

The material analysis process encompassed:

- reading the research material, with simultaneous marking of fragments of importance in terms of the research questions;

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<sup>15</sup>Kvale S., *InterViews. Wprowadzenie do jakościowego wywiadu badawczego*, Wydawnictwo Uniwersyteckie „Trans Humana”, Białystok 2009, p. 17.



- reading the marked fragments, underlining key words or sentences, creating specific categories based on these;
- assigning selected fragments to research questions;
- a synthesis of specific research problems according to the topics of issues;
- an analysis and verification of the delineated categories.

The categories that I have delineated are:

1. The conscious and demanding parent;
2. Fixed assignment of roles in the family of a disabled child;
3. Parent "in action" - focus of the parent on coping with difficulties;
4. The Internet as an important source of knowledge;
5. Fear related to the child's future.

In the descriptions of these, I shall provide examples from the statements of the parents, and I will also endeavour to indicate the areas that to me seem meaningful for the purpose of further analyses and scientific exploration.

#### Ad. 1. The conscious and demanding parent

The decisive majority of the analysed parents described their expectations concerning the child's therapy and education very precisely. The statements of the parents encompassed both the way the child should be guided, the exercises that the therapist should choose, and the attitude that they were supposed to represent, as well as the types and forms of support that were due to the child from therapeutic and educational agencies.

Sample statements by parents:

Paulina's mother<sup>16</sup>: *"It looks the way it looks, there is talk that schools should implement everything that the consultation offices prescribe. On the other hand, there is the act of law that when it comes to the headmaster, they get... Paulina received very good additional financing, because she has multiple disabilities, and the headmaster re-*

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<sup>16</sup>Out of respect for privacy, the children's names were altered.

*ceives per each division, meaning, per any given class, financing for ten hours per week, meaning, if there are five children, these are two classes, and if Paulina should be attending sensory integration, a course with a speech therapist, rehabilitation and eye therapy, these are already four classes, and there are five children. So it is like that, two children in rehabilitation, while she should be exercising only and exclusively so to speak very precisely focusing on the given exercise and rehabilitation type so that she, well, would be doing sit-ups, but not all the way, or not reaching the floor all the way with her bottom, more at a right angle at the knees, she has habitual dislocation of the patellae, so these patellae can make holes in the knees, the patellae are on the side, because she has such soft joints. Also to be guided by the therapist, she should not be doing this on her own. So the therapist chooses exercises if I may say so blah blah, because this is the way rehabilitation is in school. I tell You, the consulting agencies say one thing, the law says another, the headmasters are all confused and we have to look elsewhere. And this is what it really looks like"*

Jaś's father: *"In order to be a good therapist, one has to empathise with the child. Simply, if they don't want to do it, then the child does not have to do it. The courses have to be attractive, so the child can eagerly participate. If they are not attractive, they won't cooperate."*

Bartek's mother: *"Sadly umm the process of finding the preschool that would be an integrated one, that would offer the therapy that I wanted, was very long, so I kept searching and searching."*

Characteristic in this regard were also other statements of the interviewees concerning changes of the location, therapies or therapists that would not fulfil the parents' requirements.

I look for the cause of such conscious and demanding attitudes of parents both in the limited capacities of the system on the level of early child development support, as well as in the better access to knowledge, even specialised knowledge. The lack of systemic support (even in terms of provision of information) for the parent in the area of medical care and therapy for the child qualifies the shift onto

them of the responsibility for the development of their disabled child. Common access to the Internet, literature as well as training courses and seminars, in turn, causes the parent of a disabled child to more often have – in the given area concerning the specifics of functioning and needs of their descendant – knowledge that surpasses that of the education specialist or therapist, particularly of those that are just beginning their professional work.

The indicated modes of behaviour, attitudes or needs of the interviewees seem impactful against the backdrop of the cooperation of parents with education specialists, therapists or the education or therapy agencies. A parent with knowledge and one that is certain of their convictions concerning the support for the child's development is a challenge to the people working with their child. In this aspect, accordingly, considerations and analyses concerning the quality and the forms of cooperation with parents, as well as those applying to the place and role of the parent within the interdisciplinary team working with the disabled child, seem to be key.

#### Ad. 2. Fixed assignment of roles in the family of a disabled child

The fixed assignment of roles in the family of a child, in the form of the person providing care and the one providing for the family by gainful work, is traditional in character, however, it can still be seen in many families, irrespective of the level of fitness or abilities of the child. In analysing the statements of the interviewed mothers, however, I have noticed factors accentuating their situation. Namely, the burden on the interviewees is decidedly greater. Activities amounting to care are in many cases maximised due to the limited level of self-sufficiency of the child, or due to their needs (e. g. catheterisation). In addition, the interviewees indicated, among others, the need to take the child to the therapy by road, continue therapy at home, arrange additional financing as well as purchasing and maintaining rehabilitation equipment. Significant is also the fact that the time spent by the parent of a disabled child at home is not transitional (as is the case with maternity leave or child care leave), but can continue for many years, or even all of the child's life. However,

the increased costs of supporting the development and functioning of the disabled child imply engaging the second parent in gainful work. The fixed assignment of roles in the family of a disabled child and the negative emotions and stresses this may cause between the parents are described e. g. by the statement of the mother of Julek about her relationship with the husband:

*“There were fights between us. There was lack of understanding. I envied him that he’s going to work, getting out. At the time I thought that his life had not changed at all, that he’s got it great. He goes to work, sees people and does what he ever did. And my life turned upside down, didn’t it... Because I had to arrange everything, I had to let go for instance my off days, thoughts about myself. Anything, even simple shopping, because my thoughts were just the clinic, the hospital, the agency, rehabilitation, prescriptions and caring for the ill child. I thought I’d go crazy and this also impacted the fact of my arguments with Krzysiek.”*

In this regard, the phenomenon that I would call a systemic conditioning of the fixed assignment of roles, as indicated e. g. by the mother of Michał, would seem significant:

*“One thing! Another thing that could be useful, it’s related to finances and organisation, so that one could tie their benefits with gainful employment. Because now you either work or you don’t work at all and you get your benefits. When you get benefits, you cannot work at all, and work in a case like that is often like salvation. In the sense that if you go to work, you forget what you leave behind at home.”*

Beside the specific characteristics of the functioning of a child that might require care and the presence of a parent around the clock, conditions of receiving financial benefits constitute an important factor imposing a fixed assignment of roles in the family. Its consequences in the socio-emotional situation of the mothers (who usually remain home with the child), the internal family relations, even in the aspect of acceptance of the disability of the child by the

parents are described by me as important for further scientific analyses research, as well as in terms of considerations on the optimisation of systemic support.

Ad. 3. Parent “in action” – focus of the parent on coping with difficulties

*Paulina’s mother: “However this focus on Paulinka for health reasons is very strong. Kajka has quite a few problems with nutrition. And I constantly sit in the kitchen. Paulinka can only eat very little. Yesterday it was just the pancakes for Paulina that she had for yesterday and today, I froze some of them, and the time I spent on these pancakes is 2.5 hours. [...] We try to live normally in these abnormal conditions.”*

The above quite is one of the many statements of parents concerning the additional duties that arise from the specifics of functioning and the needs of a disabled child (duties that often are great burdens for the parents). The majority of the interviewees spoke of additional activities concerning care, preparation of educational aids, implementation of the recommendations of therapists or including therapy in everyday life, arranging equipment supporting the functioning of the child, hospital visits, visits to therapy centres or rehabilitation tours at special facilities. The day of the interviewees is in many cases backed from dawn until dusk by activities that they have, or feel obligated, to do.

Significant in this area is also the importance ascribed by the parents to therapy in the process of support of the child’s development. The majority of the analysed children participates in the week in many different therapies that almost completely take up their free time (and fill the time of the parent who participates in therapy or waits for the child). An example here can be a fragment of the statement of the mother of Martyna describing her day:

*“Short quick breakfast and at 8 we go to the integrated preschool. Martyna stays there for six hours. At two, I pick Her up from pre-*

*school and we go to additional courses. The courses are varied, every day they're different and take place elsewhere. When we get home, we continue work at home and around six, Martyna goes to bathe [...] After her bath, around eight, she falls asleep, and sometimes she sleeps eight hours, sometimes four, it's really varied here with us. This is what our typical day looks like. On Saturdays we additionally go to courses in Bydgoszcz."*

Referring to the research of M. Sekułowicz on the burn-out of the strength of mothers of disabled children<sup>17</sup>, as indicated above, I stress the importance that the psychological and physical condition of the parent, lack of rest, time for themselves, the ability to form a distance to their role may have to their emotional fitness. The statements of the interviewees also show tension between the experienced weariness and the burdens on the one hand, and such categories as acceptance of the 'difficult' behaviour of the child, cooperation with therapists or forming social relations. Important in this regard seems consideration of the optimum support of the disabled child at the simultaneous burden of the parent. In the perspective of analyses of the research material, this seems important in terms of the parent processing and handling the issue of the child's disability, and for the purpose of reinforcing their relationship with the child.

#### Ad. 4 The Internet as an important source of knowledge

In their statements, all interviewees underscored the importance of the Internet as a significant source of knowledge, both on the illness or the disability of the child, as well as the options of treatment or therapy and obtaining system support. Important, however, in light of my earlier research, seems to be the fact that none of the parents mentioned the Internet as the "place" they receive social and emotional support. Thus, blogs or on-line forums constitute

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<sup>17</sup> Conf.: M. Sekułowicz, *Wypalanie się sił rodziców dzieci z niepełnosprawnością*, Wydawnictwo Naukowe Dolnośląskiej Szkoły Wyższej, Wrocław 2013.

normalisation tools that in this aspect are unused by the interviewees, even though the great majority describes themselves in their statements as lonely or isolated from their social environment (by lack of time as well). In this regard, there arise questions concerning the formation of social relations of parents of little disabled children and position of the Internet in the area of their social activities.

#### Ad. 5 Exposure of the difficulties in accepting the disability of a descendant in the process of setting out the goals for the support of the child's development

During analyses of the interviews, it came to light that a reply to the question concerning the future of the child posed a great difficulty for almost half of the interviewees. Observed can also be a broad dichotomy in the emotional charge of statements concerning on the one hand the daily functioning, therapy or relations with the child and those concerning the goals set in the framework of support of the child, and the way the parent sees their descendant in a few years, exemplified e. g. by the statement of the mother of Martyna:

*"I cannot imagine that Martyna would not be able to speak... It is still difficult for me to cope with the thought that Martyna has an intellectual disability... Thanks to our work, Martyna started to walk when she was two. I don't know what it would be like today, if I wouldn't have worked on it, she probably would not be walking today. We struggle all the time, we don't give up. Let's hope it just gets better and time will tell what happens. Frankly, I sometimes have enough of this... In reality, I am all alone with this, but I struggle on, struggle for Martyna to have a better future. Maybe once, one day, she would stand in my room, we could watch old photos together, the way it once was and the way it is now... We would speak about what we've fought out in these difficult times. Maybe she would thank me for this once and I still have it in my head that she would once tell me I LOVE YOU MUM!"*

The question concerning the future of the child confronted the parents with their own fear, sorrow and hope. The majority of the

interviewees seems quite strongly focused on the present, a fact that is also determined by the great burdens I have indicated above. In this perspective, a “parent in action” is a parent who has no ability and no time to process the topic of the disability of their child, and, in consequence, to accept it. Contrary to what may seem the case, the attitude of the parent that is often expected from the therapeutic and education environment, meaning – strong engagement of the interviewees in the therapy, setting goals, compensating, balancing and facilitating – can make coping with the negative emotions difficult.

The properties of the process of acceptance of the child and their disability by the parent constitute an area of scientific research that I intend to explore further. The discussed pilot study indicates activity in the category of parenthood and motherhood burdened by disability in areas such as acceptance of disability or support for the child’s development.

## Summary

To summarise the conducted pilot study and my thoughts on the topic of the emotional crisis of the parent of a disabled child, I would like to stress just how important and complex the process of formation of parenthood is in light of the child’s disability, in the period of their early childhood. Characteristically, the new attitudes of the parents of disabled children, their greater knowledge and awareness of the expectations of therapies and therapists or the focus on the child’s rehabilitation process, do not exclude difficulties or burdens that mar being a parent of a disabled child. The socio-emotional situation of the interviewed parents, an outline of which I had attempted to convey, encourages to conduct further reflections and studies concerning the factors implying the parents coping with emotions and difficult (crisis) situations, and suggests an aim towards studying the moments of “transition” between the subsequent stages of emergence of the identity of the parent of



a disabled child. Understanding the drivers behind the behaviour of parents by special education professionals may in turn contribute to an expansion of the area of their considerations of support offered to the family of a disabled child.

## References

- Adamski F. (2002), *Rodzina. Wymiar społeczno-kulturowy*, Wydawnictwo Uniwersytetu Jagiellońskiego, Kraków.
- Borzyszkowska H. (1997), *Isolacja społeczna rodzin mających dziecko upośledzone umysłowo w stopniu lekkim*, Wydawnictwo Uniwersytetu Gdańskiego, Gdańsk.
- Cunningham C.C. (1996), *Families of children with Down syndrome*, "Down Syndrome Research and Practice", no. 4.
- Doroszuk J. (2015), *Sytuacja społeczna rodzin dzieci z niepełnosprawnością. Rekonstrukcja problemowa badań H.Borzyszkowskiej*, Uniwersytet Gdański, unpublished thesis, pp. 233–270.
- Hodapp R.M., Urbano R.C. (2007), *Adult siblings of individuals with Down syndrome versus with autism. Findings from large scale US survey*, "Journal of Intellectual Disability Research", no. 51.
- Krause A. (2011), *Współczesne paradygmaty pedagogiki specjalnej*, Oficyna Wydawnicza „Impuls”, Kraków.
- Kvale S. (2009), *InterViews. Wprowadzenie do jakościowego wywiadu badawczego*, Wydawnictwo Uniwersyteckie „Trans Humana”, Białystok.
- Łobocki M. (1999), *Wprowadzenie do metodologii badań pedagogicznych*, Oficyna Wydawnicza „Impuls”, Kraków 1999.
- Matyjas B. (2008), *Dzieciństwo w kryzysie: etiologia zjawiska*, Wydawnictwo Akademickie „Żak”, Warszawa.
- Pisula E. (1998), *Psychologiczne problemy rodziców dzieci z zaburzeniami rozwoju*, Wydawnictwo Uniwersytetu Warszawskiego, Warszawa.
- Poston D., Turnbull A.P., Park J., Mannan H., Marquis J., Wang M. (2003), *Family quality of life: a qualitative inquiry*. "Mental Retardation", no. 41.
- Sekułowicz M. (2013), *Wypalanie się sił rodziców dzieci z niepełnosprawnością*, Wydawnictwo Naukowe Dolnośląskiej Szkoły Wyższej, Wrocław.
- Szymański M. (2006), *O znaczeniu badań jakościowych nad wartościami*, [in:] *Z badań nad wartościami w pedagogice*, ed. by W. Furmanek, Zakład Dydaktyki, Techniki i Informatyki Uniwersytetu Rzeszowskiego, Rzeszów.
- Twardowski A. (1991), *Sytuacja rodzin dzieci niepełnosprawnych*, [in:] *Dziecko niepełnosprawne w rodzinie*, ed. by I. Obuchowska, WSiP, Warszawa.
- Twardowski A. (2012), *Wczesne wspomaganie rozwoju dzieci z niepełnosprawnościami w środowisku rodzinnym*, Wydawnictwo Naukowe UAM, Poznań.