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PSYCHOSOCIAL FUNCTIONING OF THE FAMILY, RAISING A CHILD WITH DISABILITY, IN THE LIGHT OF RESEARCH AND SOME SELECTED ANALYSIS

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Діана Аксаміт. Психологічне функціонування сім'ї, виховання дитини з недорозвитком у світлі дослідження і вибіркового аналізу. У світі постійних соціальних змін сім'я також переживає зміни. Основні функції сім'ї, її характеристики, батьківські підходи, материнство і батьківство – усе це проходить крізь зміни. Залежно від контексту цих змін, з'являються різноманітні проблеми. Зокрема, сім'я, що виховує дитину з порушеннями, стає місцем, яке ми відкриваємо заново і досі хибно розуміємо. Здавалося, що стратегії підтримки для сімей з дітьми з порушеннями розвивалися протягом років, теоретичні знання і знання проблем середовища достатньо глибокі, щоб ефективно сягати мети, що буде зазначена далі у статті, так щоб це не мало великого значення у життях сімей. Ця стаття оглядає останні дослідження сімей, що виховують дітей з порушеннями, і фокусується на наступних рівнях у цих дослідженнях: народження дитини з порушеннями, важливість соціальної і установчої підтримки, материнство і батьківство, шлюб, діти, виключення з соціуму. Дослідження багатьох авторів, подані у статті, показують зміни в аналізі сімей, що виховують дітей з порушеннями; демонструють не лише проблеми, але й позитивні процеси у таких сім'ях.

Ключові слова: сім'я, дитина, інвалідність, материнство, батьківство, соціальне виключення.

Диана Аксамит. Психологическое функционирование семьи, воспитания ребенка с недоразвитием в свете исследования и выборочного анализа. В мире постоянных социальных изменений семья также переживает изменения. Основные функции семьи, ее характеристики, родительские подходы, материнство и отцовство - все это проходит через изменения. В зависимости от контекста этих

изменений, появляются различные проблемы. В частности, семья, воспитывающая ребенка с нарушениями, становится местом, которое мы открываем заново до сих пор ошибочно понимаем. Казалось, что стратегии поддержки для семей с детьми с нарушениями развивались годами, теоретические знания и знание проблем среды достаточно глубоки, чтобы эффективно достигать цели, будет указана далее в статье, так чтобы это не имело большого значения в жизнях семей. Эта статья осматривает последние исследования семей, воспитывающих детей с нарушениями, и фокусируется на следующих уровнях в этих исследованиях: рождение ребенка с нарушениями, важность социальной и учредительной поддержки, материнство и отцовство, брак, дети, исключение из социума. Исследования многих авторов, представленные в статье, показывают изменения в анализе семей, воспитывающих детей с нарушениями; демонстрируют не только проблемы, но и позитивные процессы в таких семьях.

Ключевые слова: семья, ребенок, инвалидность, материнство, отцовство, социальное исключение.

Diana Aksamit. Psychosocial functioning of the family, raising a child with disability, in the light of research and some selected analysis. In the world of the constant social change the family also undergoes changes. The main functions of the family, its characteristics, parental attitudes, motherhood and fatherhood undergo changes, too. It causes various problems, depending on the context. However, the family, raising a child with disability, becomes the area which is discovered again and still misunderstood. It has seemed that the strategies of support for families with children with disabilities developed over the years, the theoretical knowledge and the knowledge of environmental problems are deep enough to effectively address the issues, which will be mentioned later in the article, so as not to have a greater significance in the lives of families. This article reviews the latest research on families raising a disabled child and focuses on the following levels in the area of research as: the birth of a disabled child, the importance of the social and institutional support, motherhood and fatherhood, marriage, siblings, social exclusion. Studies of many authors, presented in the article, show a change in the analysis of the family, raising a disabled child; showing not only problems but exposing also the positive processes inside the family.

Key words: family, child, disability, support, motherhood, fatherhood, social exclusion.

Introduction

Research on the difficulties with raising a disabled child, the parents' psychic life and other arising problems, have been continued from 40 years.

This might be due to the need to examine this area of research in the multifaceted way because having the child with disability radically changes the situation of the family, especially members of the family (Popielecki, Zeman, 2000).

Many authors do research, guided by the subjective feeling about the problems of this group. According Butkevičienė (2001), the subjective feelings of parents should provide a basis for planning any studies of families with disabled children. The literature shows that parents and siblings are the most common research group, but a disabled child as well, for example: some research on the psychological portrait of a disabled child with in the family (Simanavičienė, 2008).

1. The main research assumptions

It is interesting that with the social change - the increasing number of births of children with multiple disabilities and growing parenting problems - motherhood and fatherhood are becoming increasingly important for the human development, mainly as the personal development (Kornas-Biela, 2007).

The fact is that the family, raising a child with disability, needs a special support. It plays the most important role, helping children to such extent that can not be compared to any social and institutional support. It happens regardless of the perceived dysfunctionality of one of the family's member. No doubt, having a child, whether disabled or not, brings a lot of changes. Research indicates that disability changes the rhythm of family life. Roles, which have been performed so far, not only by the father or mother, but by others in the family, are radically transformed (Popielecki, Zieman, 2000; Ruškus, Gerulaitis, Vaitkevičienė, 2004; Szarkowicz, 2009). The role, which is performed by the family, does not result from the child's disability but also from the other factors (Twardowski, 1991), which will be discussed in the article.

The aim of this article is the analysis of research of parents, raising a child with disability and the analysis of factors, which affect the overall functioning of the family. As a criterion for the analysis of existing research in Poland and in the world the following categories, which affect the functioning of the family, its individual members and the child with disability, were taken into consideration: the birth of a child with disability, the importance of social and institutional support, maternity and paternity as the role of life; marriage; siblings, the social exclusion. Due to the volume of the article, the most important factors will be presented and located in the selected category.

1.2 The image of families, raising a child with an intellectual disability, in the light of literature

In the recent years, the image of people with disability has changed and is still changing. The disability is considered, not in the individual, but social dimension, and the support and rehabilitation – in the holistic way. It entails

the change in functioning, needs, support, all problems in families, raising a child with disability (Gvaldaitė, 2010; Kavaliauskienė, 2010). For the purposes of the system, the individual members of the family are recognized as sub-systems, affecting the functioning of the whole system. Therefore, disability of one family member changes the functioning of the whole family. There are efforts, which aimed to create a model family with a child with disability, which refer to the system approach, not a cause – and – effect relationship (Liberska, Matuszewska 2012).

The results of the latest research in this area demonstrate the need for cooperation of the family with various institutions, supporting the child in the early stages of rehabilitation (Naess, Grue, 2012). According to recent reports, there is a problem in cooperation between different supporting sectors, mainly between the educational institutions and therapeutic, medical sector and social care (Kreivinienė, Pertulla, 2011).

No doubt that recent research has brought a lot of new and effective solutions, new models of support, methods of cooperation with family, raising a child with disability. However, the internal family system generates the most desirable and appropriate system of support for the child. The solutions we are looking for, using the quantitative and qualitative methods, are found in the subjective perception of the individual family member.

The quality of family life – satisfaction from the support, parents mental health, working – has a significant impact on the process of adaptation to disability (Woolfson, 2004; Nedelisky, 2004, Henderson, Bryan, 2011).

During the years, researchers were interested in the etiology of disability and its causes. Today, not only the answers are sought but researchers follow in the direction of constructing multi-dimensional models. As has been mentioned, most of the research look for practical solutions to problems existing for years. This is the result of attention to areas which have not yet been taken into account, and which are very important in this problem: the parental identity (Kobosko, 2000), the importance of communication with the child, a bond, acceptance, perception of their own parenthood (Bakiera, Stelter, 2010), as well as measuring the quality of maternity development of a child with disability (Karwowska, 2007). There are attempts to analyze: the spiritual strength, internal mechanisms of support between family members, capabilities and positive aspects of the functioning of such families (Tway, Connolly, Novak, 2007).

The birth of the child with disability

The multidirectionality research of the family may also result from the fact that problems, occurring shortly after birth, after the diagnosis, may be continued for years. They might take a different form, change the intensity, but are still. Several years ago, the information about the child's disability, manner and place of the information about disability, were not taken into account during research.

In contrast, today these issues attribute a great importance to the

functioning of the family in the next few years (Starke, Moller, 2002; Butkevičienė, 2000; Gundersen, 2011). The first information about disability is the beginning of rehabilitation and thus – the beginning of parents' shock, crisis, questions and blame. No doubt, it has a great impact on the functioning of the family, marriage, parents' mental health and other members of the family. The research Ustilaitė et al. (2015) shows that parents are informed in an improper manner, without ethical principles, in the presence of another person, in an incomprehensible way, sometimes causing great hopes and parents' expectations, and sometimes giving a restorative hope or chance of the child's development.

The functioning of the family and its individual members indirectly influence the development of the child (Wojciechowski, 2007; Kościelska, Bassam, 2004; Twardowski, 1999).

The importance of social and institutional support

Analysis of the literature shows that the causes of family problems - in motherhood or fatherhood - are dealt with the social and support dimension. Parents who receive a variety of support, not only financial but also some social and psychological help, feel happier, they see fewer obstacles in raising their child. This also applies to the importance of support between spouses (Jusiene, Bagdonaite, 2004), and such analysis was carried out earlier (Heward, Orlansky, 1992; Geatheart et al., 1992). Research conducted by Borowicz (2012) shows that the spouse is the most indicated person. In the group of fathers who got support from wives is higher than in the group of mothers who received support from their husbands.

Accepting a child with disability is a long process, not only completed successfully. It depends, however, on the interactions within family, the using of the support, the parents' lifestyle (McLaughlin, Goodley, Clavering, Fisher, 2008). This is confirmed by study on the parents' emotional well-being (Raudeliūnaitė, Rympo, 2012). Studies conducted in Norway in the group of families, raising a child with disability, show that the third part of respondents seeks information and support in the Internet (Gundersen, 2011).

The educational institutions, centres of early intervention, preschools, schools and revalidation centres are the most important sectors of support. The right choice of the form of child's education is very difficult. As Górnicka (2013) points out, the moment of starting the school, is the time when the family experience a lot of difficulties. They arise from the fact, that this is a time when the child must cope alone, without parents' help and involvement. Sometimes, the school does not normalize the family's life, often the problems are even worse. At this point, the child's perception of relationship between mother and father, their emotional ties, their life's attitude is very important. It has also a great impact on the child's development and functioning (Wojciechowski, 2007).

Motherhood and fatherhood

The emergence of disability carries a lot of emotionally and socially

difficult situations. As a result, the life of families' members starts to be disorganized. The process of adaptation to the role of parents of child with disability is long, leading to the use of inappropriate educational methods, the wrong approach to child's emotional life (Twardowski, 1999). They developed a model to adapt to the social role of the parent of a child with disability, in which the model takes into account the category of parents' suffering (Moose, 2002), and the fetishization to the role of the parent is recognized as a way to limit the process of adapting to it. This model was modified by Będkowska-Heine (2007), which, unlike the previous author, recognizes that the fetishization limits the development of the child. According to her, in the process of adaptation to the role of a parent of a child with disability can be distinguished: falling into the trap of the role, become familiar with the role, identification with the role, imprinting to the role, ingrown to the role, the empowerment of the role. Raising a child, whether it is with a disturbed development, and a healthy child, is associated with a variety of conflicts, which is somehow placed in parenting. Such processes as fetishization, manipulation, denial, creation are considered a sign of maladjustment of the role of parent (Będkowska-Heine, 2007).

Motherhood and fatherhood may be considered as a value. Functioning as a mother or a father gives sense of fulfilment, meaning of the existence. Analysing the researches on the family with a disabled child shows that being a parent of a disabled child is like being a parent in general. It is crucial to notice that among the factors which influence the quality of fulfilling the role of a parent by a mother as well as a father, kinds and levels of the child's disability and his/her behaviour are also listed (Upadhyay, Singh, 2009). Reachardson (2012), who studied that issue, claims that the worse the parents estimate their child's development and his/her abilities, the more stressed they are. It was visible in the researches in which the respondents were talking about the feeling of the lack of self-acceptance, accompanying them for many years of disability.

The roles of a mother and a father in a family with a disabled child are completely different. The researches by Bakiera and Steller (2010) prove that parents of the disabled child show limited acceptance of their parental role if comparing with parents of a healthy child. They more often express negative statements about their roles. The difference can be seen if talking about mothers as well as about fathers. According to Pisuli (2007), especially fathers are involved in complicated social and emotional situation when in the family appears a disabled child. Fathers adopt a defensive strategy, they mask their feelings, they do not express their feelings, they do not seek for support, and unlike the mothers, they do not ask for psychological help. The written sources give many examples of the researches on the influence of the child's sex and the level of his/her disability on the parental fulfilment. And what is more on the fulfilment of a father. Those researches prove that for the father the most difficult to accept is the disability of the son. The research by

Ustilaitė et.al., (2012) shows that the quality and the direction of the inner processes taking place in the family with a disabled child depend on the quality of the parents' life and their professional and social activity.

Parents of both disabled and healthy children have some expectations towards their parenthood. As Biedrzycka (2007) claims, along with the disability of the child the whole value system of parents may change, their professional career, the way of spending their free time and their social successes become of subsidiary meaning. The research made by Stelter (2014) shows that accepting the maternity role by the mother of the disabled child has an influence on her professional career. Which is also proved by the researches by other authors (Bańka, 2007; Barnett, Hyde, 2001).

It has been noticed that in many researches conducted on the family, the mothers are the main research group. What is more there still lack some researches on the situation of the fathers in the families with a disabled child. As an example we can mention here the research made by Stelter and Harwas-Napierała (2010). The result of that research proves that the mothers are the most emotionally involved in bringing up a child with a disability. It goes in accordance with the researches done in the 90s of the 20th century, which indicate that men in contrary to women concentrate on the problem, whereas women focus on emotions (Billings, Moos, 1984).

It can originate in the fact that women are more involved in nursing their children, which results in their exhaustion, mental overload, but also in building some emotional bonds (Mikołajczyk-Lerman, 2011; Maciarz, 2004). According to Karwowska (2007) it may result in a longer process of accepting disabled children by their fathers, rejection, breaking of the emotional bonds in the family. However, it is possible to involve the father of the disabled child in the process of the child's upbringing, what is proved by some researches.

The factors in favour of the process mentioned above are: psycho-education, bringing the mother out of herself and letting the father taking care of his child (MacDonald, Hastings, Fitzsimons, 2010). The researches' results given above do not prove that fathers are indifferent to disability of their children, they just experience it in different way and express it in different way, they have different mechanisms of managing with this situation (Buczyński, 2001; Twardowski, 1999). It can be proved by the results of the researches conducted in the 90s of the 20th century by Dorota Kornas-Biela.

The fathers of mentally disabled children, who were the subjects of her research, pretended to be indifferent towards the whole situation. In the opinion of some of the researchers, the father's position very often excludes him from the child's upbringing, which results in dysfunction of the father's identity and in the lack of closer bonds with the child (Wojciechowska, Cierpka, 2007).

Marriage

The clashes between the spouses have got different origins. Some of the

researches indicate that in the families upbringing a disabled child may appear some clashes caused by the disability (Mikołajczyk-Lerman, 2011), but some other researches (Mansell, Morris 2004; Gerulaitis, 2006; Raudeliūnaitė, Rympo, 2012) prove that disability of the child is not a cause of the conflicts between the spouses. The shape of the inner family bond, the level of the support given each other by the family members, even before the birth of the disabled child may also be a reason of the conflicts.

A very important factor in this kind of researches is gaining some satisfaction within a marriage by both of the spouses (Deater-Deckard, 2004, by: Dubbs, 2008). Very often, the marriage who raise a child with disability is not in a relationship any more, but they become a group of people working together in order to rehabilitate their child (Karwowska, 2007). Here is the point at which we can observe the differences in the level of the support given each other by the spouses. The higher the degree of the disability the lower the level of the support given each other by the spouses (Jusienė, Bagdonaitė, 2004).

In some cases, it is not the disability of the child that disturbs the functioning of a marriage, but the lack of close bonds and help between the spouses, which may result in a decay of the family. The marriage as an intimate relationship between two people does not exist any more if the bonds between them are broken and the two of spouses take care of rehabilitation of the child. The higher the degree of the disability the lower the level of satisfaction in the relationship (Bobkowicz-Lewartowska, Tarnowska, 2012). The research made by Stelter (2014) which studied some of the factors influencing the fulfilling the role of a father and the mother of a disabled child are also very interesting. The research proves that the fulfilling of the role depends on the child's features, but also on the level of satisfaction gained within the marriage.

Siblings

The family is a system which consists of smaller subsystems. The disabled child is not the only one subsystem in the family, his/her siblings are also the family subsystems. According to Wojciechowska (2007) a disabled child may also influence the social functioning of his/her siblings. The disabled child may shape empathy and tolerance of his/her siblings for disability. But there might also appear some problems in contacts with other people and difficulties in making a relationship. According to Biedrzyckia (2007) being in contact with a disability since the young age may positively affect the siblings. There are some researches proving that a disabled sibling has a positive psychosocial influence on a healthy sister or a healthy brother. As Sidor (2005) claims 25% of children who have a disabled sibling had improper relations with their peers.

Exclusion

Together with social and economic changes, we can observe some changes in inner and external functioning of the family. Some social and

companionable bonds are weaker. It may be caused by isolating the family by itself or by the society. According to the researchers of this aspect of functioning of the family, it is caused by the reaction of the surrounding to the disability (Janion, 2007), by the excessive care or exclusion, by the fear, the lack of time and by the shame (Kawczyńska-Butrym, 2007; Twardowski, 1999). According to Pisula (20017) the inner isolation of the family may be also caused by the excessive curiosity of the surrounding and by comparing to other families. The research by Skórczyńska (2007) shows that the financial issues are ones of the most stressful for the family. The phenomenon of exclusion is also an indicator of the quality of life and it influences the process of socialising the child.

Conclusion

The analysis of the researches proves that the family is very important in life of a disabled person and inversely, disabled children and adults play a crucial role in functioning of the family. There are many models of the family: supportive and accepting, but also rejecting or overprotective.

Studying the sources proves that the quality of inner family interactions depends on the intensity of the influence of disability on functioning the family as a cell and on functioning individual members of the family. As it arises from the researches discussed above disability of a child somehow deranges stability of the family, but it dose not destruct the family. This conclusion changes the point of view connected with functioning those kinds of families not only in the categories of the problem.

The acceptance by the family members very positively influences self-confidence and possibility of fulfilling social roles by the disabled children. In conclusion some results of the researches by Mikołajczyk-Lerman (2011) have to be quoted. According to those researches parents do not perceive the disability of the child negatively, but they believe that their child is wonderful, they appreciate the fact that taking care of the disabled child gives them possibility to get to know people from different perspective. The bigger the number of the families the bigger the number of factors of life quality, maybe not those academically standardised, but those being subjectively felt by parents. It may be also connected with the family support models, since in the process of planning the support it is important to take under consideration individual needs of every single family, its uniqueness, which is also confirmed by many other authors (Grue, 2011; Harnett et.al., 2009; Rahi et.al., 2004).

The case of the family with a disabled child may be considered in a unitary way but also in a general way. It has to be admitted that the researches conducted on that case have their reflection in some researches done by some other authors, regardless of their character, they could be qualitative or quantitative. The family of the disabled child can not be considered as a problem, because as the researches show in that study group hope may be found, and the inner family support is also of a great importance. This article

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НОРМАТИВНО-ПРАВОВЕ ЗАБЕЗПЕЧЕННЯ ОРГАНІЗАЦІЇ ІНДИВІДУАЛЬНОГО НАВЧАННЯ ДІТЕЙ ІЗ КОМПЛЕКСНИМИ ПОРУШЕННЯМИ РОЗВИТКУ

Відомості про автора: Юлія Олександрівна Антибура, аспірантка кафедри педагогіки та корекційної освіти Дніпропетровського національного університету імені Олеся Гончара, Україна. Email: Julie_Antibura@mail.ru

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Антибура Ю.О. Нормативно-правове забезпечення організації індивідуального навчання із комплексними порушеннями розвитку. Розглянуто основні методичні підходи до організації індивідуального навчання дітей з особливими освітніми потребами, а саме із комплексними порушеннями розвитку. Проаналізовано проблеми законодавчого забезпечення організації індивідуального навчання із комплексними порушеннями розвитку зокрема порушеннями слуху і затримкою психічного розвитку. Порушено питання організаційно-педагогічних умов індивідуального навчання, індивідуального навчального плану для учня на основі даних психолого-педагогічної діагностики, специфіки опанування учнів з освітніми особливими потребами знаннями і навичками, визначення характеру і причин труднощів навчальної діяльності, їх запобігання не знайшли в спеціальній літературі достатньої науково-дидактичної і методичної реалізації. Виявлено значні прогалини в організації індивідуального навчання дітей з особливими освітніми потребами: роз'єднаність зусиль всіх його учасників; неоднозначне розуміння шляхів і засобів подолання