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The effects of involvement in non-governmental organization activities as an example of Lifelong Learning – the example of the experience families of children with ASD

The aim of this paper is to describe and analyse how families with autistic children self-organize and how they evaluate received support. The author is going to show how parents from provincial area cooperate with the local community to create support group and educational meetings for their families. This research is based on project which involves about 30 families from the countryside. The present study was run between April and December 2015 and followed action-research methodology. The objectives of the project were to create qualitative changes in the life of families with autistic children and to strive for equalize the equality in access to social support and specialists among parents living in the city and in the countryside. The paper is going to show how project participants describe taken actions, especially in context of Lifelong Learning perspective.

Keywords: ASD, parents of disabled children, social support, lifelong learning

Wpływ zaangażowania w działalność organizacji pozarządowych jako przykład Lifelong Learningu – na przykładzie rodzin dzieci z ASD

Celem niniejszego artykułu jest opis i analiza procesu samoorganizacji rodzin dzieci z autyzmem oraz ich ocena otrzymanego wsparcia. Autor zamierza przedstawić jak rodzice z terenów wiejskich poprzez współpracę z lokalną społecznością tworzą grupę wsparcia i warsztaty szkoleniowe dla ich rodzin. Opisywane badanie jest oparte na projekcie angażującym 30 rodzin dzieci z autyzmem z terenów wiejskich, który odbywał się na przełomie kwietnia i grudnia 2015 na podstawie metodologii badań w działaniu. Celami projektu było wprowadzenie jakościowych zmian w życiu rodzin dzieci z autyzmem oraz wyrównanie nierówności w dostępie do wsparcia społecznego i specjalistycznego wśród rodziców żyjących na terenach wiejskich. Artykuł przedstawia jak uczestnicy projektu opisują podejmowane działania w odniesieniu do perspektywy Lifelong Learningu.

Słowa kluczowe: ASD, rodzice dzieci z niepełnosprawnością, wsparcie społeczne, lifelong learning

Disabled children in families

A literature review around the issue of disabled children in families shows many aspects. Much of the literature describes problems related to the diagnosis, treatment, education, social functioning of both the child and the whole family, as well as issues related to social assistance (Błęszyński 2004; Kościelska 1998; Maciarz 2001; Pisula 2003, 2012; Obuchowska 1991; Stelter 2013 *et al.*). For me what is most interesting is the parents' point of view. Parents describe waiting for a diagnostic assessment as the most meaningful and stressful moment, and the experience of waiting is reported as "turned on its head" (Connolly, Gerschb 2013: 299–302). They compare getting the information about their child's disability to entering into a different world with completely new rules and a new order. This situation results in a wave of questions about the reasons for this state of affairs and the search for the guilty, often associated with blaming one another. The path which the parents of children with disabilities must go from the moment of the child's birth to accepting the fact of its "otherness" is very long. Social acceptance, a sense of support and the understanding of the nature of the child's disorders allows, however, for a gradual organization of their lives again (Lipińska-Lokś 2010: 341–342).

Their situation is very often described as a crisis in the family – the crisis of the new, the crisis of the values and the real crisis relevant to everyday life, resulting from the fact of having a child with a disability, which often lasts for life: financial problems, rehabilitation of the child, social acceptance (Tomczyszyn 2009: 178–182). This, in turn, can significantly affect the implementation of roles in the family – of a parent or a spouse. Often, in the event of a child with a disability appearing in a family, we can speak about discrepancies between the expectations and the reality in which the family has found itself. What awaits them, is not only the so-called normative crisis resulting from a change in the cycle of the family life, in connection with the birth of the child, but also the tensions associated with the necessity of accepting the child's disability and with high social expectations. The devotion of a considerable amount of time to the child and to its treatment, the frequent feeling of lacking competence in fulfilling the role of the parent (which refers both to the child with the disability and to the healthy siblings) and the lack of mutual support may also adversely affect the roles of the partners. Inconsistency in accepting and fulfilling the roles in which the parents have found themselves may in turn cause frustration and permanent stress and, therefore, the breakdown of the family (Stelter 2013: 82–89). For some parents, their child's disability is, on the other hand, a binder of family life – a challenge posed in front of them, a task to help ensure the best possible life for the child (Ossowski 1999: 156).

Non- typicality of families of children with autism

My research interests are focused on families of children with autism/ ASD (autism syndrome disorder). What makes them different? Firstly, the lack of information about the exact etiology of the disorder and the difficult and long diagnostic process. Secondly, the disorder has an unconventional course. The previously described process of stepping into the role of the parent and accepting the child with a disability is quite differently shaped for parents of a child with ASD. At the time of birth and the first tests it is usually indicated that the child is "safe and sound", which parents receive with a relief and joy, and start making plans for the future of the child of their dreams. However, most children with ASD may appear to develop normally even until 2 or even 3 years of age, but then start to lose interest in others and become silent, withdrawn or indifferent to social signals. Also the children's non-typical behaviours (such as aggression, autoaggression, echolalia, stereotyped movements) very often are meaningless for society, which results in the whole family stigma (Randall, Parker 2010: 28–30). Thirdly, ASD forces both the family members and the entire close environment to adapt to the specificity of the disorders, in particular through sensory integration dysfunction and abnormal sensual reception of stimuli from the environment and by the rigid and limited behavioral repertoires (Bleszyński 2005: 102).

Parents find themselves in a new, and unknown situation, incomprehensible for them, which raises many questions and doubts. They begin their struggle – in pursuit of explanations, which they will never fully get. The long and frustrating journey through the diagnostic process and the search for assistance and appropriate therapy is related to strong emotions and the lack of understanding and acceptance on the part of the close ones – which often involves superficial assessments and painful labels rather than support and reassurance (Płażewska, 2009: 167). In such situation, even the best preparation for the role by learning it (which begins in early childhood), the possibility of planning their own activities and social support are inadequate (Gutowska, 2008: 32–34). Parents must understand the importance of the situation happening to them, analyze and re-evaluate their expectations, goals and their foregoing knowledge about the education of their offspring. This involves the redefinition of roles served in life – of a parent, partner, employee, etc. (Wiatr 2014: 100). They learn them again, by getting to know the mysteries associated with the symptoms of autism, with the therapy and support for the development of their child. This raises the need to read through specialist journals, publications or official documents, which is not easy for all. What is essential in the first stage of the struggle with the diagnosis of the child is not only the emotional or economic support, but, above all, support with information.

Social support conditioning

Effective support of a child with developmental disorders is largely dependent on the full cooperation between the family environment and specialists. It is expected from the parents that they will make a partner relation with therapists, teachers and psychologists, and this in turn requires that they have an open attitude, confidence and communication skills, enabling mutual understanding. The tasks which parents are facing, often extremely difficult and complex, require continuous improvement of the level of their knowledge and systematic work with the child (Garbiec 2014: 129).

The assistance provided to families of people with developmental disabilities by institutions is primarily to meet their expectations and needs, as well as to increase their competences in fulfilling the basic functions. It is important to diagnose and trigger their skills, capabilities and resources, so that they can deal with a crisis situation by themselves (Szymanowska 2008: 61). In this aspect, what is important is access to a social support institution, specialists and an educational centre for the disabled, all of which is significantly limited in the countryside. Very often parents are uninformed about social support and therapeutic possibilities, because of a lack of supporting institution in their area. How to effectively support families from the countryside?

My perception of social support is related to a Polish educational therapist Stanislaw Kawula's concept, which emphasizes the active role of people in the process of changing their living situation. It is based on social interaction, during which emotions, information and values are exchanged. That exchange can take place within four types of relations: individual- individual, individual- group, individual -institution and individual - wider social system (Kawula 2012: 154-155). The ultimate goal of such interaction is to build a spiral of kindness, where the individual needs to give an impulse to social support that leads to self-development (Ibidem: 58-59). Working on Kawula's concept helped me to imagine his spiral in a different way. From my perspective, I would like to interpret the model of "the spiral of kindness" after Maria Mendel as a robust design, a backrest frame for building reciprocity of human relations (Mendel 1999: 56). Going further in the interpretation of Kawula's model, I would like to treat the described "spiral" in a more spatial way, comparing it to a spring. This model, based on social interactions, shows that the more arms of the spiral there are, the bigger is the power to achieve autonomy.

One of the significant issues on the way to support families with autistic children is the partnership of family, school and local communities. That may give people a chance to create a space where social progress through cooperation will be possible. An important place, when referring to the mobilisation of the society

for people with autism, is taken by environmental cooperation on the “educational partnership”, defined and promoted by Maria Mendel. I understand educational partnership here after Joyce L. Epstein as the concept of cooperation of the school with the family and the local environment, recognizing it as an alliance both for the optimal development of the child's possibilities and for the cooperation aiming at broadly understood social progress. This allows for a creation of a space in which the influences of the family, the school and the local community are intermingling, and they create cooperation, which is essential for all the elements (Mendel 2002: 25). The common space is created mainly by the influence of parents to the other components. This is because they are the ones who, motivated by improving the conditions and quality of life and education of their children, are the most plastic binder of the ties needed for the cooperation of the family environment, the school and the local community (Mendel 2000: 20).

All these environments are in fact more or less involved (but equally important) in the development of people with autism – their education, socialization, rehabilitation and social integration. The group under research in my project is the parents from the Association “The World of Autism”, who by taking actions to change the situation of their children, aim at the aforementioned cooperation, by involving the representatives of their children's schools, the municipal and district institutions acting in favor of people with disabilities, the non-governmental organizations, as well as their friends and neighbours in the projects they plan. In principle, the partnership between these institutions aims at improving the understanding of the needs and problematic aspects related to their functioning and at allowing the development of joint solutions related to education, upbringing and rehabilitation of children with disabilities.

Lifelong Learning

In the context of social progress, the most important goal for parents is to achieve greater knowledge about their child's disorder, therapy methods and also to achieve skills of coping with difficult behaviour. That allows for understanding their situation in the perspective of Lifelong Learning. I understand LLL as “a process which stimulates and empowers individuals to acquire all the knowledge, values, skills and understanding they will require throughout their lifetimes and to apply them with confidence, creativity and enjoyment, in all roles circumstances, and environments” (Watson 2003: 3) or as Peter Jarvis explained: „as the combination of processes throughout a lifetime whereby the whole person – body (genetic, physical and biological) and mind (knowledge, skills, attitudes, values, emotions, beliefs and senses) – experiences social situations, the perceived content

of which is then transformed cognitively, emotively or practically (or through any combination) and integrated into the individual person's biography resulting in a continually changing (or more experienced) person" (Jarvis 2007: 2).

Lifelong Learning is also important in the context of social policy. In the European Union, LLL has been the cornerstone of numerous social development strategies for years as a way to overcome the economic crisis and compete with other economies. In Poland there is also a document (*The Lifelong Learning Perspective*¹) implementing the LLL perspective as a strategy of Polish policy assuming social investment – investment in people via education. So far the idea of learning through all stages of life as a policy is implemented by the Ministry only through spreading information about the value of LLL on conferences and other events promoting LLL among schools directors and teachers (Mendel 2016: 159). Nevertheless, the educational system in Poland does not provide any workshops or training program for parents of disabled children, which could have ensured competence to become more conscious and involved in the development of their child (even though the state supports the activities of NGOs in this field). It shows that "education" is being displaced by "learning" and it is becoming increasingly difficult to isolate an educational policy from a socioeconomic policy. Many researchers noticed, that lifelong education was transformed into a lifelong learning (Borg, Mayo 2004: 20–25; Mendel 2016: 159–160). This change proved moving the responsibility for the education. As we can assume, the governments and their agencies are identifying and promoting general interest, so that the role of NGOs and civil society is to "challenge governments to ensure that their conception of the general interest includes a commitment to the development of all adults, recognising the diversity of their needs and inspiration, and providing space for the realisation of their creativity and imagination" (Tuckett 2009: 331) to secure their (the NGOs and the civil society's) own goals. Research shows (Sobotka 2011; Cyboran 2013) that the educational context is placed at the margins of strategic planning in the local community and the local government policy. When children's and young people's education increasingly arise in the local development strategy, adults are predominantly left to their own means. It is similarly in local calls for proposals (including the most important – since it is most funded – call for proposals to support the implementation of public tasks), thanks to which NGOs can count on being funded. In the Kartuski district, which is the area of my research, if parents working in associations for children with disabilities want to obtain funding for a project that includes training for them, they must present the rationale of the project in such a way that they demonstrate that these

¹ The Lifelong Learning Perspective – an annex to the resolution no. 160/2013 by the Councils of Ministers from 10th September 2013.

actions have an impact on the development of their children, because only activities improving the well-being of persons with disabilities are financed and not the ones targeted at their families².

Research project and findings

So how can we support families of children with disabilities? I will briefly present here the research project carried out together with the Special Educational Centre and the Association "The World of Autism", which aimed at creating an offer tailored to the needs of parents. The objectives of the study were as follows: to explore the needs and experiences of families with autistic children in their everyday life, to create a support group for parents, to enhance local partnerships, to create changes in the life of families with ASD children, to equalize opportunities in access to social support and specialists between the city and the countryside. In order to achieve these objectives, the research project has followed action research methodology, which by definition is focused on solving specific social problems. The researcher in this orientation takes on the task of resolving the specific problems relating to the functioning of a certain program, organization or community, becoming the inspirer and active participant in the events covered by the study (Juszczak 2013: 183).

During the whole time of creating the support group, the researcher collected information through registering audiovisual data, making notes and interviews. The stages of the research were: diagnosing, planning actions, taking actions and reflections. As we can find in source literature: "Through the spirals of these activities, action research creates conditions under which learning communities may be established; that is, communities of enquiries committed to learning about and understanding the problems and effects of their own strategic action, and the improvement of this strategic action in practice" (Carr, Kemmis 1995: 164).

The first stage was an organizational process, which started with a meeting with the association's members, who decided to invite other parents from the local area to take part in planning the actions. In January 2015, we conducted a survey among 30 families from the association and from the educational centre for the disabled in Żukowo. The parents responded to 14 questions. The results served to create a project called "Parasol" (eng. Umbrella). After a discussion of the results of the survey, parents from the association started to cooperate with local actors, teachers and specialist, who helped in organizational tasks and took part in the project. Also a group of students from the University of Gdańsk were involved

² An exemplary call for proposals can be found at: http://www.kartuskipowiat.com.pl/userfiles/files/kuczowska/2016_konkurs_caly.pdf [access: 23.12.2016].

in the project as volunteers. What is important is that parents started partnerships with other associations focusing on families with disabled children and with local schools that have offered meeting-places for the whole project. The draft project was based on literature review, the survey results and the parents' suggestions. It was structured in order to fit into the District Governor's Office competition, which funds the project.

The second stage – taking actions, was based on meetings with parents. Before we started the project, during the first meeting for participants, the parents noted their needs and expectations from the support group, which were: joint meetings and discussions with other parents, exchange of information and experience between them, learning how to deal with stress, ways to relax, accepting the child's disability, dealing with difficult child behaviours, improving communication among parents, enhancing cooperation with teachers and schools, getting knowledge about local specialists, possibilities of social support and education. As parents said, the impulse to take part in the project was the invitation to joint meetings and integration activities based on their and their children's needs.

The support received was based on the project. According to the results of the survey meetings were organised on Saturday mornings in two places – Kartuzy and Żukowo (so that families might choose a place with better access). The project took place from April to December 2015. Classes for children were at the same time as meetings for parents. They also had a possibility to bring other children. All children were in the care of therapists and students from the University of Gdańsk, so that the parents could be fully involved in the meetings. The parents had workshops with specialists and teachers about dealing with stress, working with children at home, cooperation with schools, social workers and relevant institutions. The support also included cooperation between parents, who started to act by exchanging telephone numbers, creating a mailing list, discussion group on Facebook and creating a website. They also helped each other in dealing with official matters in schools and institutions and shared their skills (e.g. in feeding, handling with difficult behaviours, ways to motivate and cooperate with the child).

Additionally, there were organised meetings, during which parents discussed the association's activities, which had been planned. Moreover, they organised a library with books about autism, which they had got from their own sources and had bought from a special fund. At the end of the project the parents received a CD, where they could find quick references to most significant information from the workshops, pictures from the meetings and a compendium with contacts to doctors, specialists, therapists and educational centres for the disabled – it was supposed to be a kind of a "first aid kit". One of the results of the project was establishing a support group, which is still working twice a month. The prior-

ity for parents is to recruit volunteers to take care of their children during the planned meetings and activities. Parents have also acquired a place for the association, which has been renovated by themselves. They organised a conference for celebrating the World Autism Awareness Day for teachers from the countryside. They also organised trips together to the cinema, restaurants and playgrounds. Recently, they are caring out next project, fourth one.

The fourth stage of research – reflections – is based on the researcher's observations and the parents' statements. What is most significant is that parents have become more open to other people. Very often it was the first time they started to speak about their own problems and difficulties – not just about ASD and their children, but about themselves as parents and partners in relationships. Most of parents who have participated in project have joined the association. They have started to resolve their problems based on other parents' experiences and tips. They have found a common line of action in social problems. They have started to cooperate with each other and with their child's school, creating new ideas, arranging joint meetings and other activities.

The observations and notes conducted during the "Parasol" project, and also the conducted focus group interviews have, however, not been satisfying for the researcher. The reflections on the impact of the activities undertaken during the project on the lives of the families, have become an impulse to continue studies including intensive qualitative interviews with project participants. The qualitative interview as a research method, is understood in this paper as "a mutual exchange of the overview of the situation by the people who talk about a subject of their mutual interests" (Kvale 2004: 26). This "mutual exchange of the overview of the situation", can be further, after Kvale, compared to a drawing by Rubin, where you can see either a vase or two faces facing each other. The interview also has two aspects, dependent on what we focus on – the personal relation, that is, the interaction between the one doing the interview and the interviewed person, or on the mutual flow of information, where there is continuous exchange on the line of the one getting to know and the one being studied and also between the one creating knowledge, and the knowledge created (Ibidem: 26–27).

The interviews were conducted with ten mothers of both younger and older children. These were, therefore, women with varying experience of "living with ASD". The questions were focused around the impact of participation in the project on the life of people under research. What was mentioned by mothers as the greatest value of the project was its educational value. The acquired knowledge and skills can be divided into two groups – interpersonal and intrapersonal. What the research participants primarily described as an asset was "breaking the ice", understood both as starting to talk on problematic topics with one's partner or family, making new contacts and having courage to make conversations about

one's difficulties with others, as well as having confidence while undertaking administrative and official affairs. In their statements, mothers often referred to themselves as "the struggling mothers", highlighting the effort and courage they show while undertaking difficulties associated with obtaining benefits and support for their children. On the other hand, however, there were comparisons to "the begging mothers" – "You have to hide your pride in the pocket and that's it. Go and beg, just beg" (B2). The research participants have also considered the formation of a support group and the increase in the number of members of the association as valuable. They mentioned here both the initiatives already taken and the planned ones, as well as the benefits of working in a group – "(...) they will look differently at us, when we say that we are in an association, and that we are in some organization, than if you are, well, an individual person, who does not have this knowledge and capabilities, so to say (B4)".

In terms of intrapersonal competence, the mothers taking part in the study talked about gaining more knowledge about autism and about themselves (mainly in the context of recognition of their own needs and ways of coping with stressful situations), a greater sense of confidence and security, which they had gained thanks to the support of other parents and to acquiring the ability of being assertive. The project was for them also an opportunity to reflect on the role of ASD in their lives: "[...] autism is not the centre, it is a kind of companion in our lives, and not the most important thing, it does not have to affect the family, or rearrange everything in our lives" (B7).

In relation to the LLL perspective, the most significant thing for parents was the opportunity to share their experiences and knowledge. Educational experiences among the mothers taking part in the research are different. As one of the mothers said when I asked her what the project has given her: "Greater self-confidence, feeling that I'm not alone with this situation and also new experiences and a lot of new knowledge – about basic information, like: which doctor is good, which psychiatrist is good, which medicine works better, what to do and not to do – a lot of experiences and knowledge" (B6). Or another one: "What has the project given me? It has given me a lot! From meetings with parents of kids like Antoś, conversations – it has built me up. It involved sharing new things, how to handle the kids and myself to function properly". In the longer term, the mothers speak positively about the possibility of sharing their knowledge and experiences with others, both in terms of addressing current difficulties, and seeing a potential route for the future: "Because after all the time spent seating with your child and going through all this behaviourism and those other methods, what was left was either to be a therapist, or just to get involved in a different way" (B8). The image a parent of a child with autism as an experienced therapist makes it possible to take advantage of the recognition of prior learning outside formal education and

of getting professional education. Thus, it has the potential of enabling one to find a job and gain greater autonomy.

Conclusion

The association described by me and the project which is being implemented exemplify the ability to self-organize by a community striving for change. It is at the same time a community that does not work for profit but in order to solve problems through unconventional, fast and competent adaptation to the needs and expectations of people who are being supported. Commitment to a common problem and a similar system of values is the motivation to take actions that are carried out on the basis of democracy and partnership, as well as the work of volunteers (Wejcman 2011: 60–64). The mobilization of society for persons with autism is associated with the community's cooperation, which should be based on a previously described "educational partnership" of both the family, the school and the local community. The parents from the "World of Autism" Association take actions to change the situation of their children and this way aspire to the described cooperation, involving in the planned projects both the representatives of their children's schools, municipality and county institutions working for persons with disabilities, non-governmental organizations, as well as their own friends and neighbours. In principle, the partnership between these institutions should increase the understanding of the needs and the problematic aspects related to their functioning, and to allow for the development of common solutions related to education, upbringing and rehabilitation of children with disabilities. Developing one's own knowledge and competence in the field of therapy and education, as well as the ability to draw conclusions from their own experiences and to share them with other parents also indicates the potential for educational development of the parents and for taking work as therapists or supporting teachers.

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