Competence of Mothers Raising Children with Autism

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Abstract
The article presents the research aimed at investigation of knowledge, skills and values of mothers who raise children with autism focusing on those competences which enable families to successfully solve questions of their child education in a family. Qualitative methods were used to achieve the aim. Results indicate that mothers who overcome stress related to the birth of an autistic child often assume leadership for the creation of relevant educational environment for the child, learn to manage family’s socioeconomic situation, search for and use external resources important for the child’s development.

Keywords: parents’ competence, autism syndrome, leadership, ecological map, stress.

Introduction
Research problem and relevance. In Lithuania, as well as in other countries, a lot has been done in developing scientific knowledge about the prerequisites of education of children with disabilities and its peculiarities: more precise criteria of special needs’ assessment have been created, children’s needs and strengths, requirements for educational environment were better understood, etc. The directions for positive changes are often set not only by prominent scientists of the field, but by parents of children with disabilities as well, because for them the success of their children is not just a result of academic teaching, but the outcome of consistent efforts of a whole family as well. This proves that parents not only have exceptional motivation, but also – exceptional competences which empower them to initiate changes and participate in their implementation.

However, in the scientific research communication between parents of disabled children and teachers are often defined as problematic and manifest in a lack of mutual confidence, sharing responsibility, etc. (Ališauskienė, 2002; Tarleton, Porter, 2012; Cheatham, Hart, Malian, McDonald, 2012; Nilsen, Jensen, 2012, Kairienė, Ališauskienė, 2013; Raudeliūnaitė, Rympo, 2012). There is discussion about the lack of parents’ cooperative competence, poor motivation to participate in the process of child’s education, irrelevant expectations for the child’s
achievements. This can be also said about the parents whose children have autism. Meanwhile, special needs of an autistic child require not just fragmentary impact of educators, but consistent and permanent work, largest part of which naturally takes place in a family. However, there is no much research which would focus not on the problematic aspects of cooperation, but on a family strengths and among them – on special competences which parents develop when raise a child with autism. Therefore it is important to investigate how parents perceive their ability to solve difficult problems of a child’s education, what resources they refer to, and what is their attitude towards self-education. **The aim of the article** – based on the results of the qualitative research to reveal the competence of mothers having children with autism to bring up their children in the family. This will allow identifying family strengths which professionals from education and other fields can build upon.

**Concept of parents’ competence.** There are various definitions of competence, but it is generally admitted that it is comprised of knowledge, skills, experience, beliefs and values, which altogether enable to perform a certain activity (Tarptautinių žodžių žodinas, 2007, p. 571; Teresevičienė, Zuzevičiūtė, Kabišaitytė, 2008; Bulajeva, Jakubė, Lepaitė, Teresevičienė, Zuzevičiūtė, 2011). Analysis of scientific research (Kuhn, Carter, 2006; Michejeva, 2001; Ovčarová, 2003, 2006; Jonyienė, 2010) allows summarising parents’ competence as integration of knowledge, skills, feelings and actions, which allow to efficiently performing parent’s role. With reference to authors indicated above the following structural components of parents’ competence can be distinguished: cognitive – knowledge about a child’s age and individual (including the disability) peculiarities, image of a perfect mother/father, understanding of parents’ functions, image of a child, self-reflection skills; emotional component – subjective perception of oneself as a father/mother, attitude to a spouse, parental feelings, attitude to a child, empathy, ability to manage stress; behavioural component – parental skills, activities which secure child’s care, economic welfare, nurture and education. All these elements of competence are closely related and to a large extent determine success of education of an autistic child. Further in the article due to the language reasons the term "(cap)ability" will be used as a synonym to "competence".

**Challenges to competences of parents who raise an autistic child.** Birth of a child with disability disarrays normal family functioning and has an impact on all areas of family life as well as modifies its functions. Psychosocial characteristics of a family after the birth of a disabled child depend not only on sociodemographic family features, but also on a type of a child’s disability. Authors have identified that families raising children with autism often find themselves in a more difficult social and psychological situation than the others (Hock, Timm, Ramisch, 2012; Cashin, 2004; Dabrowska, Pisula, 2010; Lesinskienė, 2002).
On emotional level parents of autistic children (compared with parents of children with Down syndrome or having cystic fibrosis) experience higher level of anxiety, depression and are more stigmatized in society (Dabrowska, Pisula, 2010; Mickevičienė, Šinkariova, Perminas, 2009; Hock, Timm, Ramish, 2012). Negative feelings are further strengthened by difficulties of a child’s care, which manifest during feeding, putting to sleep, communication (Lesinskiene, Viliunaitė, Pakevičiūtė, 2002; Dovydaite, Vaitiekutė, Nasytienė, 2013). Peculiarities of inadequate child’s behaviour and its frequency cause parents’ anxiety, powerlessness, confusion and even psychosomatic disorders (Kuhn, Carter, 2006; Mickevičienė et al., 2009). On emotional level parental efficiency is also influenced by a degree of guilt, which parents (especially, mothers) experience due to a disability of their child. Not recognized, not expressed and not reflected feeling of guilt has a negative impact on the perception of one’s parental efficiency (Chavira, Lopez, Blacher, Shapiro, 2000, quoted in Kuhn, Carter, 2006). On the contrary, feeling of one’s parental competence has a positive impact on decrease of depression and stress control. It is admitted, that parent’s gender influences the degree of emotional stress: mothers experience more stress compared to fathers, because they more often assume responsibility for a child’s care and collaboration with specialists. (Dabrowska, Pisula, 2010). Besides, mothers more often use praise and encouragements, while fathers require stricter discipline (Ivoškuvienė, Urbutytė, 2008; etc.).

The time when the disability is identified also influences how parents perceive their competence. When a child’s disability is diagnosed with delay and her care and education requires especial efforts, parents start hesitating about their parental abilities (Lasser, Corley, 2008, quoted in Gill, Liamputtong, 2013). On the other hand, some data reveals that parents of autistic children more appreciate life, have more patience and empathy and a stronger social network (Altiere, Von Kluge, 2009; Bayat, 2007, quoted in Hock et al., 2012).

An important role in the process of social adaptation of a family and a disabled child belongs to parents’ personal qualities – resilience to stress, capability of cooperation with specialists from different fields (Dabrowska, Pisula, 2010; Tkačiova, 2006; Kairienė, Ališauskienė, 2013; etc.). Strategies used in the family to cope with chronical stress are divided into internal ones (which manifest either by active solution of problems or their elusion) and external (ability to find and use help of others, find spiritual support, etc.) (Mastiukova, Moskorskina, 2003). These strategies influence quality and degree of changes taking place in the family. Dabrowska, Pisula (2010) building on Strelau, Jaworowska, Wrzesniewski (2005), have distinguished the following strategies which help
parents to cope with stress and are closely related to their cognitive, emotional and social competence: 1) task-oriented coping, when parents try to solve a problem, to change a situation or their attitude towards it; 2) emotion-orientated coping, when they seek to decrease emotional tension invoked by an event; 3) avoidance-orientated coping – when it is sought to elude from the stressful situation by refocusing attention to socially pleasant things (a call to a friend) or by going to “cheer up” (to a cafe or else).

Intensive help of specialists, a need to develop specialised parental skills, to obey to a rigid routine and lifestyle, constant feeling that they are “different” has impact on the relationships among spouses as well (Hock et al., 2012). This does not mean that relationships break – if they are successfully reconstructed, couples state a higher mutual intimacy and trust. However, family resources have limits and the more attention is attributed to the implementation of one function the more difficult it is to implement the other ones. This negatively influences not only functioning of a whole family, but, specifically, education of an autistic child in the family.

On a cognitive level parental competence is influenced by how parents understand the impact of child’s autism on her behaviour and how they react to that behaviour. For instance, the more responsibility mothers attribute to a child for her behaviour, the more it is likely that they will experience negative emotions (anger, frustration) if a child fails to obey the rules (Chavira et al., 2000, quoted in Kuhn, Carter, 2006). On the contrary, adequate perception of child’s disorder may help parents to attribute negative traits of her behaviour to a syndrome rather than to a lack of their parental competence. The degree of assumed leadership also is important for the perception of one’s competence – mothers who have taken upon themselves a proactive role in the development of their children (initiate games, cooperate with specialists, etc.) feel more competent comparing to those whose relation with a child is more reactive (ibid.). Kuhn, Carter (2006) argue that consciously assumed leadership in issues of child’s education, mastered feeling of guilt and subjective inner wellbeing rather than understanding of child’s disability contribute most to the perception of one’s parental capabilities.

On a social level perception of one’s parental competence is influenced not that much by the formal help of professionals but more by the informal help of the family and friends: the latter presupposes emotional help of other parents to the whole family, meanwhile professional help often does not include direct emotional support to parents, but mostly concentrates on the help to a child (Beckman, 1991, quoted in Kuhn, Carter, 2006). Regrettably, as often as not
due to parents’ attitudes (fear, shame) or tiredness (when allocating all time to a child’s treatment and education family forgets about common leisure time and rest) a circle of family communication narrows down (Levčenko, Tkačíova, 2008; Olifirović, Zinkevič-Kuzemkina, Velenta, 2006), thus a possibility to receive emotional support of nearest people is also reduced. It is acknowledged (Dabrowska, Pisula, 2004) that mothers more often than fathers search for social support and they more often apply the style of emotion-orientated copying.

While analysing parents’ competence it is important to note that experience of raising an autistic child strongly influences parents’ identity and their communication (Cashin, 2004; Dabrowska, Pisula, 2010). Bringing up an autistic child causes change of parents’ social interaction with the environment. “The parent does not develop autism as such but is impacted upon by the triad of impairment. The parent’s social and communicative interface with the world is altered. The parent is subjected to a restricted and repetitive way of being-in-the-world” (Cashin, 2004, p.166). In the in-depths interviews parents characterize their daily life as the one in which there is “less self” (Cashin, 2004, p.167): a role of a father/mother shades all other roles, little time or energy is left to a role of a marriage partner or nurturance of individual interests. Research of Dabrowska, Pisula (2010) allow the authors to suggest “...the existence of genetically influenced, common profiles of social functioning of parents and children with autism” (p. 276).

In those cases when parents lack educational competence an inappropriate style of a child’s upbringing might form. This can manifest by (Šipicyna, 2005): incomprehension and denial of a child’s individuality, developmental stages; mismatch of parents’ requirements, expectations and a child’s possibilities and needs which results in psychological tension; inflexibility of parents’ relationships with a child, which manifests by ill-timed reaction to a difficult situation, lack of alternative solutions, fixation on problems; inconsistence in relationships with a child; inconsistence of parents’ actions; lack of mutual understanding and respect which may cause conflicts in a family. All these features indicate low parental competence and have a negative impact on relationships between parents and their autistic children and socialization of children in general.

Thus difficulties which face the parents who raise the autistic child are determined by a type of child’s disability and psychological and socioeconomic characteristics of a family. In turn, these difficulties influence parents’ wellbeing and at the same time – the results of a child’s upbringing (Kuhn, Carter, 2006). Long-term difficulties of a child’s care do not allow parents to experience sense of
subjective wellbeing and to believe in their parental abilities. In order to provide a well-rounded help to a family it is important to investigate what competences related to a child’s education parents have developed and how they use those competences to achieve educational aims and cooperate with specialists.

Conceptual base of the research – theories of stress and resources (for instance, Uriel Foa, 1971; Lazarus and Folkman 1984), ecological systems theory of U. Bronfenbrenner (1981) which help to identify internal and external resources and hindrances influencing research phenomenon.

**Research aim** is to identify parents’ competence to create favourable educational conditions for their children with autism syndrome.

**Research object** – competence of parents raising a child with autism syndrome.

To achieve the research aim the triangulation of methods – combination of a few qualitative and one quantitative method – was chosen. It allowed analysing the research phenomenon from different angles. By a *semi-structured interview* it was sought to define family’s psychosocial situation and to identify strategies which are used in a family for coping with problematic situations related to an upbringing of an autistic child. With agreement of research participants interviews were recorded and later transcribed. Qualitative content analysis was used for processing the data, analysis and interpretation. During the content analysis the recorded material (utterances of respondents) were subdivided into notional units and combined into categories.

The second qualitative method used – the method of *sociogram* developed by Tkačiova V. (2006) for the research of families having children with developmental disorders. This method encompasses three stages of a family life: before a birth of a child with a disability, immediately after her birth and at present time. Participants filled in three schemas: "My family before the birth of the child with autism", "My family after the birth of the child with autism" and "My family at present time". Parents were asked to fill in the names of their family members in each of the circles which represented their family. Comparison of pictures and discussion allowed identifying changes which occurred in the family relationships and roles of its members after the birth of the autistic child.

By the third method – family *ecological map* (based on U. Bronfenbrenner (1989) model of ecological systems) – it was sought to find out what external resources families with autistic children use and how often they do that. Participants were provided with a prepared schema: in its central oval they were asked to
mark their family and in other ovals – to write down most significant family
resources, which positively or negatively contribute to child’s education in the
family. Participants were also asked to use three different lines (solid, dashed and
dotted) which had to signify different type of relations with a specific resource
(the meaning of lines will be explained further in the comment of the 2 figure).
In the context of the research this information was important, because capability
to develop efficient relations with others and to find external support which
reduces stress related to the upbringing of a disabled child is one of the features
of a competent parental behaviour. Analysis of completed ecological maps gave
the opportunity to evaluate interaction of families with various external factors
and their attitude to efficiency of that interaction.

Selection of the graphic methods – sociogram and ecological map – was based
on approach of Wodak, Krzyzanowsky (2008), Abell, Myers (2008) arguing that
discourse which exists in every social context “embeds” speech (interview as
well) into a certain predictable schema, which reflects dominating attitudes and
content of the discourse on a certain topic. It was assumed that application of
other, nonverbal methods might help researchers to have a deeper look at the
psychosocial situation in a family and manifestation of competences in its context.
A quantitative research based on Zacharova’s questionnaire of emotional states
(see Liders A., 2007) was also used, but due to the limits of the article, its results
will not be discussed.

*Research participants.* Parents of children with autism were recruited in
schools. Part of parents refused to participate in the research indicating busyness
and lack of time. As a result only members of the families with autistic children
(a necessary condition) and described by specialists as actively participating
in their child’s education willingly agreed to participate in the research. An
important criterion of participants’ selection was a stable positive dynamics of
their child’s social development. All research participants were acquainted with
confidentiality of data. It is important to note, that one of the authors of this
research is herself a mother raising a child with autism syndrome.

Seven mothers between the age of 31 and 48 participated in the research. All
of them raise 8-13 years old autistic children (having moderate or severe special
educational needs). Two mothers are divorced, others live in full families. All have
higher education; one was studying in a college. Two families raise three children
each, others – two each, one of whom has autism spectrum developmental
disorders. In two cases the autistic child is the youngest, in other – the oldest,
that is, the first child.
Research outcomes

Management of the socioeconomic situation of a family. Interview data revealed that despite the problems which a birth of the autistic child causes, families are capable to meet main material needs of all family members. At the same time, it is evident that needs of the autistic child is a priority, and parents tend to spend additional resources for creation of better educational conditions for their child. According to the participants, personal space is one of the main needs of the autistic child: a child needs place to be alone, to rest from others, to restore mental balance. If there is no such place, not only a child suffers, but other family members as well. Therefore, in most families parents try to find ways to solve the problem of a scarce space. For instance, one family was preparing to move to a larger apartment, even though in a not prestigious area, the other one discussed the possibility of a flat exchange, the rest hoped to expand their living space in the nearest future.

The following utterance illustrates the ability of mothers to manage socioeconomic situation in the family: “[Economic situation] probably has changed, considering how much money is spent searching for various “treatment” methods: traveling to various medical centres, activities with dolphins, horses, various osteopaths, homeopaths, etc. But it is difficult to imagine what would have happened if all that wasn’t there. Comparing our economic situation before the birth and now, there is no special difference. Sometimes I do think where from has that money for our child’s education come and continue coming? Maybe it is some inner power which helps to concentrate and find recourse from the situation we are in: to give up one thing, to save on the other. Above all it is important to correctly set priorities, to define what is important for the family and what can wait” (7).  

Creation of the favourable psychological atmosphere in a family. Analysis of the interview revealed that mother’s ability to recognize a child’s disability, to understand it and to react appropriately depended not only on a timely diagnosis, but also on parental experience. All mothers whose child with autism was the oldest stated that they were not the first to recognize developmental disorder. In most cases it was older members of the family and only in one case – a physician. Inappropriate child’s behaviour, hysterics and insularity mothers explained as mistakes of upbringing: “I always knew that Rita was a naughty child and I raised her badly. Wicked, no discipline – this was the opinion of my husband and mother-in-law” (1); “They accused me that I spoiled her” (4).

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1 An arbitrary family code is indicated in the brackets.
According to the participants, their husbands observe educational process somewhat from a distance, require from mothers more rigour even after the diagnosis when all “strange” child’s behaviour can be explained by autism. As to the mothers, they gradually learn to better understand child’s wishes, moods, causes of behaviour, and their relationships with their children rise to another level comparing with early childhood: “I understand better what happens with him when hysteries starts. I react appropriately, control myself more. First years I lacked patience. I just used to ask questions: “Why? Why this happens to me?” (4); “The main thing – not rigour, the main thing – understanding” (1).

When there are disagreements about the child education, the main method to solve them, according to the mothers, is a compromise: “We try to find compromise” (5); “We always find some compromise” (2). All mothers emphasise that it is very important to find an agreement because tension in the family has a huge negative impact on emotional state of the autistic child. Therefore partners’ ability to make concessions, to understand and support each other is an important feature of a competent parental behaviour.

In the families where younger children are born after the autistic child a very important role is played by senior members of the family. It can be explained by the fact that a young family, not yet recovered after the stress which accompanied birth of the autistic child, receives an additional load of care and upbringing of a new-born. In order to alleviate family life grandmothers and grandfathers come to the rescue. They assume some functions of care about the older, autistic child. The problem is that sometimes this help is too big. The cases were mentioned when matured and experienced mother felt strength and wish to independently nurture all her children, but the older generation accepted that as ingratitude of a younger generation, which led to mutual accusations, harassments and caused tension in the family relationships.

In the families where autistic child is much younger that other children, mothers are main organizers of their autistic children’s education and fathers actively support them. “We have the same opinions, there are no contentions. I pay more attention to children’s education. Because I do that, I convey my views, information which I get from all possible resources to all family members. We discuss and all agree with me. We are all like one” (6). Besides, in such families the older generation almost doesn’t influence the education of the autistic children, because experienced mothers are confident in their capabilities, have personal approach to education, its principles and methods.

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The nature of family relationships is illustrated graphically by sociograms (see the example in the 1 Fig.). Analysis of pictures reveals how interconnectedness of the family increases during the different stages of family life; in the pictures members of the family are painted closer and closer to each other. On the top of all three sociograms the mother has noted herself, as if she feels the leader of the family and personally responsible for the future of all its members. When asked why the autistic child is not indicated in the pictures, the mother explained: "I even haven’t thought that he has to be mentioned. He is this big circle in which I’ve inscribed all and who unites all of us".

1 Fig. Sociogram of the family (6) before the birth of the autistic child, after her birth and at present

The other research participant didn’t indicate herself in any sociogram. However, the phrase in the interview revealed her increasing awareness of her role in the family and strengthening identity: "I don’t want to be “a pioneer” anymore and to do everything what is told to me. I am the mother and I know better how to raise my children" (1).

Parents’ self-education. Interview data showed that all mothers were actively interested in information on autism received from various sources. They evaluated that information critically, analysed it and chose only what seemed to them most trustable and valuable for education of their autistic children. The majority of mothers mostly appreciated knowledge on autism which they got during consultation with specialists, meetings with other parents of autistic children and information found in the internet. Popular articles in journals and newspapers, as well as movies and fiction were evaluated by parents as not very useful in terms of information. One mother even named the danger caused by some articles and films, because "autism is perverted there and romanticized. Autistic children are pictured as if every one of them is genius and we just have to wait until all this will manifest" (6).
Interest in autism problems helps parents to accept the child as it is, not to raise excessive demands and unachievable aims; such attitude improves both their and their child’s psychological wellbeing: “Now we understand real situation, perceive the child realistically and understand what we have to do. Now it is easier because unrealistic illusions have been dismissed” (6).

Thus the process of the autistic child’s education in the family is not just an accumulation of knowledge useful for the parents, but also self-reflection of that knowledge and experience, correction of life aims and attitudes, change of personal qualities and continuous learning.

*Personal qualities.* Main character traits which, according to the mothers, parents of autistic children should develop are the following: patience, calmness, equanimity (5 statements); fondness (3 statements); insistence (2 statements); impartiality (1 statement); ability to work in a team, avoid conflicts (1 statement): “A lot of patience, but it comes gradually, it is possible to learn everything...to always be balanced, even cool-headed in any situation” (3); “To be temperate, less emotions, iron patience and inner strength... to evaluate everything objectively”, “Competence, calm behaviour without sharp transitions...to be more patient” (4).

*Educational aims.* Knowledge and skills which parents acquire help them to specify educational aims for their children and to find appropriate methods and tools to achieve them. Data analysis reveals that the main aim for all parents is their child’s independence and socialization: “First of all, that he could take care of himself, without the help of others...and socialization, that he could communicate, could ask for anything he needs” (2); “That he would be independent, would understand that he has to stand up and dress, and not to run naked wherever... that he would understand that these are clothes and they have to be dressed correctly and beautifully, nails have to be cut and hair combed” (6).

Besides, the level of independence which mothers expect from their children is very different and depends on the severity of autism and the degree of intellectual disability. In one case, this should only be “some occupation, maybe a day centre; but most important – any activity at all...” (3); “That she could go to a shop and independently buy what she needs” (1); in other cases it’s a hope that the child when he grows up “is able to realize one’s potential in some profession and to live independently” (5).
Such answers indicate mothers’ critical attitude to the child’s abilities. In some cases, however, when a child is small, parents tend to more optimistically look at the future, but when time passes by the child’s developmental dynamics makes parents’ expectations more realistic.

*Educational methods.* Education of a child with autism syndrome is a very complex process, and without the specially selected and individually adapted methods a child’s development can be much encumbered. Despite that all research participants stated that they did not use specific educational methods created for autistic children (ABA therapy, PECS, structured teaching, etc.), all mothers confirmed that they knew about these methods and their main principles, but didn’t think they had to apply them to their children (6 statements): “This is not a concentration camp to always live according to some rules. Sometimes it is important to allow the child to relax, because he gets tired and needs rest, the same as we (about ABA therapy)” (4); “Our approach to education is somewhat similar to ABA therapy, but this is not ABA, just few elements adapted to our child...we have created this method ourselves, based on some information from a former work, consultations with specialists” (6).

One mother (1) said that she used cards, but those cards were specifically designed for her daughter with one specific aim – to teach her hygiene. In the table 1 the educational methods applied in the families and identified during interviews are presented:
Table 1

**Educational methods used in the families**

<table>
<thead>
<tr>
<th>Educational methods</th>
<th>Illustrating statements</th>
<th>Number of statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respect of a daily routine</td>
<td>&quot;Our daily routine is iron, even on the weekends. Lack of the habitual routine overbalances him...we are already used to it, we all live in such commonness&quot; (3); &quot;We do have an approximate daily routine, but we often change something and postpone time depending on a situation&quot; (5).</td>
<td>4</td>
</tr>
<tr>
<td>Learning in steps from simple to complex, multiple repetition for the achievement of a result</td>
<td>&quot;Gradually we increase complexity...if he masters we go further, if not – we go back and...slowly learn&quot; (6); &quot;We leave nothing without the result. If we don't succeed we return to the same thing after some time, and then we achieve the result&quot; (3).</td>
<td>4</td>
</tr>
<tr>
<td>Play methods</td>
<td>„A play is very important to my child, almost everything what he knows we learned by using some elements of play“ (7).</td>
<td>2</td>
</tr>
<tr>
<td>Commenting on activities and events</td>
<td>&quot;From the very childhood we talk about everything on the street...firstly, we tried to attract his interest by house numbers because he loved numbers most of all. For instance, we walk through the house No.10, and on the way I continue commenting on everything what we see and what we do“ (3).</td>
<td>2</td>
</tr>
<tr>
<td>Using cards</td>
<td>&quot;We use cards for learning hygiene and this helps a lot...Rita¹ likes it; her self-esteem is less affected when I don't instruct but show a card instead...for instance, earlier on she didn't want to wash her hands; but now, when she is given a card, she doesn't argue“(1).</td>
<td>1</td>
</tr>
</tbody>
</table>

Education of an autistic child is a permanent continuous process during which methods of education are revised taking into account the child’s changing needs and conditions. One mother (6) figuratively said: “*Parents have to understand that*
we don't run a hundred meter run, nothing can be done quickly...we run a marathon, and the result will be after we surmount it'. Moreover, another participant stated: "Yes, those parents who actively educate their children also become somewhat “autistic”... and we cannot say that they suffer because of that, they just have chosen a bit different life style trying to alleviate life for themselves and their child" (7).

In order to achieve educational aims of an autistic child it is not enough to build on family internal resources – personal qualities, economic possibilities. Parents have to search and find external sources which could relieve moral and economic burden of the family and to help educate their autistic child.

External family resources: data of the interview and the ecological map. School and additional activities outside the school are the external resources most actively used by the families. All mothers expressed great appreciation of teachers working with their children and emphasised teachers’ importance in their child’s life: “We had a strong teacher. Nice women...I think we were lucky” (6); “A lot depends on a teacher... a school for our son is the family prolongation and the teacher is prolongation of our family as well” (3).

However, some mothers do not feel partners with teachers, they tend more to just listen to professionals and implement their recommendations, but don’t suggest own strategies which they have found for the solution of the child’s problems: “I better call, I don’t intervene into a teaching process...I just get informed...I can only transfer the opinion of the grandmother, she is a schoolteacher” (1).

The rest of mothers cooperate with teachers more closely and on an equal ground and believe that they are heard and their wishes are met (5 statements): “I try to help teachers: I say what can scare Kasparas, what can trigger his negative reaction and how to avoid that. I hope my opinion is important” (5).

One of the main principles of education of autistic children is taking advantage of their special dispositions, interests and abilities for enhancement of learning motivation. Therefore the attendance of various after-school activities together with other children is a very important prerequisite for development of their social skills. The majority of mothers value these additional activities as an essential help in education of their children. It has been found out that most children attend three or more different activities (except one child who attends only a swimming pool). Most popular activities are related to music and swimming.
The significance which families allocate to additional activities is illustrated by the families’ ecological maps (ecograms). Additional activities and a school are indicated in these maps as external resources significantly contributing to the family life; other sources of support are also mentioned (for instance, in the ecogram of the (4) family, Figure 2). Apart from additional activities with the speech therapist and the school where the child is learning, more external resources providing an essential help to the family were indicated in this ecological map (a solid line): work, relatives, friends, mother’s studies (after the birth of the autistic child she decided to acquire a primary school teacher’s profession), leisure trips and activities with dolphins, after which, according to the mother, the child makes a good progress in his development.

**Fig. 2.** Ecological map of the family (4)

A dashed line in this ecogram marks resources which provide insufficient help to the family (a doctor, a psychologist, church community), and a dotted line indicates external sources of stress. As such Child Development Centre and a primary school were indicated: the mother told that her child had to quit the latter due to the family conflict with school administration. Now he attends a special school which, according to the map, is a source of essential support for the family.
In the table 2 the external resources are summarised and the number of times when a specific resource was mentioned is indicated; the contribution of each resource to a child’s education is also presented:

### Table 2

**Evaluation of external resources important for a child’s education**
*(summary of the ecological maps)*

<table>
<thead>
<tr>
<th>External resources</th>
<th>Essential support</th>
<th>Insufficient support</th>
<th>Source of stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>School/teacher</td>
<td>7</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Additional activities</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work/studies</td>
<td>4</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Leisure (trips, parks, theatre, playgrounds, homestead, garden)</td>
<td>4</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Relatives</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Social services/centres</td>
<td>4</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td>3</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Doctors/medical centres</td>
<td>3</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Church</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Neighbours’ dog</td>
<td></td>
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<td>1</td>
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</tbody>
</table>

Table 2 reveals that mothers who have participated in the research consider a school and additional after-school activities as most significant sources of help. Work/studies and leisure is also seen as a source of support. As for relatives, only closest of them provide essential support to a family, the support of distant relatives is considered as insufficient. Help of friends is also evaluated as insufficient. Families do not fully use social services as well: four times social services were evaluated as providing an essential help and three times – as insufficient. Families almost don’t use support of religious organizations (a church is indicated only in one ecological map and only as a source of insufficient support).

In one ecological map a neighbour’s dog was indicated as a source of stress. This shows that a sensitive psychological balance of an autistic child can be disturbed by a seemingly insignificant thing, and this has a negative impact on psychological climate of the whole family.
However, most complicated relationships form between the mothers of autistic children and doctors or medical centres. This category of external resources (a rehabilitation physician, Development Centre, etc.) was often defined in ecological maps as a source of stress. Moreover, seven times physicians and medical centres were indicated as a source of insufficient help and only in three cases parents received from them essential help (from a psychotherapist, a centre of mental health, and a family doctor).

Summarizing information about the external resources used by parents it can be stated, that most actively and efficiently they use the ones which directly contribute to the child’s education (school, after-school activities) and those which help to meet family material needs (such as work).

**Discussion**

The research data revealed that development of competences of parents who raise children with autism syndrome and manifestation of these competences is influenced by both psychological climate in the family and external resources and their quality. In the interaction of internal (relationships in a family) and external (formal and informal help, institutions, etc.) family resources mothers develop capability to master stress related to the child’s birth, to find coping strategies and to use support of help institutions.

Data revealed the importance of early diagnosis of autism for the adequate evaluation of one’s parental competence: timely apprehension of the child’s disability and its characteristics allows to have more confidence in oneself and not to explain negative manifestations of the child’s behaviour by one’s incompetence as a parent. An order of the autistic child’s birth also influences parents’ capabilities to cope with the child’s care difficulties. When a family already has children, mother relies on her experience and is more confident in herself. A husband in such situation also trusts his wife more because the example of successful upbringing of older children is already evident (in investigated families).

Interview analysis indicated that mother’s ability to assume leader’s position plays an important role in raising and educating a child with autism syndrome. Active stance (analysis of autism problems, search for specialists, methods of rehabilitation and education), ability to convey acquired information to a husband persuades him in his wife’s competence and necessity to support her efforts in the child’s education. These data is consistent with the statement of Kuhn and Carter (2006) that parents’ perception of their competence is strongly influenced by the consciously accepted leadership for their child’s education. The emergence of a
leader in the family where upbringing often means stress and tiredness and who assumes responsibility for creation of the favourable educational conditions for the child is one of the factors of family integration, its increasing ability to successfully solve problems. Aiming at family preservation and development of the appropriate emotional environment for the child’s education, parents are also obliged to search for the forms of mutual relationships which would be based on mutual respect, mutual compromises and concessions. This ability to find common solutions in difficult situations of the child’s education is one of the prerequisites of parents’ competent behaviour; necessary for the successful education of the autistic child.

The personal qualities emphasised by the majority of mothers – patience, self-control, calmness, equanimity – reveal their resilience to stress, that is to say, their ability to endure a huge mental tension in situations related to the child’s education. Data revealed that mothers who raise small children with autism apply the method of emotional copying (this is consistent with the data of Dabrowska, Pisula, 2010). Later, when the family “gets used” to the child’s disability, mothers learn task-orientated copying strategy, trying to solve a problem, to change a situation or attitude towards it (ibid.). Such qualitative change of mothers’ competence manifests a gradually assumed leader’s role and indicates significance of knowledge about the disability and the child’s needs as well as parents’ self-education. Knowledge about cycles of a family life and how strategies of copying with the child’s care difficulties change can help professionals to recommend the families relevant education methods.

Most research participants define cooperation with the child’s teachers as one of the most significant sources of external help, but by searching for additional knowledge on autism disorder, mothers tend not to confine their child’s education to education institutions, but to find additional forms of learning – after-school activities, sport clubs, etc. Analysis of ecological maps indicated that there are large reserves of external resources that can help to better meet family material and spiritual needs. However, not only parents’ competence is important in order to use these resources – it is necessary that they are accessible to them both in psychological sense and in terms of time. Support of relatives, social services, communication with friends, religious communities are resources not used sufficiently. It might be that difficulties of the daily life distract parents from searching for this kind of support; at the same time, some statements indicate that a strict structure of the daily life caused by the child autism forms a different social stance of parents and changes their interests and priorities (such assumption is also found in Dabrowska, Pisula, 2010).
Data also confirmed a regret often articulated by parents during informal communication about the difficulties of creating partnership with professionals from medical field (for instance, Ho, Yi, Griffiths, Chan, Murray, 2014). This problem can be interpreted using the term "power", when in collision of parental stress, vulnerability and physicians' power (professional knowledge, status, etc.), the latter ones fail to create a symmetric relationship with a family: to convey medical conclusions, recommendations in a language understandable to parents and to remain sensitive to their emotional state. On the other hand, it might be that dissatisfaction with specialists develops not as much due to the lack of physicians' communication skills in stressful situations (or not only), but due to the complexity of autism itself, when doctors' possibilities to help a family do not coincide with parents' expectations.

Graphic methods applied in the research – ecological map and sociogram – helped research participants to distance themselves from the concepts and/or cognitive structures habitual in the disability discourse and to represent the situation of their families in a nonverbal way. For the researchers analysis of graphical data and discussion about it allowed complementing interview material with delicate aspects which did not manifest during interviews – maybe interview questions did pose a well-defined interview direction which participants usually refrain from breaking (Wodak, Krzyzanowsky, 2008, etc.).

It is important to mention that few months after the research the list of identified competences was presented to all participants in a form of a Likert scale asking to assess to what level they have the listed competences. This quantitative element of the research allowed confirming authors' conclusions: all mothers assessed competences identified earlier as developed well and very well. Two mothers evaluated their ability to control their emotions and capability to create favourable psychological atmosphere in the family as averagely developed. However, no one competence presented in the conclusions of the article was assessed as poorly mastered. Besides, in the control scale the list of competences was enriched with one statement which reveals well the capability to cope with difficult psychosocial situations: it is the ability to take care of oneself. Almost all participants assessed this ability as very well developed (except one who assessed it as satisfactory). Therefore, it could be argued that despite the huge emotional, cognitive and social challenges related to the child's disability, mothers who successfully master the stress not only develop competences necessary for solution of educational problems of their autistic child, but find in themselves inner resources for nourishing their own personalities.
Conclusions

Research data allows grouping competences which mothers develop and which enable them to meet the educational needs of their autistic children into a few categories:

1. Capability to master emotional stress related to the birth of the autistic child and to create favourable psychological atmosphere in the family which manifests in: the ability to find solutions of the problems on the base of compromise, the ability to convey necessary information about a brother’s/sister’s disability to other children; to revise one’s attitudes and believes.

2. Capability to master socioeconomic situation of the family: to rationally use available family economic resources; to plan additional expenses for creation of favourable educational conditions for the autistic child; to master austerity of the daily life.

3. Capability to efficiently solve questions of the child’s education: to understand needs of the autistic child, to critically and realistically evaluate the child’s possibilities, to raise relevant educational aims; to consciously plan the child’s education according to the economic and social situation of the family and the child’s abilities; to choose educational methods concordant with the child’s needs and abilities; to build on the child’s special dispositions, interests and abilities in order to increase her learning motivation; to delegate as much responsibility to the child as she can handle; to search for information on autism, to evaluate it critically and be able to select and apply.

4. Leadership and cooperation skills: to assume leadership for the creation of favourable conditions for the child’s development at the same time considering interests of all family members; to convey information to professionals about the child’s needs and possibilities and discuss with specialists issues of the child’s education.

In summary, the main aim of parents raising autistic children is as high level of their child's socialization and self-care skills as possible. In order to achieve this aim parents apply methods which are based on their experience and knowledge, on the child’s needs and possibilities and efficiently use help of external resources.
Research limitations

Despite that research revealed huge psychosocial resources (competences) of the families raising autistic children it encompassed only families of the middle socioeconomic status, therefore in families which live in less favourable psychosocial and economic conditions the identified competences might be considered as a possibility and aspiration, but not as a common phenomenon. In the future research it would be useful to investigate competences which manifest in the families of a lower social economic status and to identify social and psychological prerequisites for the development of the identified parental competences.

References


