INTEGRATION OF AUTISTIC CHILDREN IN ALBANIA

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Abstract

In recent decades there is an increase awareness of Autism Spectrum Disorder. One reason for this is the increase in rate. Based on the evidence reviewed, the median of prevalence estimates of autism spectrum disorders is 62/10 000. Elsabbagh, M, et al., (2012). Secondly, parents of autistic children as the best 'advocates' of their children are fighting for their children`s rights for education. Based on Article 24 of the Universal Declaration of Human Rights no one can deny these children the access to school. The best form of social integration for these children is to give the possibility to study in regular classes. Children can learn from each other. Children without disabilities can learn about diversity and autistic children are provided the support they need. But are all the actors prepared for this step? This study is focused on teachers` and parent`s point of view. During the interviews the participants raised some important issues. Integrating autistic children through inclusive education seems to be the challenge of the future.

Keywords: Autism, Integration, Parents, School.

1. INTRODUCTION

In Albania there are hundreds of children diagnosed with Autism Spectrum Disorder, but there is no evidence about the real size of this disorder because there are not statistics about it. Among several factors for this situation two are the most evident: prejudice and parents` poor knowledge about this topic. Compared to urban zones in rural areas prejudices are stronger. Pango Y.2005. In 1990 in Albania there were no institutions for autistic children. Tupja E. 2009. Today there are some non-governmental organizations and a few centers where parents can receive the services they need.

Autism can be diagnosed during the first two years of life and the early intervention is the best known therapy. In recent years there is a tendency to use IEP program even in kindergarten. Kinder garden teachers and pre-school teachers are being trained by psychologists and other professionals on different aspects of this new program. The Individualized Education Program (IEP) intent to help children reach educational goals more easily than they otherwise would. IEP must be done based on the individual student's needs as identified by the IEP evaluation process. The IEP describes how the student learns, how the student best demonstrates that learning and what teachers and service providers will do to help the student learn more effectively. Developing an IEP requires assessing students in all areas related to the known disabilities, simultaneously considering ability to access the general curriculum, forming goals and objectives that correspond to the needs of the student, and choosing a placement with other peer students

As long as a student qualifies for special education, the IEP is mandated to be regularly maintained and updated up to the point of high school graduation.

Even though it is too early to talk about results, parents are the most optimistic actors of this process. They are aware that there would never be a Pigmalion effect (Woolfolk A. 2010) but they are satisfied even with small "steps". All the parents dream their autistic children be accepted by others. Based on "All-inclusive education – new millennium need" project, the non-governmental organization MEDPAK (Protect the Rights of Parents of Persons with Disabilities) supported by Save the Children conducted a pilot study in three Albanian Districts: Korce, Vlora and Gjirokaster. The focus was the improvement of school community culture in order to have all-inclusive schools. The aim was to prepare IEP objectives for different children. This study showed that institutions of education and local authorities were not fully prepared for the implementation of this project. Even though the Article 26 of the Universal Declaration of Human Rights guarantees the right for education and full development of human personality, a lot of parents had poor knowledge about their children rights.

This problem is not isolated,

"In Organization for Economic Co-operation and Development (OECD) countries and countries in transition, many children with disabilities are also out of school. Children with disabilities do not attend school with their non-disabled peers or do not receive the supports they need." (Global report 2009)

Parents dream is to have a normal child and they know that education is the only way to fulfill this dream.
The first schools for disabled children mainly sustained by parent were like islands. The children were isolated and they were not learning to get along with others – and non-disabled students were not learning to get along with them. The next won battle for these parents was integration of their children. The disabled children attended school in the same classrooms with non-disabled children, but the class structure didn't change. Students and the regular classroom teacher did not accept responsibility for the children with disabilities.

The Salamanca Statement of 1994 held in Spain was a light for the future. The Conference adopted a new Framework for Action, the guiding principle of which was that ordinary schools should accommodate all children, regardless of their physical, intellectual, social, emotional, linguistic or other conditions. They agreed a dynamic new Statement on the education of all disabled children, which called for **inclusion** to be the norm. Inclusive classrooms are ones where students enjoy learning. They are dynamic. They recognize that there are many different types of intelligence – including verbal linguistic, musical/rhythmic, body /kinesthetic, visual/spatial interpersonal, intrapersonal and naturalistic (Gardner, 1983) – and a good teacher taps them all.

UNESCO, in 2006, describes inclusive education as a process of addressing and responding to the diversity of needs of all learners through inclusive practices in learning, cultures and communities and reducing exclusion within and from education. It involves changes and modifications in content, approaches structures and strategies, with a common vision which covers all children of the appropriate age and a conviction that it is the responsibility of the regular system to educate all children. (UNESCO, 2006)

2. ACTORS AND FACTS

The inclusive education development is based on Social ecological framework. Social ecological context was pioneered by Bronfenbrenner (1979), who suggests that the ecological system comprises a number of subsystems: the microsystem, mesosystem, exosystem and macrosystem. Every person lives in a microsystem (family, friends, teachers, etc) that is inside a mesosystem (interactions between all the factors) which is inside exosystem (social environment that influence on the child). These three systems form a macrosystem. (law, society, values, etc) Woolfolk A.2010.

The microsystem is the nearest environment where a child can experience different emotion in interaction with his parents, other children or teachers. This relation is two directional. What happen to the child has impact on the parents and what happens to the parents is felt even by the child. Mesosystem has to do with interaction of all the actors of microsystem. Ekzosystem includes interaction between two or more environments such as friends and neighbors, medical care, extended family, peers outside the school, other parents, support groups, and local community. Even psychologists or experts of the field are an important part of this system. The child is not directly connected with this system but it has an impact upon the child, for example the mass media can describe disabled people as people in need or undesirable.

Based on child`s disorder neighbors can be humanist and friendly or stigmatizing. The impact that economic and political factors have on the child has to do with macrosystem. Macrosystem is the society expressed in values, law, conventions, traditions and has impact upon families. The bioecologic system of a child can be expressed as: the child is influenced by microsystem of his mother, father, brothers, friends, teacher, by mesosystem of interaction between these people and by eksosystem of governmental policies. (Woolfolk A 2010)

The implementation of all-inclusive process involves teachers, children, parents and even infrastructure. (Leatherman and Niemeyer 2005).

"The role of the teacher is primarily a teaching role, conditioned by the nature of teaching, by different kinds of methods the teachers use, by their individual personality and by their cultural backgrounds." Tafani V.2003.The teachers of this millennium are challenged by diversity of children they teach. Classrooms of today are formed on base of different race, ethnicity, language, economic status and student`s intelligence and development. In order to succeed in using IEP in the class, teachers not only need support by professionals of the field, but they would have better results if they worked with smaller group of children. (Wehbi 2006). The process of "burn out" is another problem concerning teachers. If a teacher is not motivated, he would never create a warm environment in the class. Personal factors, behavior and environment are in continuous interaction. The major part of the studies conclude that training teachers and teachers that have experience with disabled children have a positive attitude towards these children.(EADSNE,2003)

Caring for a child with autism can be very tiresome. Parents or caregivers should take care of these children during all their lifetime. Because of difficult communication and physical behaviors of the child, parents feel distressed. Patience is one of the virtues of parents of autistic children.(Tupja E. 2009). Mothers can not follow their careers due to their child's disability. Tupja E. admits that when his son was diagnosed with autism spectrum disorder, his wife could not follow her dreams anymore. Before she was a painter, but now she has to stay at home taking care of their child. Even in parents role there is a difference. Lamb, 1975, observed that fathers were more likely to hold their infants for play and try to connect the child with the outside environmental, while mothers held them mainly for physical care giving. Compared to mothers, fathers can provide aspects of parenting that are unique but there is a limited research concerning father`s role in parenting a child with autism. The role of mother is un substituted in a child`s life especially when there is a child with autistic disorder. Compared to fathers the role of mothers is much more important. As a father of an autistic boy Tupja, E. wishes his child survive after his death, but specially after his wife`s death. Tupja, E (2009). Sometime the disability of the child, like autism, can lead to undesired results for the couple. A child with autism is a large stressor on the family because of the ambiguity of diagnosis, the severity and duration of the disorder, and problems with the child's lack of adherence to social norms (Bristol, 1984). But having a child with special needs does not mean always a crisis/stress in the family if we take into consideration the ABCX model. The ABCX family crisis model can be used to describe the stress that can attack the family after the recognition of autism in a child. "A" stands for the stressor event (child with autism), "B" is the family's crisis-meeting resources, "C" is the way the family defines the event, and "X" is the crisis/stress (McCubbin & McCubbin, 1987). The "A" factor is a significant transition in the family's life that can produce a change in the family system. The family may need to activate its existing resources to prevent the stressor from becoming a crisis. The "B" factor is related with the use of the family resources, by utilizing community services, social support. The "C" factor is the way the family defines the event of having a child with autism. This factor is a product of the family's values and its previous experience in dealing with crises. Functioning on all three factors together represents the family's ability to prevent the stressor from creating a crisis/stress ("X" factor).

3. RESULT

3.1.1 Participants

The sample for the current study included 30 teachers of different schools in two different towns. The 20% were men. The major part had over 9 years of experience. There were 15 mothers of children diagnosed with autism spectrum disorder. (Asperger`s disorder, Autistic Disorder, Rett`s syndrome, Childhood Disintegrative Disorder, Pervasive Developmental Disorder, not otherwise specified) based on DSM-IV-TR

(Diagnostic and Statistical Manual of Mental Disabilities). Mothers are member of MEDPAK (Protect the Rights of Persons with Disabilities) non- governmental organization in Albania.

3.1.2. Procedure

Information was collected from teachers during interviews. The teachers and mothers were told they could withdraw whenever they wanted. Some of the interviews were conducted in the school.

3.1.3. Measures

The first three questions were about school process in general, the number of the children per class and the number of disabled children. 11 questions were about teaching process and disabled children. There were ended questions and semi-ended questions.

Four of the teachers had not had experiences with disabled children and were in dilemma about having or not disable children in the class.

".... I don`t know. Really. If I had a child diagnosed with autism. I have heard about it, but I hardly understand what it is."   teacher

"... What can I do if he would do something? Should I call the principal, the head teacher?   Teacher

Some of the teachers were absolutely negative about it.

"...I had a disabled child once. He was super active .I couldn`t explain the lesson."   teacher

A lot of teachers were positive about it, but they needed help.

"...If we had some leaflets or small guides about the child`s problem, it would be better."   Teacher

 Some parents thank God they have their children in the school with other students, but they are suspicious about love and support their children get during the school process.

"..If I worked here, would be perfect. Thank God he is ok, but you now I am worried. You know" parent

"...I know they don`t like my child, but what can I do?"   parent

4. DISCUSION

In 2015, all-inclusive school is a need for all disabled children. For autistic children, being part of a regular class is and will be a debated issue. This fact has to do with culture and values that each of us carries. The fact that teachers do not know if they want to teach in a classrooms with disabled students means that they are afraid of the unknown. There is a gap of knowledge about disabled children problems. This vacuum concerning teachers point of view is related with poor training of the teachers.

".. teachers lack the training, leadership, knowledge and supports to adapt curriculum and make inclusive classrooms work." (Global Report EFA 2009)

University curricula should include more information about disabled children needs. The students should have a lot of information about these parts of society. A good teacher should never stigmatize. Diversity in classes should be a positive challenge and not a stressful situation.

 Infrastructure remains one of the most debated topics. Teachers cannot answer to the children needs without the tools that should help them during the teaching process. Because the classrooms are overcrowded, it seems to be impossible for the teacher to follow all the students. The necessary involvement of the assistant teacher would be the future challenge.

It seems that parents are left alone in the process of integration of their children. They are aware of their children limits and they spend a lot of time at school. There were cases of mothers that wanted to work in the school, just to be with the child. In this way parents are taking the role of teacher assistant.

In 2015, inclusive school is a need for all disabled children. Being in a regular class means to be in a real life situation. Even though there are still a lot of problems to be solved about all-inclusive schools, at least people are aware of this new millennium problem.

5. AKNOLEDGEMENT

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