

Maria Dishkova

An Autistic Child Would Like to Say “Hello”

Abstract

There is so much information about autistic children in educational theory. And there is not so much know-how in educational practice. This statue is about science research which main goal is to prove that autistic children and their families shouldn't be isolate by society because it is the worst way to be supported. There are many options now for children with SEN (special educational needs) and they have law-defined rights that must be followed. Options must be used by parents, families and relatives, so they to be better care-givers for diagnosed child. Research shows that social isolation gives negative results and must be avoided.

Keywords: autistic child, autistic spectrum disorder (ASD), early intervention, children with special educational needs (SEN)

Introduction

Imagine a life without being able to express yourself: your need, your dreams, your thoughts, your feelings, your wishes. Imagine a life in which you are not capable to make a contact with others, with people around you; and you are not capable to share your head's content with them. Imagine an endless isolation and reason for that is unaccountable for people around you are you are not able to explain what happens in your heart. Imagine an endless need of help with no ability to ask for her.

A world in a world: this is the life of an autistic in our lives. It is like living on another planet or on a lonely island and it is not possible to be reached. It is like an extra-terrestrial coming on earth and wanting to say “hello” but doesn't speak human language. When you are looking at an autistic may be you are thinking that they look happy on their well protected island, they don't look like feeling lonely, and they don't look like being sad because of luck of friends. But definitely needs help and support. It is a fact that the number of autistic children increases with every day now.

Childish autism is a bad diagnosis about child and about its family. They begin a life in double isolation. Once it is an isolation defined by diagnosis. And second it is isolation from society that doesn't like different people.

The word “autistic” is first used by Eugen Bleuler in meaning of “social withdrawal” when he is looking at group of schizophrenics. Later both Leo Kanner and Hans Asperger, independently of one another, use the same word with no meaning schizophrenics (Dimitrova, 2012, p. 53). Leo Kanner meant to describe a group of children which he was observing. The word autism means “alone” (from Latin). The group of children Kanner had observed had a preference to be alone (Koegel & LaZebnik, 2004). In 1944 Hans Asperger made another research that includes observation of four boys with strange behavior and abilities. He defined their behavior as “autistic psychopathology” – a condition that has some specific features: lack of empathy; low abilities for making friends; monologue speech

without searching to a real communication; limited and specific interests; clumsy movements (Dimitrova, 2012).

The words “spectrum disorder” has been added later onto the term “autism” because children can have a wide range of symptoms or characteristics. They could affect them that range from mild to severe (Willis, 2006).

Autism spectrum disorder could be described as a complex developmental disorder that affects someone’s ability:

- to socialize;
- to communicate;
- to respond to environment.

One of the most severe disabilities that reach young children is autism disorder. This is a disorder that affects almost every aspect of the child’s development (Benson, 2006). Some specific features of autistic spectrum disorder are: there is no speech at all, or speech is not adequate to age; child doesn’t fix his eyes – it seems like he/she is looking through us; child doesn’t respond to the emotion of human in front of him; child doesn’t respond with face and mimics; child has no imagination; child has no interest in playing with other children at the same age; child doesn’t include in other’s children playing; not able to work in team; doesn’t seem to feel pleasure; doesn’t try to get attention of adults; child has unusual and repetitive movements; has unusual fears (Stankova, 2012a, pp. 76-77).

“Autism is identified by two primary diagnostic markers: difficulties in social communication and restricted or repetitive behaviors and interests” (Wong et al., 2014). Usually starts from the first year of child’s life.

Children with ASD often have symptoms of other psychical disorders as behavior difficulties, aggression, auto-aggression, hyperactivity and anxiety. Anxiety is very interesting about scientists because it seems to be connected with basic symptoms. Any change of environment and any interruption of stereotypical behavior could increase anxiety, pressure and emotional stress in children. Another hypothesis is that repeating one and the same makes children calmer (Stankova, 2012b, pp. 138-139).

It should be said that early intervention is completely required if we want to get any positive results and significantly positive effect on long-term outcomes for children with ASD (Autism Spectrum Disorder). It is exactly early identification that is a key to early intervention. Early signs of autism are often noticed by 18 months of age, or even earlier. Some early signs or “red flags” that a child may have an ASD include the following:

- lack of or delay in spoken language;
- repetitive use of language;
- little or no eye contact;
- lack of interest in other children;
- lack of spontaneous or make-believe play;
- persistent fixation on parts of objects;
- poor response to his/her name;
- fails to imitate caregivers;
- motor mannerisms (hand-flapping);
- fails to point or show joint attention (Lindgren & Doobay, 2011).

Here it is the right formula: early diagnosis leads to early intervention that leads to optimal development of children with ASD.

“Appropriate treatment of ASD should begin with a careful assessment to determine the child’s specific strengths and needs. There are no specific medical tests for diagnosing autism although there are genetic tests for some disorders that may be associated with behaviors on the autism spectrum. An accurate diagnosis is based on systematic interviewing, observation, and assessment of the child’s communication, social interaction, behavior, and developmental level. In addition to assessing the key symptoms of autism, a review of sleep, feeding, coordination problems, and sensory sensitivities is often recommended. Medical factors that may be causing pain or irritability should be recognized and treated whenever possible” (Lindgren & Doobay, 2011, p. 7).

Each person, each child, each social-pedagogical case, and each child with ASD is different. All these are unique. So plans for intervention must be individualized. They must be based on the needs of the individual and family. Early intervention can achieve significant result in improving cognitive and social development for children with ASD (Lindgren & Doobay, 2011). Some children with ASD are very well affected by components in “sensor room”: they become more concentrated, calmer and purposeful (Boycheva, 2013, pp. 189-193).

“The call for the use of interventions that have proven their effectiveness is particularly important for the ASD community, which has long been plagued by the use of unsupported and often controversial interventions. In fact, it has been suggested that the uncritical use of unproven “miracle” interventions has encouraged unrealistic, implausible, and unhealthy expectations about treatment results and have ultimately impeded the progress of identifying effective interventions for children and adolescents with ASD” (Simpson, 2005, p. 140).

All these words above have provoked a research about the necessity of social-pedagogical intervention to autistic children.

Research methodology

Hypothesis of research is that social isolation is critical about a child with autism and its family. There are so many options for intervention today. It is hard to say that all of them are effective and useful; or some interventions are working to a child and other interventions are not working to a child. It is usual practice in social-pedagogical work: there is no universal medicine for all people and for all their problems. But there is always a hope. That is why someone should search ways to help and a person with problems should allow to be helped by someone.

Main goal of research is a comparison to be made between two groups of children and their families:

1) First group are children with autism which are object of professional interventions, made by different specialists. And their families are getting professional help as well.

2) Second group are children with autism that are “under home arrest”. They are not object of professional social-pedagogical help. And their families are “under home arrest” as well and don’t get any help.

Some concrete tasks are completed because of this main goal:

- following the condition of an autistic child that has been working with by specialists;
- following the condition of an autistic child that hasn't been working with by specialists;
- comparing both above;
- following the condition of an autistic child's parents that has been receiving professional help;
- following the condition of an autistic child's parents that hasn't been receiving professional help;
- comparing both above.

Object of this research are 20 children diagnosed with disorder of the autistic spectrum. They are separated in two groups:

- a) ten of these children are have been visiting a daily center for one year in specialized institution. This daily center is licensed to work with autistic children. They have permission from Direction "Social Assistance" (Department of Child Protection) and they get this help absolutely free. In this daily center children are object of different kind of interventions – they meet social worker, psychologist, art-therapist, music-therapist, speech therapist. They get medicine help if necessary as well. Different interventions are included in their daily program according to their age, individuality and common condition. They follow special diet and way to feed. Meeting between specialists and parents are organized as well, aiming interaction and cooperation. This group of ten autistic children is in this social service from one year till now and continuing. Five of these children are visiting public school and they are evaluated as children with SEN (special educational needs);
- b) the other ten of these children are growing at home only by their parents and families. They don't get any kind of help and their parents don't get any kind of support. These children and their families have no contacts with environment. They communicate with no one. These are families in which mother is unemployed to be able to take care of child 24-hours in day. She almost has no friends and begins to see everyone as mocker or even enemy. Children don't visit kindergarten, school or any other forms of education.

Subject of research are all activities which autistic children are taking part in or are not taking part in. Subject of research are all results (positive and negative) of working or no working with autistic children and their families.

Results

It is one year now from beginning of research and some results could be published, because they show difference clearly between two groups of examined children. Hypothesis of research is that social isolation is critical about a child with autism and its family has been confirmed. There is still no universal strategy for social-pedagogical intervention that works the same in all cases of child with autistic disorder. And there are still many children that don't point progress. But it is clear that is better to receive professional help than not to get. It is the same with parents as well. Results of research show that they become more optimistic and much more

able to care adequately after their kids. Level of stress is getting lower. Depression is almost overcome. Mothers have some time to rest and then to be better mummies of children, because they need all mother's time, energy and strength.

Children meet more people. They become less isolated. Learn new words or ways to express themselves. They receive the possibility to find their talent and many of them are in possession of talent to exhibit.

On the other side are children staying at home. They are absolutely besides any help, support, professional advice and intervention. Parents are angry and hopeless. They don't have goals and they don't believe in future. Sadness and depression are their best friend now. No others. No progress in child development; often regress is pointed.

Conclusion

When I first made a research about autism it was in years of 2001-2002. There was no information about autism in Bulgaria then. Children with autism were diagnosed with different disorders of development and have received inadequate or no support and help. Some of them have visited special schools along with other children with different diagnosis. In these schools autistic children were fated to total regress. Other children were closed at home, most in country. There were no books, only Internet sites full of international experience. It was very interesting to compare good practices and strategies of specialists from other countries and our national experience, or lack of experience in this area.

Today, almost 15 years later practice is very different and world of science is optimistic. In Bulgaria there are a lot of possibilities for children with autism: teams of specialists, daily and weekly centers for care and education, special diets, different educational programs, specialized projects, sensor rooms, smart TV, exchange of experience with other countries, association of parents, groups of each other support, government and non-government organizations, laws and rights for children with SEN, resource teachers, multidisciplinary team at schools, including psychologist and speech therapist. There is hope and there are so double checked advices for optimal development of an autistic child:

1) Autistic child should be professionally helped and supported so to be able to say "hello" and to feel comfortable in our world. There is still no one opinion on strategies used in practice. But there is one opinion that it is compulsory to have strategies and to be practiced as well.

2) Autistic child's parents should be professionally helped and supported so to be able to look after their child adequately and in best possible way. After hearing the diagnose most of them came into a condition and really need help to overcome it. They need support to face, to accept and to manage problem. They have to be supported to support their children. They have to be educated how to educate them. But first of all they have to be convinced to confess that they and their child have problem.

3) Child with autism look like living in a box or a room without doors in and out. This room is of glass. And all people around are able to see what is doing child inside but no one could get in. Child could not get out as well. Specialists' task is to find a door: a door to pass through, to get in and to make contact with child; and a door out to help child to join our world. If room stay closed it will deep child's

problems. And shouldn't be forgotten that he/she will not make first step outside alone, because he/she:

- don't want to do that;
- is not able to do that;
- don't know how to do that.

4) Society in common should be informed and prepared to meet and to accept different children and different people. Rights of children with SEN must be promoted in society. It is not just a law to be written – it is not enough. Rights of people should be known by other people. This is first step to a law obeying. And children with SEN should be more protected by law, because initially they are more unprotected.

5) ASD are unique in his specifics and expressions. So it is necessary to be affected by not always standard methods for intervention. It must not be expected that a regular teacher in public school will manage to fix and to overcome problems in classrooms. **Wrong intervention is worse than no intervention!** Patience in meeting a child with ASD is compulsory more than other social-pedagogical case or problem to be solved. Main goal is not to cure ASD, but to make child more independent and to integrate him/her in social life as much as possible.

6) Situations are difficult for the other family's members as well. Children with ASD may have brothers or sisters that are not affected by illness. They have to be under psychological help for two reasons: first to manage problem and second to be support for the child with ASD. There are many cases when father or even mother has no strength to accept diagnosis and leave family or leave the child for governmental care. Here another problem occurs: economical. If father leave family and mother is forced to stay at home and not to work money become not enough and this affects every member of family.

7) Methodology used in current research include different methods for intervention. Its goal is not to define most efficient of these methods, but to prove that intervention is compulsory. Every child affects in different way by different methods. But staying at home and hiding from society is never a good way to meet problem.

It must be clarified that research is continuing now and will achieve more specific results. They will be shared in further publications and statues. Science must not be silence on this topic and new methods for intervention should be found because these kind of children desert every effort made for them.

References

- Benson, P. (2006): The impact of child symptom severity on depressed mood among parents of children with ASD: The mediating role of stress proliferation. *Journal of Autism and Developmental Disorders*, 36(5), 685-695.
- Boycheva, M. P. (2013): *Sensor room - horizon for supportive environment in kindergarten*. Book with statues about good practices. Burgas: Forms.
- Dimitrova, M. (2012): Autism – markers for detection of the disorder and guidance for work. *Methodologies for working with children with SEN* (pp. 52-74). Sofia: Eto.
- Koegel, L. & LaZebnik, C. (2004): *Overcoming autism*. New York, NY: Penguin Group.

- Lindgren, S. & Doobay, A. (2011): *Evidence-Based Interventions for Autism Spectrum Disorders*. Iowa Department of Human Services by the Center for Disabilities and Development of the University of Iowa Children's Hospital.
- Simpson, R. L. (2005): Evidence-Based Practices and Students with Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities*, 20(3), 140-149.
- Stankova, M. (2012a): Evaluation of communication and cognitive abilities and planning activities. *Methodologies for working with children with SEN* (pp. 75-98). Sofia: Eto.
- Stankova, M. (2012b): Anxiety disorders. *Methodologies for working with children with SEN* (pp. 137-141). Sofia: Eto.
- Willis, C. (2006): *Teaching young children with autism spectrum disorder*. Beltsville, MD: Gryphon House, Inc.
- Wong, C. et al. (2014): *Evidence-Based Practices for Children, Youth, and Young Adults with Autism Spectrum Disorder*. Chapel Hill: The University of North Carolina. Available at: <http://autismpdc.fpg.unc.edu/sites/autismpdc.fpg.unc.edu/files/2014-EBP-Report.pdf>.

Ch. Assist. Prof. Dr. Maria Dishkova, Burgas University "Prof. Dr. Asen Zlatarov", Bulgaria, msshtereva@gmail.com