

Autistic children: from social isolation to social aid

Maksim Aleksandrovich Kostenko

Altai State University, pr. Lenina, 61, Barnaul, 656049, Russia

Abstract. The article deals with the poorly studied problem of arranging social aid to families parenting children with autism spectrum disorders (ASD). Based on the analysis of the actual daily needs of the families having autistic children, the main channels of aid rendered to such families as well as the frustrated needs of the families are revealed. Discussion of the results of the empirical research shows the inconsistency of the existing system of formal aid to the families, fragmentary and incomplete nature of the resource of professional aid to families affected by ASD. This article analyzes the daily experience of parents of children who have ASD as the immediate subjects of the aftercare process and closely studies the process of objectivation of the role of families affected by ASD in the governmental system of social aid rendered to atypical children. Analysis of the frustrated demands of the life activities of the families affected by ASD allowed to reveal the main obstacles at rendering the social aid as well as the professional "targets" of further optimization of the structure and content of social services for this category of the population.

[Kostenko M.A. **Autistic children: from social isolation to social aid.** *Life Sci J* 2014;11(6):530-534] (ISSN:1097-8135). <http://www.lifesciencesite.com>. 77

Keywords: social isolation, social aid to children who have autism spectrum disorders, the model of disability, social attitude.

Introduction

Children with the autism diagnosis always differ from other people: they have a low level of socialization and adaptation to the environment. The signs of autism are displayed starting from early childhood and gently become more and more noticeable for the people around, which results in their social isolation. Until now, autistic people in Russia have been being treated using the medical model of disability, which is explained by the reasoning that "such people" cannot become useful for the society in the future. Therefore, the main aid by the government rendered to autists is social allowances for disability and medicinal treatment. This social attitude has been formed not only with respect to autists: all other disabled persons in Russia are more likely treated as groups of social isolation (rejection). Tendencies of social integration that emerged in the late 20th century insignificantly promoted the ideas of inclusive education, but the problems of complete social inclusion remain not implemented in practice. The suggested research identifies several analysis lines – these are services of early aid to families with children who have ASD, contemporary infrastructure of social services for such families, their adequacy to the demands of the daily living activities of the families, and development of children who have ASD. Therefore, special attention has been paid to parents of children who have ASD, as the parents are the only available and comprehensive source of information on this issue.

Methods

The research is based on the quantitative

(analysis of statistic data, secondary analysis of sociological research, and analysis of official documents) and qualitative data about the status of the families parenting children who have ASD, their needs, and existing social services (semi-standardized interviews and focus groups of parents).

The main part

The urgency of the autism issue in Russian regions is determined by a number of facts: high degree of ASD incidence among disabled children, complexity and diversity of the clinical characteristic of the disease, difficulty of corrective work manifested in underevaluation of the problem's significance by the government and the society, and, consequently, poor coordination and insufficient efforts of various public authorities and social organizations of children aftercare [1].

The world statistics evidences the growth of ASD incidence: in 2000, the incidence was equal to 5-26 cases for 10,000 children; in 2005, it was 1 case for 250-300 newborn babies [2]. According to the WHO, in 2008, the frequency was equal to 1 case for 150 children [2]. The Russian statistics on the precise number of autistic people in the country is not available. According to some sources, there are at least 250,000-300,000 children under 18 years of age who have ASD in Russia [1]. Obviously, because of the absence of reliable statistic information, it is impossible to plan the work on creation of the governmental system of social aid to the people with autism and their families, provide monitoring and evaluate the quality of such work. At the same time, people with severe disorders of development,

including the overwhelming majority of people who have ASD, need specially arranged comprehensive aid starting from the birth and, sometimes, until their death. Specialized support is required in the family, at kindergarten, at school, at a child care center and residential care centers, at places of employment and residence. With the purposes of social orphanage prevention and family preservation, the aid is to be rendered not only to the child, but also to the whole family, in which the child is parented. Currently in Russia, social servicing of disabled persons does not include their support, and there is no legislative regulation of rendering the services to people with severe disorders of development [3].

Another important problem of the process of development and implementation of the social and psychological aftercare of autistic people and their families is the professional attitude of specialists of aiding professions. Analysis of the results of our research showed that such approach to the methods of both medicinal treatment and sociopsychological and pedagogical correction of autism are quite numerous, versatile, and often contradictory. The principles of both in-house and interdepartmental interaction are vague and arbitrary; the coordinating and supervising function of the state with respect to the correction of autism in fact is missing, which adversely affects the efficiency of treatment, parenting, and aftercare of autistic people and their families. Helping these people to adapt to the environment, creating favorable conditions for their living, aiding to form the skills of self-servicing, teaching them to overcome shyness and anxiety, and, which is most important, preventing adults who have ASD from being taken to closed medical (or socially residential) establishments are the main tasks of social researches and social practice in the nearest future.

At studying the problems, demands, and models of the aid offered to families who parent children who have ASD as well as developing new, in-demand, and efficient services and models of help, it is necessary to understand the peculiarities of the target group of the services recipients and the nature of this group of disorders. Autism and development disorders similar to it are not a new problem for Russia and other countries. However, in view of the increasing professional and public interest to the issues of aiding children with development deviations and their families, more and more attention has been being paid to the issues of revealing, diagnosing, supporting them, and ensuring their social integration over the last years.

Early infantile autism was described by L. Kanner (1943, Kanner syndrome). The results of studies conclusively evidence the biological cause of autism, which at the final stage of its pathogenesis

result in disorders characterized by certain common attributes [4]. These disorders are characterized by varying combination of the disorder of the social and communicative interaction ability and the restricted stereotyped repeating set of interests and types of activity [5]. The demand for services to families with children who have ASD emerges very early, when the peculiarities of a child's development start being noticed. Therefore, the agenda of designing social services adequate to the level of demands, development, the context of social life of the family and the child is always timely. When considering any model of social aid organization, it is necessary to focus on the two principally important issues: who is the recipient of the service and what need this service aims to satisfy (demand-oriented approach in the social work) [6].

In this view, the most prospective for designing services targeting the children who have ASD and their families is the methodology of environmental model of aid by U. Bronfenbrenner [7]. According to this theory, the child development environment consists of four systems embedded into each other: the microsystem – the family of the child; the mesosystem – kindergarten, school, yard, the quarter where the child lives; the exosystem – social organizations for adults; and the macrosystem – cultural customs of the country, values, traditions, and resources. The most important role in the children development belongs to the macrosystem, as it is able to influence on all other levels. The values and the resources, which the macrosystem offers for development of other systems and their interaction, directly affect the situation in the families parenting the children. The macrosystem also regulates the existence of certain services in the society: whether bodies, programs, and services will be created, which would meet the demands of the child and its family, and, in turn, contribute to the development of parents' competences and the child. What is happening between the systems has greater importance for the child development than what is happening inside each of them. For example, the search for a solution inside only the microsystem (the family) can turn out to be rather costly and ineffective for achievement of the desired result. At the moment when the resources of a family are weak, it is necessary to seek support, which can be provided by meso- and exosystems ensuring social ties, for example, relatives, neighbors, etc. The level of the exosystem, which provides for the performance of the respective bodies, is the level, on which decisions on the future fate of the child and the family are taken and supportive services are provided [7].

The described model gives the conceptual understanding of how various levels (environmental

systems) of the space of developing the social aid to children who have ASD interact: the services rendered to the parents of children who have ASD and the "supportive" attitude to autists in the society have indirect but equally important influence on each specific child. Therefore, it is wrong to limit to only the aid to a child (as the center of the system), it is necessary to include "representatives" of all environmental systems: the main fostering person (the parent or the caretaker), specialists of the "aiding" spheres, and persons taking decisions. To create efficient models of aid to children who have ASD, the support system must meet the needs of this category taking into account the needs of the systems of other people around them. One of such requirements will be the existence of reverse interconnection of the revised needs and systematic response to them in the form of services [8].

The diversity and variability of the rendered services cannot be considered without understanding the nature of the needs, which are best represented by the theory of the Maslow's hierarchy of needs [8], which not only ensures understanding of the content-related aspect of the social services rendered to the child ("with what the child should be helped"), but also determines the priority, i.e. builds the prioritized lines of support.

The dynamics of satisfaction and actualization of certain needs composes the quality of living. This approach allows to focus all resources that the system has for changing the current situation to better and helping a particular child. Acknowledgment of the "quality of living" category as the basic one at development of the plan of handling a particular case pushes the envelope for implementation of the cross-disciplinary approach and actualizes the responsibility areas for various spheres of the "supporting" activity. The subjective evaluation of own needs by clients is an important tool used for evaluation of the services performance and evaluation of the efficiency of the entire system performance [9].

One of the main factors deteriorating the efficiency of the aid to autists is the late coming in the sight of specialists – they are usually identified at 3-4 years of age and later, when the development peculiarities become obvious enough for the people around [10]. The age of social interference beginning directly influences on the result – the sooner a child starts receiving help, the more positive the changes in the functional development of the child who has ASD will be. Currently, even at the first year of life, it is possible to identify peculiarities in the behavior and reactions of a child, but absence of necessary minimum knowledge of parents, and sometimes even experts (medical and social professionals) result in

losing time, which adversely affects the results of rehabilitation.

The problems of early aid to children who have ASD are urgent. About 57% of parents said that they started noticing certain peculiarities or signs of delay in development of their children at a rather early age (before 1.5-2 years of age). They noticed certain differences of their children from other ones, but at that time did not have enough information on what autism or ASD was. The majority of the mentioned singularities are related to the "triad of autistic spectrum": communication disorder, social interaction difficulties, and behavior singularities [11]. The first signs that something was wrong were noticed by themselves, or their friends or relatives told them:

"I started noticing some certain peculiar features when he was approximately one year old. I was not quite sure... Between 1 and 1.5 years of age, I was just watching after the child and trying to change something".

Less than 1% of questioned people claimed that the first signs were noticed by medics (a visiting nurse): *"...the nurse came from the hospital and said that it was clear something was wrong with the child..."*

After the peculiar features of the child were revealed, the "rehabilitation route" typically was as follows: visiting the hospital (the pediatrician) at the domicile, then they were forwarded to the psychiatrist, taken to the psychoneurological hospital, less than 25% of parents were admitted to social rehabilitation at social service institutions. Thus, the governmental system of support objectified the parents' role, frustrated their position as an active subject of aftercare:

"When we came to the neurologist, she said: 'What's up with Dima?', while I was expecting her to tell me what was up with Dima. Then, she sent us to the hospital, we passed the examination, the polyclinics forwarded us to the hospital, and they made the diagnosis: neurological damage of the central nervous system. Nobody told me what was the cause of that, nobody even talked with me. Then, we were sent to out-patient psychiatric facility, then, at the age of four, we were admitted to ... [municipal psychiatric hospital], and I cannot say at all what they examined there".

According to parents, diagnosing autism qualitatively affected both their lives and the lives of their families. Answers to this question also allow us to understand the certain difficulties of personal and social nature, which the families with children who have ASD face.

"I became panic-stricken... the most important thing was to accept the child as it was"; "Everything changed. We even divorced with the

husband, and I stayed alone with my son"; "I try to avoid going outside with my child...".

Parents say their free time is restricted or they need help from their close families if necessary, which also results in conflicts with them: "My life was changing hard, because the child was with my mother, his grandmother, all the time. I work. When I come home and start telling my mother that she has done something wrong, it results in conflicts with her, then with the child".

Parents also attracted the attention to the fact that there were problems in finding information and understanding the certain algorithm of actions after they had been told the child's diagnosis: "I would prefer that after the diagnosis was made, we would not be knocking about, but be told what disease we had, and then what exactly we were to do and in what sequence".

The next block discussed by the participants within the framework of focus groups concerns the existing services, which their children received, or which could be received by them. Many parents mentioned larger number of medical services that were needed initially for making proper diagnosis and later, for the behavior and treatment correction, and also mentioned various medicines, though they expressed their common opinion that it did not help their children: "We don't visit doctors any longer - there is no much sense in it. They won't give us more than just assigning some medicines. And the treatment they offer is only with medicines".

When discussing medical services, the main problem is that it is quite difficult to get common medical aid for a child with autistic spectrum disorders due to the singularities of his behavior. Staying in a polyclinics causes multiple problems to parents: "We don't have specialists who can be attended with such a child. Polyclinic is one making me and my child suffer. Yet they have long queues, too. But we have to go there because there's nothing else we can do".

When communicating parents, we discussed the necessary changes that could improve the situation. The majority of proposals were associated with the possibility of socialization of their children, inclusion of them into the society, giving the opportunity to communicate with others as equals: "Communication for children, so that the children could be left for some time alone, and could play with each other under supervision. Just for a little while, so that we could have some free time, and that children could visit something for some period, communication".

Another very important change according to the parents was their ability to stay apart from the child for some time, start communicating other

people, try to live a social life: "I want to hear some other information from normal people who have not been affected by this, let those be even merely common things, not all about the disease".

Thus, it is reasonable to point out the changes in the system of social services rendered to families affected by ASD: not only the child who has ASD must be addressed, but also people close to him – the environment of primary socialization, first of all – the family [12]. Consequently, specialists of the institutions must receive tools that would target not only evaluation of the development and functional singularities of a child, but also evaluation of the needs of the family and rendering services according to the conducted evaluation. Such an approach to rendering social services assumes serious structural and organizational changes in the activity of the institutions.

Summary

The battery of indicators of the living activities of families with children who have ASD provided in this article allows to illustrate the mechanisms of social isolation of such families from the social life. The prevailing attitude of specialists, the social environment of the families with a "special" child reproduce these mechanisms, which result in formation of the family as an object of social interaction, but not an equal subject. Reduction of the subjective potential of a family with a child who has ASD directly and implicitly encourages formation of social frustratedness of the main groups of needs of such families (and each particular member of such a family), decrease in the rehabilitation potential of the child, and makes implementation of social integration and adaptation of "atypical" individuals in the contemporary society virtually impossible. At the same time, studying the microsystem of a child who has ASD allows formulating the models of help, developing social services, which can be transposed on the structures, which are on the exo- and macrolevel, and forming the political and program content of these levels. It is understood that such an approach will allow providing for necessary structural changes in the policy and activity in the sphere of aiding the families, which parent children who have ASD.

Conclusions

The fact of social isolation of families parenting children who have ASD requires being paid special attention by the persons who take decisions in the sphere of social policy. Planning the system of support and implementation of services developed with account of the needs of families will allow not only to decrease or even eliminate the social isolation of the families, but also to activate the internal potential of families, which is one of the important

factors of positive changes for both the children and the entire families.

The social aid to the families affected by ASD in Russia is not currently institutionalized, and is of fragmentary and initiative nature. Particularly, it manifests itself in the fact that parents and specialists lack information about both the disorder itself and the services and programs for children who have ASD, the sources, from which the parents and specialists receive the information. The system of early aid to families rendered at the time of revealing the ASD diagnosis with little children has not been formed. The "rehabilitation route" of a child who has ASD is formed by parents intuitively, unassistedly, following the segmental (incidental) information, which they have found in mass media and/or social environment. The activity of professional subjects of rehabilitation of children who have ASD (and their families) is functionally limited, set by their (specialists) representations of ASD, and does not have any traditional forms of interaction and succession.

The main resource of meeting the prevailing needs of development and daily living activities of the families affected with ASD is the informal support from the closest environment of the family. However, there is a significant list of needs, which cannot be satisfied by the mentioned resource, and these needs remain frustrated, as the services of the existing professional system of aid do not address these needs or are developed insufficiently. If possible, these services rendered by social institutions are insignificant and do not affect (or affect insignificantly) the quality of the child's life; or – the services are of auxiliary nature and do not meet the urgent needs of the child and the family; or – the services needed by the child, the parents, and the family are rendered far from the residential place. In order to meet the frustrated needs, it is necessary to develop and/or reform the existing national system of help in the sphere of rendering services to families and children who have ASD.

It is necessary to develop a methodology of family-focused aid to a child who has ASD, so that the whole family would be in the focus of the aid. Specialists of the institutions must receive tools that would target not only evaluation of the development and functional singularities of a child, but also evaluation of the needs of the family and rendering services according to the conducted evaluation. Parents must be treated not only as the recipients of the services, but also as equal partners in the process of planning and implementing the aid programs. Planning the system of support and implementation of

services developed with account of the needs of families will allow not only to decrease or even eliminate the social isolation of the families, but also to activate the internal potential of families, which is one of the important factors of positive changes for both the children and the entire families.

Corresponding Author:

Dr.Kostenko Maksim Aleksandrovich
Altai State University, pr. Lenina, 61, Barnaul, 656049, Russia.

References

1. Morozov, S.A. and T.I. Morozova, 2011. Problems of Aid to Children who Have Autism Spectrum Disorder. Date Views: 10.03.2014 http://www.autisminrussia.ru/html/science/research_soc_morozov.htm.
2. Overall Coordinated Efforts on Treatment of the Whole Spectrum of Disorders Associated with Autism, Report by the Secretariat of WHO dated 08.04.2013. Date Views: 23.02.2014 http://apps.who.int/gb/ebwha/pdf_files/EB133/B133_4-ru.pdf.
3. Kostenko, M.A. and N.B. Kostenko, 2013. Severe Treatment with Regard to Under Ages: the Problems of Prevention and Arrangement of Psychosocial Aid. Barnaul: Altai State University, pp: 25-56.
4. Kanner, L., 1973. Childhood Psychosis: Initial Studies and New Insights. Washigton: Winston & son, pp: 77-90.
5. Treffert, D.A., 2006, Dr. Down and "Developmental Disorders". Journal of Autism and Developmental Disabilities, 36: 965-966.
6. Geeraert, L., W. van den Nootgate, H. Grietens and P. Onghena, 2004. The effects of early prevention programs for families with young children at risk for physical child abuse and neglect: a meta-analysis. Child Maltreatment, 9: 276-297.
7. Bronfenbrenner, U., 1979. The Ecology of Human Development: Experiments by Nature and Design. Cambridge: Harvard University Press, pp: 187-250.
8. Rycus, J. and R. Huges, 2009. Filed guide to child welfare. Washington DC: CWLA, pp: 82-234.
9. Harper-Dorton, K. and M. Herbert, 2000. Working with Children and Their Families. Oxford: BPS: Blackwell, pp: 180-198.
10. Gilliland, B. and R. James, 1999. Crisis Intervention Strategies. University of Memphis, pp: 139-147.
11. International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10). Date Views: 15.02.2014 <http://mkb-10.com>.
12. Cleaver, H., I. Unell and J. Aldgate, 1999. Children's Needs-Parenting Capacity: The Impact of Parental Mental Illness, Problem Alcohol and Drug Use, and Domestic Violence on Children's Behaviour, London: The Stationery Office. pp: 97-137.

5/12/2014