

Parents' Perception of Therapy and Education for Autistic Children

Maria Belea

*Lecturer PhD, Technical University of Cluj-Napoca; North University Centre of Baia Mare, Romania
maria.belea@sssuta.utcluj.ro*

ABSTRACT: Autism spectrum disorders (ASD) often represent for parents a confusing situation, creating changes in both the dynamics of the interfamily relationships and the family's relationships with society in general. The path to understanding autism and managing the issues it generates can be challenging, often testing parents' coping mechanisms. This paper emphasizes the necessity of qualitative inclusive education and consistent therapeutic interventions, which are among the main concerns of parents with autistic children. Additionally, the paper aims to highlight the main facilitating factors and obstacles that interfere with the socio-educational integration of children with special educational needs, proposing several strategies for improvement.

KEYWORDS: autism spectrum disorders, parents of the autistic children, facilitator factors, inclusive education, therapy

Introduction

Autism, one of the most common developmental disorders of neurobiological origin found in children, has been the subject of numerous medical and psychological research in recent years, with the aim of understanding the etiopathogenetic factors and the most appropriate therapeutic methods. The autism spectrum is very comprehensive, given its multiple manifestations and different levels of impairment in development and functioning, but there are also many identical features along the continuum (Chantal 2017, 19).

Many researchers and scientists around the world have contributed to the advancement of knowledge about ASD. The latest studies in this direction highlight that a number of genetic changes are associated with autism spectrum disorders, stressing the importance of early detection and intervention, as early as around the age of one, which could change the course of the later course of the disorder (UCDavis Health and Mind Institute 2024), thus maximizing learning and development. In reality, parents typically notice a child's atypical development around the age of two, while most diagnoses and therapies occur after the age of four, depriving the child of crucial early intervention. This highlights the urgent need for both parents and pediatricians or family doctors to recognize and identify the signs of autism at an early stage. According to research, the earlier a child is included in a treatment and therapy program, the better the prognosis. However, research on the neuroplasticity of the brain demonstrates the brain's ability to reorganize itself by forming neural connections throughout life, which should encourage parents of these children to help their own children (Chantal 2017, 54).

The impact of having a child with ASD on the family

The diagnosis of autism in a child can be experienced by parents as a real trauma, which disrupts the natural course and development of a family, both in terms of the relationships between its members, as well as the family's relations with friends and society in general. The birth of a child with a disability is a crisis in any family, which can create feelings of insecurity and insecurity, especially about what will happen to the child or even the family in the future. Parents may experience diffuse feelings about both the child and the cause of the child's disability, which can lead to remorse, self-blame and blame (Chelemen 2006, 7).

The initial phase of shock is characterized by strong emotions on the part of the parents, such as anger, helplessness, disappointment, and confusion in the face of discovering a health problem in the child (Secrii and Balica 2021, 114). Behavioral deviations, lack of communication on the part of the child, and diagnostic hesitations mark the family life, which goes through a real crisis and affects the couple's relationships. Parents make special efforts to maintain the couple's relationship and the bond with other family members, given that much of their time and attention must be devoted to the child with ASD (Divan et al. 2021, 190-200). In addition to relational difficulties, parents often feel disoriented and lonely, mainly due to the lack of information about diagnosis and therapies, and are unprepared to cope with a life that will involve continuous therapies, countless interactions with specialists and dependence on services in the hope of getting better.

The lack of emotional as well as material support, as well as the autistic child's specific symptoms, makes parents even more vulnerable to stress and they are more prone to depression and mental illness (Săndica 2016, 41). Silva and Schalock (2011, 566-574) reached the same results and found that families who have children with ASD suffer two to five times more from stress than parents who have typically developing or developmentally delayed children.

Certainly, caring for a child with autism requires a readaptation effort on the part of the parents, who face numerous challenges from a medical, educational, and therapeutic point of view. It is extremely important that, in parallel with medical and psychological research into autism, special attention should be paid to the parents of these special children. Understanding their needs and the challenges they encounter in their efforts to make their children's lives better is vital. Therefore, prioritizing both intervention and prevention strategies is necessary to ensure that parents receive the psychological and social support required to navigate this journey effectively (Rotaru 2016, 29-43). Another aspect to keep in mind is that the family needs support to cope with the child with autism when difficulties arise, starting with therapy, integration into an appropriate educational system, acceptance in the community, etc. Studies show that parents of children with ASD cope with feelings of shame, exclusion from social and educational activities, and feelings of stigmatization or resistance from the community (Farrugia 2009, 1011-1027).

Needs of parents of children with ASD. Study results

Deepening the issues in the field of autism implies, therefore, knowing the needs felt by families caring for children with autism, their opinions about the education and services received by these children, and how therapy, interventions, and socio-educational inclusion for children with autism can be improved. In line with these objectives, the present paper aims to analyze from a theoretical-methodological perspective the psycho-social impact on the family following the birth of a child with disabilities. The study was conducted on a number of 45 mothers whose children with autism access the services offered by state institutions or some associations and private centers in urban areas. The average age of the participants was 35, the youngest mother being 24 and the oldest 42. Percentage-wise, about 63% of the respondents belong to the age group 20-35 years, while 17% belong to the age group 35-45 years.

Regarding the educational level of the mothers, about 32% of them have a university education, 45.35% have completed high school, 13.64% have vocational education, and 9% have completed secondary education at most. Also, the mothers who participated in this study have children aged between 2 and 7 years, with an average age of 4.5 years, most of them (77%) being boys, which confirms that autism affects boys more than girls. Also, the majority of mothers who participated in this study are employed as caregivers for their own children, 86.5% are married and 13.5% are divorced or unmarried.

A questionnaire was used as a research method, containing 30 closed and semi-closed questions, which aimed to collect information on the type of therapies the child receives, the level of inclusion in the education system, the child's progress at school, manifested by

difficulties encountered in this regard, including the existence of requests from the educational institution to reduce the child's school program or even to withdraw him from the education system, the factors contributing to the difficulties in school integration of the child with autism, the educational activities and therapeutic services available to the child and the parents' satisfaction with their use, the therapeutic services and activities in the educational system that the child would need, as well as the support measures experienced by the whole family and, last but not least, the parents' concerns about the current problematic situation and the future of their child.

For the application of the questionnaire, the persons in charge of some state and private educational and rehabilitation services and institutions attended by children with autism and their parents were contacted, and the parents were also explained the purpose of the questionnaire and how to fill it in.

In approaching this study, the following considerations were taken into account:

- the birth of a child with a disability disrupts a family's lifestyle and its natural way of development;
- there is an increased need for parents to have specialized information about the diagnosis, intervention, development and school integration of a child with autism;
- parents of children with disabilities need support to cope with the challenges and difficulties of caring for a child with autism;
- early detection of the disorder, followed by early intervention, can help the child not to suffer from the side effects of the disorder (chronic anxiety, fear and difficult behavior).

In accordance with these premises, the aim of the study was to know the needs of services/therapies for children with autism, the degree of accessibility to these services/therapies, as well as the difficulties encountered in the process of socio-educational inclusion (Rotaru 2021b, 190-196).

In the following, we briefly present the results of the main questions in the questionnaire. Regarding the children's diagnosis, according to the parents' statements, 80% of the children were diagnosed with ASD, 10% with ASD and ADHD, and 10% with ASD and various forms of psychomotor retardation or language delay.

The majority of children (95.5%) whose parents participated in this research are enrolled in an educational program. However, for some children, health problems were a hindrance to attending the educational program from an early age. A total of 68.6% are enrolled in a mainstream school or kindergarten, are enrolled in a state special school for children with disabilities, 13.3% attend a private school or center, and 9% are enrolled in special classes for children with disabilities in a mainstream school, 9% are not enrolled in an educational program.

The integration of children with autism into the socio-educational environment (Rotaru 2021a, 87-92) seems to be gradually being resolved. However, due to the lack of specialized teachers, in some educational institutions, children are not accompanied by a chaperone, which is a great disadvantage for them. Thus, 60% of parents perceive teachers as competent, motivated, and concerned about the child's needs and educational priorities, but 35% of them consider that the teaching staff is not specialized in working with children with special educational needs or that they are incompetent and demotivated.

The results of this study indicate that the parent-school relationship and assertive communication are very important. From the responses on whether the school informs parents about their child's progress, we can see that only 45% of parents meet regularly with teachers and more than a quarter of parents did not have regular meetings with their child's teacher or head teacher.

The services that children benefit from primarily include therapy (58.3%), assessment services, school and vocational guidance (16%), as well as specialized medical services provided by psychiatrist, pediatrician, neurologist (15%), and counseling services (10.7%). Unfortunately, not all therapies are free of charge, depending on the needs, only 28.5% receive these services free of charge, 25.4% do not receive them at all, while for 46% of children, these therapies are only partially covered, highlighting significant disparities in access to necessary support. The majority of children with autism receive therapy services in NGOs (65.3%), they provide specific therapeutic services in public day-care centers (16.2%), but also in educational units, medical and psychological clinics (18.5%). Of the parents surveyed, 57.2% are satisfied with the quality of the services they have received, both in NGOs and in public day care centers, and 42.2% are very satisfied. Of the parents who took part in this study, 68% are worried about the child's future, the fact that the child will not cope without his/her parents, the child's degree of independence, the child's degree of integration in school and in society, the child's medical and communication difficulties, possible experiences of bullying, discrimination, marginalization that may occur when the child enters school, etc.

The last part of the survey considered service suggestions from parents. About 35% of them consider that it would be beneficial to participate in training in behavioral therapy techniques, to know how to act in crisis situations, to be offered advice on the upbringing and education of the child with autism at different stages of development, to receive financial support for the payment of therapies, as well as emotional support and psychological counseling (both at the time of diagnosis and during the course of therapy). Parents also want home-based therapies for their children, more competent therapists, and therapies to be individualized, taking into account the child's needs. Also, parents of children with ASD revealed that there is a need for more involvement in the educational system, support, and adaptation measures for children with ASD, as well as counseling programs for parents and siblings, and, last but not least, community education programs to promote social integration.

Conclusions

On the basis of the results obtained, the quality of life of families with children with disabilities is affected both by the birth of such a child and by the lack of adequate informational support about the problems faced by the child, to which must be added material and financial deprivation and lack of prospects for the future of these children. Therefore, it is important for families with children with ASD to have access to psychological counseling services, to be aware of the signs of autism at an early age, and to have information on therapy and educational alternatives for their child. Parents should be encouraged to become co-therapists for their own children (by developing communication skills and learning behavioral therapy techniques), and to be active members of the education their child should receive. It should not be forgotten that parents who have children diagnosed with autism spectrum disorders face a high level of stress, therefore, in addition to emotional support, it would be useful to provide respite services where the child can be cared for in a center for a few hours/days, which can be a concrete support for these families. Consideration should also be given to more substantial financial support from the state, given the high cost of therapies. Another aspect that needs to be improved is the awareness and sensitization of the local community in terms of understanding, acceptance and integration of people with autism in society.

The school and social integration of these children remains an intense concern for parents, but we should not overlook the fact that forcing their integration into regular classes can be a failure, with important repercussions on family dynamics. Therefore, integrating these children into regular mainstream education classes must be well prepared, considering both the benefits and disadvantages (Chantal, 2017, 182-183). Last but not least, there is a need to improve social protection services, emphasizing quality professional intervention and training social protection professionals on the diagnosis of ASD, thus contributing to the understanding and support of families who are affected by this diagnosis.

References

- Chantal, Sicile-Kira. 2017. *Tulburarea de spectru autist. Ghidul complet pentru înțelegerea autismului [Autism Spectrum Disorder. The complete guide to understanding autism]*. Bucharest: Herald Publishing House.
- Chelemen, Ioan. 2006. *Impactul pisho-social asupra familiei ca urmare a dizabilității copilului [The psycho-social impact on the family as a result of the child's disability]*. Oradea: University of Oradea Publishing House.
- Divan, Gauri, et al. 2021. "Challenges, coping strategies, and unmet needs of families with a child with autism spectrum disorder in Goa, India." *Autism Research* 5: 190-200. DOI: 10.1016/S0140-6736(21)01541-5.
- Farrugia, David. 2009. "Explaining stigma: medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder." *Sociology of Health and Illness* 31: 1011-1027.
- Rotaru, Ioan-Gheorghe. 2021a. "Current Values of Education and Culture." In *Proceedings of the 23rd International RAIS Conference on Social Sciences and Humanities*, edited by Nicoleta-Elena Hegheș, 87-92. New Jersey: Princeton. DOI:10.5281/zenodo.5506908.
- Rotaru, Ioan-Gheorghe. 2021b. "Valences of Education." In *Proceedings of the 23rd International RAIS Conference on Social Sciences and Humanities*, edited by Nicoleta-Elena Hegheș, 190-196. New Jersey: Princeton. doi:10.5281/zenodo.5506908.
- Rotaru, Ioan-Gheorghe. 2016. "Plea for Human Dignity." *Scientia Moralitas. Human Dignity - A Contemporary Perspectives* 1: 29-43.
- Săndica, Ion. 2016. *Identificarea nevoilor în rândul familiilor care au copii diagnosticați cu tulburări din spectrul autismului [Identifying needs among families with children diagnosed with autism spectrum disorders]*. Bucharest: University of Bucharest Publishing House.
- Secrii, Vera and Nina Balica. April 16, 2021. „Asistența psihosocială a familiei cu copii cu dizabilități” [Psychosocial assistance for families with disabled children]. Paper presented at the conference *Asistența psihosocială în contextul noilor realități pe timp de pandemie [Psychosocial care in the context of new realities in pandemic times]*. Chișinău, Republic of Moldova.
- Silva, Louisa M. and Mark Schalock. 2011. "Autism Parenting Stress Index: Initial Psychometric Evidence." *Journal of Autism Developmental Disorder* 42: 566-574.
- UCDavis Health and Mind Institute. 2024. "Autism Resources." <https://health.ucdavis.edu/mindinstitute/resources/autism.html>. Accessed on November 10, 2024.