

**Revista Romaneasca pentru Educatie
Multidimensionala**

Romanian Journal for Multidimensional Education

ISSN: 2066 – 7329 (print), ISSN: 2067 – 9270
(electronic)

Covered in: Index Copernicus, Ideas RePeC,
EconPapers, Socionet, Ulrich Pro Quest, Cabell, SSRN,
Appreciative Inquiry Commons, Journalseek, Scipio,
EBSCO, CEEOL, ERIH PLUS

**THE ROLE OF ASSOCIATIVE SECTOR IN
INTERVENTION OF CHILDREN WITH AUTISM**

Mihaela GRASU

Revista Romaneasca pentru Educatie Multidimensionala,
2015, Volume 7, Issue 1, June, pp. 117-128

The online version of this article can be found at:

<http://revistaromaneasca.ro>

Published by:

Lumen Publishing House

On behalf of:

Lumen Research Center in Social and Humanistic Sciences

The Role of Associative Sector in Intervention of Children with Autism

Mihaela GRASU¹

Abstract

The aim of this empirical investigation is to analyse the role of associations in the development of intervention on children with autism in Iasi. Research methodology is a qualitative fieldwork based on observation and semi-structured interview. Professionals from two NGOs and a special school and parents of children with autism were interviewed. Research results show that associations have set up establishment of specialized structures, adapted to children with autism care. The development of these services was achieved through financial and logistical support received from outside, by attracting local authorities who provided locations, conducting awareness campaigns and fundraising etc. If before the parents of children with autism were desperate they did not know where to go, now they have several alternatives after receiving the diagnosis. The study concludes that the transition from resigned and submissive attitude of Romanian Government to provide a small financial support for families in an active attitude in which the emphasis is on development of educational and behavioural methods social integration of people with autism was made possible by the development of the NGO sector.

Keywords:

autism, psycho-social services for children with autism, parents' associations, public-private partnership, qualitative research.

¹ PhD, postdoctoral researcher, Alexandru Ioan Cuza University, Romania, grasumihaela73@gmail.com.

Introduction

Autism, originally discovered in 1943 by psychiatrist Leo Kanner, incited many experts around the world to undertake research to identify causes and find appropriate treatment. Over time have tried a variety of therapies to improve symptoms associated with autism: from very structured therapies requiring behavioural approach guided by a therapist to drug therapy, complementary therapies based diet, occupational therapies, therapies based images, to programs that focus on children's interests and incorporate them into daily activities in its natural environment or therapies involving the use of robots. The most effective interventions have proven to be educational and behavioural methods, which were initially developed in the US in 1980 and then were spread on large-scale in many countries (Chamak, 2008).

If for clinicians and scientists autism is a mystery for families is a painful experience. Parents of children with autism face stress, depressive symptoms and fear of the future (Abbeduto & al., 2004; Baker-Ericzén & al., 2005; Athari, Ghaedi & Kosnin, 2013).

In addition to these problems, parents of children with autism in Romania struggle with the indifference of authorities, which does not create sufficient intervention and therapy services to facilitate their social integration later (Grasu, 2014). Since the state does not even concern the official estimate the number of people with autism (Iosub, 2011). Lack of understanding, support, state involvement leads parents to accumulate a series of negative feelings (Stefanescu & Oșvat, 2011) and to unite to fight for children's rights.

Since 1991, parents of children with autism in Romania were organized in associations to make known to the authorities and community issues people with autism and their needs. The first organization is the National Association for Children and Adults with Autism in Romania (Asociația Națională pentru Copii și Adulți cu Autism din România - ANCAAR), which currently has branches in several counties. Also were established and other organizations of parents, almost all counties also campaigning to promote the most effective ways to care, education and development of the potential of children so as to become as independent as possible.

Associations are forms of organization of civil society, built around the concept of collective interest and citizen involvement. They are communities that share a problem that has to fight. They intervene

with the makers, linking the private space of the individual and the family of state power (Vlăsceanu, 2002). Associations are funded by contributions from members, donations, but can receive state support if proving that the activities they carry out are of national interest.

Besides associations in Romania also allowed establish foundations. If associations are "indicative of the spirit of solidarity and mutual aid," foundations is "philanthropy", and "the financial resources" because foundations have a distinct patrimony independent of its founder to meet a goal of general interest or Community (Lambriu, Vameşu, 2010). The two categories of NGOs have different requirements for their establishment by legal, a different structure of governing bodies and different conditions of dissolution and liquidation.

When pursuing common goals, NGOs can unite in a federation. In this way increases their visibility and have an important role in influencing public policies in their field of work.

Another group of NGOs are extending their business in another geographic area by opening branches, either nationally or internationally. After 1990, several international NGOs such as Caritas, Star of Hope, Holt etc. began to work in our country and, while they opened their branches. In 2010, several organizations of parents in Romania have decided to join the Federation Rights and Resources for People with autistic spectrum disorders to be a stronger voice and adopt a common vision of educational integration, social and professional individuals with autism. This Federation contributed to the norms proposals for law 151/2010 on specialized integrated health and social education for people with autistic spectrum disorders and related mental health disorders. It also participated in the National Strategy for social and professional integration of people with ASD and has been involved in efforts to amend the Order no 762/992/2007 of admission to degree of disability which regulate that autistic spectrum disorder in children is maintained and age adult.

This article aims to present a social-historical perspective how are developed the main institutions that provide services for children with autism in Iasi. Another objective of the study is to describe and analyse the role of associations in the development of psychosocial services for people with autism. For this we conducted a fieldwork in four institutions that provide services to children with autism.

Method

The fieldwork was conducted in Iași, from November 2014 to January 2015. The research methods used were the semi structured interview and the documentation. A number of 22 specialists were interviewed: a specialist in Department of Social Welfare and Child Protection Iasi, eight specialists from two NGOs, eight special education teachers and five parents. Interviews were recorded with the consent of subjects. Interviews were transcribed and analysed using the thematic analysis.

Questions addressed to professionals aimed: when working with autistic children, since children with autism were taken in their service, what other specialists collaborate, description of the activities they carry out with the kids and objectives that aim in working with children with autism and their families, how they trained to work with children with autism. Parents were asked questions related to what issues were taken when the child, what specialists and what services they are called, as were supported, what kind of support was most effective, their expectations from specialists, future plans.

Results

1. Social-historical perspective

The historical perspective on key social institutions providing services for children with autism in Iasi it serves to highlight who the founders and where we started initiatives.

The first day center for children with autism opened in Iași in 2003 at the initiative of the *Ancora Salvării* Foundation. This foundation was established by a person in the Netherlands and was supported financially and professionally in this country. Within this NGO the specialists were trained therapists working in the Netherlands and in particular the methods TEACCH, Give me five and PECS. In the period 2008-2011 this foundation held a partnership with the Special School *C. Paunescu* in order to create the first class adapted of children with autism.

Due to the large number of requests from parents, two NGOs specialized in the treatment of children with disabilities, *Star of Hope* Organization and *Maranatha* Association began to provide services to children with autism.

Star of Hope Romania Organization, a partner of *Star of Hope International* Organization of Sweden, supported by financial and

technical, working since 1990 with children with disabilities in Romania. In 2010 this organization founded a modern rehabilitation center for children and youth with disabilities. Another objective of the Organization *Star of Hope* is to help parents to form associations to be united and fight for the rights of children: *We help parents organize to fight, we help them from behind when they have problems as an organization. (...). Parents need to be supported to find resources in them, help them in key moments when we feel that they need* (interview specialist).

Rehabilitation Center *Penilla* of *Maranatha* Association was opened in 1994 and has received from Sweden funding, training and technical assistance. In this center a team of educators, psychologist, speech therapist, physical therapist and physician conducted intervention programs for children with autism between 3-8 years.

In 2003, parents of autistic children founded ANCAAR, Iași branch, with the support of the *Star of Hope*. In 2009, the association received from the municipality an office and organized *Weekend Club* for children and young people with autism.

The Day Center *Sf. Andrei* of Department of Child Protection and Social Welfare was founded in 2005 a special group for children with autism. The personals of this Center received support from a foundation in the Netherlands to apply TEACCH method, *so that children have progressed, some of them were integrated into mainstream schools* (interview specialist).

C. Păunescu Special School continued to educate students with autism in separate classes. Number of classes of students with autism increased, from two classes with 10 students in the school year 2008-2009, it was reached 13 classes with 84 students in 2014-2015, representing almost one third of school students (interview specialist *Păunescu* School).

In 2011, several parents of children with autism founded *Surâsul Albastru (Blue Smile)* Association. In 2013, the Association *Surâsul Albastru*, in collaboration with the Department of Community Social Work Iasi opened Multifunctional Center of Social – Community Services. In this center, 26 children with autism benefit from specific therapies, and social activities.

In 2012 opened Counselling and Guidance Center for Persons with Autism, part of a national network of 40 centers funded by the Romanian Angel Appeal Foundation from Bucharest, in partnership

with Department of Child Protection and Social Welfare. The center specialists were trained to assess, develop personalized intervention programs and advise parents to implement.

In conclusion, after 2003 specific interventions on children with autism have developed. An important role was played by international NGOs, parents who organized themselves in associations and partnership between NGOs and state institutions.

2. The current situation

In the year 2015, the city is seven establishments where children with autism aged 3-18 can benefit recovery. Of these, a number two institutions are public, three are international NGOs and two are associations set up by parents. These institutions should take a number of over 300 beneficiaries and the number of children with autism Iasi (interview specialist Department of Child Protection).

2.1. Types of services

The main types of services in the 7 establishments are day centers, individual or group therapy or support group for parents.

Day Centers for children with autism in Iasi works generally under a day-care center where children were enrolled in recovery programs. The number of hours that a child stay in these centers is different, the program of public institutions is 8 hours, while the NGOs not exceed 4 hours. In general, children are organized into groups or classes in special school. There is a noticeable difference between the number of children in forming a group of NGOs and day care of the Department of Child Protection. The ABA therapy practiced in Association *Surâsul Albastru* involves a ratio of one to one, a specialist works with one child. Two specialists from *Star of Hope* Foundation work with a group of four - six children, while in the Day Center *St. Andrei* from Department of Child Protection two educators work with twelve children. Within the special school, classes have a number of four – eight pupils. These pupils have in the morning the educational program with a special education teacher and in the afternoon recovery- compensation therapies with another teacher.

The Weekend Club of the parents' association complements day centers because it works when they are closed, respectively on weekends and during school holiday. This club is a place for socialization and

development of useful activities under the guidance of experts, for parents functions as a respite center. In this way, parents are temporarily freed from the load of childcare, thus having the opportunity to rebuild their resources.

In general, therapeutic intervention is performed by child psychologists, pedagogues, psychopedagogues who have trained in autism. All services are employed or collaborate with a speech therapist or a physical therapist because the children with autism have low skills in the communication, general and motor skills, temporal and spatial orientation. In the Day Center St. Andrew two specialized educators implement individualized intervention plans drawn up by the psychologist. In addition to this task, the psychologist helps the parents to exceed the period of denial, blame or depression that occurs after the diagnosis, to normalize the life, to accept the situation and to search optimal solutions for children.

The social worker is present only in a few institutional structures, such as the Star of Hope Foundation and St. Andrew's Day Center. His role is to intervene on parents, giving them psychological support to solve the problems they face, which shows a more complex cases, with positive influences on the development of children.

While not all establishments have hired a specialist to deal with parents and the problems that they have, all organized group meetings with parents in various forms. *Group meetings* are designed to help parents to understand their children and teach them to cope with difficult situations. Group also provides a suitable framework in which they can support each other emotionally. In the special school, the teachers discussed organizational issues or student assessment etc. at meetings with parents, but for parents can be an opportunity for socializing, exchange of views and offering mutual support.

2.2. Staff training

International NGOs funded from Sweden and Netherlands were trained staff to work with the methods TEACCH, Give me five and PECS. Experts from abroad recommends "child watch and apply the most appropriate method" (interview specialist Star of Hope).

Department of Child Protection in collaboration with a NGO from Netherlands formed the St. Andrew's day center staff to use the TEACCH and PECS methods. Staff training has helped increase the

effectiveness of intervention on children: "people trained and with a bit of interest, we had success very beautiful, children integrated into mainstream schools and parents very satisfied (interview specialist Child Protection).

Moreover, the long-term training in autism issues was organized in 2007-2010, by the Department of Child Protection and Social Welfare in partnership with two NGOs in the Netherlands. This training included round 400 psychologists, psychopedagogists, educators, speech therapists, physiotherapists, social workers, teachers, doctors, etc. from several institutions in Iasi and parents of children with autism.

The partnership between *C. Paunescu* Special School and *Ancora Salvării* Foundation was reference for teachers who worked on the first class of students with autism. They received logistical and material support: "From the foundation specialists we have learned to work with pictograms, with schedules, to organize the furniture, to sit banks to the wall, as not many stimuli" (interview specialist Paunescu School).

Instead parents brought from Bucharest and from abroad specialists in ABA therapy, considered the most effective method of therapy. Graduates of Psychology, Special Education, Pedagogy or Social Work, especially students from these areas were initiated in ABA therapy and were subsequently employed by parents.

In addition to initial training an important role to play and continue periodic training. In the NGO *Surásul Albastru și Star of Hope* team meets weekly to discuss difficult cases, organize groups or to establish priority areas of intervention for children. The special school teachers meet monthly in methodical commissions. They discuss on theoretical papers, case studies or hold demonstration lessons.

Discuss

This study presents a historical perspective on key social institutions providing services for children with autism in Iasi. Another objective of this paper is to analyze the role that NGOs have it in developing services for children with autism.

The results show that from 2003 until now in Iasi have developed seven services for children with autism. The first service was initiated by an NGO funded by the Netherlands, but due to the large number of requests from parents and other institutions dealing with

children with disabilities have specialized in working with children with autism.

Romanian state's attitude towards children with autism was to provide financial support to families where the child was placed in degree disability. Some parents did not accept this attitude of resignation and strove to find solutions. They brought experienced specialists, therapists formed, showing that children with autism can progress if they have specific therapies. Moreover, parents were organized in associations to advocate for children's rights. Government authorities have not yet found solutions for main requests of parents, such as educational and behavioural therapies settlement by the Health Insurance Fund, the establishment of free intervention services, development of services for adults with autism etc. Instead, parents were able to mobilize local authorities and community awareness Iasi. The City Hall of Iași has allocated spaces where ANCAAR Iasi Branch and *Surâsul Albastru* Association may work with children or parents. Also Department of Child Protection and Social Welfare and Special School *C. Păunescu*, along with other NGOs working with children with disabilities, answered of numerous requests of parents and created special groups and classes for children with autism, which occurs through specific methods.

NGO created the first intervention services for children with autism. But this services cannot take all the over 300 children with autism in Iasi County. This requires greater state involvement, as to fund services that have been shown to be effective as NGOs and local authorities do not have the financial strength to support a large number of cases, but also to regulate the training of professionals involved, so as to live up to international quality standards.

The other research shows that, the parents' associations with autistic children have contributed to public awareness and have taken on an ever-increasing role in shaping public policy and actions in the field of autism. Parents associations in France, for instance, argued applying behavioral and educational therapies inspired by the American model, despite resistance by French specialists who remained loyal psychoanalytic model approach to autism (Chamack, 2008).

Conclusions

Parents and associations of parents of children with autism had a role in the development of psycho-social services adapted to the needs

of children with autism and their families in Iasi. Parents did not accept the resignation of the government's attitude towards people with autism and were able to organize themselves in associations to mobilize local authorities and other NGOs and to raise awareness for the cause of autism. Because public-private partnership were able to develop more services for children with autism, such as day centers, weekend club etc., and training for parents and professionals, support groups and counselling.

However, to maximize their chances of social integration of people with autism need greater state involvement. It should take financial the pilot projects set up by NGOs that have proven to be effective.

Acknowledgements

This paper is a result of a research made possible by the financial support of the Sectoral Operational Programme for Human Resources Development 2007-2013, co-financed by the European Social Fund, under the project POSDRU/159/1.5/S/132400 - “Young successful researchers – professional development in an international and interdisciplinary environment”.

References

- Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss M. W., Orsmond, G. & Murphy, M. M. (2004). Psychological Well-Being and Coping in Mothers of Youths With Autism, Down Syndrome, or Fragile X Syndrome. *American Journal on Mental Retardation*, 109, 3, 237–254.
- Athari, P., Ghaedi, L. & Kosnin, A. B. M. (2013). Mother's depression and stress, severity of autism among children and family income. *International Journal of Psychological Research*, 6, 2, 98-106.
- Baker-Ericzén, M. J., Brookman-Frazee, L & Stahmer, A. (2005). Stress Levels and Adaptability in Parents of Toddlers With and Without Autism Spectrum Disorders. *Research & Practice for Persons with Severe Disabilities*, 30, 4, 194-204.
- Chamak, B. (2008). Autism and social movements: French parents' associations and international autistic individuals' organisations. *Sociology of Health & Illness*, 30, 1, 76– 96.

- Grasu, M. (2014). Challenges parents of children with autism in local and national press. In Boldea, I. (coord.), *Communication, Context, Interdisciplinarity, Studies and Articles. Vol. III, Section Psychology and Sociology* (pp. 370-375). Târgu-Mureș: *Petru Maior University Press*.
- Iosub, F. (2011) *Formarea și schimbarea atitudinilor față de copiii cu autism. Rezumat teză de doctorat*, Universitatea București.
- *** Law no. 151/2010 regarding integrated specialized services of health, education and social ones, addressed to persons with issues from the autistic spectrum and with associated mental health issues, published in Monitorul Oficial al României, Part 1, nr. 483 from 14.07.2010. [Legea nr. 151/2010 privind serviciile specializate integrate de sănătate, educație și sociale adresate persoanelor cu tulburări din spectrul autist și cu tulburări de sănătate mintală asociate, publicată în Monitorul Oficial al României, Partea I, nr. 483 din 14.07.2010.]
- Lambriu, M., Vameșu, A. (2010). *România 2010. Sectorul neguvernamental - profil, tendințe, provocări*, Fundația pentru Dezvoltarea Societății Civile.
- *** Order no. 692/982/2013 of the Ministry of Health and Ministry of Labour, Family and Social Protection regarding the modification chapter 1 from the Appendix of the Order of the Ministry of Labour, Family and Equality of Chances and of the Ministry of Public Health no. 762/1.992/2007 for approving the medical-psychosocial criteria based on which it establishes the classification in grade of handicap, published in Monitorul Oficial al României, Part 1, no. 313 from 05.03.2013 [Ordinul nr 692/982/2013 al Ministerului Sănătății și Ministerul Muncii, Familiei și Protecției Sociale privind modificarea cap. 1 din anexa la Ordinul ministrului muncii, familiei și egalității de șanse și al ministrului sănătății publice nr. 762/1.992/2007 pentru aprobarea criteriilor medico-psihosociale pe baza cărora se stabilește încadrarea în grad de handicap, publicat în Monitorul Oficial al României, Partea I, nr. 313 din 05.30.2013.]
- Ștefănescu, F. & Oșvat, C. (2011) Socioeconomic Implications of Autism Case Study on Realities. *Revista de Asistență Socială*, 2, 79-88.
- Vlăsceanu, M. (2002) Sectorul nonprofit - furnizor al bunăstării sociale. In Pop, L. M., *Dictionar de politici sociale* (p. 717-720), București: Editura Expert.

Biodata



Dr. Mihaela Grasu is a postdoctoral researcher at the "Al. I. Cuza" University, Faculty of Philosophy and Social-Political Sciences, with the theme "Parents and professionals against autism". She graduated in Special Psycho-Pedagogy at the same university.

She obtained a PhD in sociology, "Al. I. Cuza" University. Her PhD thesis appeared in 2014 under the title "Sociology field of professional intervention. Inclusion of children with special educational needs in mainstream schools ", Publishing "Al. I. Cuza" University. She has published several articles on the integration of children with SEN in mainstream schools in scientific journals.