

CHALLENGES PARENTS OF CHILDREN WITH AUTISM IN LOCAL AND NATIONAL PRESS

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Abstract: Autism is a neuro-biological disorder with a wide variety of clinical manifestations. The central elements are the isolation and indifference to others, delays in expressive language development and repetitive behaviors, stereotyped, rigid or self-and heteroaggression. Having a child with autism is one of the biggest challenges for parents, because autism does not heal. Obvious improvement in symptoms and increasing social integration occur when therapeutic intervention occurs early and intensive.

The study is based on the analyze of the central and local Romanian press, for five years, during 2009 – august 2014. The main challenges of parent concern: low involvement of the state in creating centers for autism diagnosis and intervention, lack of perspective on the future of the child, delayed or wrong diagnosis due to lack of information, difficulties in school integration of children with autism, financial hardship, as well as discrimination and social prejudices.

Organizing parents' associations is one of the solutions that they have resorted to succeed lobbying to rights of children with autism in Romania.

Keywords: *autism, media content analysis, the rights of children with autism, early intervention, assessment, diagnostic and therapy services for children with autism.*

Introduction

Raising a child with autism is a challenge for parents because this is a complex developmental disorder of neurobiological nature, no healing. Equal opportunities for children with autism is to start as early therapy to develop communication skills, social, behavioral and academic and prevent repetitive behaviors and inadequacy. Autism is a lifelong disorder, not cure, so this creates greater maternal stress, depressive symptoms and fear of the future (Abbeduto and others, 2004). A child's level of social skills was a significant predictor of child-related maternal stress, thus the level of children's social skills are low, the stress experienced by mothers is higher (Baker-Ericzén and others, 2005). Ghaedi and Kosnin (2013) found that increase in the level of depression and stress among mothers will increase the severity of autism among children and vice versa. Results showed that a decrease in family income is followed by an increase in depression and stress level in mothers, autism is more severe when the families income is low. Integrating the children with autism in inclusive education program contributes to reducing maternal stress (Baker-Ericzén and others, 2005). Woodgate, Ateah, Secco (2008) reported that parents of children with autism feel misunderstood and stigmatized by society. Moreover, they expressed frustrations in accessing services and in dealing with professionals.

Altieri și Von Kluge (2009) found five challenges that emerged from the family's experiences of children with autism: *Development, Questioning, Devastation, Solutions, and Growth*. That which causes parents to contact specialists are in special delays in language development. In such cases, the parents begin to ask questions, like: is my child different? What's wrong with him? Usually from pediatrician they expecting answers to these questions. Every parent described the confusion that resulted from their child's behavioural presentation

and the feelings of loss and devastation that occurred after discovering their child has autism. Parents, however, were swift and eager to mobilise resources to help their child, sometimes in any possible way. Almost every parent described significant, positive experiences that resulted from raising a child with autism, despite the hardships.

After Scorgie et al. (2004), the parents pass through three stages after the child is diagnosed. In the early stages following diagnosis, parents are confronted with a number of critical emergent questions: Who is my child? Who can he/she become? What is my life going to be like, now and in the future? Secondly, the parents try to make sense of the diagnosis and its impact on their lives: Why did this happen to us? How can I make sense of it? Finally, the parents wonder themselves how they are going to manage life: How am I going to respond? What options are available to me and my family.

The purpose of this study is to identify the main challenges of families of children with autism reflected in the media. Furthermore, we identify solutions used by parents to defend the rights of children with autism.

Method

To fulfill the research objective, I chose to do a content analysis of a sample of newspaper articles on autism topics. I used electronic editions of one national newspaper: *Jurnalul național*, which initiated a media campaign to autism and two local newspapers: *Ziarul de Iasi*, calling itself the leader of the local press and *Buna Ziua Iasi*, which describes himself, the most complete and objective newspaper. These newspapers were monitored for a five years, from January 2009 to July 2014. The content analysis aimed to identify the difficulties of parents of children with autism. To identify articles were searched for the terms "autism" and "autist" on the websites of these publications. The research involved a total of 322 articles (131 articles in *Jurnalul National*, 71 articles in *Ziarul de Iasi* and 120 articles in *Bună Ziua Iasi*). The main topics covered in these articles were: awareness campaigns for the cause of autism (97 articles), presentation of cases (71 articles), presenting the findings of scientific studies (68 articles), new services for people with autism (42 articles), presenting scientific events such as conferences, seminars, training courses or launch book (29 articles) and discussion of legislative issues (27 articles).

Results

Difficulties of parents of children with autism results from the analysis of press articles are following: 1) parental frustration that the state is not involved to create of free services for persons with autism and the parents make sacrifices to pay for therapy (86 articles); 2) problems to integrate the children into mainstream schools (53 articles); 3) concern about the child's future in the absence of services for adults with autism, unrecognized disorder in adulthood and cessation of financial support received from the state for youth with autism (40 articles); 4) lack of information on autism, which resulted in incorrect or delayed diagnosis (29 articles); 5) fight social prejudices (25 articles).

Romanian authorities' indifference to the problem of children with autism

In a number of 86 articles appears the idea that the authorities are indifferent to the problem of autism, so that parents are responsible for the diagnosis, assessment and therapeutic intervention as for educational and social inclusion. The lack of access to rehabilitation programs, and the absence of experts in autism therapy, the only option for parents has been the therapy at home, with specialists brought from abroad. This involves high costs and some parents has left his job to become the caregiver of child. The attention of policy makers for autism came only in 2010, when it adopted the Law no. 151/2010 on services for people with autistic spectrum disorders. This law does not clarify what the parents wanted the most: the settlement of therapies, strategies to integrate the children into mainstream schools and creating the centers for adolescents and adults with autism.

Difficulties of school integration

The difficulties of integration in public kindergartens and schools for children with autism are reported in a number of 53 articles. From a legal standpoint, parents of children with autism can choose between special and mainstream schools. Some parents refuse special school option because they fear that their children will not progress, further that they could be abused. In fact, the acceptance of children with SEN in a mainstream school is difficult. On the one hand, children must reach a certain level of development, so that they can be accepted by peers, participate in group activities. On the other hand, mainstream schools in Romania are insufficiently prepared to receive pupils with SEN. Teachers work experience in inclusive classes as a "double constraint", having to choose between them attention of pupils with SEN or other students in the class. Thus resort to refusing the enrolling children in mainstream school because there are no seats or adopting the secondary mechanisms of coping, as neglected the children with SEN or treat in the same way as the other students in the class. (Grasu, 2013).

Most times, they excuse that kindergarten was already overcrowded. Or they tell us that they can not accept the assistant in the classroom, because the law does not allow foreigners in the kindergarten (...).Or heard the diagnosis, telling us that they can not receive, because disrupting classes (Lazăr, Cireș, 2013).

The lack of perspective on the child's future

A total of 40 articles is dedicated parents worry about the future of the child, which will make it when they no longer live. Before 2013, the legislation provides that granting the degree of disability based on IQ. This leads to not receive degree disability and caregiver because the people with autism had IQs greater than that provided for in legislation. Yet to be given financial support, parents could choose between changing diagnosis of schizophrenia or passing a lower IQ. After the family of a young man with autism won in court the right to receive money for caregiver appeared Order 692 of 23 May 2013 the Ministry of Health, which recognized the existence in Romania of adults with ASD.

When my son will be over 18 years, I do not know what I'll do: o center, no community where they can learn to be autonomous. My only peace, as a parent, is that after his mother and I will no longer live, Damian's brothers will take care of him (Gavriliu, 2011).

Lack of information and professionalism of specialists

In Romanian, 10 years ago, autism was a disorder that experts knew a little. So, many children were diagnosed late or wrong. Thus, autism was often confused with deafness, delay in mental development or parental indulgence. Many parents were quiet by pediatricians that the child will recover:

The child was two years old when I noticed that something was wrong with him (...).But doctors told us that there is nothing more or less. That all is well. That we, parents should change our attitude, to be more severe, less tolerant with him insolence. He is a boy and boys talk later. (...).Only at the age of 3 years or so we have had a clear diagnosis of autism (Lazăr, Ursache, 2013).

Before receiving a diagnosis, parents are scared and confused. Confusion of parents continues and after diagnosis because they do not get explanations from experts. In addition, the Romanian mental health system for children is excessively oriented towards medication (Grădinaru, 2010), and children with autism receive only drugs to be quiet:

"What is autism and what should I do?", mother asked the doctor who gave the verdict: " Nothing. Go to make for her the handicap certificate " (Chiscop, 2009).

Fight social prejudices

People with autism are different from most people and therefore are stigmatized. Stigma affects the whole family, so the parents coping hard the feelings of shame, guilt and isolates:

About people in the village I do not say, « look at her, she has a disabled child who screaming and hitting his head against the wall », that is the vision. For three years I was completely isolated, almost I do not leave the house only when I have to bring Karina in Iasi (Bunduc, 2011).

Conclusion

This study provides an overview of media representation of the challenges of parents of children with autism. The study was limited to gathering information from the media, but to be continued through field surveys.

The results of this study show that parents of children with autism in Romania struggle as stress, depression, social stigma, and the indifference of authorities. In the absence of free therapy services, parents themselves have created centers for their children or they bring therapist at home. With individualized, intensive and early therapy (the most popular being the ABA) they were able to make their children to progress, despite mentality that for autism can not do anything. Although incomes are low, because most mothers do not work and are the caregivers of children, parents pay expensive therapies for children, to become as independent as possible. They manage this by forming NGOs, making fundraising campaign in the community, accessing European funds, and through cooperation with local authorities or political personalities. In some cities, parents organized in association received from local authorities locations for day care centers. The first major public-private partnership which opened 40 assessment and therapy centers for people with autism and were formed over 580 specialists was initiated by Asociația de Psihoterapii Cognitive și Comportamentale din Romania, Fundația Romanian Angel Appeal and Department of Child Protection.

A victory for parents is recognition of autism after adulthood. Thus persons with autism who are over 18 year old can benefit from caregiver, because the evaluating the disability does not depend on IQ. Parents still struggling for the settlement therapies by the state, inclusion of children in mainstream schools, professional integration for adults with autism.

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*** 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.

*** Ordinul nr. 692/982/2013 al Ministerului Sănătății și al Ministerului 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. 762/1992/2007 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 30.05.2013.

Acknowledgements

This article was supported by European Social Fund in Romania, under the responsibility of the the Sectoral Operational Program Human Resources Development 2007-2013: POSDRU/159/1.5/S/132400; Project Grant: Successful young researchers - professional development in interdisciplinary and international context.