

CHALLENGES IN FAMILIES WITH A CHILD WITH AUTISM SPECTRUM DISORDER

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Abstract: *By a content analysis of newspaper articles were identified main challenges of parents of children with autism spectrum disorder present in the media: lack of services reimbursed by the state, difficulties of inclusion in mainstream schools, fear of the future because the lack of services for adults with autism, unrecognized disorder in adulthood and cessation of financial support received from the state, fight social prejudices, lack of information on autism, incorrect or delayed diagnosis or financial difficulties. From this research result some practical implications, such as widening the range of free services for people with autism spectrum disorders and public awareness about the problems of this category of persons.*

Key words: *autism; media content analysis; the rights of children with autism spectrum disorder; services for persons with autism spectrum disorder.*

1. Introduction

The numerous studies have shown that raising a child with a disability is a challenge for parents. Neely-Barnes and Dia [17] conducted a literature review on research on the families of children with disabilities, which revealed that parents allocate more time, emotional and financial resources for this group of children than for typical children in order to provide care to them. For this reason, mothers are particularly prone to stress and depression. In particular, children's behavioural disorders predict a negative impact on the family.

Literature shows that, of all the disabilities, autism is one of the biggest challenges for parents. Autism is a

complex developmental disorder with a neurobiological character, characterized by problems of communication and relating to others as well as interests, activities and behaviours that are restricted, repetitive and stereotypical. There has been no cure for autism so far, equal opportunities for children with autism spectrum disorder (ASD) consist in starting as early as possible a therapy that should develop the communication, social, behavioural and academic skills and prevent the repetitive and maladjustment behaviours. In addition, the diagnostic criteria are related to behavioural descriptions and no medical test can determine exactly whether a person with ASD not, as in the case of the Down syndrome. This creates greater maternal stress, depressive symptoms and

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fear of the future [1], [4]. Besides stress, parents of children with ASD have a lower level of social support than in the case of parents of typical children [5]. The result of another research is that children's low social skills determine an increase in the stress among mothers, while integrating children with ASD in an inclusive education program contributes to reducing maternal stress [4]. Woodgate, Ateah et al. [22] undertook a qualitative research to catch the experience of parents of children with ASD. They reported the following issues: that the parents of children with ASD feel that they are living in a world of their own because that they feel misunderstood and stigmatized by society. Furthermore, they face the lack of professionalism and resources of the services and institutions to which they resort to for the child's disease. A third reason is the feeling of disconnection from family, respectively the isolation in the couple, from the extended family, being centered only on the child.

The purpose of this study is to conduct an analysis of the content of media materials in order to identify the basic structure of the main messages on autism that the print media promotes. We also intend to answer to the question: What are the main challenges experienced by the families of children with ASD and that are reflected in the media?

2. Method

In order to answer the research questions, we chose to draw a content analysis of a sample of online written newspaper articles dealing with the issue of autism. The electronic editions of two local daily newspapers were used: *Ziarul de Iasi (Newspaper from Iasi)* [24], self-entitled the leader of the local press from Iasi and *Buna Ziua Iasi (Good Day Iasi)* [23] – a newspaper addressing political

investigations and inquiries, the most complex and objective newspaper.

These newspapers were monitored for a longer period of time, from 2000 until August 2014 in order to also track the way in which the difficulties faced by parents evolved over the years. The quantitative analysis aimed at quantifying the number of press materials, their frequency by years and topics, while the content analysis aimed at identifying the difficulties faced by the parents of children with ASD. Through this research we intended to provide a picture of the way in which the media communicate the issues related to autism. In order to identify the articles, the terms "autism" and "autist" were searched on the websites of these publications. The research involved a total of 226 articles (83 articles in *Ziarul de Iasi (Newspaper from Iasi)* [24] and 143 articles in *Bună Ziua Iasi (Good Day Iasi)* [23]). The main topics covered in these articles were: presentation of cases, campaigns aiming at raising the awareness regarding the cause of autism, presenting the findings of scientific studies, signalling the emergence of new services for people with ASD, presenting scientific events such as conferences, seminars, training courses or book launch and debate upon legislative issues.

3. Results

Quantitative analysis of press articles show that issue of autism began to arouse a growing interest. Thus, during the period 2000-2008 a total of 17 articles on autism were written, while during 2009-2014 a total of 209 articles were written.

The content analysis of articles written in the online local press from 2000 until August 2014 revealed the following difficulties faced by the parents of children with ASD: 1) the lack of services reimbursed by the state, therefore parents seek therapy at home (24 articles);

2) difficulties related to school integration (18 articles); 3) concern about the child's future in the absence of services for adults with ASD, unrecognized disorder in adulthood and the cessation of the financial support received from the state for young people with ASD (16 articles); 4) fighting social prejudices (16 articles); 5) the lack of specialized information on autism, which resulted in incorrect or delayed diagnosis (12 articles); 6) financial difficulties (6 articles).

Lack of services reimbursed by the state

In 24 articles emerges the idea that the authorities are indifferent to the problem of autism, and the number of services available for children with ASD is low, consequently, parents are responsible for the diagnosis, assessment and therapeutic intervention with a view to the social inclusion of children with ASD. For example in Iași, the first NGO that dealt with the treatment of children with ASD appeared in 2003 at the initiative of a volunteer from the Netherlands. Due to the lack of specialized intervention services for children with ASD, the only option for parents has been the therapy at home, financially supported by them. The issue of autism was brought to the attention of policy makers only in 2010, when they adopted Law no. 151/2010 [25] on services for people with autistic spectrum disorders, but which cannot be implemented due to the lack of enforcement guidelines. Moreover, most of the parents prefer the ABA therapy. It was scientifically proven that this therapy offers up to 50% chances of recovery for children if intervention is early, intensive and individualized. It is a therapy that involves significant monthly costs, i.e. 1000-2000 euros per month, because specialists from abroad must be brought.

Difficulties related to school integration

The difficulties related to integration in public kindergartens and schools for children with ASD are reported in a number of 18 news articles: *At age 4, his mother tried to take him to a state kindergarten. (...) As soon as I entered, the kindergarten staff (...) treated me with indifference (...) and asked nicely to leave* [11].

From a legal standpoint, parents of children with ASD can choose between special and mainstream schools. 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 experience their activity in inclusive classes as a "double constraint", being obliged to choose between paying attention to pupils with SEN or to other students in the class. Thus, they resort to secondary coping mechanisms or neglect the children with SEN or treat them in the same way as the other students in the class. Some parents reject the option offered by the special school because of prejudices and stigmatization [14].

The lack of perspectives concerning the child's future

A total number of 16 articles is dedicated to parents who worry about the child's future, what will happen to him/her when they are no longer alive. Especially that, up to 2013, the diagnosis of autism disappeared once the child reached the age of 18, this being also followed by the suspension of financial assistance which parents received from the state: *When he was a minor, received 500 lei because I was his companion. After he became major, we were stopped this right (...). If the families of people with autism were*

taken by legislation, should leave their children alone, because the state says they do not require companion. (...) But this is impossible. I cannot ever leave him alone. (...) Get out and do not know where he goes, no signs of life. How to leave your sick child alone? [9]. However, in order to be granted financial support, parents could choose between changing the diagnosis to schizophrenia or declaring a lower IQ. Parents of children with ASD have reported to the Ministry of Health and the Ministry of Labour that it is not normal that autism disappears after young people are 18, given that it is a disorder that does not heal. After the family of a young man with autism won in the court the right to receive money for the attendant, Order no. 692 of 23 May 2013 of the Ministry of Health [26] recognized the existence of adults with ASD in Romania.

Fighting social prejudices

Another challenge for the parents of children with ASD reported in 16 articles, is fighting social prejudices. People with ASD are different from most of the people and therefore, they are stigmatized. Stigma, defined as an attribute that discredits the person and prevents him/her from being accepted by society [12] influences the entire family, therefore, parents experience feelings of shame, guilt and they isolate themselves. They often live very unpleasant situation because the child's behavior is often seen as a symptom of lack of education or parental indulgence: *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* [6].

The lack of information on autism

Out of a number of 12 articles, it results that, 10 years ago, autism was a disorder

that experts knew little about. Due to the lack of information on autism among professionals, many children were diagnosed at a later stage or incorrectly. Thus, autism was often confused with deafness or the delay in mental development, which has created confusion among parents and thus, children did not receive the appropriate therapy: *I went with the girl to a psychologist since the age of 9 months, but I was told that it's me who had psychic problems. The girl was diagnosed with autism when she was two years and a half* [7].

Moreover many specialists have the mindset that for the children with autism can not do anything: *He will never heal. Both specialists told us. I felt like the sky fell on us* [9]; *What is the autism and what should I do? mother asked the doctor who gave the verdict: Nothing. Go to make for her the certified disabled* [7].

Financial Difficulties

A total of six newspaper articles indicate the financial difficulties experienced by the families of children with ASD. In the absence of specialized services and of the difficulties related to integration in kindergartens and schools, one of the parents resigns from his/her job and dedicates himself/herself to taking care of the child. In addition, treatment costs are high and they are incurred by parents: *The girl was diagnosed at 2 years. Only at the age of 4 years we started working with her, after we looked for explanations and specialists. The last barrier is financial. We made bank loans for Maria's therapy* [2].

Another problem that may occur is that a parent leaves the family because he does not accept the child's disorder. In this way, the other parent who has strength to fight, is overloaded: *I am certified in music pedagogy, I worked eight years in Iasi. Ever since I got my daughter can not have*

a job, I must always stay with her. So my only income should be the personal assistant of 600 lei [6].

4. Discussion

This study aims to identify the difficulties of the parents of children with ASD reflected in the online written local press. The most common difficulty reported in local press is the lack of services reimbursed by the state. The limited access to health and education services revealed also from the other studies [22], [18]. Analysis of online media in Romania shows that parents feel frustrated because the state is not involved in creating free services for people with autism [13]. Lack of understanding, support and state involvement leads parents to accumulate a series of negative feelings [21].

The difficulties of integration in mainstream schools are another topic frequently reported both in the local and national press [13]. Moreover, mainstream schools in Romania are poor prepared to accept children with special educational needs. Students lack curricula tailored to their needs and the number of support teachers and school counselors is very low [15]. The inadequate material resources, poor organization of the work of inclusion, lack of training and motivation of teachers, non-involvement of parents are some of the causes which led to the phenomenon of institutional violence against children with special educational needs [8].

Lack of perspectives on the future of the child is the third challenge for parents of children with autism who appears in the newspaper articles. This concern of parents appears in other research and is caused by lack of services for adults with ASD [21] but that autism was not known until 2013 as the disorder in adulthood. The state does not provide financial support for young

people with autism who reach the age of 18 [13].

The fourth challenge, i.e. fight social prejudice, is also present in other studies. Parents of children with autism feel that they live in a world of its own being isolated from friends and extended family [18], [16], [22].

Lack of professionalism of specialists is another challenge for parents of children with ASD, found in other research. Parents are confused because the child is diagnosed late or wrong. They are forced to long waiting times at specialized institutions, and they receive conflicting information on how to help their child. Support for parents is also inadequate during and immediately after the diagnostic process, so that is difficult to cope with disbelief or denial, to profound sadness and depressed mood [18], [22].

Financial difficulties reported by the press articles are found in other research. A greater financial support for parents is required for acquisition of technical aids; the need for respite services, i.e. development of services taking temporary childcare, both at a special institution and at home [19]. Athari, Ghaedi et al. [3] found correlations between low family income and increasing severity of autism. The socio-economic level influences the age when diagnosed the child. Thus, children from families with an increased socioeconomic level are diagnosed earlier than those from families with low socioeconomic level. In this way will increase the chances of social integration [10].

5. Conclusions

This study provides an overview of the media representation of the challenges of the parents of children with ASD. Since 2009, autism has become an increasingly present issue in Romania, the number of newspaper articles in the period 2009-2014

was significantly higher than in the period 2000-2009. Therefore, from the "invisible" children for to the Romanian authorities, the children with ASD are becoming more visible [20].

The study was limited to gathering information from the local media, but it will be continued by analyzing the regional and national press and through field surveys.

From this research result some practical implications:

- Development of free services for evaluation and early diagnosis of autism in which parents can address when they have suspicions regarding child development.
- Create free services for intervention and therapy so that children with ASD can begin as early therapeutic intervention. Such services should be organized in the form of daycare centers so that parents can go to work.
- Initial and continuous training for specialists, given that goodwill is not enough to work with children with ASD.
- Supporting the integration of children with ASD in mainstream school by training teachers to know how to work with them and to create an inclusive attitude in class.
- Support for educational assistance for children with ASD integrated in mainstream schools; such a program could be developed with the help of volunteers. They should be "shadow" of children with ASD and help them when they need it, so the teacher to be able to deal with other pupils in the class.
- An adequate number of pupils in the classroom, where children with ASD are integrated so that they can receive the attention and support.
- Assisting and supporting parents in all stages from evaluation and diagnosis, to information on intervention and therapy, but also prepare them so they know how to intervene in the case of behavioural

disorders or to stimulate the child to initiate communication with him.

- Development of services for adults with autism, such as protected workshops, sheltered housing or and daycare centers to facilitate their social integration.
- Organize public awareness campaigns to increase engagement and tolerance towards people with ASD and their families.

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