

# PRACTICAL ASPECTS OF THE INTERVENTION ON CHILDREN WITH AUTISM SPECTRUM DISORDER

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## **Abstract**

Autism is a complex disorder that affects many levels of mental development therefore requires a comprehensive and multidisciplinary intervention. Autism spectrum disorders (ASD) have become increasingly more common in Romania, which required the creation of services in which to intervene in specific ways. This article aims to analyse the difficulties of professionals who working with children with ASD and solutions they use. Research methodology is a qualitative, a fieldwork based on semi-structured interviews in two non-governmental organizations and a special school have as beneficiaries children with ASD. The subjects interviewed are from different professions: teachers, psychologists, social workers and managers, but also parents of children with ASD. Data analysis shows that the greatest difficulties are related to working with parents, their children's challenging behaviours and the organization and coordination of services. Research findings include several measures to improve their services dealing with people with ASD, based primarily on practical solutions identified.

**Keywords:** autism, educational and behavioural methods, teamwork, partnership with parents, qualitative research

## **Résumé**

L'autisme est un trouble complexe qui affecte de nombreux niveaux de développement mental et nécessite donc une intervention globale et multidisciplinaire. L'autisme est un trouble de plus en plus répandue en Roumanie, qui a nécessité la création de services dans lesquels intervenir de manière spécifique. Cet article vise à analyser les difficultés rencontrées par les professionnels travaillant avec des enfants avec troubles du spectre autistique (TSA), et des solutions qui fonctionnent. Cette recherche est basée sur la méthodologie qualitative: des entretiens semi-structurés en deux organisations non gouvernementales et une école spéciale. Sujets interrogés ont diverses professions: enseignants, psychologues, travailleurs sociaux et les managers. En dehors des spécialistes ont été interrogés des parents d'enfants avec TSA. Analyse des données a montré que les plus grandes difficultés des spécialistes sont liées de collaboration avec les parents, les comportements difficiles des enfants et l'organisation et la coordination des services. Les résultats de recherche comprennent plusieurs mesures pour améliorer les services pour les personnes avec TSA, basées principalement sur des solutions pratiques identifiées.

**Mots-clés:** autisme, les méthodes d'intervention sur l'autisme, le travail d'équipe, le partenariat avec les parents, la recherche qualitative

## **Rezumat**

Autismul este o tulburare complexă, ce afectează mai multe paliere ale dezvoltării psihice de aceea necesită o intervenție complexă și multidisciplinară. Autismul începe să

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devină o tulburare din ce în ce mai frecventă și în România, ceea ce a impus crearea de servicii în care să se intervină prin metode specifice. Acest articol își propune să analizeze dificultățile cu care se confruntă specialiștii care lucrează cu copii cu tulburări din spectrul autist (TSA), dar și soluțiile care funcționează. Metodologia de cercetare aleasă este una calitativă, respectiv o anchetă de teren pe bază de interviuri semi-structurate în două organizații non-guvernamentale și o școală specială care au ca beneficiari copii cu TSA. Subiecții intervievați au diferite profesii: profesori, psihologi, asistenți sociali și manageri. Pe lângă specialiști, au fost intervievați și câțiva părinți ai copiilor cu TSA. În urma analizei datelor a reieșit că cele mai mari dificultăți întâmpinate de specialiști sunt legate de colaborarea cu părinții, comportamentele provocatoare ale copiilor și de organizarea și coordonarea serviciilor. Concluziile cercetării conțin câteva măsuri care să îmbunătățească activitatea serviciilor care se ocupă de persoanele cu TSA, bazate în principal pe soluțiile identificate în practică.

**Cuvinte cheie:** autism, metode de intervenție în autism, munca în echipă, parteneriatul cu părinții, cercetare calitativă

## 1. Introduction

Autism is one of the most controversial mental disorders, whose frequency has increased alarmingly in recent years. Originally discovered in 1943 by psychiatrist Leo Kanner, ASD 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 ASD: from very structured therapies requiring behavioural approach guided by a therapist, such as Applied Behaviour Analysis (ABA), to drug therapy, complementary therapies based diet, occupational therapy, therapies based images, to programs that focus on children's interests and incorporate them into daily activities in his natural environment.

ASD affects many areas of neuro-psycho-social development of children, so assessment and intervention is interdisciplinary and involves psychiatrists, psychologists, speech therapists, occupational therapists and specialized educators. One of the team members should be coordinator and serves to communicate with parents, organize team meetings etc. (Zach, Ben-Itzhak and Rabinovich 2007 Ozonoff, Goodlin-Jones and Solomon 2005).

There are some important issues in intervention on children with ASD, such as: to be early (Ozonoff and Cathcart, 1998), intensive (Corsello 2005), to be involved family (Ozonoff and Cathcart 1998) and based on educational and behavioural methods (Corsello 2005). Early intervention, intensive and individual around 35 hours a week would save significant costs of schooling children because they may be integrated into mainstream schools and not in special education (Chasson, Harris and Neely 2007). Educating parents is another method of intervention for children with ASD, early intervention services preferred because it contributes to the effectiveness of therapy (Oono, Honey and McConachie 2013 Beaudoin, Sebire and Couture 2014). Involving parents reduce costs therapy (Matson, Mahan and

Matson 2009), especially if they live in rural areas at a distance from the therapy centre (Suppo and Floyd 2012). The main therapeutic methods used in ASD are: ABA, Picture Exchange Communication System (PECS) and Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH). The ABA therapy involves individual work using behavioural theories based on stimulus, response and reward. ABA therapy begins by focusing on clearly stated objectives, divided into small tasks using stimuli and rewards. Family counselling is a major component of this program (Zach, Ben-Itzhak and Rabinovich 2007 Sallows and Graupner 2005 Ringdahl, Kopelman, and Falcom 2009). PECS is a program that is based on exchange pictures. PECS is easily learned by most participants and provides a means of nonverbal communication for people. PECS is to develop functional communication skills, especially to ask what they want (Boesch *et al.* 2013). TEACCH method is based on structuring the environment and activities to be easily perceived by people with ASD, using visual information as instructions for activities, using the special interests of the person to engage in learning and self-initiative to generate communication (Mesibov and Shea 2010). TEACCH uses a variety of techniques and methods that can be combined in an individualized program that seeks to increase the independence and focus on people's preference for routine. TEACCH method is commonly used in schools (Hess *et al.* 2008), considered a comprehensive intervention (Virues-Ortega *et al.* 2013).

To determine which is the most effective therapy were compared several therapeutic methods. For example, ABA is considered more effective than intervention “elective” in particular to improve core symptoms in language and communication in children with ASD (Howard *et al.* 2005; Zach, Ben-Itzhak and Rabinovich 2007; Howard *et al.* 2014) but also in terms of intellectual functioning and socialization (Ospina *et al.* 2008). TEACCH method proved to be more effective than an integration program for people with disabilities (Panerai, Ferrante and Zingale 2002; Panerai *et al.* 2009). According to other authors, TEACCH has small effects on perceptual skills, motor, verbal and cognitive, communication and operation effects are negligible or small motor while gains in social behaviour are high and reduce the frequency of behavioural disorders (Virues-Ortega, Julio and Pastor-Barriuso 2013). Due to the heterogeneity of clinical pictures, other authors recommended elective approach by choosing the most appropriate methods and adapt them to each case (Diaconu *et al.* 2009).

This study aims to identify the difficulties encountered from specialists who working with children with ASD in Iasi. Another objective of the research was focused on identifying the solutions applied by specialists in order to establish a strategy for the development of services for people with ASD.

## **2. Method**

The research took place in Iasi, in November-December 2014. The research method used was semi-structured interview based on an interview guide. 21

interviews were conducted with eight experts from two non-governmental organisations (two managers, one social worker, one psycho-pedagogue and four psychologists), eight teachers of Special School “C. Păunescu” and five parents of children with ASD. Questions for professionals aimed circumstances in which they begin to work with these children, if they did training in ASD issues and what are the main challenges of working with children with ASD. Parents were asked about their child's disorder history, institutional path followed, difficulties and expectations of institutions and professionals. Interviews were recorded with the consent of the subjects were transcribed and interpreted using thematic analysis.

### **3. Results**

#### ***3.1. Difficulties encountered by professionals***

Empirical material analysis revealed a number of difficulties faced by specialists. The most common are related to working with parents, children's challenging behaviours and lack of coordination of teamwork or discontinuity of services provided.

##### ***3.1.1. Difficulties in collaboration with parents***

All specialists, both the experienced and the beginners feel like a difficult thing to create good relationships with parents of children with ASD. This is because parents are overwhelmed with problems, do not understand this condition and have unrealistic expectations. Some of them begin therapy with the hope that the child's problems will be solved immediately and they find that it takes months for a minimum progress. They think fear the child's future, especially the lack of services for adults with ASD:

“Parents want results here and now. They are obtained in time by continuous stimulation, progress is minimal. Parents are confused, discouraged, ask themselves questions, blame the specialist ... (psycho-pedagogue interview); There are parents who do not see realistic problem ... baby is 8 months cognitive state, but parents want to know when he will speak ... will be enrolled in a mainstream school. It is hard for parents to accept that we insist on personal autonomy skills training. We teach them to go to the bathroom alone, eat alone, to bathe themselves. (...) Parents want to see progress on children, especially in the field of language” (psychologist interview).

One barrier to creating a good collaboration occurs when the parent believes that only specialists are responsible to stimulate the child. But a child with ASD needs continually to structure and organize daily activities. For this condition are recommended at least 20 hours of weekly therapy, which for many parents is a financial effort too high or they live at a great distance towards the centre. To see progress in children, experts are trying to form their parents to continue the treatment at home:

“They believe that if they take him to therapy, they do not have to do anything but children lose the knowledge they have acquired if the parent does not continue. They must understand that the stimulation in another environment is very important. Time with me is insufficient if the parent does not continue the therapy at home. On the other hand, some other factors ... the job, other children ... but they must do more (psycho-pedagogue interview); Are parents issued requests, but without effective collaboration. It works on personal autonomy at school ... home parents dressed him ... it is easier for parents, they do not have patience, they say they do it out of pity, they see that children are struggling” (teacher interview).

Partnership with parents is very important for children's problem behaviours. In such situations, it is necessary that all who come into contact with the child firmly and consistently comply with the same rules:

“The team observes the child establishes the rules and the consequences, communicate their parents and ask them to be consistent. If the specialists and parents are consistent, the behaviour will certainly disappear” (psychologist interview).

### *3.1.2. Challenging behaviours of children*

Another frequent cause of difficulties is challenging behaviour specialist children. Novice therapists or those who have received training have the greatest difficulty in working with children with ASD. Also, when one person is working with a group of children may be made to situations difficult to manage. When a child externalizing their frustrations, others cannot concentrate on the task time or may become, in turn, shake:

“In the first year of teaching I had a good class, of pupils with moderate mental deficiency. The following year, I got a teacher in a class of children with autism. I was scared I knew nothing ... just from books. It was too sudden this transition (teacher interview); They are provocative, insistent ... When some children begin to cry or scream, you cannot calm them all day and disturb the others ... when you are alone with children and has a crisis is different, but when you're with the whole class ... it angry other children (...). Some children come home with bad mood and scream morning or if you give them to work” (teacher interview).

### *3.1.3. Lack of organizational teamwork and discontinuity between services*

Another problem encountered is the lack of coordination of team work, because there is no communication between specialists, they did not meet to discuss their proposed goals in working with children and do not establish a common plan. In addition discontinuity occurs between services. For example, at the local level, there are few early intervention services or centre for adults. The children are enrolled in special schools without basic acquisitions and after the state invested in their education they are sent home and remain in the care of parents:

“I find it unacceptable that pupils are kept so long in a system when finished “goodbye” ... no longer give them any attention ... necessarily have to do something. There are some

paid services, not everyone can afford them, should come from the authorities, to be accessible to all, because there are people who have rights” (teacher interview).

### **3.2. Solutions**

The analysis of the interviews were identified several solutions encountered in practice, partnership with parents, training of specialists, organization of teamwork and cooperation and continuity between services. Partnership with parents is based on communication, openness and negotiation. Institution's policy to stimulate initial and continuous training of specialists and teamwork improve the quality of the intervention on children with ASD. Cooperation between existing services has the same role.

#### *3.2.1. Building good relationships with parents*

A good relationship with parents is based on the following aspects. First the specialists have valued the experience of parents in child problems, because the parents are the ones who spend the most time with him:

“It is very important to contact parents to send us some information about your child and what he likes more, so that we can motivate him” (psychologist interview).

Secondly the specialists must adopt an open attitude, which involves communicating realistic, both child problems, and his acquisitions. The weaknesses of the child shall be the objectives of the intervention, while acquisition will support the therapeutic approach:

“When we communicate evaluation result, we acknowledge that the child cannot achieve, but also highlighted what he has already acquired, using the strengths to develop skills or eliminate unwanted behaviours” (psychologist interview).

Also, parent counselling after each therapy session with the child, contribute to a partnership. The specialist will inform the parent about which aims to work with the child, what went well, what problems observed or parent asks what difficulties encountered:

“After each hour of therapy with the child remain with the parent to talk about what went well or what difficulties he encountered in my absence and some of the solutions I can give immediately, others after I think days (psychologist interview); It's important to communicate, I discuss with the parent 10 minutes after each meeting with the child. I explain what worked, where there are problems, I ask them what they noticed that it is not okay, so parents to be an active part of the therapeutic process” (psychologist interview).

In addition, specialists empower the parents and to continue at home the therapeutic approach. Teachers make use of homework to involve parents. In these situations it is very important that specialists consider that parents may have other

responsibilities or be overwhelmed by problems. For this reason, the tasks they give parents must be simple and assumed by parents:

“The parent can remain in the room to see how I work and continue at home (...). We empower the parents, they are co-therapists cannot be otherwise, without burdening them too much” (psychologist interview)

“We require parents to mainly occupational therapy activities, to dress appropriately, personal care, to sit bedside, to prepare a tea ... ask him to tell what they did that day, to read story (...), to go outdoors” (psychologist interview)

“When you do something new with them in class, we give pupils homework which they do with parents. Mostly parents worked, continued what we did” (teacher interview).

Specialists use support group to help parents understand the disorder suffered by the child or to learn to cope with challenging behaviours. However, support group helps parents to discharge and to support each other emotionally. In the special school, parent meetings are formal as discussing issues of organization, evaluation of pupils, etc., but they can be an opportunity to socialize, exchange of views, offering mutual support:

“I worked more with parents on their need to understand and support each other, to understand the child's diagnosis, information on the stages of development. They watch movies with stages of development and I have a few topics for discussion, how to be thankful, to give love, support (social worker interview); We begin with the more formal issues, evaluation results, and then we discuss various issues, we ask the parents if they have complaints. At the last meeting, parents have even begun to talk among themselves I challenged asking about holiday” (teacher interview).

### *3.2.2. Training of specialists*

The majority of professionals working with children with ASD in Iasi received training “Intervention for children with autism”, organized by the Department of Social Work and Child Protection (DSWCP) Iași and other associations in the Netherlands. This training was held during 2007-2010 and 400 specialists from several institutions in Iasi benefited from it. In October 2011 DSWCP Iași and an organization from Bucharest was organized another intensive training involving specialists from several counties. The specialists who participated in these courses have appreciated that these trainings had a strong practical use, as demonstrated various methods and techniques for working with children with ASD:

“It was a very useful course, I learned a lot about the main methods ABA, TEACCH, PECS and how to work with children with ASD. We need to know more methods, a technique might be useful for a child, while the other child must use something else” (teacher interview).

In addition to these courses, attended by specialists from several institutions in Iasi, professionals working in the foundations receive regular training supported by

specialists from abroad, exchanges or supervision in activities with children. These trainings have the role to increase team cohesion and to do share common values:

“Politics of the Foundation is to form specialists continuously. Thus, every year there are trainings held by psychologists, physiotherapists or counsellors from Sweden, Norway, America or England. The oldest, who work for 14-15-20 years, we have benefited from an exchange in Sweden for two weeks. It was something to see live, though always brought us footage” (psychologist interview).

While in foundations supported by the Swedish and Dutch preferred elective approach, adapting methods and techniques based on the child's problems, the parents agree ABA therapy. Thus, in 2004-2005 a group of parents from Iasi brought ABA specialists from Bucharest and abroad and formed therapists recruited generally between students of social sciences faculties. Subsequently, these therapists have worked with children of families with financial possibilities:

“Graduated in 2005 and a family brought a specialist from Bucharest in ABA therapy. (...) And I went, I made training. I found a family who then seek a therapist. (...) And then I work with a girl” (psychologist interview).

For specialists dedicated to children with ASD therapy, initial training courses are insufficient. They participate in various conferences and seminars and in addition, they also document alone to face various problems encountered:

“I began to learn alone as much as I could. (...) I still learn, read, nights stay on the net to look for materials. I went to training in Bucharest” (psychologist interview).

In addition to training, another way to learn to approach children with ASD is to work with a colleague who has experience. For example, in 2008-2010, special school teachers were helped by a therapist from the Foundation “Ancora Salvării”. From these specialists, teachers learned how to deal with children with ASD, how to react in case of challenging behaviours, how to organize class:

“To me it was very useful collaboration with Ancora, I learned from them TEACCH, how to act in certain situations, how to make children to work, how to make use of methods. It matters to tell someone that their reaction is so in certain situations. They helped to structure classroom space, furniture organization. I did not know how important visual support” (teacher interview).

### 3.2.3. *Teamwork*

Teamwork involves establishing a common goal and mutual support in achieving objectives. The team provides security and helps to find solutions when you're at an impasse and, in this way, work becomes more efficient. The team is and unloading of accumulated negative emotions, because working with children with ASD is very demanding. Specialists working in foundations meet weekly to discuss difficult cases. School teachers meet monthly in methodical commissions. Here they show patterns of activities with the pupils, case studies, discussing problematic situations and seeking alternatives:



“Through our actions we try to support each other. (...) I choose how to work with the child according to my style and time, but to work together on the same areas of work (teacher interview); I have a very good collaboration with another teacher in afternoon program. We meet every week, we have a partnership hour. It is important for children to use the same approach. (...) We set goals at the beginning, we discussed, we agreed (teacher interview); When I have difficulties I ask the support of other specialists, there are situations when I not know what to do (psychologist interview); I am pleased to participate in committees methodical, attend the lessons, I learned (...). The exchange of information is important ... get advices and choose what's best” (teacher interview).

### *3.2.4. Continuity of service*

ASD requires a multidisciplinary approach at diagnosis, assessment and education. A single institution cannot cover the full range of services and needs that these beneficiaries have. For this reason, services involved in work with children with ASD must cooperate so that there is continuity of the intervention. For example, in addition to assessment and diagnostic services should be early intervention services. Moreover, investment in education of children with ASD should be continued through the establishment of sheltered workshops in which people with ASD can perform paid work:

“I went to the psychiatrist with little girl aged 3 years and 9 months 3 years and 9 months and I can say that I was lucky to put away the diagnosis, the other parents have delayed that it does not, it does not have that. He told me: autism and exactly that day and recommended me Star of Hope (...) and I went on the same day (...). Since then my daughter goes to therapy” (parent interview).

“Diagnosed on time and work with them to recover them, ie you lead them to an occupation in sheltered workshops to carry out routine activities such as Sweden, the Netherlands or Spain. I think we can help children with autism to become some adults to pay insurance and are not supported by the state” (manager interview).

## **4. Discussion**

This study aims to identify the difficulties faced by professionals working with children with ASD in institutions in Iasi. Another problem addressed this study is to identify solutions that they use professionals to overcome these difficulties.

From the point of view of professionals, unrealistic expectations of parents and their lack of involvement in the therapeutic process are some of the main difficulties. In such situations professionals feel powerless. Parents not understanding the disorder and having too high expectations, they do not notice that children are making small progress and this can discourage professionals. In addition, the child's progress does not occur when the hours of therapy are too few and working with the child at the centre only. Solutions to streamline collaboration with parents who were identified by this research are consistent with those found in the literature. This and other investigations show that professionals need to consider

them experts in child's parents and to look at the child as a whole, identifying both weak side and skills (Hodge and Runswick-Cole 2008). To teach parents strategies for interaction and communication with children (Beaudoin, Sebire and Couture 2014) as well as behaviour management (Oono, Honey and McConachie 2013) are other ways that stimulate partnership between professionals and parents.

Another difficulty reported by professionals is challenging behaviour of children. Or to work effectively with children with ASD and know how to react in certain situations, goodwill is not enough. Specialists need to have in-depth knowledge to apply specific educational methods or adapt the strategies to their needs. In addition to the initial training is required to continue education by sharing practices with other professionals. In this way the work becomes more efficient and specialists avoid moral wear, given that the children with ASD therapy involves very emotionally charged.

A third difficulty emerging from this research is the lack of coordination of specialists or services involved with children with ASD. The child may be disrupted if the specialists working without consulting each other, each in the area that it considers a priority. In this case, the solution identified is that of team meetings. Effective intervention team hides a “backstage work” (Goffman 2007, p. 137), well designed and directed, the activity is planned in advance and the roles involved are clarified. Child's progress is more evident when there is a vision on the activity of each specialist. “Organized cooperation” between team members through regular meetings (Gheorghiu and Moatty 2005, p. 56) is intended to clarify the objectives of the intervention, to discuss what worked or difficulties and seek solutions together. As far as specialists cooperate propose similar purposes, agreed, have a common set of values and beliefs, we can say that they are a team (Goffman, 2007, p. 111).

## 5. Conclusions

This study presents an image of the reality for intervention on children with ASD. Research is limited to Iasi, so its results cannot be generalized. From this research result some practical implications. First, it requires the establishment of free services to parents to turn to when they have doubts concerning the development and behaviour of children. Then, to focus on early intervention so that children with ASD can be involved in intervention programs as early as possible. Counselling for parents in all phases of detection, diagnosis, assessment and intervention to facilitate their active involvement to encourage child development and knowing how to react to difficult behaviours. For specialists is necessary to have good communication between them, regular meetings to share information, to discuss the child's progress and to plan the next steps of intervention. Finally, it is necessary to need to be developed services for adults with ASD to support them in their social integration.

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