

## EARLY INTERVENTION IN CHILDREN WITH AUTISM SPECTRUM DISORDERS IN REPUBLIC OF MACEDONIA

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### SUMMARY

**Introduction:** Epidemiological studies detected that autism spectrum disorders (ASD) are currently raising, and there is a need for early effective interventions to manage the characteristics of the disorder. The evidence suggests that early intervention programs are beneficial for children with autism, often improving developmental functioning and decreasing maladaptive behaviors and symptom severity.

The **aim** of this research is to gain the opinion of the parents of children with ASD in Republic of Macedonia concerning the early intervention programs which are currently being conducted.

**Methodology:** Internet based research was conducted from 1<sup>st</sup> of April until 1<sup>st</sup> of June. Parents of children with ASD completed 72 questionnaires via an online Google Form. The participants were from all across the Republic of Macedonia.

**Results:** Around 2/3 of participants started with early childhood treatments aged between 2 and 4 years. The most popular treatments are: training of social skills in 24% of children, psychomotor re-education in 22%, biomedical treatment and treatment with medicaments in 26%. 38% are not satisfied with the current treatments. Around half of participants were optimistic and expect a high level of improvement. One third of parents spent between 250 and 350 Euros for the treatments.

**Conclusions:** In Republic of Macedonia there is no systematic approach to early intervention services and programs. Sometimes they use unproven treatments which can be dangerous for the health. ABA and TEACCH approaches are used for a very low number of children. Authorities must start with use of certificated programs for training the professionals.

Key words: early intervention, treatment, autism spectrum disorders, Republic of Macedonia

### INTRODUCTION

Autism spectrum disorders (ASD), characterized by impaired social communication and interaction and by restrictive patterns of behaviors and interests, affects more than 1% of children (Center for Disease Control and Prevention, 2014). Cognitive impairment, psychiatric disorders, sensory disturbances, and behavioral problems are co-morbid conditions with ASD. The complexity of the clinical presentation therefore requires early and appropriate intervention to promote positive outcomes for children and families.

Early intervention can be defined as a combination of services such as occupational therapy, speech and language therapy, physical therapy, developmental therapy,

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psychological services, and social work services. Although all of these services are available, depending on the specific child, services will be chosen accordingly. Each child who receives early intervention services is assessed under three categories being “a) child has a developmental delay, b) child has a diagnosed medical or physical condition with a high probability of leading to developmental delay, and c) child is at risk of developmental delay (the final category is up to the state’s discretion)” (Boyd & Shaw, 2010).

Many research studies have shown that there is a great difference in the development of children with autism who have been involved in early intervention (EI) or early treatment programs.

According to Schumway and Wetherby (2009) the second year of life is a critical time to examine the early development and emerging symptoms of ASD with the hope that EI can preempt significant symptoms. Due to this recent knowledge, it is critical to not only identify the disorder early, but also begin to receive various early intervention services in a timely manner.

Evidence has been presented that behavioral treatment for ASD makes the most impact when it is started early, is of high quality with adequately trained and supervised staff, gives a sufficient intensity-level of services (25-40 hours a week) and adheres to evidence-based strategies published in the scientific literature (Stahmer & Ingersoll, 2004).

Parent-mediated early intervention probably does ameliorate the core symptoms of autism, although the magnitude of the effect is too small to recommend its use in routine secondary care settings. A case can be made for employing low-intensity interventions in suitably screened populations, in an attempt to reduce population prevalence. While the overall case for the added benefit of high-intensity interventions is moot, it seems clear that they do work especially well in some cases, for example in young children in whom significant autistic symptomatology is present alongside good linguistic and cognitive ability (Smith, Klorman and Mruzek, 2015).

There have been several research studies to show the effects of early treatment program. At least six comprehensive treatment programs designed to stimulate widespread changes in young children with autism have published positive outcome data in peer-reviewed journals. It is important to point out that none of these studies used the most rigorous experimental designs, involving random assignments of children to groups and the use of evaluators blind to all aspects of the study. The studies differed in many ways, including different curricula, different settings and ratios, different ages and functioning levels, different ways of measuring progress, and different kinds of comparison groups or strategies for looking at change. However, many commonalities occurred in the results of the six studies. All the studies reported significant acceleration of developmental rates, resulting in significant IQ gains; significant language gains in the treated children; improved social behavior and decreased symptoms of autism (Rogers, 1996).

Methods of providing services are changing. Instead of being directed on a particular disability, early intervention is increasingly being organized as non-categorical or cross-categorical services. This trend is somewhat bypassed in the area of autism spectrum disorders due to the fact that treatment of certain forms is highly specialized and focused on core deficits in autism (Glumbić, Brojčin and Đorđević, 2013).

## METHODOLOGY

The goal of the research is to see what the opinion is of the parents of children with ASD in the Republic of Macedonia regarding the early intervention programs that are currently being conducted and which programs would they wish to be able to choose from or to have chosen if they had the chance as an early intervention program for behavior treatment. During the period in which we have conducted the research we gave out 72 questionnaires which were completed by parents of children with ASD. There were no age or sex limitations in the study. This internet based research took place from the 1<sup>st</sup> of April until the 1<sup>st</sup> of June. Parents of children with ASD completed 72 questionnaires via an online Google Form. The participants were from across all regions of the Republic of Macedonia. The data were analyzed using descriptive analysis. For the purpose of the research we have made a questionnaire that was adapted towards the needs in the Macedonian population (we took into account all the differences between our society and the western countries and adapted the questionnaire). The questionnaire is a closed form consisting of 21 questions, where there are several answers to which the parents may choose from. The results are shown by relative frequencies.

## RESULTS

This is a first study about early intervention of children with autism spectrum disorders in the Republic of Macedonia, which has shown that there is no systematic approach for early treatment of that vulnerable group of children. In this study 72 parental questionnaires were analyzed.

On the first question, at what age they started with the first treatment for their child, we found that around 19% started at age 2 years, 63% between 2 and 4 years, 17% between 4 and 7 years and last 1% older than 7 years of age. The distribution of the answers is not so concerning because around 2/3 of participants started with early childhood treatment at age 2 to 4 years which is world trend (figure 1).

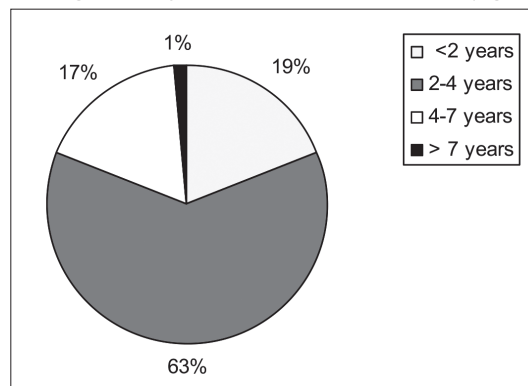


Figure 1 Age of starting early treatment

At the time of the research, the children were receiving various kinds of treatments. The most popular were: social skills training in 24% of children, psychomotor reeducation in 22%, biomedical treatment and treatment with medicaments in 26% and 21% were accessing other kind of treatments. A very small number of children, 4%, used ABA and 3% TEACCH approaches, which shows a very low level of usage of those evidence based treatments in our country (figure 2). There are no certificated professionals who can implement these approaches.

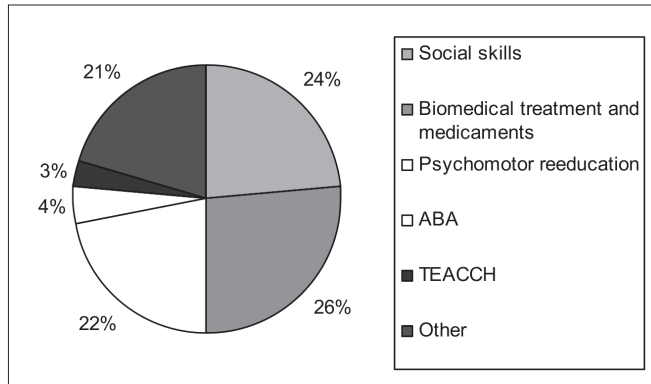


Figure 2 Type of treatments

Parents were asked who covered expenses for the treatment and they replied that 1% are funded by the public school system, 10% by state fund early childhood programs, 3% by a special school and 86% from their own resources (figure 3). This is very frustrating for the parents because the government doesn't allocate enough resources in this sector and parents have to pay from their own budget which impacts their quality of life.

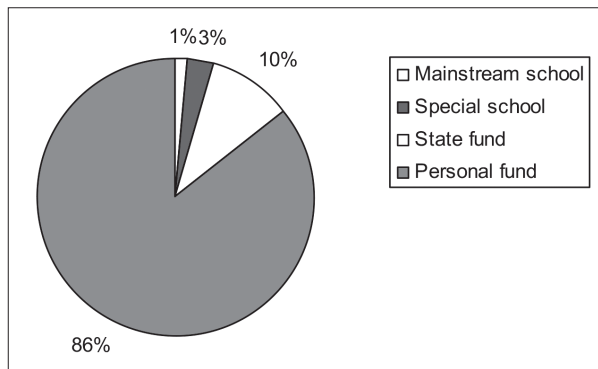


Figure 3 Funding of early treatment

Around one third or 35% of parents were satisfied with the early intervention which their child received at the time of researching. Despite this group of parents, 38% are not satisfied and they think that the Ministry of Health should introduce new interventions. The other 27% of parents gave no opinion either way (figure 4).

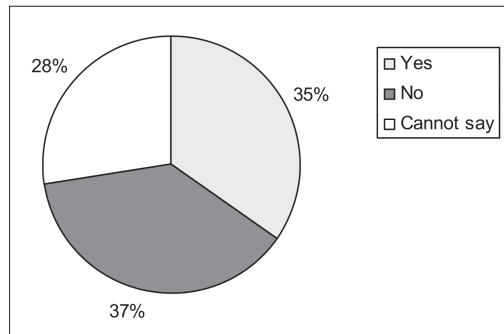


Figure 4 Satisfaction with early intervention

Among parents, 3% didn't expect any improvements of the condition of their child with the usage of an early intervention program, whilst 13% expected minimal improvement and 37% expected a moderate improvement. Around half of participants or 47% were optimistic and expected a high level of improvement (figure 5).

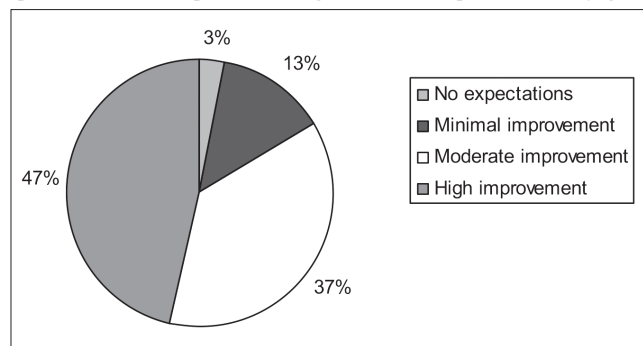


Figure 5 Expectations of improving the condition

Related to the previous question, the next question asked about the actual improvement of the condition of their child. The question whether treatment improved the condition of their child, 81% answered positively and other 19% could not see any improvements in the symptoms and characteristics of their child (figure 6).

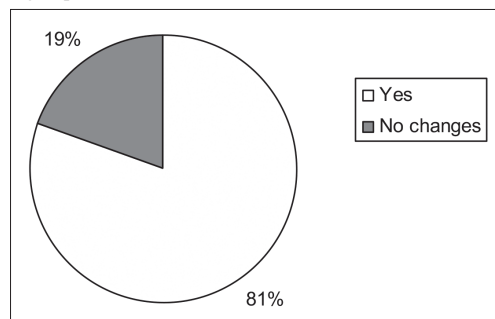


Figure 6 Whether treatment improved the condition of the child

Figure 7 shows the results of cost of the treatment. It is notable that 35% of parents spent 5000 Denars on various kinds of treatments. 33% of them spent 10000 Denars from their own budget. The other third of parents spent more than 10000 Denars, of which 16% spent 15000 Denars and the last 16% of parents spent more than 20000 Denars per month, which is the average salary in Republic of Macedonia. It is a large amount of money. This is because the Ministry of Health doesn't prioritize the needs of the children with ASD.

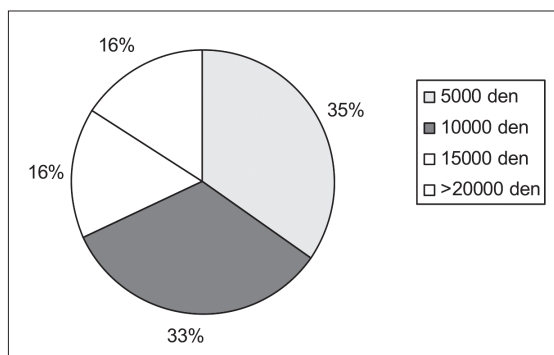


Figure 7 Cost of the treatment

Relating to the question, "Which early intervention program do you think should be implemented in state institutions in the Republic of Macedonia?", 50% of parents want ABA, 22% answered Son-Rise, 17% would like TEACCH and 11% want other programs (figure 8). The distribution of these answers clearly shows the urgent need of the implementation of ABA programs in the larger towns in the country.

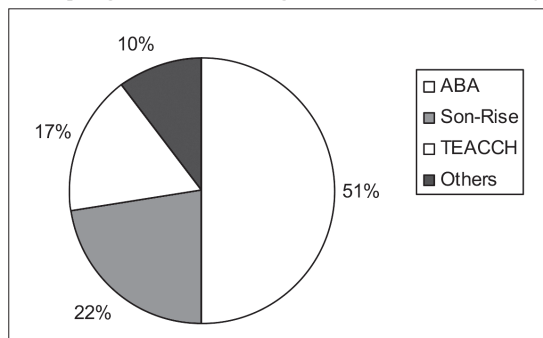


Figure 8 Which early intervention program should be implemented in state institutions

## DISCUSSION

When early intervention is implemented into the daily life of a child with autism there are certain guidelines as to which programs are to be used. Guidelines are based on programs used in evidence-based practice in which researchers which have

produced overwhelming success in the therapy process when working with several different individuals diagnosed with autism (Dugger, 2012).

Faced with the difficulties of autism, parents are understandably desperate for guidance and hope, and turn to policy makers for advice as to which approaches to use. Unfortunately, in our country there are no guidelines, nor model policies. Cumulative effectiveness research then has to be the best guide – even though this can seem slow when definite help is needed immediately. The pace of research into treatments is quickening but in comparison with many other areas of health is at an early stage, even in western countries.

Over the years, there have been many treatments developed for children with autism, evolving from different philosophies. These include behavioral interventions, developmental interventions, and cognitive behavioral interventions. While each program is based on a different philosophy and uses unique intervention strategies, there is also considerable overlap in components of the programs (Corseolo, 2005).

Evidence based comprehensive treatments for autism were introduced by Lovaas who published papers describing the “recovery” of almost 50% of a group of very young children with autism, treated intensively with applied behavioral analysis for several years (Lovaas, 1987; Lovaas, 1993).

These papers suggested an entirely new way of thinking about autism: as a disorder marked by considerable plasticity, for which there is some hope of recovery given appropriate intervention. The papers have had tremendous impact on public schools and other public service agencies that fund interventions for all children with disabilities, resulting in the development of specialized intervention programs for children with autism that differ markedly for those of children with other developmental disorders. The papers also had a tremendous effect on thousands of parents, who hope to achieve a similar recovery for their own children. Macedonian parents have little knowledge about these early intervention programs. Many parents have spent large amounts of their own money purchasing the interventions and hundreds to thousands of hours of their own time mobilizing services and funding for their children’s interventions, including many hearings and court cases.

Practitioners involved in early intervention for infants and toddlers with ASD and their families, have been limited by the relative scarcity of information on evidence-based practices. Nevertheless, researchers have been diligently working to establish the research base as a guide for selecting appropriate intervention strategies. There is scientific evidence from research with pre-school children with ASD about the efficacy of many focused intervention practices (Odom et al., 2007).

Strategies and tactics employed with older pre-school children with ASD may be promising for use with younger children with ASD. Service providers should use their professional wisdom in selecting practices found to be effective for older children with ASD and then determine if those procedures adequately address the needs of infants and toddlers and comport with the values of families (Buysse & Wesley, 2006).

As additional intervention practices and models for infants and toddlers with ASD emerge, two fundamental considerations will be (a) the validation and replication of the efficacy of focused intervention practices and CTMs for infants and toddlers with ASD and (b) validation and dissemination of models of professional development that will

support the implementation of evidence-based interventions by service providers and families (Boyd et al., 2010).

The field of autism early intervention has changed in the last 20-30 years. Since the development of the first empirically-validated and highly-structured ABA interventions that changed the lives of children with autism, continued research has expanded these efforts by moving towards more naturalistic interventions that integrate principles identified by developmental science with ABA principles. Whereas behavioral and developmental research and treatment in ASD initially proceeded separately, the increasing emphasis and evidence on autism intervention during the early childhood period have brought these fields together. These Naturalistic Developmental Behavioral Interventions represent the integration of ABA and developmental science and they not only allow us to achieve more substantial and accelerated child learning and behavior change, but they are particularly well suited to the infant and toddler autism population now being served (Schreibman et al., 2015).

Macedonian pediatricians, psychologists and rehabilitators lack the skills to conduct such early kinds of treatments.

In Republic of Macedonia there is no systematic approach to early intervention services and programs. There are no service providers for the early intervention of children with ASD. Parents access various kinds of treatments for their children, the most popular are: training of social skills, psychomotor re-education, biomedical treatment and treatment with medicaments. Sometimes they use unproven treatments which can be dangerous for the health. The use of ABA and TEACCH is at an incidental level.

One of our previous epidemiological studies showed that data for children with ASD is inconsistent in the centers for social welfare and in the medical centers. The complexities in diagnosis, making of procedures, insufficient information of the population, absence of a legislative registration and National Register for Autism, are all part of tasks for a team of professionals who must work on this problem (Trajkovski et al., 2005).

The Macedonian Scientific Society for Autism (an organisation run by professionals set up in the year 2000) provides free education about autism and specific approaches, such as PECS, TEACCH and Re-Attach method. The Association also participates in EU funded projects developing parent and professional education. Family counselling and psycho-social support by state institutions is very poorly developed.

A lot of parents are turning to alternative and complementary medicine treatments such as: homeopathy, gluten and casein free diet, CD autism protocol, cannabis oil, DAN treatment and stem cells treatment, all searching for a way to improve the recovery of their children. Some of the parents do not accept medical therapy for children with autism. A lot of children are hyperactive, aggressive and auto-aggressive, and parents have to live with these behaviors.

There is no effective law in Republic of Macedonia for early intervention practices. Also for education in schools, there is no legislation to guide and support parents into choosing the type of school to send their children to. Great numbers of parents send their children to mainstream schools with a 1:1 specialist assistant who is financed by the parents. Having a child with autism spectrum disorders in Macedonia can have a huge financial impact for the family. It appears that policy makers are not interested



in this area and have no understanding of the problems families face who take care of children with autism.

Authorities have to start with certificated programs for training the professionals. Almost half of parents are not satisfied with early intervention programs in our country. One third of parents spend between 250-350 Euros on early treatment which is a significant amount of their own budget.

In developed countries most of the empirical studies have been conducted on ABA interventions. While there is evidence that certain strategies can be effective for teaching specific skills to children with autism, there is not currently evidence that one program is better than any other. Despite this difficult situation with early intervention in Macedonia, western world countries have very good evidence-based systems for a number of years.

There are two classifications of practice: focused intervention practices and comprehensive treatment models. Focused intervention practices are specific teaching procedures that practitioners or parents use to promote children's learning and development or decrease challenging behaviors. Early intervention service providers select specific focused intervention practices to address individual goals and objectives for infants and toddlers as well as their families. In comparison, comprehensive treatment models (CTMs) are conceptually organized and multicomponent practices that have been integrated in a comprehensive manner (e.g. across developmental domains, across longer periods, across the employment of a variety of focused practices) to promote positive outcomes for children with ASD (Boyd et al., 2010).

There have been two basic assumptions about services for children with ASD: firstly, that early intervention service providers use research as a guide for selecting focused intervention practices or CTMs for infants and children with ASD and their families (Odom et al., 2007); secondly, that practitioners use their professional judgment about context and values (their own and those of the family) in the application of such practices (Buisse & Wesley, 2006). Efficacy research that includes infants and toddlers with ASD has been relatively limited.

Focused intervention practices consist of: Behavioral intervention strategies, Positive behavior support, Naturalistic interventions, Parent-implemented interventions, Picture exchange communication systems, Pivotal response training, Structured work systems, Visual supports (Boyd et al., 2010).

Comprehensive Treatment Models (CTMs) differ from focused interventions in scope, intensity, and complexity. CTMs consist of multiple focused intervention practices organized around a conceptual framework; they address multiple developmental areas or core behavioral features of ASD. They are implemented over extended periods (e.g., a year or more). These models varied by conceptual and theoretical frameworks as well as by quality of development and empirical support. Model developers who were affiliated with 20 of the 30 models reported their appropriateness for children below the age of 3. However, some CTMs were specifically designed for infants and toddlers with ASD, or those models were explicitly adapted from the original CTMs for older children. In this group following methods are included: Children's Toddler School, Project Data for Toddlers, Early Start Denver Model, Early Social Interaction Project, Walden Toddler Program (Boyd et al., 2010).

Parent involvement is crucial in implementing strategies and new techniques into the daily lives of children with autism. The amount of parent involvement could possibly be the most important of all strategies to allow for carry over. The reason for this is because it allows for more family support due to the focus of the caregiver's needs. By allowing this, caregivers are able to understand how to teach their child while also being able to reduce challenging behaviors that might be exhibited (Moes & Frea, 2002).

When family involvement is mentioned as an approach used in early intervention, there are many different things that can happen. It can be as simple as the family implementing what the child is learning during direct therapy hours into everyday living situations, but it can also be direct interventions programs that parents learn how to implement during therapy. This could include the Early Social Interaction program which is a "parent-implemented intervention model designed to individualize social communication goals and monitor child progress, to identify family routines for targeted goals, to teach parents to implement teaching strategies within selected everyday routines, and to support family implementation of intervention" (Wetherby & Woods, 2006).

By allowing for a strong family-professional partnership, confidence is gained, paired with a sense of empowerment with in family members or caregivers. Results of parental empowerment are increased in the likelihood that the caregiver will communicate with professionals about concerns. Family and caregivers will also feel comfortable in continuing to incorporate newly learned skill with their child (Dugger, 2012).

Legislators and researchers are currently emphasizing the delivery of research-based practices in many areas, including autism services. Therefore, it is critically important to examine the attitudes and experiences of service providers in community-based settings. Although many service providers reported being supportive of the use of evidence-based techniques, most did not have a good understanding of what the research was saying in the area of autism. Most of the providers reported using at least one evidence-based technique; however, these same providers were just as likely to report using poorly researched techniques as well. These findings provide insight into recommendations for successful translation of research based practices into EI programs for children with autism. Pragmatic issues regarding the use of the techniques in classroom settings must be addressed. Validity concerns when techniques are combined or modified should also be examined. In addition, adoption of any new intervention is likely to be facilitated by increased marketing to both community agencies and family members, access to low-cost training, and methods for use in group teaching situations (Stahmer, Collings & Palinkas, 2005).

Over the last two decades, research and public policy efforts for children with ASD and their families have focused on early warning signs of the disorder and on the earlier identification of young children with ASD (Johnson & Myers, 2007; Osterling & Dawson, 1994). As policy and practice recommendations to improve early screening and assessment of ASD have been implemented across the country, personnel in EI programs have been challenged to provide evidenced-based services for very young children with ASD. Moreover, parents have been confronted with the issue of how best to access the service delivery system for young children with ASD. Currently in the USA, intervention services for infants, toddlers, and preschoolers with ASD and their

families have been accessed through different funding streams, including the federal and state government (Boyd et al., 2010).

The lifetime cost of autism spectrum disorder in the UK has been estimated at £3-4.6 million per individual, with a likely financial burden of between £5 billion and £30 billion (McClure and Couteur, 2007). There is some evidence that interventions that are effective in addressing conduct disorder may also have some efficacy for children with, or at risk of, autism spectrum disorder. Social and communication impairments are especially critical (Woods and Wetherby, 2003).

This amount of money sounds fantastic and it is unrealistic to expect spending at a similar level by governments of any low-income Balkan country.

The hope of many professionals and advocates is that earlier identification and assessment of ASD will lead to effective early intervention, which at present includes both behavioral and developmentally based treatments (Landa, 2008). With access to high-quality interventions in the infant and toddler years, the possibility exists for the prevention of autism (Dawson, 2008) or at least a reduction in the severity of children's symptoms over the lifespan because of the malleability of the brain during this critical period of development.

## CONCLUSIONS

There are many strategies for working with children with ASD and not all of them are equally known or available to all parents. Most of the empirical studies have been conducted on ABA interventions. While there is evidence that certain strategies can be effective for teaching specific skills to children with autism, there is not currently evidence that one program is better than any other.

The available evidence from a variety of programs and studies suggests that EI leads to better outcomes. A number of studies have demonstrated that children make greater gains when they enter a program at a younger age. It is important to keep in mind that most of the empirical support for the difference in gains is comparing children younger than 4 or 5 years to children older than 4-5 years of age. The pre-school years are still considered "early" when it comes to early intervention.

In Republic of Macedonia there is no systematic approach to early intervention services and programs. Policy makers have to start with certificated programs for training the professionals. The government should allocate more financial resources to this sector.

There is a great deal of interest in the common elements of the programs when making recommendations, including parent involvement, intensity, a predictable environment, incorporating the child's interests, actively engaging the child and focusing on individualized developmental goals. It is important that professionals and parents are informed about the progress they can expect for their child, as well as remain aware that most research does not support a "cure" or "recovery" from autism.

It is essential for researchers to continue to validate effective and efficient interventions, for practitioners to strive to co-ordinate and integrate effective day-to-day services, and for policy makers to implement adequate, well-coordinated and well-

integrated service delivery systems; if optimal outcomes for infants and toddlers with ASD and their families are our ultimate goal.

The authorities need to begin to see this disorder as treatable, and to invest the same energy, money, and efforts into treating autism that we have put into treating cystic fibrosis, leukemia, childhood cancers and other chronic medical disorders that affect young children.

Future research should lead to interventions that are even more effective, efficient and individualized. Better understanding of the active ingredients of these interventions, fidelity of implementation needed for good outcomes in both research and community settings and the components that have the strongest effect on outcomes for sub-groups of children are critical research goals as the next generation of studies is designed.

### Conflict of interest

Authors declare no conflict of interests.

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