

УДРУЖЕЊЕ ПЕДИЈАТАРА СРБИЈЕ

*XXI семинар*

ПЕДИЈАТРИЈСКА ШКОЛА  
СРБИЈЕ

*од 10. до 16. јуна 2018. године, Златибор*

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## **XXI СЕМИНАР ПЕДИЈАТРИЈСКЕ ШКОЛЕ СРБИЈЕ**

*Златибор, 10 – 16. јун 2018.*

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## 11.1. CHILDREN WITH SPECIAL NEEDS REVIEW OF PUBLIC INFORMATION AT WWW, AS PARENTAL GUIDANCE IN CHOOSING LEARNING RESOURCES

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### INTRODUCTION

“Convention on the Rights of the Child”

General Assembly resolution 44/25 of 20 November 1989

#### Article 23

1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.

3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development

4. States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries (1).

## DEFINITION

It is very hard to define special needs in the reviewed literature, a description is used rather than definition.

In USA up to 10% of the child and adolescent population belong to some type of special needs. Developed countries refer smaller incidence, but it is still 5-6%. Special needs is a very heterogeneous group of conditions, its occurrence is often age dependant and lifelong (2).

“Isn't every child special? We think so. But what do we mean when we say “children with special needs”? This means any child that might need extra help because of a medical, emotional, or learning problem (3). “Special Needs” is an umbrella underneath which a staggering array of diagnoses can be wedged. Children with special needs may have mild learning disabilities or profound cognitive impairments; food allergies or terminal illness; developmental delays that catch up quickly or remain entrenched; occasional panic attacks or serious psychiatric problems. The designation is useful for getting needed services, setting appropriate goals, and gaining understanding of the child and the stressed family (4).

## DIAGNOSIS

The diagnostic process is multidisciplinary, slow, and with included follow-up for confirming the condition. Certain conditions as autism, learning disabilities, mild mental retardation, psychiatric disorders are age dependant and with overlapping symptoms and not always easily recognised. As professionals in the developmental field, often we start the treatment before we have definitive diagnosis.

The diagnostic process is a big burden for the parents as their dreams about their child's future are being blown by the condition. It is a big shock for the parent, but also a great need for recognising the changes in expectation, by establishing new goals for the child, compared to the condition limits and possibilities. There are several phases in accepting the condition going from disbelief, grief, fear, anger or guilt, as well as relief and determination to help their child.

“Being a parent of a child with special needs really doesn't come with a handbook. Depending on the diagnosis, and the severity of your child's condition, you may be besieged with worries about the future. Things you had previously taken for granted, or never had cause to consider, such as a child's access to education, ability to form friendships and romantic relationships, the possibility of them living independently, having children of their own, holding down a job and so on may suddenly seem to have been snatched away. Suddenly, it may feel as if you and your child inhabit a different world than everyone else (5).”

*The diagnostic process by Terri Mauro (4) should include:*

### **“Medical Issues**

Medical issues for children include serious conditions like cancer and heart defects, muscular dystrophy and cystic fibrosis; chronic conditions like asthma and diabetes; congenital conditions like cerebral palsy and dwarfism; and health threats like food allergies and obesity.

### **Behavioural Issues**

Children with behavioural issues don't respond to traditional discipline. With diagnoses like ADHD, Fetal Alcohol Spectrum Disorder, Dysfunction of Sensory Integration, and Tourette syndrome, they require specialized strategies that are tailored to their specific abilities and disabilities.

### **Developmental Issues**

Developmental disabilities are some of the most devastating issues for a family to deal with, changing visions of the future and providing immediate difficulties in caring for and educating a child. Diagnoses like autism, Down syndrome and intellectual disabilities often cause children to be removed from the mainstream, and parents must act as fierce advocates to make sure their children receive the services, therapy, schooling, and inclusion they need and deserve.

### **Learning Issues**

Children with learning disabilities like dyslexia and Central Auditory Processing Disorder struggle with schoolwork regardless of their intellectual abilities.

### **Mental Health Issues**

A child's problems with anxiety or depression can sneak up on parents; problems with attachment may smack them right in the face. Living with a child with mental health issues can put family members on a roller coaster of mood swings and crises, as well as defiance.(4)”

Sometimes parent will postpone diagnosis for “explainable reasons” such as:

1. Child has normal behaviour
2. Should wait for the condition to correct itself.
3. Insurance won't cover the diagnosis or therapy.
4. The child's behaviour may make an accurate diagnosis impossible.
5. “A diagnosis won't change anything.”
6. “I don't want her to be labelled.”

“Diagnosis is really important: based on observational, medical tests for known conditions, psychometry, psychiatric evaluation, radiologic examination, genetic testing and etc. It also offers an endless list of possibilities which are always expensive and what is more important, time consuming. When identifying a child’s disability a decisions must be made based on the child’s needs, not on the parent’s fears (6).”

## **TREATMENT**

“A diagnosis doesn’t change a child; it explains them“(4).

“The best treatment regimens are the result of an individualized treatment plan formed by a team of health care multidisciplinary professionals. The plan will be based on the severity of the disability and should involve patients, families, teachers, and caregivers in all phases of planning, decision making, and treatment. The individualized treatment plan will take into consideration both the immediate needs of the patient, and the long term prognosis for development.

- Behavioral Therapy
- Cognitive Therapy
- Drug Therapy
- Physical Therapy
- Occupational Therapy
- Speech Therapy (7)”

Depending on the child’s age we often speak about:

### **Early Intervention**

“In early intervention we act on symptoms rather than definitive diagnosis. In some cases, a child’s developmental problems may be evident from birth. Sometimes it may take several months to realize that developmental milestones are not being met. Early intervention is the term used to describe services that reach a child early in his or her development, usually from birth through age three. Intervention is vital during this very early time because this is the time when children learn and develop the fastest; during the first few years. It’s important not to miss out on this crucial part of a child’s development, as it may be more difficult to teach skills to your child as he or she gets older. At age three, children generally become eligible for other educational services (7).”

### **Education Planning**

“The value of the preparation and implementation of Individual Education Plans (IEPs) for children with special educational needs is internationally accepted and is



underpinned by law in many countries including the USA, Australia, Canada, New Zealand and the UK.

An Individual Education Plan (IEP) is a written document prepared for a named student which specifies the learning goals that are to be achieved by the student over a set period of time and the teaching strategies, resources and supports necessary to achieve those goals (8).”

### **Family Support Services**

“Family support services are community-based services that assist and support parents in their role as caregivers. Such services can take many different forms depending on the strengths and needs of the family, but their overarching goal is to help parents enhance skills and resolve problems to promote optimal child development. All families can benefit from support in some way; the principles of family support should be incorporated into casework across the child welfare service continuum (9).”

### **Special Needs Planning**

“Caring for a child with a disability can often feel like being trapped in a labyrinth. Special needs planning allows parents to find their way out of this maze and get their children the support they deserve (7).”

## **ASSISTIVE TECHNOLOGY**

### **“Assistive technology devices**

Any item, piece of equipment or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of children with disabilities.

### **Assistive technology service**

Any service that directly assists a child with a disability in the selection, acquisition, and use of an assistive technology device (10). “

## **COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM)**

“Complementary and alternative medicine (CAM) is a group of medical and health care systems, practices and products that are not generally considered to be part of conventional medicine (7).”

“Complementary means treatments that are used along with conventional medicine. Alternative means treatments used in place of conventional medicine. Integrative medicine combines, or integrates, the best of conventional medical care with the best of evidence-based CAM (11).”

### **“What are some examples of Alternative Medicine?”**

- Acupuncture
- Adeli Suit (Neurosuit, Euromed, Intensive PT)
- Chiropractic Manipulation for certain conditions
- Conductive Education
- Craniosacral Therapy (CST)
- Feldenkrais
- Hippotherapy (integrating therapy with horseback riding)
- Homeopathic treatments
- Hyperbaric Oxygen Therapy (HBOT)
- Music therapy
- Patterning (Doman-Delecatto)
- Stem cell therapy
- Therapeutic Electrical Stimulation (TES)
- Yoga

### **Feeding and Nutrition**

“A feeding problem occurs when a child has difficulty consuming solid foods or liquids due to a physical impairment, behavioural issue, or both. Some conditions that may disrupt feeding include oral cavity, neuromuscular, or neurologic defects. If special accommodations are not made for feeding, it can have a detrimental impact on the nutritional status of these children (12).”

### **Mental health care**

“Children with special needs and their families have special health care needs and they are often at risk for not receiving needed mental health care services (7).” “Mental health — an essential part of children’s overall health — has a complex interactive relationship with their physical health and their ability to succeed in school, at work and in society. Both physical and mental health affect how we think, feel and act on the inside and outside (13).”

## DISCUSSION

In every phase of their life a child depends on proper support by parent, medical system, educational system, social support. Early intervention, integration, sometimes rehabilitation is a part of their, and their family's everyday routines. There is no shortcut to those routines.

“As it is, these children are tied to many services, (educational, occupational, therapeutic ...), we have to provide availability. Many families rely on child care from the time their children are infants and well into the school years (13).”

“Good quality childcare is beneficial for all children. It can play a hugely important role in your child's development, allowing them to become independent, to mix with other children and to learn new things. But choosing the right childcare can be a difficult decision for every parent, particularly if your child has a special educational need or disability (14)”

“Research shows that all children can benefit from participating in high-quality child care programs that work closely with family members and provide their children with environments, materials, and relationships that enrich learning and development (13).”

“There are laws to protect children from discrimination and improve support and access to services, play opportunities, education and information (14).”

“Everyone benefits when child care programs include children with special needs. Children with disabilities benefit greatly from being with other children and from receiving consistent care from a caring adult. Typically developing children benefit from having a classmate with a special need because they learn respect for a child whose abilities are different from theirs as well as how to respond appropriately and offer help to the child (15). “

“And everyone learns to know one another as human beings with strengths and challenges (13).”

## CONCLUSIONS

When addressing children with special needs, rather than conditions, statistics, educational and treatment plans and different programs, we should bear in mind that each child, their families, social and educational environment need an individual and specific program tailored to the needs of the individual and the family and their needs.

As medical workers we can help professionally:

1. Early recognition, by qualified examination, proper usage of developmental scales, M-chat, proper referral for further medical examination. Developmental process is tied to the specific age, once it is missed repairs are hard and expansive or impossible.

2. Early intervention by early and appropriate referral for physical, occupational, speech therapies, psychiatric treatment.
3. Facilitating inclusion by consulting the parents for appropriate educational services.
4. Providing knowledge for social and educational services and the special rights for these children.

As an individual and as a parent by accepting public programs that take care of those children's needs. (Education, everyday living conditions, parks, crossings, new buildings, public transportation.)

By presenting this review of the publicly available literature, we would like be able to:

1. Provide better and complete services for this children.
2. Awareness that by adding to the quality of their life, we also improve the quality of our lives.
3. Change the public picture of these children and introduce new way of thinking in integration of the children with special needs and their families.
4. Whenever possible make them an active and productive participants in our society.
5. Understanding of the complicity and the complexity of the interaction and coordination between deferent services in order to get proper result.
6. All the services provided should take in care the need of the child to be integrated rather than separated, provision of services at their home, kindergarten, school rather than different hospitals and institution should be a must.
7. Living with the child with special needs is an enriching process for the child without special needs, if channelled properly their interaction can be productive on both sides.
8. Provide quality information for all the parties included including the parents, underlines the necessity for search through the publicly available literature.

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