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Innovative Academic Course on Integrative Interventions for Children with Autism Spectrum Disorders

Student manual

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Foreword

This manual was developed within the Erasmus + project „Innovative Academic Course on Integrative Interventions for Children with Autism Spectrum Disorders (IACIIC-ASD)", 2017-1-RO01-KA203-037296. The project partners, Universitatea de Vest din Timisoara, Romania, Universita degli studi di Firenze, Italy, Universitatea Lucian Blaga din Sibiu, Romania and Edukacijsko-Rehabilitacijski Fakultet, Zagreb, Croatia jointly developed this academic course and its materials- Student Manual and Teacher Manual.

The Student Manual is intended as a resource for the students, trainers (academics) but also to all those interested (practitioners, non-governmental organizations, parents, teachers). The Student Manual is accompanied by the Teacher Manual, which describes the course concept and operationalize it in a teaching program.

The Student Manual is organized in five modules. **All the modules** are inspired by the principles of evidence-based and research-based practice.

This first module focus is on diagnosing ASD and other evaluations (medical, clinical, educational), all grouped under the term of **Assessment**.

Evaluation and diagnose alone without intervention is useless. So, **the second module** on **Specific therapies** for ASD will familiarise you to diversity of interventions developed for TSA, offered by different providers in different settings - medical centers, schools or even at home - where especially before school age - the child spends the most of his time, That is why the third module of our course on ASD is dedicated to the families of people on the spectrum.

The third module on **Counselling** will show you how to support the parents right from the moment they show up at the specialist door for an assessment and how to communicate the diagnose if positive, the necessity for other evaluation and the bad news that there is no cure for ASD.

The fourth module on **Education and ASD**, maybe the most important for you as future specialists in the field of education, will require to remember what you will learn here, at this first module on assessment, about educational assessment, multidisciplinary team, and case management.

The last module, **Module 5** on **Advocacy** will stress one more time the importance of early detection leading to early intervention learned here but also will show you how you- as a specialist working with people on the spectrum-can contribute to policies and programs and be a trusted voice in supporting individuals and their families.

The course content is also accessible on-line, with supplementary learning resources both in a moodle-type presentation but also as an e-learning module. These resources can be found on the on-line platform for the Virtual University Clinic for ASD, which is also an intellectual output of our project at the address https://clinica.uvt.ro/.

Sometimes you will see that we indicate “OPTIONAL” next to some materials/resources. This means that you don’t *have to* read the **articles**, but might like to search for them, download and read them later. We may recommend **relevant books** for **further reading**. These resources will provide you with a deeper understanding of the course material. And also we refer you to important **websites** to expand your view of the field of ASD.

We will make use of **examples and illustrations** to enable you to connect theory with practice. Sometimes, the theoretical considerations are illustrated in notorious or real-life examples that can best assure a solid understanding of the concepts.

We invite you to go along in a collaborative learning process that will lay the foundation of your future professional competency.

The editors

Introduction to Autism Spectrum Disorder

Loredana Al Ghazi[1]

We will introduce you to the universe of ASD through a short historical excursus pointing at the important figures of the field. Then we will present the definition and the list of symptoms/the behavioral indicators for possible ASD traits. We will also discuss the possible causes of the prevalence of autism. Many more abilities, strengths and positive attitudes toward autism, will be developed in the modules that are to come.

The discovery of autism

The history of autism begins 75 years ago when Leo Kanner, a child psychiatrist at Johns Hopkins University School of Medicine in Baltimore, coined the term "autism" in his landmark articles on ”autistic disturbances” (Kanner, 1943) and ”early infantile autism" (Kanner, 1944). The term autism comes from the Greek *autos* (self) + *-ismos* (suffix of action or state), and literally means to be absorbed in oneself, a morbid self-absorption ("autism | Origin and meaning of autism by Online Etymology Dictionary" ; Evans, 2013). Kanner did not create the term but borrowed it from Eugene Bleuler, the Swiss psychiatrist that ever described the schizophrenia and introduced the term into psychiatry. Kanner claimed that it was for the first time, in 1943, that such cases were described in the literature, so he was the first to name those features as autistic. But history shows he was not the first (Silberman, 2015). Before him, Grunia Suchareva and Hans Asperger (Manouilenko & Bejerot, 2015) described autistic features. Actually, Asperger was the first to use the term ”autistic” for labeling the specific features he observed at University Children's Clinic in Vienna. He gave the first-ever public lecture on autism as early as 1938, at Vienna University, calling the boys he worked

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[1] West University of Timișoara, University Clinic for Therapies and Psycho-pedagogic Counselling, Romania

with “Autistischen Psychopathen”—autistic psychopaths. In German, the word “psychopathy” was akin to the term personality disorder with none of the connotations of the deranged or criminal mind that it bore in English” (Donvan & Zucker, 2016, p. 238). Asperger published *“The ‘Autistic Psychopaths’ in Childhood” (in German, “Die ‘Autistischen Psychopathen’ im Kindesalter”) in Archiv fur Psychiatrie und Nervenkrankheiten*, in 1944, a year after Kanner published ”Autistic disturbances of affective contact” in Nervous Child (Robison, 2017). The non-German-speaking researchers remained unfamiliar with the work of Asperger until 1981 when Lorna Wing presented the features of what she named Asperger Syndrome, and Uta Frith translated Asperger s article, 47 years after first published in German (Asperger, 1991).

Kanner was the first to publish an article in which appeared both the differential diagnosis of the features he observed from childhood schizophrenia (as in Sukhareva and Asperger) and the label for them, *autistic disturbances*. He was the first to show that this complex set of behaviors constituted a single, never-before-recognized diagnosis: autism. The infantile autism, also known as ”Kanner syndrome”, was formally recognized by the American Psychiatric Association (APA) only in 1980, in the third edition of the Diagnostic Statistical Manual (APA, 1980). Fifty years after Hans Asperger published his four cases of “autistic psychopaths,” whose traits were described as early as 1938, APA introduced the “Asperger syndrome” in the fourth edition of DSM(1994)

DSM-5 and ICD-11 definitions and criteria of diagnosis

Diagnostic and Statistical Manual

Diagnostic and Statistical Manual of Mental Disorders (DSM) is used by clinicians worldwide as becoming an instrument that has allowed standardization of diagnostics. For the first time, autism appeared in DSM III (APA, 1980), as a Pervasive Developmental Disorder (PDD). Then, for the first time, infantile autism was differentiated from schizophrenia; its core characteristics considered to be communication and social difficulties and bizarre behavior, manifested before 30 months of age. DSM III-R (APA, 1987) recognized disintegrative forms and increased the age to which symptoms may begin to manifest. This meant the possibility of receiving a clinical diagnosis for other children that could not be included in any category until then. DSM IV (APA, 1994) and DSM IV-TR (APA, 2000) first introduced the idea of a class of autistic disorders, including Asperger`s Syndrome and PDDNOS along with infantile autism in a category of five PDDs. The core recognized characteristics were social, behavioral and communication difficulties in all areas of development.

DSM-5 (APA, 2013) introduced the concept of ASD, from the need of clarification and due to the common core features of the conditions. Also, the emphasis shift to a functional perspective, the levels of severity is described related to the degree of support needed, and the new specific criteria for diagnostic are more strict and comprehensive. These specifiers provide clinicians with an opportunity to individualize the diagnosis and communicate a richer clinical description of the affected individuals. For example, many individuals previously diagnosed with Asperger's disorder would now receive a diagnosis of autism spectrum disorder without language or intellectual impairment.

Because symptoms change with development and may be masked by compensatory mechanisms, the diagnostic criteria could be met based on historical information, although the current presentation must cause significant impairment.

DSM-5 definition:

„*Autism spectrum disorder is characterized by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviors used for social interaction, and skills in developing, maintaining, and understanding relationships. In addition to the social communication deficits, the diagnosis of autism spectrum disorder requires the presence of restricted, repetitive patterns of behavior, interests, or activities*." (APA, 2013).

International Classiffication of Diseases

World Health Organization's *International Classification of Diseases* (ICD), propose another classification of disorders. In June 2018, the World

Health Organization (WHO) released The last edition of ICD, the 11th, its new International Classification of Diseases (ICD-11). The ICD catalogs different pathologies and conditions in order to provide a common language to inform and control their development, as well as comparing and sharing data following standard criteria between hospitals, regions and countries in different time periods. To do this, the diagnostic terms are converted into around 55 000 unique alphanumeric codes.
According to General Public Edition) of the DSM-UPAX which provides commentary/annotations to the DSM-5, DSM-5 and ICD-11 are harmonized in terms of classification and diagnosis criteria:

> ”Most of the differences between the DSM and the ICD classifications do not reflect real scientific differences, but rather represent historical by-products of independent committee processes.
> Within the diagnosis of autism spectrum disorder, individual clinical characteristics are noted through the use of specifiers (with or without accompanying intellectual impairment;with or without accompanying structural language impairment; associated with a known medical/genetic or environmental/acquired condition; associated with another neurodevelopmental, mental, or behavioral disorder), as well as specifiers that describe the autistic symptoms (age at first concern; with or without loss of established skills; severity).
> Autism features outlined in the ICD-11 fall into the same two categories as those in the DSM-5: difficulties in initiating and sustaining social communication and social interaction, and restricted interests and repetitive behaviors”.

lfnexus.com

However, the ICD-11 and the DSM-5 do vary in some aspects. For example, the ICD-11’s classification provides detailed guidelines to distinguish autism with and without an intellectual disability. The DSM-5 just states that autism and intellectual disability can occur simultaneously. The ICD-11 includes the loss of previously acquired competences as a characteristic to be taken into account when making a diagnosis while DSM-5 does not.
ICD definition:

"*Autism spectrum disorder is characterized by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour and interests. The onset of the disorder occurs during the developmental period, typically in early childhood, but symptoms may not become fully manifest until later when social demands exceed limited capacities. Deficits are sufficiently severe to cause impairment in personal, family, social, educational, occupational or other important areas of functioning and are usually a pervasive feature of the individual's functioning observable in all settings, although they may vary according to social, educational, or other context. Individuals along the spectrum exhibit a full range of intellectual functioning and language abilities*." (The 11th edition of the International Classification of Diseases and Related Health Problems).
We will present further the DSM-5 and ICD 11 diagnostic criteria.

Causes of autism

The etiology of autism is unknown. Probably there is not one single cause but a combination of factors that lead to autism. And probably as autism is a spectrum, the causes are also ranged in a spectrum.

In 1998, Wakefield published a paper in The Lancet claiming a link between the measles, mumps, and rubella (MMR) vaccine and autism. The Institute of Medicine, The Centers for Disease Control, has repeatedly investigated this and there is no credible evidence that vaccines cause autism. The study was retracted from the journal in 2010 after being proved fraudulent and the author lost his medical license. Furthermore, in 1992, thimerosal, one of the ingredients in vaccines, incriminated to be the cause, was removed from vaccines, and no effect was seen in the prevalence of autism.

Other investigated causes were the age of parents at the time of conception and prenatal factors. Based on epidemiological data, it was shown that advanced paternal age and exposure to some agents during pregnancy, while the fetal brain is developing, can increase the risk of autism (in particular, valproic acid, a medication for epilepsy administrated in pregnancy or some infectious agents).

Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures: to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1.Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).

4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

For A and B, we must Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behavior.

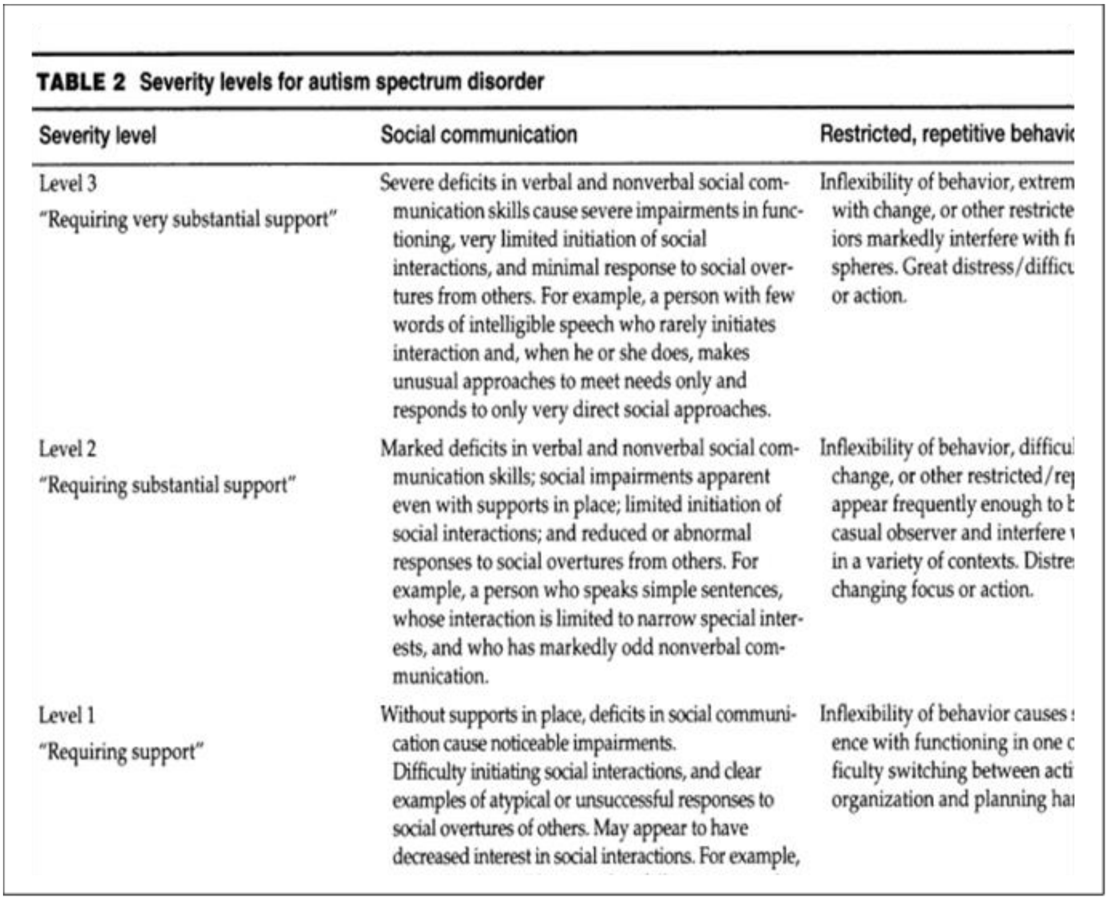

TABLE 2 Severity levels for autism spectrum disorder

Severity level	Social communication	Restricted, repetitive behavi
Level 3 "Requiring very substantial support"	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches.	Inflexibility of behavior, extrem with change, or other restricte iors markedly interfere with f spheres. Great distress/difficu or action.
Level 2 "Requiring substantial support"	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication.	Inflexibility of behavior, difficul change, or other restricted/re appear frequently enough to b casual observer and interfere in a variety of contexts. Distre changing focus or action.
Level 1 "Requiring support"	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions. For example,	Inflexibility of behavior causes ence with functioning in one c ficulty switching between acti organization and planning ha

DSM-5 Diagnostic Criteria **(**APA**,** 2013, p. 50)

ICD-11 Diagnostic criteria

http://www.researchautism.net/conditions/7/autism-(autism-spectrum-disorder)/Diagnosis

(World Health Orbanization, 2018)

6A02 Autism spectrum disorder
Autism spectrum disorder is characterized by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behavior and interests. The onset of the disorder occurs during the developmental period, typically in early childhood, but symptoms may not become fully manifest until later, when social demands exceed limited capacities. Deficits are sufficiently severe to cause impairment in personal, family, social, educational, occupational or other important areas of functioning and are usually a pervasive feature of the individual’s functioning observable in all settings, although they may vary according to social, educational, or other context. Individuals along the spectrum exhibit a full range of intellectual functioning and language abilities.

Inclusions

- Autistic disorder
- Pervasive developmental delay

Exclusions

- Developmental language disorder (6A01.2)
- Schizophrenia or other primary psychotic disorders (6A20-6A2Z)

It also notes that there are several sub-types of autism spectrum disorder:

- "6A02.0 Autism spectrum disorder without disorder of intellectual development and with mild or no impairment of functional language. All definitional requirements for autism spectrum disorder are met, intellectual functioning and adaptive behavior are found to be at least within the average range (approximately greater than the 2.3rd percentile), and there is only mild or no impairment in the individual's capacity to use functional language (spoken or signed) for instrumental purposes, such as to express personal needs and desires.
- "6A02.1 Autism spectrum disorder with disorder of intellectual development and with mild or no impairment of functional language. All definitional requirements for both autism spectrum disorder and disorder of intellectual development are met and there is only mild or no impairment in the individual's capacity to use functional language (spoken or signed) for instrumental purposes, such as to express personal needs and desires.
- "6A02.2 Autism spectrum disorder without disorder of intellectual development and with impaired functional language. All definitional requirements for autism spectrum disorder are met, intellectual functioning and adaptive behavior are found to be at least within the average range (approximately greater than the 2.3rd percentile), and there is marked impairment in functional language (spoken or signed) relative to the individual’s age, with the individual not able to use more than single words or simple phrases for instrumental purposes, such as to express personal needs and desires.
- "6A02.3 Autism spectrum disorder with disorder of intellectual development and with impaired functional language. All definitional requirements for both autism spectrum disorder and disorder of intellectual development are met and there is marked impairment in functional language (spoken or signed) relative to the individual’s age, with the individual not able to use more than single words or simple phrases for instrumental purposes, such as to express personal needs and desires.
- "6A02.4 Autism spectrum disorder without disorder of intellectual development and with absence of functional language. All definitional requirements for autism spectrum disorder are met, intellectual functioning and adaptive behavior are found to be at least within the average range (approximately greater than the 2.3rd percentile), and there is complete, or almost complete, absence of ability relative to the individual’s age to use functional language (spoken or signed) for instrumental purposes, such as to express personal needs and desires.
- "6A02.5 Autism spectrum disorder with disorder of intellectual development and with absence of functional language. All definitional requirements for both autism spectrum disorder and disorder of intellectual development are met and there is complete, or almost complete, absence of ability relative to the individual’s age to use functional language (spoken or signed) for instrumental purposes, such as to express personal needs and desires."

Lately, more and more studies focus on genes. One of the genetic factors that it is not clear is the significant difference between males and females. Males are affected four to one compared to females with autism. One of the methods used to check if genetics is a factor is investigating the concordance rate. The researchers ask if one sibling has autism, what is the probability that another sibling in that family will have autism and they look at three types of siblings: identical twins (twins that share 100 percent of their genetic information and shared the same intrauterine environment); fraternal twins (twins that share 50 percent of their genetic information; regular siblings (also sharing 50 percent of their genetic information but not sharing the same intrauterine environment). The concordance rate, in identical twins, is 77 percent, not 100 percent. It means that genes do not account for all of the risk , but for a significant proportion of that risk, because when analyzing fraternal twins, that concordance rate drops to31 percent. There is a difference between those fraternal twins and the siblings, suggesting that there are common exposures for those fraternal twins that may not be shared as commonly with siblings alone

So this provides some of the data that autism is genetic and when comparing to other conditions (diabetes, heart disease, cancer), the role of genetics is more important in autism than in any other conditions. If is just one gene responsible or a combination of genes, if the genes are passed down generation through generation within the family or if starts ”brand new” in certain individuals (mutations of genes being present in the egg or the sperm at the time of conception)- this are questions that Simons Foundation Autism Research Initiative (SFARI https://www.sfari.org/resource/simons-searchlight/) aims to better understand.

Wendy Chung gives a glimpse of what genetic research means:

So in fact, at the Simons Foundation, we took 2,600 individuals that had no family history of autism, and we took that child and their mother and father and used them to try and understand what were those genes causing autism in those cases?

To do that, we actually had to comprehensively be able to look at all that genetic information and determine what those were between the mother, the differences father and the child.

I'm going to use an outdated analogy of encyclopedias rather than Wikipedia, but I'm going to do so to try and help make the point that as we did this inventory, we needed to be able to look at massive amounts of information. Our genetic information is organized into a set of 46 volumes, and when we did that, we had to be able to account for each of those 46 volumes, because in some cases with autism, there's actually a single volume that's missing. We had to get more granular than that, though, and so we had to start opening those books, and in some cases, the genetic change was more subtle. It might have been a single paragraph that was missing, or yet, even more subtle than that, a single letter, one out of three billion letters that was changed, that was altered, yet had profound effects in terms of how the brain functions and affects behavior. In doing this within these families, we were able to account for approximately 25 percent of the individuals and determine that there was a single powerful genetic factor that caused autism within those families.On the other hand, there's 75 percent that we still haven't figured out. As we did this, though, it was really quite humbling, because we realized that there was not simply one gene for autism.

In fact, the current estimates are that there are 200 to 400 different genes that can cause autism. And that explains, in part, why we see such a broad spectrum in terms of its effects. Although there are that many genes, there is some method to the madness. It's not simply random 200, 400 different genes, but in fact they fit together.They fit together in a pathway.They fit together in a network that's starting to make sense now in terms of how the brain functions. We're starting to have a bottom-up approach where we're identifying those genes, those proteins, those molecules, understanding how they interact together to make that neuron work, understanding how those neurons interact together to make circuits work, and understand how those circuits work to now control behavior,and understand that both in individuals with autism as well as individuals who have normal cognition.

https://www.ted.com/talks/wendy_chung_autism_what_we_know_and_what_we_don_t_know_yet

Prevalence

In the USA, is estimated that 1 in 59 children has been identified with ASD according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. ASD occurs in all racial, ethnic, and socioeconomic groups and is about 4 times more common among boys than among girls.(https://www.cdc.gov/ncbddd/autism/data.html)

This explosion can be a result of increased awareness of autism among health care professionals, parents and the broader population; changes to the diagnostic criteria for autism; children being diagnosed at a younger age; demographic and geographical variables.

In Europe, some research indicates that autism spectrum disorder affects around 1 in 100 people. https://www.autismeurope.org/about-autism/prevalence-rate-of-autism/

Six main studies published in English 1992–2015 on ASD Screening at early years (aged 14-36 months) within the general population. In the studies chosen there was a big difference in prevalence rates. For example, a study in the Netherlands (2006) found 5.6 per 10,000. However, data from a 2010 study in Belgium estimated the cases of ASD to be 60.22 per 10,000. This fits in the same estimation as the UK based study (2000) which found 57.9 cases per 10,000. This difference in prevalence could be down to a high drop-out rate, a low participation rate or no procedures in place to check for accurate classification or for double negatives. The authors of the literature search are critical of the studies that are used in terms of the lack of socioeconomic information of their participants. Such data could have offered important information in terms of the participants' ability to access and engage with services.
http://asdeu.eu/wp-content/uploads/2016/12/WP2-Current-Best-Practices-on-Early-Intervention-update-27_7_18.pdf

http://asdeu.eu/wp-content/uploads/2016/12/WP1_Prevalence_13_7_18_MP.pdf

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https://www.cdc.gov/ncbddd/autism/data.html)

https://www.autismeurope.org/about-autism/prevalence-rate-of-autism/

https://www.ted.com/talks/wendy_chung_autism_what_we_know_and_what_we_don_t_know_yet

Module 1: Autism Spectrum Disorder assessment

Elena Lucia Mara, Daniel Mara, Cristina Danciu[2]

Introduction

Autism spectrum disorder (ASD) refers to ”a group of complex neurodevelopmental disorders characterized by repetitive and characteristic patterns of behavior and difficulties with social communication and interaction” (APA, 2013, *DSM-5).* The symptoms are present from early childhood, they can range from mild to profound, and show a strong persistence into adulthood (80-90%), but in all the cases the daily functioning, the family life, and schooling are affected.

Although there is no cure for ASD, early detection is the first and therefore most important element of intervention as it leads to early diagnosis and recovery of children with ASD, given that early and intensive intervention will help children to develop and learn new skills.

In this module we will present the definition and the list of the behavioral indicators for possible ASD traits. We will explain the process of identification, emphasizing the importance of early identification and early intervention. We will introduce you to ***Case management*** and progressing to the next modules, you will understand more about the powerful effects of this integrative approach in different contexts.

Module objectives

By the end of the module, you will be able to provide an understanding of assessment in autism spectrum disorders (ASD).

- To master the assessment criteria for ASD;
- To describe the ASD assessment domains;
- To identify and select the main tests used in the ASD assessment;
- To determine the importance of assessment as an intervention feed-back process.

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Topics covered by this module

Assessment process

- ASD Screening
- ASD Clinical Assessment/ Diagnostic evaluation. Diagnostic criteria (DSM-5, ICD 11)
- Evaluation to Determine Eligibility for Special Education
- Important areas of assessment for developing the IIP/IEP

*Assessment Tools for

1. screening
2. diagnosis
3. abilities

*The Case management model

Assessment process in ASD

Assessment in Special Needs domain is a very complex procedure due to the variety of manifestations and multiple domains of analysis:

- Must take into consideration a variety a needs and domains of intervention: medical, psychological, educational, social and daily life functioning.
- Involves different specialists from specific fields: doctors, psychologists, teachers, psycho-pedagogues, social workers, school management staff but also parents or the child himself.
- Must be performed in a comprehensive manner, and address all the developmental areas: cognitive, communication and language, socialization, motor and personal autonomy.
- To be valid it must appeal to various methods of evaluation: observation, experiment, interviews, standardized tests.
- Must be conducted in different life environments: home, school, playground, in social situations.
- Assessment accommodations are necessary to better adjust the child’s needs to the standardized testing situations.

ASD assessment is even more complex due to the diversity of specific developmental trajectories and the uniqueness of each case. The complexity of ASD assessment, in addition to the general Special Education, results from:

- The lack of a certain biological marker that makes the ASD assessment basically a behavioral one.
- The atypical character of behaviors in all areas of development.
- Diffuse boundaries between spectrum conditions that make difficult the differential diagnosis in the spectrum.
- The comorbid conditions of ASD: ADHD, sleep and feeding problems, OCD, anxiety.
- The need to focus on the functional aspects of daily living.

Also, ASD assessment can be sometimes a difficult process due to the necessity of collaboration between so many specialists who must agree on the best schema of evaluation, select the most appropriate methods and tests for the child’s needs, build up a time schedule and organize the process effectively. The assessment needs to be rigorous and comprehensive, but also time-effective, so the intervention can start as soon as possible.

The ASD assessment should be conducted in the early stages of symptom manifestation, and if possible earlier as a screening, in at-risk situations (family history, hostile environment or early social risk factors such as institutionalization).

ASD assessment should be considered from the developmental perspective. Although the first symptoms occur in the early stages of development, ASD is a life-time condition, and it puts its mark on all developmental stages. Even the children who following intervention are out of the spectrum assumes ASD as part of their ongoing life. We must assess and plan not only for the present but especially for the future, targeting life skills and gaining an independent and autonomous life.

ASD assessment is recommended to embrace the ecological model of intervention. In ASD, maybe more than in other conditions, we must know the child in its uniqueness and developmental specificity, taken into consideration all its relevant relations. We must primarily assess the functional aspects of behavior, to plan for adaptive targets in all life situations. In the early stages of development and interventions, the most relevant life domains for the child are family and home, in attempt to learn basic daily skills, such as communication, social interaction, play, self-care. Later, the school becomes a central domain for daily life and we must assess and plan for educational progress and school adaptation. The transition periods are also important, in the attempt to ease the adjustment to new situation. Essential is planning for adult and independent life transition, which can involve a work and career planning.

Not least, ASD assessment is an interdisciplinary team effort, as all the intervention. Different specialists evaluate the child from medical, psychological, educational and social perspectives. They meet and share information, work together to understand the child and describe him in an complex manner, with emphasis on qualitative aspects. It is relevant for intervention planning to have a large amount of knowledge about how the child behave, do things, adapt, react or relate, but also the triggers of these behaviors.

Due to all the arguments above and the complexity of the process the specialists must be competent in their field of expertise but also in the case management process. Therefore we aim to present all the intervention stages – assessment, planning, conducting, monitor and transition from the interdisciplinary case management perspective.

Principles of ASD assessment

Filipek et al. (1999) propose several principles of ASD assessment, covering all important aspects of the process:

1. The assessment should be conducted by specialists with experience in working with children with ASD. The uniqueness of children`s behaviors cannot be fully comprehended by someone who are not familiar with children with ASD and its problematic. They cannot take the best decisions about test accommodations needed nor correctly interpret the results of assessment.
2. The diagnostic of ASD should be made on DSM and clinical criteria and should be performed using at least one instrument specific for ASD.
3. In the assessment process a mixed indirect and direct methods should be used. Parents structured interviews must be supported by data gathered in direct observations.

4. All grades of ASD should benefit from same attention, even the mild forms should be addressed with same intervention protocols and concern.
5. In the assessment process other factors non-specific for ASD should be addressed too: other disabilities, sensory impairments, mental illness, ADHD, whose effect can influence not only the diagnostic of ASD but also the following steps, for example planning.
6. The evaluation process should include a medical and neurologic assessment, to detect possible comorbid conditions or acquired brain injury.
7. A detailed family history should be investigated through anamnesis, to determine causalities and the child developmental progress.
8. A variety of strategies should be used to assess the communication development, from parents` interviews to direct observation in the child natural environment.
9. Also, a cognitive assessment should be performed, by a ASD specialist. The test battery should be carefully selected, to be age and cognitive appropriate with the child`s needs.
10. Adaptive functioning should be also targeted in assessment; much relevant information can be obtained from this field. In DSM V the diagnostic criteria is fundamentally based on the functional aspects of everyday life, so to put a diagnostic the assessment of adaptive functioning is a must. In this assessment an occupational therapist should participate to analyze the functional aspects of activity.
11. Also, an assessment of sensorimotor skills can contribute to the full picture: information about sensory processing abilities, gross and fine motor skills, repetitive and self-stimulation behaviors.
12. An academic assessment is also needed. It provides information about the current level of acquisitions, knowledge and skills mastered. It should determine the adaptive possibilities to school rigors and the social interactions required in school.
13. The family should be assessed to determine the level of acceptance and understanding of the child`s condition but also the family potential to be involved in the therapeutic process.
14. Reevaluation in one-year time and a permanent process of monitoring the child development and the intervention efficacy.

Purposes of ASD assessment

Mason (2008) identifies the following purposes of ASD assessment in the clinical context:

1. Screening and diagnosis

The primary purpose is screening. A screening can be understood as a selection process of cases who can potentially present symptom of ASD. Usually, traditional screenings scan the entire population of the certain age for specific disabilities (auditory or neonatal neurologic screening). In nowadays the screening for ASD is not yet applied to the mass population, but to at-risk cases, in general with a history of neurodevelopment disorders in the family. Also, family physicians are train to keep track of any atypical behaviors of the child. Researchers endeavor to develop screening tests for ASD for younger and younger ages, stressing the importance of early diagnosis and intervention in ASD. The diagnosis is an essential step towards individualized intervention and beginning the road into therapy. A diagnosis orients the steps in placement, intervention and educational planning.

2. Classification and placement

After receiving a diagnostic other assessment may be needed, for including in the degree of disability, placement in educational or clinical settings or in periods of transitions from one educational cycle to another or transition to adult and independent life.

3. Selection of treatment targets

The diagnostic process is not limited to inclusion in a nosologic category, but also should be a source of qualitative information regarding the child. At least the child`s strengths and weaknesses must be determine, as a base for intervention planning. The diagnosis is followed by developing aims of intervention, which can be many, we must prioritize them, select the most relevant for the child, family and child`s life stage. The assessment helps us to establish what is relevant and important in this stage to be acquired first.

4. Treatment evaluation

Periodic assessment is used as a monitoring process, to determine the child`s progress but also the validity of the applied treatment. For each child an individualized collection of techniques, methods and activities are designed and we must assess if the treatment schema is appropriate or nor, if it determine the expected progress or not.

For educational context Brown, Snell and Lehr (2006) propose the following purposes:

1. Making educational placement decisions

A child with ASD can be placed in special or inclusive education or homeschooled. The placement decision should be made according to the least restrictive environment principle, but also the child`s happiness. The diagnosis is the first factor that should be taken into consideration in the placement decision. The severity of ASD is another important factor, the mild cases should be placed in inclusive educational settings. Also, the school possibility to offer qualitative resources and accommodations should matter.

2. Designing curriculum

Students with ASD need curricular adaptations which allow them to take part and progress in the general education curriculum. For each child an Individualized Education Plan (IEP) is developed. The IEP stipulates the curricular adaptation needed: in curriculum (what and how much they will learn), instruction (how will they learn, the designed strategies, with whom, with how much support) and environment (individual environment and learning).

3. Planning educational programs

The most important instrument for educational planning is the IEP, a tool for planning, implementing and monitoring the child`s educational progress. IEP stipulates the educational and therapeutic goals, the curricular adaptations, instructional strategies, and record the child`s development. Each child should be enrolled in an IEP service planning and should benefit of individualized education.

4. Evaluating student progress

Monitoring students` progress and the intervention efficacy is another function of the IEP. The intervention goals are plan for a determined period of time, 3 or 6 month. At the end of this instructional period an assessment is made to monitor student`s progress. In assessment as a monitoring activity we evaluate the level of goals achievement and the child`s progress.

Screening for ASD

Screening refers to the use of specific standardized instruments to identify an individual’s risk for an ASD.

ASD screening refers to a process of selecting from the general population those cases susceptible to develop ASD. Since there is not yet developed an objective test for identifying ASD (such a blood test, or CT scan) screening for ASD must take the form of a behavioral evaluation (Wilkinson, 2010). For other disabilities such hearing impairment or neurological deficits mass-screening tests were developed, including the neonatal type. All children of an age are tested with objective procedures to select the cases that may develop a disability, and referred to further evaluations. For ASD such a complex process is not yet developed, but researchers are working to find the relevant criteria for screening. Even if the primary form of prevention is not yet applied, secondary prevention is common practice. For at-risk children and their families screening for ASD services are offered. If in the family exist a form of neurodevelopmental deficits or the environment is hostile for the child development the child`s evolution can be monitored.

Autism spectrum disorders are recommended to be assessed by multidisciplinary teams (psychiatrist, clinician psychiatrist, pediatrician, speech therapist, psycho-pedagogue / special education teacher, social assistant) using validated diagnostic tools: questionnaires, interviews, observation scales.

Case study

Andrew is a five year old boy from rural Romania. His parents are teachers in the home village and have one more child, a seven years old daughter. Andrew was very desired and expected by the whole family, his coming to the world was an occasion of joy for all. Everything went on typically, the boy developed as expected, reached every developmental milestone in time and was a delight for his parents and sister. One of the family stories is about Andrew saying his first words: one morning when he was 11 month old open his yeas and said “ma-ti” (in Romanian a combination between mami, mother, and tati, father), His parents disputed over a day time what he said first, mother or father, until a day late he clearly said mami and then tati. He was a happy but shy boy, as his mother described, he liked to play with toys and animals and showed early signs of was to become a bright, happy boy.

All changed around 16 month when his mother began to notice a change in his behavior. Firstly, he seems to lost the appetite for social interactions, frequently ignoring his sisters` attempts to play or his mothers tickling games. He become more and more interested in certain objects, toy cars who arranged for hours. After that, his language became to deteriorate; he did not use the words he used to say, until he began to stop talking at all. What worried his parents the most was the tantrums he begun to display, when something changed in his daily routine. There were so strong that did not stop crying for hours, and nothing could comfort him. There were something that they never seen and were very worried.

His parents first seek help from the personal physician when Andrew was 20 month old. The family doctor examined Andrew, the physical check was passed with flying colors. He listen to the family`s concerns about Andrew behavior and decided to refer him to a specialist, a pediatric neurologist. This was the first obstacle, the specialist being 250 km from their residence and they need to wait for two months before the consult. The specialist was very thorough, involving EEGs, CT scans, parents interviews and child`s observations. They were recalled several times, all the procedures lasted approximately six months. The diagnostic process was lengthy and expensive and was completed with the ASD diagnostic.

The specialist gave them all of Andrew`s investigation results and the diagnostic report which specified recommendation to follow specific therapies. The parents did not understand too much of the medical papers and no recommendation for a certain centre where they can address was made.

The following months were the toughest for the family, dealing with the diagnostic, with fear and uncertainty, not knowing what to do and where to go next. The parents begun to get informed via internet and found parent support groups and NGOs. Through them they found specialized centers who offer intervention services for young children with disabilities and contacted them, the closes to their home was a centre situated at 100 km, who was able to receive them in one month time.

At the beginning for a four month period Andrew was assessed by different specialists: psychologists, special educators, and teachers. The assessment was followed by the intervention planning, a schedule for attending therapies and objectives being put in place. From then on Andrew attends the center two times a week for four hours and is enrolled in an inclusive kindergarten. Already small progress is observed and his family can look with optimism for the future.

Behavioral Concerns	Absolute indications for further evaluation
Tantrums	No babbling by 12 months
Is hyperactive/uncooperative or oppositional	No gesturing by 12 months
Doesn't know how to play with toys	No single words by 16 months
Gets stuck on things over and over	No 2- word spontaneous (not just echolalic) phrases by 24 months
Toe walks	
Has unusual attachments to toys (e.g., always is holding a certain object)	ANY Loss of ANY Language at any age
Lines things up	
Is oversensitive to certain textures or sounds	
Has odd movement patterns	

Filipek et al. (1999, p. 452)

Screening for ASD in Children Birth to Age Five

There are two important factors that inlfluence the ASD assessment in early ages. First is the need to identify and detect the specificity of development as early as posible, in order to begin individualized interventions. Secondly, a large procent of children begun to manifest specific symptoms between one and three years of age, and detection should imediately be followed by diagnosis.

Parents are an important resource in ASD screening and early identification. They are the primary factors for identifying early behavioral problems. Early detection depends on services delivered for parents `who are seeking support for their concern. Some research suggests that the parents` concern for their children atypical behavior is generally accurate (Glascoe, 2001). No matter who is making a referral, pediatricians, family physicians, nurses or teachers,

Arrangements for screening children suspected of having developmental delays should be made. The screening should be conducted by a trained professional using standardized screening instruments and natural observation. The screening is a decision making process in the end of it a resolution for need of further assessment is being made and a referral advanced.

Ideally, pediatricians and other health care specialists should conduct developmental examinations as a part of routine check-ups (Myers et al., 2007). An efficient method of screening could be to involve parents in tracking their child behavioral development. They can receive from the family physician screening instruments that describe typical behaviors on certain developmental ages. The parents can check if their child is progressing within the described milestones and if they detect atypical behaviors should seek help from a specialist. The specialist reviews the parent’s concern with the family and makes a decision.

Screening for ASD in Children Age Six and Older

Although the core symptoms of ASD are usually observed and detected since early childhood, some children are not identified as being at risk for ASD until school age or later. The mild forms, with high functioning potential, Asperger Syndrome or for children from disadvantaged social environments could reach school age and not being diagnosed or identified. In some cases, parents cannot accept the child`s disability and refuse to face the evidence, denying their own child the proper support needed. At school age the children must face other behavioral requirements from the educational environment, stricter and the adjustment difficulties can surface ASD symptoms. Teachers should be capable of detecting atypical behaviors and refer those children to school psychologists. Unfortunately, most screening tools are not designed for ages 6 and over. Specialists should rely primarily on classroom observations, psycho-pedagogical experiments and teachers` and parents` interviews.

Screening in Older Children, Adolescents, and Adults

The vast majority of people with ASD don`t reach the age of adolescents without being diagnosed. In rare cases, in mild forms of Aspergers` they can reach adolescence or adulthood strugling at school and in social situations. At this age routine screening is not longer a norm, so they

Communication Concerns

Does not respond to his/her name
Cannot tell me what (s) he wants
Language is delayed
Doesn't follow directions
Appears deaf at times
Seems to hear sometimes but not others
Doesn't point or wave bye-bye
Used to say a few words, but now he doesn't

Social Concerns

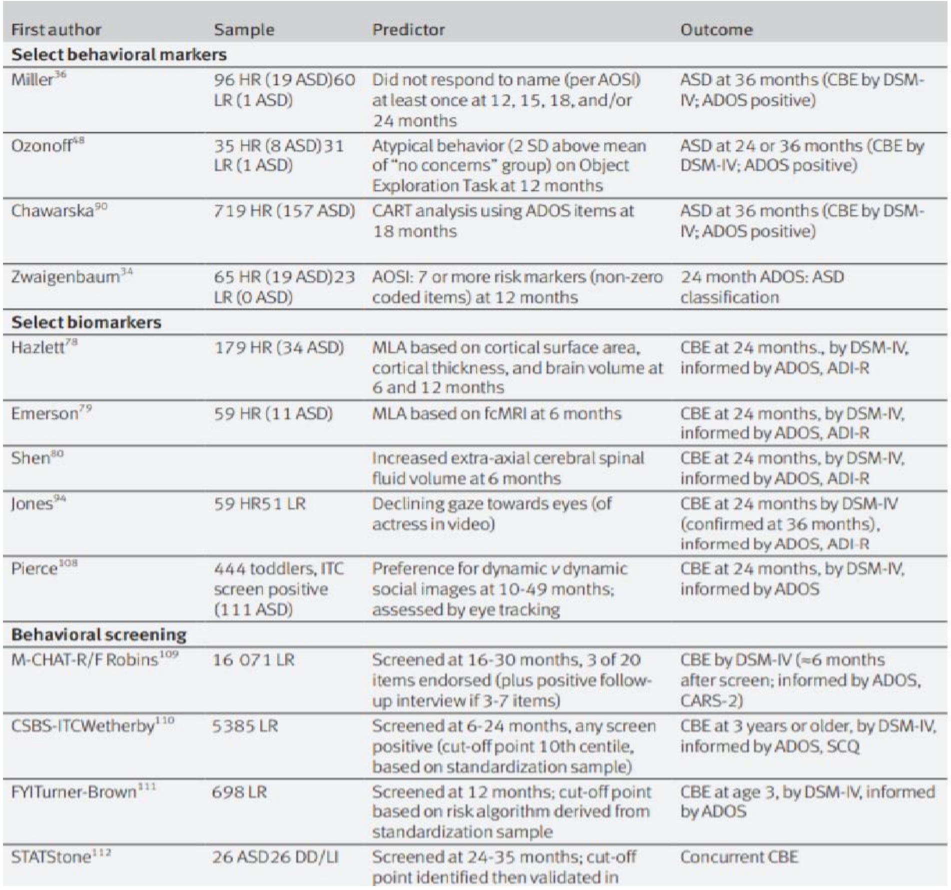
Doesn't smile socially
Seems to prefer to play alone
Gets things for himself
Is very independent
Does things "early"
Has poor eye contact
Is in his own world
Tunes us out
Is not interested in other children

are identified usually in consequence with school or social difficulties they are encounter. They can stand out through atypical behaviors, solitude, and great difficulties in making peer-relationships. Again, natural observation, teachers and parents interviews are the best screening options. Some individuals reach adulthood without being diagnosed. However, all their lifes they felt maladapted, out-of-the-way or uncanny. Sometimes a life event revels the posibility of having ASD and skeek help from a professional.

Failure to diagnose a child with ASD before 6 years of age may be due to the following factors:

- ✓ Issues of access; parents are not aware of developmental norms, or they cannot take proper care of their child, are not interested in his development or lack financial means to address a specialist.

Screening instruments and their predictors and outcomes



First author	Sample	Predictor	Outcome
Select behavioral markers			
Miller[36]	96 HR (19 ASD)60 LR (1 ASD)	Did not respond to name (per AOSI) at least once at 12, 15, 18, and/or 24 months	ASD at 36 months (CBE by DSM-IV; ADOS positive)
Ozonoff[48]	35 HR (8 ASD)31 LR (1 ASD)	Atypical behavior (2 SD above mean of "no concerns" group) on Object Exploration Task at 12 months	ASD at 24 or 36 months (CBE by DSM-IV; ADOS positive)
Chawarska[90]	719 HR (157 ASD)	CART analysis using ADOS items at 18 months	ASD at 36 months (CBE by DSM-IV; ADOS positive)
Zwaigenbaum[34]	65 HR (19 ASD)23 LR (0 ASD)	AOSI: 7 or more risk markers (non-zero coded items) at 12 months	24 month ADOS: ASD classification
Select biomarkers			
Hazlett[78]	179 HR (34 ASD)	MLA based on cortical surface area, cortical thickness, and brain volume at 6 and 12 months	CBE at 24 months., by DSM-IV, informed by ADOS, ADI-R
Emerson[79]	59 HR (11 ASD)	MLA based on fcMRI at 6 months	CBE at 24 months, by DSM-IV, informed by ADOS, ADI-R
Shen[80]		Increased extra-axial cerebral spinal fluid volume at 6 months	CBE at 24 months, by DSM-IV, informed by ADOS, ADI-R
Jones[94]	59 HR51 LR	Declining gaze towards eyes (of actress in video)	CBE at 24 months by DSM-IV (confirmed at 36 months), informed by ADOS, ADI-R
Pierce[108]	444 toddlers, ITC screen positive (111 ASD)	Preference for dynamic *v* dynamic social images at 10-49 months; assessed by eye tracking	CBE at 24 months, by DSM-IV, informed by ADOS
Behavioral screening			
M-CHAT-R/F Robins[109]	16 071 LR	Screened at 16-30 months, 3 of 20 items endorsed (plus positive follow-up interview if 3-7 items)	CBE by DSM-IV (≈6 months after screen; informed by ADOS, CARS-2)
CSBS-ITCWetherby[110]	5385 LR	Screened at 6-24 months, any screen positive (cut-off point 10th centile, based on standardization sample)	CBE at 3 years or older, by DSM-IV, informed by ADOS, SCQ
FYITurner-Brown[111]	698 LR	Screened at 12 months; cut-off point based on risk algorithm derived from standardization sample	CBE at age 3, by DSM-IV, informed by ADOS
STATStone[112]	26 ASD26 DD/LI	Screened at 24-35 months; cut-off point identified then validated in	Concurrent CBE

Zwaigenbaum & Penner, 2018, p.4

- ✓ T The child was diagnosed with another conditions such as Mental Retardation, ADHD, Communication problems, but typical ASD manifestations were overlooked.
- ✓ The child has a mild form of ASD and is high functioning but when is put in a stricter and more social situation, school for example, the symptoms become evident.

Important is that all educational and health care factors, such as teachers, physicians, special educators to be permanently childrens` development and screen for potential difficulties. They should be aware of the steps they must took if suspicion arise, pre-referral followed if needed by a specialist referral.

Screening instruments

here are still few instruments and procedures for ASD screening. Zwaigenbaum & Penner (2018) analyzed the research reports of ASD screening instruments presented in scientific journals (Table). The screening instruments used as predictors for ASD from interest to respond to name to cortical surface area, thikness and brain volume. Some procedures are complex and expensive and hard to use as screening instruments. All of them are still in the experimental phase and need to be further scientifically proved. The terms "diagnostic evaluation" and "clinical assessment" refer to the diagnostic process aimed at identifying specific developmental disorders that are affecting a person suspected of having an ASD and the rendering of a DSM-5 or ICD 11 diagnosis by a physician, psychologist, or other health or mental health professionals.

Case study

Paul is a three years old boy from one of the largest Romanian towns. He has very young parents and is the first child of the family. The parents were still college students when they had him and very busy studying and working to support the family. Taking care of Paul they were helped by the maternal grandmother, very energetic and involved. The parents spend all their free time with Paul but were overwhelmed by their responsibilities and didn't see any signs of concern in Paul`s development. He has developed physically typically, gained weight and length in normal limits and reached all milestones in time.

The maternal grandmother was the one who become worried by the lack of Paul`s social interaction. From Paul`s six months anniversary she noticed that he did not react to his own name, did not smile socially, did not established eye contact and played alone and strangely with objects, in a repetitive way. She expressed her concerns to Paul mother but she immediately dismissed them on the grounds that Paul was too small to do these things. The grandmother was still worried and spoke several times with Paul`s mother but with no result. The one-year anniversary brought about new causes for concern: the boy did not point or wave bye-by, seems to be his own world and oppositional.

At 16 month the mother finally took the grandmother advice and told her family doctor's about their concerns. The doctor immediately refereed them to a pediatric neuropsychiatrist. He admitted them at the hospital for a full consult that take two weeks. Several medical tests were performed, EEG, CT scan, blood work. Also, full family history, child observation and parents interviews were conducted. The diagnostic was ASD and the doctor`s recommendation was for early intervention services. He referred them to a specialized centre for early intervention and Paul was enrolled in the center at the age of 20 month.

The first two month consisted of a comprehensive assessment conducted by a multidisciplinary team, involving psychologists, special educators, teachers and social workers. At the end of the assessment they planned for the intervention, establishing goals and building up a schedule with multiple forms of therapy. Paul is attending the centre three times a week, four hours a day and the family is following instructions and working with him at home. He made important progresses and from fall he will be included in kindergarten.

Assessment for intervention planning

Assessment for Intervention Planning is a process of assessing child`s individual strengths and weaknesses, as a base for intervention planning and IIP/IEP development. A diagnosis offers a lot of information about the condition: core symptoms, severity of manifestations, treatment implications, or prognosis of development, the majority being quantitative information. Unfortunately a diagnosis does not offer much individualized and specific information about the child`s unique meeds and strenghts, and in itself cannot be the base for intervention planning. More qualitative information are needed to develop the IEP. We need to know not only in which extend a child communicates, interacts, social plays or typically behave, but also how does it and in what circumstances. Assessment for intervention planning continues and adds to the diagnostic by qualitatively describing the strengths and weaknesses of the individual. Assessment should be made across all functional domains, from academic functioning, through adaptive and family functioning.

The **goals** of comprehensive educational assessment for IEP planning are to:

- ✓ Determine which additional information is needed;
- ✓ Identify the child`s strengths and weaknesses across relevant domains;
- ✓ Develop an IEP that addresses the specific needs of the child..

Domains of assessment

DSM V (American Psychiatric Association, 2013) proposes two main domains of functioning influenced by ASD: social communication and interaction and restrictive, repetitive patterns of behavior. They should be the core areas of assessment, accompanied by others specific domains such as adaptive functioning and cognitive and academic functioning.

Silver (2005) considers that the assessment should:

- Emphasize on areas that most impact the child`s development and progress;
- Specify the current level of functioning in order to effectively plan for intervention.

In the IEP we should mark down not only the current developmental level but also the child progress, determined after the ongoing monitoring sessions.

Assessment of social communication and interaction

Most people with ASD have language and communication problems, but for the majority of them not acquiring pronunciation is the most difficult but the functional aspect, to use language as a social communication tool.

Therefore, for the social communication domain we must assess:

- The expressive language, including pronunciation, lexical knowledge, capacity to form sentences, and at school age the written language
- The receptive language, the capacity to understand and follow communication
- The functional language, the capacity to use language in everyday situations with meaning and reciprocity

For social communication and interaction assessment both informal and formal methods should be used.

Informal methods:

- *Natural observation* – by this method information about functional communication and social interaction are gathered. The specialist can observe the level of spontaneous language, the situation in which is used, with whom the child interacts, if he initiate the communication or just respond when approached, if the response has social meaning or is just a repetitive sequence of a limited interest and if the echolalic language is present.
- *History of medical problems and child`s evolution* – can reveal the trajectory of language acquisitions until the present time, the ages on which the child reached the communication milestones and the circumstance of eventual communicational regress, child`s communication preferences and interests, the level of communicational functionality at home.
- *Parents` interviews* – can offer a lot of qualitative information about child patterns of communication, difficulties and antecedents and consequences of atypical patterns of communication. Also can reveal parents needs in terms of learning how to communicate and interact with their child.

Formal methods:

- Standardized tests – over the time several standardized test to assess communication skills of children with ASD were developed. Among them most used worldwide are: Autism Diagnostic Observation Schedule-Generic (ADOS-G) (Lord et al., 2000), Early Social Communication Scales-ESCS (Mundy, Hogan, 1996), MacArthur-Bates Communicative Development Inventories - MCDI (Fenson et al. 2003), Language Use Inventory (O`Neill, 2002), Reynell Developmental Language Scales-III (Edwards et al., 2002), Test of Early Language Development—3 (Hresko, Reid, Hamill, 1999).

- Formal role-play tests – has been developed and validated. They propose standardized scenarios to evaluate child`s communication and social skills.

It is difficult to assess the communication skills in children with ASD because a large majority of them, especially at the beginning of the intervention are minimally verbal. Therefore a lot of information should be acquired via informal methods, natural observation and parents` interviews. For the standardized assessment some accommodation are required and several steps need to be followed (Kasari et al., 2013). Assessment goal setting can clarify the relevant information we want to gather and help in the process of assessment instruments selection. The assessment environment needs accommodations to be made: the parent and child should be informed about the procedure (the child with the help of a pictorial sequence), information from parents about child favorite reinforcements need to be obtained prior of assessment.

Cognitive assessment

An important area in ASD assessment is cognitive functioning. The knowledge in this domain contributes to determine a valid diagnostic and to develop the IIP/IEP.

The most useful information that can be obtained from a cognitive assessment of children with ASD are: the level of their cognitive skills (IQ), verbal reasoning – the capacity to use language as a cognitive tool, thinking in words and express thoughts through language, perceptual reasoning – the ability to use and transform visual information, working memory, processing speed – the ability to select and process stimuli with speed and accuracy, learning potential and the capability to transfer knowledge in new situations.

The cognitive assessment process of children with special educational needs (SEN) is very complex and difficult, and in ASD so much more:

- The cognitive evaluation requires the use of formal methods of assessment, especially standardized tests. The majority of cognitive tests on the market are developed for the typical population and their use on SEN assessment raise the question of validity. Even if the test is especially developed for ASD assessment the standardized norm-reference sample is questionable, due to the diversity and variability of ASD characteristics.
- Many IQ tests are rich in verbal stimuli, which require a minimum level of oral or written verbal knowledge. The children with ASD have verbal difficulties; they tend to do better on performance items than in verbal ones. In some tests it is allowed to use only the performance subscales (WISC for example) and a performance IQ score can be obtained. However, even if only non-verbal items are administrated, the verbal component is not fully eliminated, the standardized test instruction uses verbal knowledge.
- The assessment requires trained specialists that have a great experience and understanding of ASD problematic. The atypical nature of behaviors, the difficulty to establish social interactions are the main reasons why the assessment process is so difficult. Every standardized test has a fix algorithm of how should be administered, score and interpreted. If the communication and social interaction is difficult, the standardized norms cannot be abided and test and obtained results are questionable.
- The selection of standardized instruments should take into consideration at least 3 criteria (Filipek et al., 1999): 1. Should be adapted to child`s chronological and mental age; 2. Should provide a variate range of standard scores; 3. Should include both verbal and performance scales.

To assure the assessment`s success various testing accommodations needs to be ensured (https://www.iidc.indiana.edu/pages/Standardized-Tests-and-Students-with-an-Autism-Spectrum-Disorder):

- Examiner - is planning a pre-meeting with the child, preferably in his / her natural environment, to make acquaintance and to clear away the child`s anxiety.
- Sensory – the examiner should first examine the child`s sensory needs and preparing the test material accordingly. If the child has over stimulatory issues the test material should be presented in small parts and not to contain overly stimulating colors or sounds.

- Routine – children with ASD can follow strict routines so any disturbance can cause stress and anxiety. The examiner should inquire of these routines and try to match the test session with the student's usual schedule.
- Environment – the student should be familiar with the testing room, if the child has never been in the cabinet, a previous short visit is recommended. The testing environment should be low on distractions and stimuli.
- Time – allow extra time for test completion.
- Test directions – for children with communications delays the test instructions should be adapted, shortened as much as possible and with accessible language. For non-verbal children pictograms or gesture can be adopted.
- Motivation – to maintain child`s interest and attention, is recommended to vary the test items, even if the standard form of presentation is not respected. Child`s usual positive reinforcers can be used to maintain the motivation level.

The most used IQ tests in ASD assessment are: Wechsler Intelligence Scale for Children (WISC), Wechsler Intelligence Scale for Children, fourth edition (WISC-IV), Stanford-Binet Test and Raven’s Progressive Matrices.

Academic assessment

This area has two main purposes: to contribute to the educational diagnostic and to prepare and offer information for intervention planning. The final result of the academic assessment will be a comprehensive characterization of child`s strengths and needs, specific for the educational setting. The children with ASD present a heterogeneous development of abilities, so they can have very good reading (hiperlexia) skills but at the same time a below average phonologic awareness. All learning abilities should be examined thoroughly and determine the strengths on which we continue to build in the problematic areas.

“For school-aged children the most frequently used general achievement tests include the Woodcock-Johnson III NU Tests of Achievement (WJ III NU; Woodcock, McGrew and Mather 2007), the Wechsler Individual Achievement Test-Second Edition (WIAT-II; Wechsler 2002b), and the

Kaufman Test of Educational Achievement-Second Edition (KTEA-II; Kaufman and Kaufman 2004).” (Wilkinson, 2010, p.62)

Independent living/ adaptive skills assessment

The adaptive skills are considered to be the best predictor of functioning and independent living. More than cognitive potential, which is difficult to assess and highly variable on different assessments the adaptive skills can offer a more accurate picture of the functional behavior. The adaptive skills assessment offers information on daily living skills and level of independence in child`s natural environments. The main purpose of adaptive skills assessment is planning for intervention. It can provide useful information on daily living skills, strengths in independent functioning or in social interaction. Also, data obtained from this assessment is used to prioritize the intervention objectives, adaptive functioning being in top of the child`s needs.

A full assessment of adaptive behavior should be composed of four types of methods (Silver, 2005):

- Surveys and questionnaires: information obtained from this method inform us about the level of mastery in daily living activities and social interaction skills. The standard form of question helps us to score all important areas of daily living skills and gives as a quantitative picture of child`s functioning capabilities.
- Parents` interviews – are important because it gives us an insight of what parents` consider important for the child and for the family as a whole. Parents can name the most relevant needs of the child and we can use them in prioritizing intervention goals. What is important for the family is certainly important for the child. In the family-centered case management approach is it considered essential, especially in early developmental stages, to listen and take into consideration parents` concerns, points of view and observations.
- Direct observation can gather qualitative information that complete the quantitative knowledge from questionnaires. We can observe not only what the child do independently but also how he does it, in what circumstances, with what triggers and what motives its behavior.

- Self-report – can be used in high-function cases or in adolescence and adulthood. It provides first-hand high-quality information about ones needs and self-perceived abilities.

Assessment tools

Most professionals use the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview Revised (ADI-R) for ASD symptoms; the most widely used intelligence scale is the Wechsler Preschool & Primary Scale of Intelligence (WPPSI) and Vineland Adaptive Behaviour Scale (VABS) http://asdeu.eu/wp-content/uploads/2016/12/WP2-Current-Best-Practices-on-Early-Intervention-update-27_7_18.pdf

Autism Diagnostic Observation Schedule (ADOS) is one of the most used specific instruments in assessing ASD. It was developed by Lord and al. (2000) as a standardized, semi-structurated instrument for social-comunication ASD evaluation. The instrument consists of a sequence of tasks that engage the specialist and the assessed person in social interaction activities. The specialist observes and analyze parts of the subject's behavior and notes them to fixed observational categories. There are 4 modules of observation, each designed for a 30 minutes observations. The modules are: Preverbal/single words/simple phrases; Flexible phrase speech Fluent speech child/adolescent and Fluent speech adolescent/adult. With each subject activities are realized from a single module, depending on the stage of its development. A revision, the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2), is available from 2012. It includes updated norms, improved algorithms for Modules 1 to 3 and a new Toddler Module that facilitates assessment in children ages 12 to 30 months.

The Autism Diagnostic Interview-Revised (ADI-R), a sidekick instrument, consisted of a structured interview conducted with the parents. ADI-R investigates in the form of a anamnesis the development history of the child. The instrument is developed for ages older then 24 month and asesess behaviour in the areas of reciprocal social interaction, communication and language, and patterns of behavior. It consists of 93 questions covering the three main behavioral domains described above. ADI-R is an appropriate instrument for diagnosing, planning and monitoring intervention.

The Modified Checklist for Autism in Toddlers (M-CHAT) is a screening questionnaire aimed to assess risk for ASD in children ages 16–30 months. It consists of 20 questions filled out by the parent, and a follow-up section available for children who are classified as medium- to high-risk for ASD. Children who score in the medium to high-risk zone may not necessarily meet criteria for a diagnosis. In the first part M-CHAT describes 20 typical behavioral festures of ASD and evaluate if the child has experienced any of them. If the parent identifies an established number of behaviours in this forst part, a follow-up form should be completed, in which the most relevant questions are detailed and further examined.

Ability assessment (golden standard ABLLS-R, VB-Mapp, Caroline) is used when we want to know where the child's level is compared to the vast majority of neurotypical children or when we weant to calculate the acquisition rate in intervention every 6 months. The Carolina Curriculum test comprises two assessment scales: The Carolina Curriculum for Infants and Toddlers with Special Needs and The Carolina Curriculum for Preschoolers with Special Needs. The purpose of these assessment scales is to provide the overall picture of the child's development, being used as a starting point in the implementation of the intervention plan. The two scales cover different areas depending on the age of the child, so the Carolina Curriculum for children with special needs up to three years covers the areas of self-control and responsibility, interpersonal skills, self-concept, self-service, food, dress, toilet, visual perception, puzzle / constructions, matching / sorting, functionality of objects, symbolic game, problem solving, concept of number, attention and memory. The Carolina Curriculum for preschoolers with special needs covers the areas of cognitive development, communication, social adaptation, fine motor skills, coarse motor skills. The Carolina Curriculum test helps us in selecting the work programs, the items in each area of evaluation are in the order in which they must be taught by the child, given that the development of children with special needs is heterocratic, this test helps us to develop functional programs and in the order of priority.

Case study

Mary is a six and a half years old girl from a rural village. She is the third child of the family and has two older brothers and a younger sister, all typically developed. She grew up in her local village and currently is enrolled in the preparatory class in school. Before school she was at kindergarten for three years. The parents did not observe any problems with Mary, but they consider her a difficult and introverted child.

First concerns were formulated by the kindergarten teacher who observed that Mary was different from all her colleagues. She was not interested in other children and played alone for hours arranging toys. She did not notice what happened around her, did not follow instructions and even did not react to her own name. She had a grave language delay, spoke only a few words but not in a social manner, but rather as a repetitive pattern. She had odd movement patterns, fingering materials and flapping hands. The kindergarten teacher expressed her concerns to the mother, advising her to take the child to a specialist. But the mother did not want to accept that Mary can have problems, still asseverate that Mary is just difficult and stubborn. The teacher could not call a school psychologist to assess the child because the mother did not give her consent.

Three kindergarten years pass and Mary`s behavior was still the same, At six years she was enrolled in school, at preparatory class in a bigger town, 10 km from home. The school teacher immediately detect Mary`s behavior and try to spoke with the mother who still did not want to accept that Mary had any problems. The school had a school counselor and the teacher call him to screen all the children from the class. The counselor detect Mary`s problems and call a multidisciplinary team, consisted from the teacher, himself, the school principal and the mother, Each presented their observations about Mary and display concerns about her future. They presented to the mother the difficulties that Mary encounter at school and what a benefic effect will have on her and the family the support of the multidisciplinary team. The mother accepted for Mary to be assessed and took her to a pediatric neuropsychiatrist. After two month they received the ASD diagnostic and she could now benefit from the support from the school specialists. An IEP was developed and curricular accommodations were being made.

Currently Mary goes to the same school in the inclusive program and two times a week she sees a speech therapist. The progress is very slow, but it exists and her chances of an independent adult life increased.

The Case Management in ASD

Children with ASD have a wide range of developmental acquisitions, specific behaviors,and levels of functionality. The unitary approach of psycho-pedagogic intervention is particularly difficult in the context in which, although there are common characteristics of the spectrum, each child with ASD is unique. There is not a single recipe, a common algorithm for the therapeutic approach to ASD, each child is unique and needs a custom intervention program adjusted to its needs.

Each child must be approached in an individualized manner and must receive a psycho-pedagogical intervention customed to his needs. The general framework for approaching the children with ASD and their families is represented by the case management, a rigorous method of planning, coordinating and monitoring all interventions carried out with the child. From the moment the child is referred to be evaluated by a specialist he becomes part of the case management process. This scientific methodology is centered around the child in order to plan and provide the best educational and therapeutic activities. A group of specialists, alongside the child and its family, are working together, aiming to attain a high level of autonomy and functionality. Inside the case management, an Individualized Education Plan (IEP) is developed, a real blueprint of all planned activities.

There are several processes that are carried out for each child inside the case management (https://www.education.com/reference/article/steps-ndividualized-education-program-IEP/):

1. **Pre-referral** is a stage in which, because of some prior difficulties or atypical behaviors a child is observed by a specialist to determine if the child is eligible for a full referral. This observation is carried out in the child natural environment, where the difficulties are manifest and the specialist can determine if there are real causes of concern. The main objectives of this stage are:
    - Observe and document all the child difficulties and the context in which they occur.
    - Test the effectiveness of parent care provision or if the child is older the quality of educational services provided.
    - Monitor child`s development.

This pre-referral activities are implemented to screen the children before more formal identification are being made and to avoid unnecessary worries or more intervention measures. For the children susceptible of ASD this stage is taken place around the age of 18-24 month when for the majority the first signs occur. The pre-referral is carried out in the child`s home or its playing ground. After several observations and interviews with the parents, the specialist may propose alternative educative methods which parents will try to determine if the child`s behavior change. If the problematic behavior does not change the child is referred for formal evaluation.

2. **Referral** represents the stage when the child`s difficulties are already confirmed by a specialist that make the decision to further evaluate the child to determine if he is or is not eligible for special education services. Referrals can be made from different sources: parents, special educators, doctors, health or daycareprofessionals. For children with ASD, the referral is being made in most of the cases by parents who are worried by their child`s behavior and seek help to family physicians or psychologists. In many cases the pre-referral stage do not take place, the process of case management begins with the referral.
3. **Identification or evaluation** is the stage in which the child is assessed in order to determine if he has a disability and a diagnosis is being put. Over several weeks the child is evaluated by a team of specialists with formal and informal methods in all of the child`s life environments to determine his level of development and of functionality. The assessment is carried out by a multidisciplinary team, consisted by different specialists, psychologist, special educator, speech therapist, occupational therapist and audiologist. Each of them evaluates the child over a specific domain susceptible to be affected in ASD: social communication, play and interactive behavior, speech, cognitive behavior, personal autonomy developmental history, hearing, vision, sensory functioning, fine/gross motor functioning, atypical behaviors, academic skills and adaptive behavior. A comprehensive approach to autism identification includes data collection from a variety of sources (parents, extended family, educators, day care providers) and use of several methods (observations, interviews, tests). Educational

assessment should include observations in natural context (home, school, in environments in he performs well but also in environments where encounters difficulties), parent interviews and rating scales, teacher interviews and rating scales, direct assessment, standardized tests, standardized instruments used in non-standardize situations. The diagnosis must be put in relation with DSMV criteria: delays in social interaction, social communication, and or play all beginning prior to 3 years. That`s why information must be obtained in relation with the child`s developments in the first years of life: early warning signs of autism, evidence of skill regression, family history, medical history. The specialists have the responsibility to review all the information about the developmental level and progress, as well as the information about the current level of functioning and the context in which the student performs. In the assessment process, we must determine students strengths and weaknesses: the possibility of the pupil to access and make progress within the general curriculum, develop a basis of interventions accommodations or modifications within the kindergarten/school setting and allow the team to determine the need for specialized instruction. The outcome of the initial evaluation is not only to determine the eligibility for Special education services but also specific instructional recommendations that will enable the IEP team to develop a plan for appropriate support.

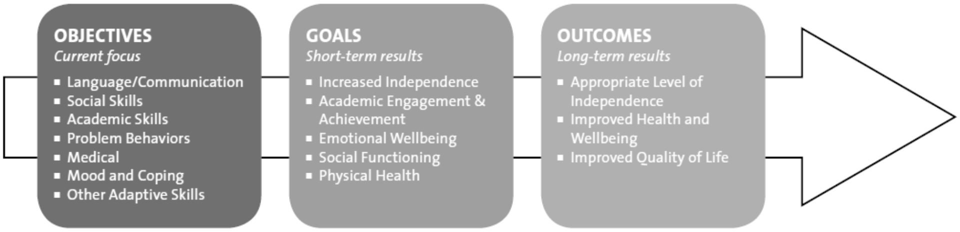
4. **Eligibility** The assessment is followed by a decision making process, when the members of the multidisciplinary team present the assessment results, discuss the case and decide if the child is eligible for special education services. The multidisciplinary team decides together, based on the child`s needs what type of support services must be provided and in which type of center or school they can be met. Also, if the child is at a school age a decision about the type of education that will be provided is made, recommending the school inclusion or the special education option.
5. **Development of the IIP**.

   The IIP is a coordinating, recording and monitoring instrument of all the activities carried out with the child. First step in developing the IIP is to establish, based on the child`s needs, the domains of intervention and the types of specific therapies and curricular adaptation that will be provided. A role is assigned to each member of the multidisciplinary team and a schedule of the hours that will be spent in class interaction and in specific therapies is made. The most important part in this stage is developing the intervention`s objectives. Each member of the team formulates several objectives specific to his domain and together they analyse and prioritize them, selecting the most important ones for the short-term intervention. The objective must be formulated respecting the SMART technique: they must be specific, measurable, achievable, realistic and time-related. The following skills must be dress for children with ASD:

- Ability to participate in instruction (engagement)
- Socialization skills
- Communication
- Independence skills
- Ability to manage anxiety
- Behaviors

The objectives must primary be related with the specific domains influenced by ASD, as they are specified in DSM-5: communication, social interaction and behavioral objectives. The communication objectives can refer to developing language skills that will help the children to interact with peers, use and understand non-verbal communication, interpret facial expressions and in general, abilitating them with a functional form of communication.

- The social domain objectives can refer to accepting the interaction with others, be cooperant in everyday activities, collaborate in learning tasks or enjoy playing with others.
- The behavioral objectives can refer to controlling maladaptive behaviors, making eye contact or respecting rules.



Note. Adapted from “Therapies for Children with Autism Spectrum

Disorders,” byZ. Warren, J. Veenstra-VanderWeele, W. Stone, J. L. Bruzek, A. S. Namias, J. H. Feig et al.,2011, AHRQ Publication No. 11-EHC029-EF. Rockville, MD: Agency for Healthcare Researchand Quality.

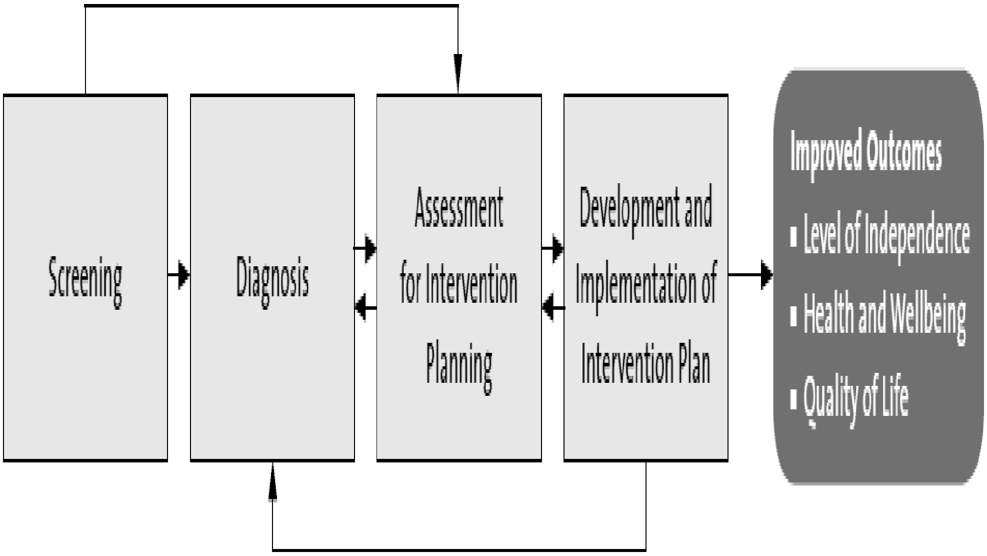
6. **Implementation of the IIP**. After the IIP is developed the planned services can be provided. The IIP will constitute the main instrument on the basis of which all the activities carried out with the child will be designed and implemented. In this way, all activities will be individualized and adapted to the child`s needs. Each specialist will provide activities aiming to reach the common goals. So although the child is attending several types of educational therapies and services, all specialists aim to achieve the same goals and the child`s progress will be faster. The main area of services provided for children with ASD must be Speech therapy, Occupational therapy, Physical therapy and other educational services.

   In addition to the services provided for children with other disabilities, the IIP for ASD must take into consideration other accommodations (Trott, Biswell, King, Sugar, 2015):

   - Extended educational programing – express the need of children with ASD to participate in educational programs when school is not in session or after a regular school day.
   - Daily schedules – each child must have a structured program during a school day, with minimum time spend in non-structured educational activities and a lot of time spent in active learning.
   - In-home training – in addition to the time spend in school the children with ASD need time spent in therapy at the home also. Here, all the skills acquired in school must be practiced in the child`s natural environment and integrated in their daily activities.
   - Positive behavior support strategies – the IIP must contain a specific plan for developing positive behaviors and the reinforcement to be provided.
   - Transition planning – the children with ASD can have a low tolerance for change and a high level of stress for novelty, so we must plan in advance for any transition.

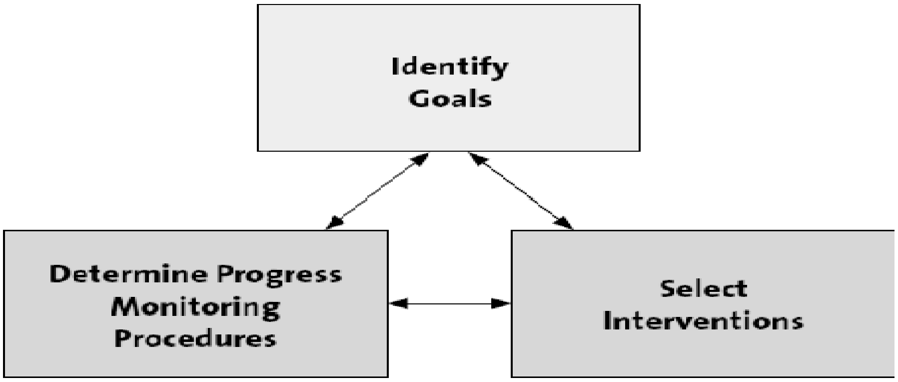
- Family training and support – the parents must be a big resource for therapy, so we have to support them in any difficulties they encounter and train them to become co-therapists and continue our work at home.
- Staff-to-student ratio – for students with lower levels of functionality this ratio must be increased, allocating additional human resources.
- Teaching strategies based on peer-reviewed and/or research-based practices -considering evidence-based teaching strategies including Applied Behavior Analysis, visual supports, functional communication, adaptive skill building.

Fig. The dynamic nature of the process from screening to improved outcomes



7. **Monitor and review.** Periodic, the IEP is reviewed assessing the child's` progress and the efficacy of the interventions. Based on the results new goals are developed and the methodology adapted. This monitoring process can take place when significant difficulties are encountered, the child does not progress or in term once or twice a year.

Fig. Intervention Plan Components



Source: Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment (www.autismguidelines.dmh.mo.gov)

Authorship statement

The authors of this paper take public responsibility for the content and have had equal contribution in concept development, design, analysis, writing, or revision of the manuscript.

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Module 2: Specific interventions for children with autism spectrum disorders

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Introduction

All interventions for children with ASD, should rely on a very good theoretical and practical understanding of their condition, children` needs and current trends in methodology. This chapter will introduce the general framework of ASD intervention, will describe the principal types, methods and techniques of interventions and will exemplify their application in some particular cases.

It is good to know that ASD interventions are not based on the generality of the diagnosis but on the specific individual needs. The approach to intervention is an individualized one, where specific needs are taken into consideration in developing the intervention plan. The ASD interventions are heterougenous, a single child can benefit from a variety of methods, techniques and alternative therapies. A child can participate and progress from educational, healthcare, ocupational or social programs. The child progress is optimum when specialists collaborate across service delivery systems and when parents are involved as co-therapists in planing and implementing interventions.

A distinctive point for ASD specific interventions is that there is no "general recipe" or cure for this condition and that there is no one therapy that is suitable for all children, but a therapy suitable for every child. The main behavioral, developmental, therapeutic and combined approaches will be presented, emphasizing on their empirical demonstrated efficacy. We will discuss how can we find, as a multidisciplinary team, the best combination of therapies and life regime that is most effective for each child and gives the best results.

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Module objectives

By the end of the module, you will be able to**:**

1. Define, characterize and analyze the psycho-pedagogical interventions and specific therapies for children with ASD
2. Analyze and compare the principles, methods, techniques, and efficacy of the principal specific therapies for children with ASD.
3. Identify and recommend the best combination of therapies, methods, and techniques in relation to the children needs.

Topics covered by this module

Interventions or therapies for ASD?
Principles of an effective intervention
What do we mean by effective therapies
Specific therapies

Interventions or therapies for ASD?

The term „interventions" is used for the treatments, therapies, programs, strategies, supports, and services for people on the autism spectrum. This term covers a wide range of approaches and it is also the term used by most professionals. It is also an comprehensive description of methods used to improve the adaptation for children with ASD. The focus of this chapter is to present only those interventions performed by psychologists and special needs educators (in Romania called psycho-pedagogues) and not those involving other professionals (medical staff, occupational therapists, kinetotherapists and so on). In order to conduct this kind of interventions, a rigorous theoretical and practical training is required. We will refer to those interventions conceived for, developed and meant to be used with people on autism spectrum as ”specific therapies” or, simply as ”therapies”, to differentiate from other interventions that can be used for people on the autism spectrum but also with other people with special needs.

We saw in the previous chapter the importance of early identification. In every disability early identification and intervention is crucial, but there is a specific situation with autism that it cannot be easily identified in early stages or does not manifest until after the first year of age. The reported age of identification varies between 2 years and 9 months and 3 years and 3 months in the USA (Adelman & Kubiszyn, 2017).

An attentive parent can observe certain signs or delays in development or changes in their child behaviour and can report them to the medical staff or simply ask ”At his/her age, is it normal for my child to/not to smile or not want to be hugged, not look into my eyes, not respond when called by name or waving the hand so much in front of the eyes, rocking, hitting the floor?”an so on. Experienced specialists can identify autism in children younger than 2 years old and subtle red flags can be observed as early as 2 to 6 month old (Jones & Klin, 2013). Not all the children that later develop ASD can be identified before 12 months of age. Some of them do not show at this stage any clear signs of autism and develop typically until one or one and a half years of age.

The recently reported success of a blood test for ASD will certainly lower the age at which children are diagnosed, leading to earlier interventions (Howsmon et al., 2018). But the problem is that once the child is diagnosed, right after, every parent hear this dreading and disappointing phrase: „There is no cure for ASD, but...”. The specialists will then explain that there is no treatment or procedure, as it is for a medical condition, that can be taken or followed to make autism disappear. Still, there is strong evidence that appropriate interventions, lifelong educational approaches, support for families and professionals, and provision of high-quality community services can improve the lives of persons with ASD and their families. http://www.autismeurope.org/wp-content/uploads/2017/08/persons-with-autism-spectrum-disorders-identification-understanding-intervention.pdf

Even though presently there is no efficient medication for ASD, drugs are prescribed to reduce behavioral symptoms associated with ASD such as hyperactivity, anxiety, aggression, and self-injury. The farmacological approach can help increse the quality of live of children with ASD, by reducing the co-morbid symptoms and offer them the chance to participate and be involved in social and kearning activities.

Assisting families of children with ASD to overcome the obstacles of daily life is a permanent and ongoing process. They need support throught life span, in different levels, from permanent support in the early stages to post-intervention follow-ups later in development. The support will focus on the same specific features of ASD, such as improving social interaction and communication, addressing challenging behaviors, school inclusion, promoting independence, and in general improving quality of life.

Before enumerating and describing the most effective and frequent used therapies for ASD we invite you to remember the model of case management presented in the first module and relate it/connect it with the principles that must guide any successful intervention.

Case study

Geogiana, mother of two kids with ASD.

Georgiana B. recounts that Alex, the eldest boy, looked like a normal baby for up to a year and a half. “Then things started to change. He played more alone, he did not respond too much when we shouted, the language disappeared, he closed and opened the doors for minutes. At one year and seven months, Alex reached out to a neurologist who, after a superficial consultation, concluded that the boy was not autistic and advised Georgiana and her husband to go to a psychologist "to teach us how to to behave with the child ”. But Alex was getting more and more agitated, he was screaming a lot, he was aggressive, he didn't respond when he was shouting, he didn't point with his finger.

While Alex was two years and three months old, a specialist at the Faenza House in Timisoara finally made the correct diagnosis, news that came as a flash - autism. Immediately, Alex started the free therapy sessions in the center of Faenza, which is financed with money from the Timisoara City Hall. At the entrance to the center he had no eye contact, he did not respond to names, he did not look with his finger, he did not respond to orders, he was hyperkinetic, self / aggressive, he did not imitate. The changes occurred after 2 years of therapy. For 4 years he acquired personal autonomy, began to verbalize, evolved in all areas. There's still more work to be done.

Radu developed normally until 1 year 5 months when he gradually began to lose his aquired skills: he stopped talking, he didn't respond to his own name, he didn't wave good bye, the eye contact disappeared. He was diagnosed at 1 year 8 months also with ASD, went on the same path with Alex (special kindergarden) but with him the changes occur at a different pace. He is now almost 4 years old, doing therapy at Casa Faenza and in particular, he is more cheerful. I hope to get my sun back soon. ”

The principles of an interventional programme

The success of intervention programs depends on many factors, but some principles must always be applied because they guide the achievement of therapeutic effectiveness:

1. **The individualized approach of each case**. Due to the complexity and variety of symptoms each child has a different clinical characterization. Only if we can accurately describe and understand how and why a child behaves in a certain way, we can propose adaptive measures that will form a functional behavior. Some researchers (Odom, Hume, Boyd, & Stabel, 2012) proposed to make the shift from models of intensive behavior treatment and eclectic approaches of ASD toward an individualized based approach, in which the therapies, techniques and activities are designed based on their efficacy on the specific child.
2. **The ecological approach of the child**. Any child cannot be understood and educated only if we see him as a person who lives, develops and progresses in context. The child is surrounded by social influences (family, community, school, friends), environmental (with opportunities and accessibility options) or educational influences (the type of school and education he receives). In order to know a child especially from a functional point of view and to understand the barriers he encounters, we need to know how he performs daily activities, communicates in the family, relates to other children or copes with the school program. The functional barriers that children with ASD encounter result from interactions with environmental restrictions or social requirements, so we need to evaluate how the child meets everyday needs and must find solutions for functional living. The importance of the ecological approach was researched in relation to family counseling (Dente & Parkinson Coles, 2012) or educational transition (Derguy, M'Bailara, Michel, Roux, & Bouvard, 2016).
3. In order to provide quality educational services, it is necessary to approach the child in **the case management paradigm**. A child with ASD has needs from several areas of development: social, language and communication, cognitive, social autonomy and medical,

educational or social needs. A single specialist cannot cover all these areas with his expertise, so there is a need for a group of specialists working together with parents for the benefit of the child. Their efforts must be harmonized and adjusted so that all work together for the progress of the child. Case management is a rigorous working method that aims to coordinate and monitor all interventions in various fields (medical, educational, psychological and social) in order to increase the level of functionality of the child's behavior (Ghergut, 2011). There are three possible types of case management: multidisciplinary, interdisciplinary and transdisciplinary case management. We recommend in early intervention a transdisciplinary model, in which specialists work together, share common assessment, goals, activities, monitoring and reporting. The activities take place in the child`s home and exploit the child's natural learning opportunities and family expertise. In the school years an interdisciplinary model is recommended, in which specialists pursue the same goals, share results and activities.

4. **Early identification and intervention** (Koegel, Koegel, Ashbaugh, & Bradshaw, 2014). One of the activities performed by the case management team is the identification of possible cases of children with ASD. The benefits of early identification and intervention are numerous:
    - Address atypical behaviors (Thye, Bednarz, Herringshaw, Sartin, & Kana, 2018) before the child withdraw completely in self and is no longer interested in knowing the reality around him or relate and communicate to others;
    - Minimizing the skill loss - the earlier the child condition is identified, the fewer acquisitions it loses in that period. Many children with ASD have a typical development to some point, but gradually decline and begin to lose them (Thurm, Manwaring, Luckenbaugh, Lord, & Swedo, 2014). If the identification, diagnosis and intervention start early the skill loss is diminished;
    - Maximizing the benefits of the best brain neuroplasticity period 0-4 years (Dawson, 2008);

   - Reducing the onset of intervention - children with ASD go through a fairly long period between diagnosis and the onset of an effective intervention. Usually, several methods are tried before the best-personalized intervention is found. Thus, the earlier the child is identified, the chances to find the ideal combination for them is increasing (Yoo, 2016);
   - The early acceptance by parents of the child's condition entails their better involvement in therapy (Magán-Maganto et al., 2017). Only parents who know and accept the child's disability can adjust their interaction and parenting techniques and establish an attachment relationship with them.
5. **Planning the intervention in a structured and organized manner**. Every child with ASD benefits from an Individualized Education Plan (IEP), a tool for planning, coordinating and recording the implemented activities (Barton, Lawrence, & Deurloo, 2011). The integrated approach to its needs implies a collaborative effort between all those working with the child: specialists, doctors, social workers, family. All of them must aim at common, prioritized and structured goals, communicate with each other, and seek common solutions to problems. Structuring activities focus on planning and systematizing all interventions. Planning the intervention means designing long-term goals from which medium- and short-term objectives can be implemented. They must be relevant to the child's needs, realistic and achievable. Objectives must be prioritized to focus primarily on the development of basic skills. For the child with ASD, basic skills are considered the acceptance of social interaction, widening of the spectrum of interests and development of functional communication. Systematization implies that the established goals and activities take place from one another and build on the previous ones so that the child naturally goes through all stages of development.
6. **Spending time in personalized therapies**. Studies (Linstead et al., 2017) have shown that the more the child spends more time in individualized face to face therapies, the faster progress is made. The needs of a child with ASD are so particular that they can only be addressed in a customized way. The time spent in therapies must be a

minimum of 5 days a week, for an equivalent of a full school day (National Research Council, 2011).

7. **Early socialization** (Vernon, Koegel, Dauterman, & Stolen, 2012). One of the main barriers encountered by the child with ASD is socialization, one of the three main areas of intervention. Only in relationship with others, adults, children, his difficulties are revealed, and we can teach him at the scene how to overcome them. Child acquisitions cannot be left to manifest themselves only in the therapeutic environment they must be transferred to everyday life situations for their behavior to become functional.
8. **Finding the best intervention schema** (https://www.autismspeaks.org). It is said that there is no therapy that is suitable for all children, but a therapy suitable for every child. Even scientifically validated therapies, such as ABA, do not work in every case. That's why we must find the most appropriate combination of methods, techniques, activities and life regime for each child. This process may take a long time, from a few months to a year, but we must look at this test time not as a lost time but as a time gained in finding the optimal intervention scheme that works for that child.
9. **Parents` involvement in therapy** (Burrell & Borrego, 2012). Parents are the ones who know the child best and spend the most time with it, can educate him in his natural life environment, can identify any barriers encountered and intervene immediately. They have the role of reinforcing the skills that are formed in therapy through everyday life activities, thus achieving their functional transfer. They can capitalize on every dailly living situation as a learning situation, and therefore the time spent by the child in the family becomes time spent toward progress.
10. **Providing a least restrictive environment** (http://nationalautismnetwork.com). The more the child has more opportunities for experimentation and independent exploration, he can progress more quickly. Children learn experimentally, and if they have the knowledge interest, they can do their exploration activities according to their interests. They must have the opportunity to be included in school alongside their typically developed peers.

11. **Early school inclusion** (Stahmer & Cunningham, 2011). Throughout the therapeutic process, one of the main goals must be to prepare the child for school and social inclusion. In the inclusive school, the child with ASD can interact with peers with typical development and find behavioral models.

What do we mean by effective therapies

We pointed out in previous sections that results are optimal when interventions are design on individual specific needs and are implemented as early as posible. Also, we showed that every intervention is a complex proces that begun with assessment and it is followed by intervention planning, designing the curriculum and ongoing monitoring. This is how we work with every child with special needs, not only with children on ASD.

The term effective refers to a high level of evidence-based research reported for a particular ty pe intervention. Still, since the specific characteristics of ASD are very heterogenous, there is no ”one size fits all” kind of intervention for people on the spectrum. For that reson, a analysis of effective interventions should take into consideration the individual traits of the subjects who benefited from the intervention and the behaviors targeted by the intervention.

Evidence-based practice has become the common reference point for specialists in different fields, including psychology, medicine, education, and other healthcare fields. Evidence-based practice represents an association of the most valid scientific evidence, professional expertise, and understanding of client characteristics.

Current research evidence offers important knowledge about efficient ASD interventions, but more research is needed. For instance, little research is reported on interventions for adults in the spectrum. Even though scientific research is the most important to evidence-based practice, specialist practical expertise and the individual characteristics of the case should be taken into consideration in making the therapeutic decision. The intervention decisions should be also based on the support network of the child with ASD. This network includes the family, the professional team, and available community resources. Where an intervention works for some people, this does not mean that it will work for everyone on the autism spectrum, because each person on the spectrum is unique. Also, the fact that an intervention works in a research setting does not mean that it will work in the real world.

Evidence-based practice provides a foundation for selecting the most suitable interventions based on the best available research, individual characteristics, and professional expertise.

The considerable and growing research on ASD makes it difficult for families and specialists to be up-to-the-minute with the current findings. But still they should make efforts to be informed and up to date with the ASD research field. A great help that facilitates the work of the specialists is the meta-analytic studies published on ASD research. There all the research in a specific topic or type of intervention is synthetized and analized in an evidence-based manner.

EVIDENCE-BASED PRACTICE

FIGURE 1.2

Source: Choosing Autism Interventions: A Research-Based Guide

Generally, a therapy is effective if it addresses the cause of the symptoms, but if the causality is not determined (as in the case of ASD), that is not possible. Therefore, specific therapies for ASD must address symptoms and specific and particular behavioral manifestations, not causes. Nowadays there are many proposed therapies for ASD being in different stages of empirical validation. Specialists and parents are often lost in a lot of options not knowing which to try first. In latest years efforts are being made to clarify the many types of approaches and therapies in ASD, because there are so many to be tried and to be put into practice (Reis, Pereira, & Almeida, 2018).

Case study

Nicoleta, Rebecca's mother, 7 years old
As parents we were appalled by the avalanche of information found on the internet versus the lack of solid recommendations from the specialists we consulted. They didn't even know how to guide us. We were asking "what's best" for our child, and they said either it's not done in our country, or they don't know the effectiveness of x or y therapy. We have wasted a lot of time combining various therapies, so that we can find out exactly which ones we put our highest hopes on, will not bring us the desired results or that the most expensive ones were not "what was written on the label" - but a mix of different "exercises" that our therapists had applied to other children who had been successful.

The increase rate of diagnosis has been determined a disconcerned advance in the number and types of therapies and procedures. The Research Autism website lists more than 1,000 different interventions, including applied behaviour analysis (ABA), chelation, dramatherapy, the gluten-free diet, Lego therapy, sensory integration training, swimming with dolphins, and vitamin supplements. Alphabetic list of interventions, treatments and therapies can be found on http://www.researchautism.net/autism-interventions/alphabetic-list-interventions.

Many interventions have little or no research evidence to show that they are effective. This doesn’t mean that they do not work; it may simply mean that more research is required to find out if they do. On the same list, unfortunately, we can find some very expensive and implemented on a long period of time interventions.

Reviewing the current best practices in ASD early intervention in the EU Member States, the reasearchers involved in ASDEU project indentified 2695 studies. They selected a total of 67 studies and the conclusion was that focused and comprehensive intervention practices that have shown greater efficacy in-group design studies are the ones aimed at the development of social and communicative skills with a behavioural methodology applying naturalistic techniques based on knowledge of early childhood development. The single case studies provide evidence of efficacy in procedures with a behavioural component such as ABA or PRT. All the studies have shown that active parental participation in the intervention increases treatment effectiveness. Increasing the hours of intervention or the number of sessions can produce benefits in the effects of the intervention.

Specific therapies for ASD

Magyar (2011) classifies specific therapies, based on the underlying theoretical models, for ASD in four major types:

Behavioral (such as Applied Behavior Analysis-ABA, Verbal Behavioral Therapy-VBT, Cognitive Behavioral Therapy-CBT or Discrete Trial Training-DTT)

Developmental (DIR method (Floortime), milieu teaching, (Relationship Development Intervention)

Therapeutic (Occupational therapy, Sensory Integration Therapy, Speech-Language Therapy, Physical Therapy)

Combined approaches (SCERT model, Spell approach).

Also, CDC proceed to classify the interventions for ASD as follows (https://www.cdc.gov/ncbddd/autism/treatment.html):

Behavior and Communication Approaches: Applied Behavioral Analysis (ABA), Discrete Trial Training (DTT), Early Intensive Behavioral Intervention (EIBI), Pivotal Response Training (PRT) Verbal Behavior Intervention (VBI), Relationship-Based Approach (DIR; also called “Floortime”), Sensory Integration Therapy, Speech Therapy, The Picture Exchange Communication System (PECS).

Dietary Approaches: that involve changes in diet, removing certain types of foods from a child’s diet and using vitamin or mineral supplements.

Medication might help manage high energy levels, inability to focus, depression, or seizures.

Complementary and Alternative Medicine, special diets, chelation (a treatment to remove heavy metals like lead from the body), biologicals (e.g., secretin), or body-based systems (like deep pressure).

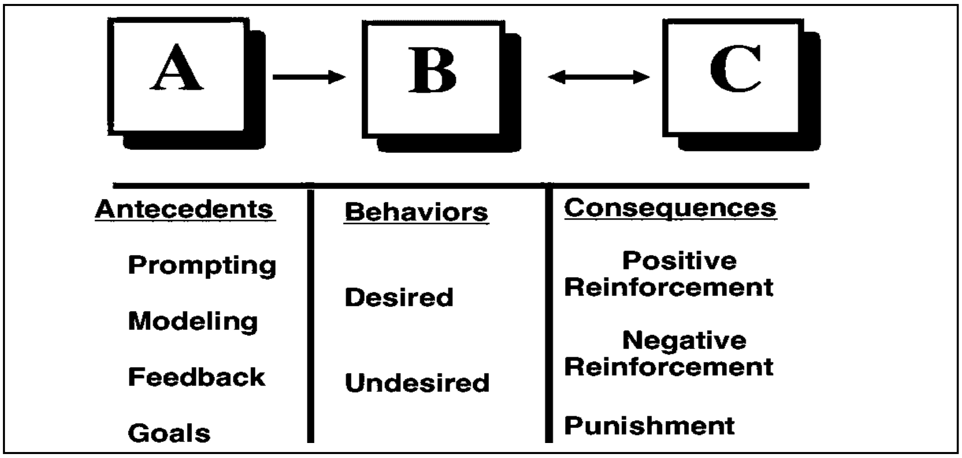
It is not our intention to suggest what interventions should or should not be used. Instead, we try to emphasize the process for intervention selection in which professional expertise and individual characteristics set the context for reviewing research findings.

Applied Behavioural Intervention (ABA). Over the past two decades, a number of researchers have reported the effectiveness of early intervention as an approach for autistic children. ABA - Applied Behavioral Analysis - considered one of the most effective therapeutic programs in autism, is based on the idea that the nervous system of people with autism spectrum disorders lacks the connections that would allow learning and socializing. ABA relies on the accumulation of cognitive, social and communication skills in a very structured manner, in accordance with the behavioral principles of reward and punishment: appropriate behaviors are rewarded, inappropriate ones are ignored and therefore not encouraged (Jackson, 2005) .

The applied behavioral analysis is based on the principle of Pavlov, the principle of conditioning operations that requires the individual to learn behaviors that are capable of controlling the environment, helping the child with autism to "enter" into society and to consider perceiving appropriate behaviors, to adapt to the environment they live in (Benga, O., 2010).

The development of ABA's behavioral therapy was flanked by the Young Autism Project (YAP), a very structured children's program with ASD, created by O. Ivar Lovaas in 1970. This program was designed to provide one-on-one behavioral, individualized at-home childcare. ABA is based on the principles of behaviorism. Behaviorism asserts that an individual's actions are neither haphazard nor unpredictable: all behaviors have a purpose. According to this theory, behaviors that are reinforced are more likely to be repeated. The primary focus of therapy for the child with autism spectrum disorders is to learn specific abilities that will increase the likelihood of becoming an independent and possibly successful man in the future.

“Applied behavior analysis is a field of practice and study that focuses on using principles of learning, particularly operant conditioning, to understand and improve people’s socially significant behavior” (Reitman, 2005, apud. Sarafino, 2012, p.11). ABA tries to change inadequate behaviors by developing social accepted responses to environment. Operant conditioning is a concept introduced by B.F.Skinner and can be defined as a learning method in which learning occurs by association between a particular behavior and a consequence. A behavior which is reinforced tends to be repeated and if not to die out.



The ABC model of operant conditioning https://www.legacee.com/motivation-at-work/

A – represent the antecedent, the reason to perform the behavior and can be consistent of prompting, modeling, feedback or goals.

B – behavior that can be desired or undesired, adaptive or maladaptive.

C – Consequences – can consists of positive or negative reinforcements, punishment, extinction or escape/avoidance.

Sarafino (2012) enumerates the following characteristics of ABA:

1. Focus on behavior. All the assessment and intervention objectives targets behavior and not traits, characteristics or attitudes. The assessment is made to determine current levels of behaviors and their functionality, the objectives aim to modify these behaviors and the interventions are made on target behaviors.
2. Importance on learning and environment. All behaviors can be altered by new experiences, which can include modifying the life environment, by changing the antecedents and consequences of the behavior.
3. Scientific orientation. ABA puts a great importance on research and scientific data collection. All concepts, methods and techniques are based on empiric research, making ABA an evidence-based method.

4. Pragmatic and active methods. The techniques used are pragmatic because they are, possible to put into practice easily, not idealistic, and active because the participants are actively involved

The first step in initiating ABA therapy by an ABA-licensed therapist is to perform functional functional analysis, identifying positive or negative patterns that promote or interfere with family functioning. Based on the principles of learning and behavior theory, the ABA therapist formulates theories about what determines different behaviors and how those behaviors are consolidated. Specific intervention techniques are used for the child with autism to produce and maintain certain desired social behaviors, so that intentions of intentional behaviors are redirected (Hollister-Sandberg, E., Spritz, L., B. 2013).

ABA is based on the idea of understanding the teaching principles of children with autism spectrum disorders by the therapist and is supported by more scientific research than any other treatment in USA. More than thirty years of research has shown that ABA methods are effective in reducing the inadequate behaviors of children with autism and encourage positive abilities. The idea behind behavioral therapy is that rewarded behavior will be repeated. Repetition is essential for the brain to learn about behaviors and abilities, so the therapist will give the child more opportunities during a session to demonstrate positive behaviors. Also, behavioral therapy teaches the child the skills of play, communication, socialization, and building relationships through other techniques. For example, a child can learn a new skill by mimicking and shaping other children in the behavioral session, or a child can learn the plan of daily activities. Therapists encourage parents to be involved in the treatment of their child, including what ABA teaches in class, to use the knowledge in everyday life.

The basic principle is to design an individual intervention based on observations of child`s behavior, determine the needs and select the most appropriate techniques of addressing them.

The Behavioural Therapy Development Curriculum is designed to teach the people with ASD a variety of abilities, including community participation, imitation, visual spatial ability, responsive language, expressive and pragmatic language and adaptability to the social environment and academic (play skills). Basic strategies in ABA are known to change the course of those with

ASD, with improvements in knowledge, language, socialization and functional adaptation, and is used to eliminate the maladaptive behaviours associated with ASD, ADHD, learning difficulties, developmental delays and disorders of behaviour. It can also be used to increase adaptive behaviour by arming and prompting (Turnbull, Knapp, 2014).

For the therapy sessions to be carried out in optimal conditions, it is necessary to work in an isolated room without distractors, as the child evolves, the work environment is as natural as possible, therefore the therapy must be carried out all over the house and also beyond. In ABA, teaching is done through distinct exercises that refer to a specific teaching method used to increase chances of success. This method refers to:

- "dividing a task into smaller parts;
- handing over such a sub-part until the child has mastered it very well;
- repeated exercises in a concentrated time frame;
- Prompt and reduce prompt;
- use of rewarding procedures "; (Leaf, McEachin, 2010, p. 19)

The author of the book "Aspects about therapies and learning activities in children with autism" speaks of this program as a therapy technique that over time has had many names such as the Lovaas, Discrete Trial (DT), intensive intervention of behaviour, evolving and transforming the analysis of applied behaviour. This method involves an intensive 8-hour program, approximately 20-40 hours per week, in which the child works individually with the therapist one to one. They usually start with simple instructions, which then lead to generalization, being used in contexts and with different people. She also points out that the application of ABA must consider certain principles underlying it:

- the behavioural must be done in the one-to-one ratio;
- the time to be allocated is 20-40 hours per week;
- therapists must be trained and specialized;
- to have a regular meeting between therapists in order to be able to analyse the child's behaviour;
- therapy sessions are fun so that the child is motivated to learn;

The learning principles based on any good ABA program are: reinforcement, setting up motivating operations, stimulus control.

A distinct exercise consists of several components: the antecedent, prompt, the child's response, feedback or other consequence and the interval between exercises.

Terms used in ABA

At the base of ABA for children with ASD is DTT (Discrete Trial Teaching) - learning unit consisting of three components: SD (Discriminative Stimulus, i.e. requirement), R (Child's Response), C (Consequence to Behaviour).

Sometimes between SD and Response is the Prompt (the help given to the child), then the Consequence.

The Discriminative Stimulus (SD) is a specific environmental event or condition in response to which a child is expected to exhibit a behaviour.

Discrete Trial Teaching is a three-part learning unit, which is a sequence of behaviour specifically used to maximize learning.

The prompting is the help given by the therapist to facilitate the performance of the child's response. It must be given at the same time or as soon as the instruction is given. Using the prompt makes learning easier and reduces frustration.

Interval between two distinct exercises - this break for several seconds must go between two distinct exercises and gives the child time to analyse the information and teaches him to wait.

Modelling - is a technique used to learn new behaviours that are approaching the target. The thrust of this technique is that it does not let the child frustrate, rewarding it immediately.

Chaining - involves creating behaviour by combining several simple behaviours that lead to the formation of a single complexity of behaviour (Siri, Lyons, & Arrange, 2012).

Extinction is" the process of withholding reinforcement from a previously reinforced behaviour to decrease the probability of the behaviour occurring in the future, it is essential to know the function of the behaviour for extinction to be an effective strategy." (https://www.abaconnect.com/autism-resources/glossary-aba-terms/)

Under the umbrella of ABA, we will find:

Discrete Trial Training (DTT) is a sequence of trials to implement every step of a desired behavior. DTT is used as a technique in early behavioral interventions, including the Lovaas method. DTT is used in the early stages because it aims to teach new behaviors and discriminations in a simple and individualized manner. DTT is a highly structured technique in which a specialist (called trainer) apply a series of learning interactions (called trials). Each "trial" is highly structured with a clear sequence of actions, a beginning and an end, hence the name "discrete". The stages in this technique are (Anderson et al., 1996): 1. Trainers` presentation of the request or question, 2. The child`s response, 3. The consequence, 4. A short pause between the consequence and the next presentation. In the beginning the trainer asks a question or gives a clear instruction and if the child does not respond on its own he offers a promt, showing him how to respond correctly. When the child make the expected behavior is promptly rewarded for reinforcement. If the child don`t do it on its own, even after prompting, the instruction is repeated or modified in a different way. For this technique to be effective the child must spend many hours per week in therapy and the instruction is delivered by a specialist.

Many studies reported a high efficacy of DTT used in EIBIs, as an important techniques that contributes to better results in interventions. A meta-analysis (Peters-Sheffer et. al., 2010) reported a high efficacy of EIBIs and another study (Downs et al., 2008) indicated that DTT is an effective technique to be used in preschool programs.

Discrimination training is an important feature of DTT, mainly focusing on haw stimuli and promts are presented and how after a while the promts are removed (Eikeseth, Smith, & Klintwall, 2014). The procedure to discriminate between stimuli such as colors, shapes, lengths, surfaces, objects makes the object of this technique. For example, to discriminate between long and short, white and black, up and down.

Incidental teaching is a technique where the specialist takes advantage of naturally occurred situations ("incidents") and transforms them in learning opportunities. The motivation of this approach is that all children learn better if the instruction is centered to their interests. The teacher design the learning environment to follow a set of pre-planned intervention objectives that take into consideration the child`s interests. When the child shows interest in a proposed activity the specialist encourage him, ask questions and further implicate the child in that specific activity. The learning occurs in the moment in which the child chooses to be implicated in the activity and initiates it. The willingness to participate in activities is very problematic in children with ASD and that`s why the specialist must design a learning environment full of options which can capture child`s attention. First, the specialist must observe the child in his natural environment to understand what are his interests and preferred objects, also the typical and the inappropriate behaviors. Afterwards the specialist prepare the environment placing as many as possible from the child`s preferred items in it. That the teacher waits for the child to take interest in one of the items and offers him a promt, by placing a hand on the child`s hand and wait for him to initiate interaction. If isn`t occur he offers the promt 2, asking “What do you want?”. If he responses the specialist continue the conversation “What color is it?” or “What shape is it?”. If the child answers then can have the object. Positive reinforcement is used to reward correct answers and behaviors, incorrect answers are ignored.

Early Intensive Behavioral Intervention (EIBI) is a variety of ABA applieble in early stages. From the intervention`s debut untill the age of five. EIBIs are a collection of behavioral techniques design to develop early skills to children under 5 years of age. Reichow (2011) conducted a meta-analysis of studies involving EIBIs` and concluded that early intervention methods are very effective for children with ASD.

Landa (2018) researched the efficacy of early interventions for infants suspected or with ASD and put together 13 recommendations or principles for early intervention:

1. Early initiation of therapy, when the first red flags occur.
2. The therapy should target all developmental areas.
3. Permanently change activities and aims when the progress in the language area occurs.
4. Provide intensive training for parents for 9/12 month at least one time a month.
5. Provide video feed/back for parents to facilitate understanding of the child behavior and the efficacy of their own interventions.
6. Provide direct coaching and mentoring.
7. Provide parts of the intervention in structured environment with minimal distractions.

8. Instruct parents in a few of engagement techniques that they can use in the consolidation activities performed at home.
9. Provide parent training in various settings to develop generalization
10. Offer parents counseling sessions to foster the continuing implementation of intervention strategies after training support ends.
11. When speech does not occur take into consideration visual and pictorial systems of communication (for example PECS).
12. Combine professional-delivered intervention with parent-mediated intervention.
13. Standardize the interventions

The best known EIBI is University of California at Los Angeles Young Autism Project model (also known as the **Lovaas method)**.

The Lovaas method is a form of early intense behavioral intervention which is based on the ABA principles. The main idea is that children with autism have difficulties in the communication domain and cannot express their needs, emotions or intensions therefore they get frustrated and have tantrums. The intervention aims to develop a teaching environment that maximize the success and minimize the failure. Desired behavior is reinforced by praise and positive feed-back and in the same time the negative behaviors are not reinforced. The Lovaas method uses a collection of behavioral techniques such as incidental teaching, discrete trial or discrimination training. The learning regime is very intense the child spends up to 40 hours a week in training, delivered by parents supervised by a specialist. Reed, Osborne and Corness (2007) compared the effectiveness of home-based early interventions for children with ASD and reported that Lovaas and application of behavioral analysis to schools approach interventions produced the larger gains.

Verbal Behavior Intervention (VBI) is a type of ABA that focuses on teaching verbal skills. VBA is derived from ABA and is more a technique than a therapy, used in behavioral interventions. The main focus is on language and communication, aiming to teach children with ASD how to use verbal communication and understand others. VBA is a structured algorithm, prescribing how to develop specific components of language, starting with the expressive part.

The parts of expressive language are named verbal operants and include mand (a request or demand), tact (a comment used to share something or draw attention), intraverbal (a response to others, an answer) and echoic (a repeated word).

Often VBA is used in early stages of intervention, when the first stages of communication are being developed. This technique is based in a solid conceptual model (Skinners` theory of verbal behavior) (Carr, 2005) and later there is an increasing research on the efficacy of VBA, demonstrating that Skinner theory has made a great impact on language development of children with ASD (Johnson, Kohler, Ross, 2016).

Pivotal Response Training (PRT) is an intervention based on empirical data from research studies, an evidence-based practice and a real intervention to promote adequate social behavior and adaptable communication for preschool and primary school children, adolescents, youth, even adults.

The PRT originally grounded on the Discrete Trial approach, a psychological approach that uses ABA to focus on the behavioral relationship with the environment using specific procedures. Pivotal Response Training was initially named the "Natural Language Paradigm" (Koegel, O'Dell & Koegel, 1987) because used communication motivational procedures to improve language use in children with ASD. The following research has shown that motivational procedures could be effectively applied in other functional areas, so this type of intervention has been renamed "pivotal response treatment, pivotal response teaching, pivotal response, and pivotal response therapy". (Bradshaw, Koegel, & Koegel, 2017). PRT is an malleable, easy to adapt method that could be used with children of diverse developmental stages (Stahmer, 1999).

Scope: „PRT teach learners with autism spectrum disorders (ASD) functional social-communicative and adaptive behaviors within a naturalistic teaching format." (Vismara & Bogin, 2009, p.32*)*

Principle: PRT applies the scientific principles of ABA through developing „four pivotal learning skills: motivation, responding to multiple cues, self-management, and self-initiations." (Koegel, Koegel & Brookman, 2003, p.292)

Age of intervention: children and youth with age from 2 to 16 years.

Intervention goals in PRT:

To teach children on the spectrum pivotal behaviors by master a set of specific procedures that will lead to the development of new behaviors. By acquiring these behaviors, children can learn new functional abilities in diverse areas of development: social, academic, communication and language, self - management.

To provide social and educational skills to students with ASD in order to form functional and independent behaviors. PRT involves the training of parents for early intervention. The PRT has been successfully implemented in diverse settings: home, play, school, community, enabling the generalization of acquired skills.

ESDM- early start denver model is an early treatment approach for early stages of ASD, which involves the use of behavioral techniques, in individual (ESDM) or group activities (G – ESDM). This approach is supported empirically by studies and research that indicate that ESDM may be effective in improving language, cognitive, social skills and abilities in children with ASD (Vivanti et al., 2017).

ESDM Principles

ESDM has appeared more than 30 years ago, Rogers & Pennington (1991) presents the key concepts of ESDM.

The most important (Rogers & Pennington, 1991) is that in ASD an obstacle can appear in the typical development of synchronization of cognitive and affective procesess during early interactions such as imitation, mutual vocalization and sharing of affections. Lack of engagement in these early social interactions, keep the child from understanding the world and develop emphaty and cognitive undestanding of others.

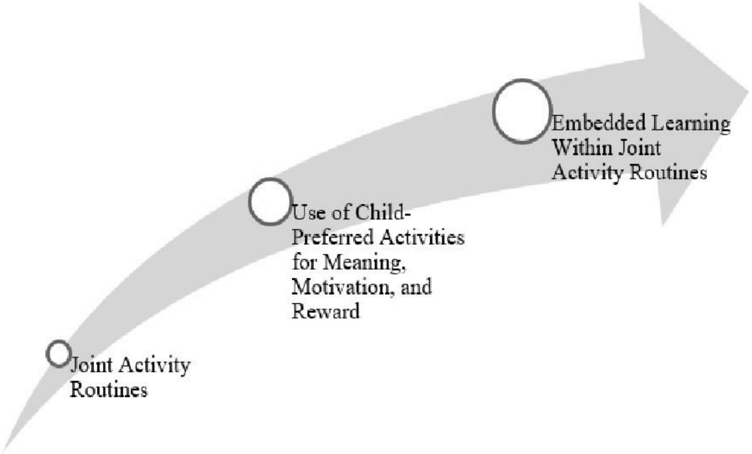
ESDM is based on the naturalistic application of the ABA principles, to develop new adaptative behaviours. ESDM involves a checklist that evaluates current development levels through a curriculum for development of social, cognitive, motric and emotional fields.

Consequently, „ESDM aims to develop spontaneous and social use of language, imitation, gestures, visual contact and others behaviors that are essential for social-cognitive development.” (Rogers & Dawson, 2010, p.21)

Componentes of ESDM

In a joint activity, two or more partners join to conduct business (books, social games, toys, meals, etc.) to promote spontaneous learning by rewarding achievements and providing meaningful actions.

By using these teaching strategies, the objectives of the intervention are included in the work routines. The goal is to increase its repertoire of flexible, adaptive, generalized and age-appropriate skills in everyday life activities, facilitating learning in complex contexts.



TEACCH- treatment and education of autistic and other communication handicapped children. This program was developed by Enrich Schopler and colleagues at the University of North Carolina in the early 1970. Treatment issues include both language and behavior focused on intervention programs that are individually prepared. Being an educational method, it provides lifelong treatment for the person with autism and must be done in as many different, well-structured environments as possible with different people to assess the potential of each child so that they can meet their needs and enable them help to enjoy success at home, in school or community.

The principles of TEACCH is the classification of learning in four areas:

- structuring the environment - the place where the actions are carried out. Each task is carried out in a defined place;

- visual schemes of the places where the actions are performed - helping the child to focus on important aspects of the task;

- personalized plans and time organization - the moment when characteristic activities take place;

- organization of activities - informs the child what should be done during task without help.

How **TEACCH** works:

It is very important and advisable that educational programs work several times a week, in a special class, where to use schedules, work schedules and work systems, and communication of the child with visual materials (icons, images, numbers) to promote independence and give meaning to the person with autistic disorder. Work systems help the child know what to do, how long has to do and when the job is over.

The Son-Rise Program was created in 1980 by Barry Neil Kaufman and Samahria Lyte Kaufman. The Son-Rise Program is a complex treatment system designed to help children with ASDto improve all areas of development, learning and communication. It provides very effective educational techniques for creating a child-centered home-based program through which the adult enters his world.

The Son-Rise program is home-based, one-on-one and is an educational program designed to help children with autism in all areas of learning (Ball, J. 2008).

This technique for children with ASDaddresses a method of training therapy that refers to getting closer to the child rather than acting against it. In order to help children, it is necessary to take into account the symptomatic criteria, namely: to have a language or non-verbal language, to exhibit stereotypical and repetitive behaviors, to have an inability to use the speech in special contexts and to find themselves unable to participate in everyday activities. At the heart of this program are certain principles that are considered the foundation stone for therapeutic deepening by:

- "tracking the child's repetitive and ritualistic behaviors so as to discover the key that untie their mystery by facilitating visual contact, social development and inclusion in the game;

- child motivation training will develop the learning process and will lay the foundations for education and skills;

- creating energetic, enchanting activities so that the child becomes more motivated, more active and enhances his love for learning and interaction;

- engaging optimistic and uncritical attitudes will maximize the child's joy, attention and desire." (Raţă, 2011, p. 107)

The Son-Rise program is used by both children and adults with special educational needs, but the most common is for children with ASD. This program is implemented by the parents of the house, which turns the child's room into a playground, specially designed to work one by one. It is a child-led approach, the parent imitates the child's own activity, which later on brings visual contact and interaction. Throughout the interaction, the adult tries to maintain an attitude of acceptance and non-judgment. In some families, an intensive program is used, with the parent having to recruit volunteers to achieve the objectives of this program.

PECS-picture exchange communication systems. This method of intervention provides a structured approach to developing early communication skills using images in a different way than other image based systems. It is originally developed in the US but also in Europe for preschool children with autism and then is successfully extended to a wider range of children with communication difficulties and also to older children and can be applied in different environments because does not require expensive materials or specialized people. Being introduced in the UK in 1996, this program has been established worldwide as a new significant initiative in the field of autism, based on the principles of the applied behavioral analysis model.

The PECS helps children learn to control their behavior, know what activities are organized according to a program, and make requests for the things they want by sharing images in their environment. If I want a drink from an adult, they will give the image that signifies the drink. There is a non-verbal communication system via symbols (icons), the child learns (by behavioral methods) to give the person around him a cardboard symbol representing his desire. In the process, interaction is amplified, the person learning to distinguish images, formulate statements, answer questions, and finally make instant appreciations. Increases the chances of expressive language, with an intentional communication capacity. The program is divided into six phases. It starts with a single image to communicate their needs, students being taught to discriminate between a variety of images, then to construct more complex phrases. These images and sentences are stored in a portable communication card attached to the velcro so that they can easily be removed when the child wishes to communicate (Baker, 1991; Benga, 2010).

Phase 1 - To learn an object, use the child's favorite toy as a reward, motivating him to communicate. The adult sits behind the child, helping him physically promptly to take the object from his hand. After several physical prompts, it diminishes, gradually giving up, and the child is able to get into the subject alone without being helped.

Phase 2 - Using the communication book, where a favorite image is attached, the child must learn to detach the image. He is taught to go to the picture panel where he will take the picture and take it to one of the adults, gradually increasing the distance between the board and the child.

Phase 3 - This phase creates a situation in which the child shows two images, one preferred and the other indifferent. If the child asks for his favorite image, then he is rewarded and taught to discriminate between his favorite customs and a multitude of images, giving him an image to ask for the thing he wants.

Phase 4 - Once in the other three phases, it brings the child a phrase structure, learns to communicate using a sentence, attaching several images on the communication card that signify a sentence.

Phase 5 - The child asks spontaneously and answers questions like "what do you want?" By giving her the "I want" image with my favorite image.

Phase 6 - In this phase, the child learns to answer other questions, "what do you want?", "What do you see" ?, using recompense after each spontaneous response (Cucuruz, 2004).

Authorship statement

The authors of this paper take public responsibility for the content and have had equal contribution in concept development, design, analysis, writing, or revision of the manuscript.

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Module 3 - Educational interventions in schools

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Introduction

This module of our course is dedicated to the relationship between autism and the school environment and to the topic of autism measures in schools. Since the family's choice to include the autistic student in a normal school class is not obvious in all Western countries, a significant premise is necessary. In Italy, the process to integrate and include students with learning disabilities in schools has a long history. For more than forty years, there have been difficulties and contradictions, but the certainty is that the introduction, integration, and inclusion of the learning-disabled student in normal classes in schools for everyone remain a fundamental goal.

The inclusion of the LD student in a school environment poses important problems and some critical issues to be addressed. ASD lies primarily in social interaction, causing the autistic student to encounter significant obstacles when introduced into a normal class of students. The social interaction deficit, the low mental functioning, typical of most students with autism, and their problem and maladaptive behaviors work against their integration in the school environment.

An underlying thesis supported here is that in order to be adequately introduced into a school, the autistic student needs an environment that is autism-friendly (McAllister & Sloan, 2017). This means one that can adapt to the peculiar characteristics of the student with autism without renouncing its objectives of educating and satisfying the needs of all its students, even the non-disabled.

Despite some difficulties and the burden of taking charge, we support that the inclusion of the autistic student in a normal class, in contact with all teachers and classmates, represents an experience of inestimable value for the purpose of its growth and maturation, the development of its potential as well as in its process of social inclusion.

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At school, the student with autism, even when appearing to have very serious learning difficulties, has the opportunity to come in contact with and acquire enormous knowledge not only on the cognitive level and curriculum skills, but also at the level of social interactions and human relationships. School is always the training ground for life for each student, including the student with ASD (Dillon *et Al*., 2014).

The approach advocated here referencing the inclusion of an autistic student in regular classes is the ICF model and a bio-psychosocial view of the disability

The serious and important deficits of a child and of an autistic teen are inclined towards an individual vision of disability. The autistic student has particular deficits, which cannot in any way be overlooked, for which the answers can only come from a special education and a range of specific, complex, and specialized measures.

However, essential contributions to approaching the problems of the student with ASD are directed against a social vision of his disability. As already mentioned, if the question of social interaction is at the forefront of autism, it is also through a systemic intervention and a strong and convincing action on the environment that we can attack and combat the problems at the root of autism.

For these reasons, we aim for a mixed, global, and complex model of approach to the problems of the student with autism. It is a bio-psychosocial approach that fits perfectly with the central issue of social inclusion.

The social inclusion of the student with autism also presupposes an overcoming of the old concept of integration. In the old perspective it was above all the student who had to adapt to the environment of the school and not vice versa. The new perspective of social inclusion implies a new attention to differences, a differentiated interest of the school for each student, for everyone and for each one.

In this sense, as Lucio Cottini (2017) has written, the student with ASD is not a guest of the class, wandering the corridors of the school without being in the classroom with his classmates, and for whom the school can guarantee some intervention specialist. The student with ASD becomes a student like all the others and even with them, and who has the right to stay in class to learn like all his other companions, albeit with his peculiarities and time to grow.

Consequently, all of this also requires an important adaptation of the curriculum tool.

As we will see, the inclusion of an autistic student in a standard school calls into question a curricular revision, the adoption of a particularly flexible perspective, without watering down its basic presuppositions and without indulging in negative expressions of educational particularism.

As we will state in these pages, for a student with ASD, the classroom is not the same as the therapy room. However, the rehabilitation actions that can be implemented in a school environment are increasingly persuasive. Social interactions at various levels, the acquisition of curricular skills, plus specialized approaches that can be implemented constitute a truly interesting and credible plan of proposals that can generally offer an overall contribution to the growth and development of children and teens with LD.

Module objectives

Learning outcome 1: Knowledge of the basic educative intervention models for the ASD.

Learning outcome 2: Understanding of the opportunities derived from the intervention's models.

Learning outcome 3: Development of skills for to project educative interventions for the student with ASD.

Learning outcome 4: Knowledge of the basic structure of the inclusive approach.

Learning outcome 5: Understanding of the opportunities derived from the inclusion.

Learning outcome 6: Development of skills for to project inclusive educative interventions for students with ASD.

Learning outcome 7: Knowledge of the basic structure of the approach.

Learning outcome 8: Understanding of the opportunities derived from the approach.

Learning outcome 9: Development of skills for to project interventions of Cooperative Learning.

Learning outcome 10: Knowledge of the basic structure of the problem behaviors.

Learning outcome 11: Knowledge of curriculum adaptation for autistic pupils.

Learning outcome 12: Knowledge of spatio-temporal structure of the classroom.

Topics covered by this module

- Inclusive educational contexts
  - The Universal Design for Learning perspective
  - The inclusive contextual strategies
- The cooperative learning
  - Cooperative learning for students with ASD
- Problems of autistic pupils in schools
  - Problem behaviors in the school
  - Adapting the curriculum
- Spatio-temporal organization at school
- Educational intervention models for the ASD
  - ABA
  - PRT
  - TEACCH
  - The Denver Model
- The Individualized Educational Plan (IEP)

Inclusive educational contexts

Introduction

The UDL approach is characterized by the development of learning environments, which can provide adequate answers to all students, including those with disabilities. The approach is derived from the movement of *Universal Design*, developed in recent times in the United States in the fields of design and architecture. The basic goal of the approach is the development of inclusive contexts characterized by *maximum levels of accessibility*.

The Universal Design for Learning Perspective

The inclusive process should present point of contact with the inclusive architectural design of contexts accessible *to all* users, including those with disabilities (Hall, Meyer & Rose, 2012). The inclusive architectural design is directly influenced by the *universal accessibility* for to encourage the participation in community activities of persons with disabilities. The right to participation in community life is a common factor reported from the ICF perspective (WHO, 2001) and from the *Index for Inclusion* (Booth & Ainscow, 2002), which highlight the need to provide opportunities for the involvement of all subjects, regardless of the presence of disability.

The principles that have influenced the approach of Universal Design for Learning (UDL) have been progressively extended from architectural design to design of inclusive learning environments, for ensure that all students may have *the same opportunities for the learning and the participation in the community life*. The prospect of Universal Design for Learning has developed in this context, and for its understanding may be adequate the analysis of his guidelines, shown in the following table.

Fairness: The product should be available to anyone.
Flexibility: The product must provide for a flexible use to suit different abilities.
Simplicity: The product provides a simple and intuitive use for all users
Perceptibility: The product has accessibility immediately perceptible in connection with any users with disabilities.
Error tolerance: The use of this product must to minimize the risk for user.

Tab. 1. Guidelines of UDL perspective. Adapted from: Hall, Meyer & Rose (2012).

The extension of Universal Design principles to teaching and learning processes has generated the UDL perspective, according which the principles of universal accessibility must characterize each component of the process, from design to implementation of educational intervention in the contexts teaching (Rose, Meyer & Hitchcock, 2005).

Every educational intervention should therefore be designed for the wider range of users as possible, and its content must be adapted to the learning potential of all students, according to guidelines of the

Education for All approach. Any barriers to accessibility of learning content should be eliminated from the architectural context and from the educational intervention (Rose, Meyer & Hitchcock, 2005; Hall, Meyer & Rose, 2012). The strong correspondences between the universal accessibility principles of architectural contexts and those of educational settings can be highlighted by the analysis of the UDL perspective.

In the perspective of Universal Design for Learning, the principles that guarantee universal accessibility are represented by three basic concepts, related to use of multiple modes of presentation, expression and involvement (Hall, Meyer & Rose, 2012). The *Multiple Modes of Presentation* allows the offering of multiple options of learning content for all the users. The information is presented through multiple modes of perception, relating to visual channels, auditory or tactile, and is modifiable by the user at any time. The *Multiple Modes of Expression* allows to each student to express his knowledge according his cognitive abilities, using multiple channels of expression visual, auditory or tactile (SIGN, 2007; ISS, 2011; Guldberg et al., 2011). The multiple expressive modes allow sharing and comparing of the knowledge with those of the peers (Rose, Meyer & Hitchcock, 2005; Parson, Guldberg, MacLeod & Jones, 2009). The use of *Multiple Modes of Engagement*, finally, allows the presentation of options through visual channels, auditory and tactile, oriented to maintaining interest and concentration, and to effort the development of collaborative and supportive relationships between the peers.

The inclusive contextual strategies

The effectiveness of collaborative engagement between the peers is evidenced by the presentation of more effective strategies for the inclusive education (Mitchell, 2008).

Collaborative teaching
Positive school culture
Promoting positive behavior
Classroom climate

Tab. 2. Inclusive Contextual Strategies. Adapted from: Mitchell (2008).

The *Collaborative Teaching* represents one of the most effective contextual strategies for the design of inclusive learning environments (Mitchell, 2008). The inclusion of the student with ASD is favored by *multicontextual intervention* (SIGN, 2007; NAC, 2009), which highlight the cooperation between different specialists. The involvement of peers, similarly, is a contextual strategy for the development of an inclusive class (Mitchell, 2008; Molteni & Guldberg, 2013; Vivanti et al., 2014). The opportunity of involvement in the learning experiences for all students promotes increase the self-esteem in child with communicative disabilities (Reichow, Steiner & Volkmar, 2013; Matson, 2014).

The *Positive School Culture* is a strategy with high levels of effectiveness for the student with ASD. The development of school culture provides for the *dissemination of inclusive culture* in all the components of the system (Guldberg et al., 2011). The adaptation of educational settings to make them usable also for child with ASD is an example of inclusive school culture. The adaptation of teaching methods according to communicative needs of the student, the text facilitation through the symbolic codes and the peer's involvement, are examples of physical and social adaptation of the educational context to the communication needs of the student (NAC, 2009).

The *Promoting of Positive Behavior* is characterized by the attempt to manage the maladaptive behaviors of the student (Mitchell, 2008; NAC, 2009; Molteni & Guldberg, 2013). This strategy has influences on the development of a friendly and motivating environment, crucial for the processes of inclusive education (Mitchell, 2008; Parson, Guldberg, MacLeod & Jones, 2009).

Similarly, the *Classroom Climate* it allows the implementation of inclusive processes, because a motivating and positive climate, promotes the learning in all students (Mitchell, 2008). The positive classroom climate can to promote processes of *mutual help* between the student with ASD and his peers. The requests for information that can to be expressed during the experience of cooperative learning, can to be involved reciprocal requests for help between the student with ASD and his peers.

Case study

Robert is 12 years old and presents ASD with high cognitive functioning (IQ = 68). It has good linguistic skills, but it presents a clear social deficit, with specific interests in relation to airplanes and ships. He often introduces his interests in conversation with his peers. Robert presents difficulties in reading, writing and textual understanding.

The teacher offers the class a presentation of the topics through multiple expressive modalities. The topics of greater complexity are presented with verbal language and are simplified through symbols and images, adapted to the students' understanding.

At the end of the presentation the teacher presents questions and exercises on the topic. Questions and exercises are also shown in images and provide for the possibility of using symbols for answers. The lessons are recorded and are accompanied by a pdf with the symbolized text and the verbal comment. Each student can view the contents of the lesson on the PC, even in the domestic context. Robert is invited to share with the teacher and with the peers the pdf displayed on his PC. The teacher asks the students questions of understanding and explains their answers through the indication of the symbols.

At the end of the school year, Robert presented improvements in reading and writing skills, with increased cognitive skills (IQ = 72). Similarly, his social skills have also improved: during the interactions with peers the references to the specific areas of interest have decreased.

The cooperative learning

Introduction

The cooperative learning processes are one of the most important aspects of inclusive education; the data is confirmed by the explicit references to the Cooperative Learning by the *Index for Inclusion* (Booth & Ainscow, 2002) and by the perspective of *Universal Design for Learning* (Hall, Meyer & Rose, 2012). In relation to educational intervention provided for the treatment of ASD, the social interaction facilitation promoted by cooperative learning processes can be considered as representative of all educational intervention models oriented on the communicative deficits.

Cooperative learning for students with ASD

In the guidelines for the educational intervention for students with ASD are present explicit references to cooperative learning experiences (SIGN, 2007; NAC, 2009; ISS, 2011). The historical foundations of the educational opportunities promoted by facilitating interaction processes between peers can to be found in the concept of *Laboratory School* (Dewey, 1938), according to which the cooperative socialization among peers represented a key element for social participation and cooperation.

The *theory of socio-cognitive* conflict of Piaget presents explicit references to cooperative learning processes, given that the possibility of comparisons between the knowledge of the peers and the possibility of discussion of different points of view represent relevant factors for the cognitive development. The comparison between different modes of knowledge is favored by participation in collaborative learning processes. The knowledge sharing between the student and his peers can to exerts positive influences on the observation of typically developing behavioral patterns (Dawson, 2008; NAC, 2009; Reichow, Steiner & Volkmar, 2013), crucial for the learning of the student with ASD.

The cooperative learning processes conduct in inclusive classes also it allows to student with ASD to *make requests* using the symbolic codes, replacing the maladaptive behaviors with others more adaptive (Guldberg et al., 2011; Reichow, Steiner & Volkmar, 2013). The sharing of a communicative code with peers in typically developed is a great communicative opportunity for the child on the ASD. The participation to cooperative learning groups conducted in natural contexts allows the development of adaptive behaviors and of motivation to social contact

(Mitchell, 2008; Fixsen, 2013; Vivanti et al., 2014). The inclusion in working groups characterized by the *achievement of common objectives* in contexts with high ecological validity (Steiner et al., 2013) is one of the most effective contextual strategies for the development of an inclusive class (Mitchell, 2008; NAC, 2009). The cooperative learning experiences can indeed allow the understanding of the social rules, with positive influences on the development of more adaptive behaviors (Steiner et al., 2013).

The *tutor system* is an inclusive system based on cooperative mode, widely used in educational intervention oriented to the student with ASD (Batten, 2005; NAC, 2009; Fixsen, 2013). The method involves the coupling of a student to that with ASD. The partner is selected by teacher according to his motivation to support the learning of the partner (Batten, 2005; Guldberg et al., 2011). Through this modality, the tutor becomes able to mediate between the needs of the student with ASD and those of the group class. Similarly, the tutor may support the partner in the consultation of agendas for the activities, and support in the remembering of the known symbols.

The data relating to such experiences must be considered in light of the Italian context, which present a tradition founded on inclusion in the regular classes since 1977(Cottini & Morganti, 2015). The possibility of observation of the behavioral modes of their peers in a regular class is crucial for to learning of the social interaction rules and for the realization of experiences of acceptance in the peer's group. The participation to cooperative learning groups conducted in a regular class natural allows furthermore the development of adaptive behaviors (Cottini & Morganti, 2015; Reichow, Steiner & Volkmar, 2013). Based on these considerations, the possibility of sharing of cooperative learning experiences could play a decisive role in the development of educational programs for the students with ASD.

Case study

Mark is an 8-year-old child with ASD, associated with intellectual disability (IQ = 47). He has a very limited vocabulary. In his behavioral repertoire are present massive motor and verbal stereotypes, which hinder inclusion with the peer group.

The teacher realizes a series of cooperative learning experiences, dividing the students into small groups of three children. Each group must search for images of marine environments on illustrated books or on the PC and use them for the collective construction of a story. The images are applied on cardboard tables and integrated with photos of the students. The topics of the research are then varied by teacher.

The cooperative learning experiences take place for 1 hour a day and continue for three months. At the end of the period, Mark has learned some new words and the appropriate use of the greeting. He can indicate the photo of best friend for to express his desire to play with him. His classmates have instead developed tolerance towards his behaviors and have increased behaviors of acceptance towards Mark.

Problems of autistic pupils inclusion in schools

Introduction

This section deals with some problems of the scholastic inclusion of autistic students. We examine the behavioral problems of autistic students. We also analyze the changes to be made to the educational curriculum. Finally, we give space to the spatio-temporal organization of a class suitable for autism.

Problem behaviors in the school

In a chapter on autism at school, reference to the issue of problem behaviors is inevitable. These behaviors are often resistant to adult intervention and are also a challenge for experienced therapists and rehabilitation specialists. Nonetheless, the school is asked to recognize them and to be able to manage them as much as possible.

Managing problem behavior is delicate in a school environment not only because such behaviors can undermine the safety of other children, but also because the school often lacks the elements suitable to a true containment setting, in which behavior problems can be adequately addressed and resolved.

First of all, a fundamental distinction between problem behavior and stereotypy is appropriate. Stereotypies are typical repetitive behaviors that are difficult to modify and for which we can assume a minimum degree of intentionality. Problem behaviors are deliberate and call the role of aggression into question.

According to Cottini (2011), there are basically three categories of problem behaviors: aggression, self-harm, and destructiveness. These aspects are not always easily distinguishable, but often constitute a typical, peculiar, and different tangle specific to each student with LD.

Among autism scholars, there is a consensus on the fact that the fundamental first step in addressing problem behavior is to try to understand the reasons for it: when it happens and why it happens (Carr *et. Al*., 1994).

From this point of view, it may be typical that low-functioning autistic individuals as well as those with a higher functioning level start to fail when they enter the school environment.

A fundamental concept in approaching the problems of the autistic adolescent and child is that he should never be left alone. If an autistic subject is left alone in an environment unknown to him, it is very likely that he will regress, acting out a typical problem behavior (Marinello, Menazza, 2013). Let's imagine this case.

Case study

Giovanni is a ten-year-old with low-functioning autism. Once at school, he is left alone in a corner before classes start. It is here that his typical stereotypies, like flicking, begin to be acted out. Moreover, he starts throwing all the books from the schoolroom’s bookcase on the floor.

This brief example shows how the existence of interpersonal containment is fundamental for keeping aggressive actions in check. In other words, the autistic student should not be left alone. He must be followed and controlled by a figure like a support teacher, a classroom teacher, or a classmate who pays attention to him, talks with him, and gives him a sense of familiarity and routine. Containment by the physical and interpersonal environment is inevitably an early aspect for managing problem behaviors. The supporting figure, the caregiver – be it the classroom teacher, the support teacher or a student in the role of a buddy – must have the ability to sympathize with the autistic student as well as to follow him and talk to him in a loud, firm voice. This individual must also give the student the feeling of personal contact, in which he does not regress towards his aggressive displays.

Starting from these assumptions, the tendency among clinicians and researchers to attribute problem behaviors mainly to difficulties of social interaction and communication has been established (Kaat, Lecavalier, 2013). In other words, the autistic student acts out aggressive or self-destructive behavior when he fails to communicate his own need or desire in an interpersonal relationship and experiences all his own powerlessness in the face of all this.

The relief experienced by autistic individuals when they can communicate, even using other channels besides verbal is typical from this point of view (Barale, Ucelli, 2006).

One important concept therefore is to try to understand what the autistic person wants at that moment, what it is he specifically wants, and what makes him happy. For example, it may seem paradoxical that an autistic student can act out a very aggressive behavior simply because he wants a toy car that a kindergarten classmate took to play with.

Another aspect that should not be underestimated is tiredness. When the autistic student is tired after having been busy with many learning activities during the morning of work at school, it is likely that he tends to regress with aggressive behavior, a retreat into his stereotypies as well as with forms of self-harm. It is therefore important to ration and distribute the various activities throughout the day, giving the autistic student relief through a rest or leisure time with his favorite toys or games.

This breakdown of sameness, repetition, and stereotypy is also a cause of problem behavior in autism (Barale, Ucelli, 2006). One topic of debate relates to how the autism stereotypies should be modified and how much the entire school and support staff as well as others who interact with the autistic student should leave them alone, without undermining them. We have taken the position that it is not the school's job to break autistic routines when they are not too maladaptive. Changing routines is a complex topic that requires an appropriate setting, like a therapy room. However, it is also true that the problem of breaking the behaviors also arises in the school environment when they last too long.

It is also typical for autistic students to show sensory problems. LD students may have forms of hypo- or hypersensitivity to stimuli, which act as triggers for problem behaviors (Bogdashina, 2016). One example can explain these aspects.

Case study

Franco is a low-functioning autistic child who is normally very calm in the classroom. However, he cannot stand the cries or wails of other children. When he hears other children crying at nursery school, he puts his hands to his ears and completely breaks down.

Lastly, problem behaviors attributable to characteristic psychotic symptoms should not be neglected. The fact that autism is no longer considered a form of psychosis does not mean that autistic students cannot also be psychotic. This last example is significant.

Case study

Matteo is an eleven-year-old autistic boy who also has characteristic psychotic symptoms. At times, he suddenly seems to have a high level of anxiety. He then loses control in a cry of desperation, screaming in pain for a very long time.

It is essential that the school environment has also been organized to contain the problem behaviors of autistic students. It is important to have a school room, even a small one, where these students can be welcomed in the presence of a counselor or teacher in times of crisis so as to receive adequate help and to calm down.

In times of explosive aggression, teachers must not worry about using physical restraint to control the autistic student (Cottini, 2011). The student can be cornered physically using the hands and stopped with a firm tone of voice.

Prevention is the best way to deal with problem behavior, which depends on knowing the autistic teen, his habits, and character limitations. Thus, he does not have to suffer to the extent that he acts out an aggressive or self-destructive behavior.

Even if this risks repetitive and obsessive trait increasing over time, it is fundamental, as previously mentioned, for the autistic student to experience an environment that is autism-friendly, one that he can get to know well, without significant variations being introduced into the environment. These variations are often distress the LD students, triggering further episodes of explosive aggression.

One hint for preventing problem behaviors concerns a functional analysis of the behavior. Based on a behavioral approach, it consists in very carefully analyzing the autistic student’s behavior (Corradori, Sangiorgi, 2017). The aim is to have a clear idea of the problem behavior, the antecedent, the previous situation that elicited the behavior and the consequence, and what happened, in the student’s mind after that the behavior was acted out.

An example can clarify these aspects.

Case study

Marco is a low-functioning autistic child. He typically wants a toy that sits on the top of a bookcase. When he cannot get it, he explodes in a highly aggressive fit of rage.

The teacher's saying no and stopping the aggressive behavior does not seem to produce results. It seems more important to proceed in this way by having an idea of what triggers the problem behavior that, in this case, is the impossibility of having the toy. The second step is that an adult explaining this behavior does not produce any results at first. Instead, it can be useful to create a visual calendar, a schedule as a reminder. It is explained to the student when he may have the toy during the course of his daily activities. It is essential that the teacher be steady but calm. The child can have the toy, but only after having completed other activities and having expressly requested it.

Adapting the curriculum

First, we can say that the possibility of staying in school with their classmates can be a great acquisition for many individuals with low-functioning autism (Humprey, 2008). Here it is appropriate to liberate the field from ideological prejudices. In some cases, spending time with classmates can be a very positive thing, and less so in others.

It is important for the autistic student to be in class with his classmates because he thus has the opportunity to learn a great deal about social rules, even when he seemingly has not learned anything about what is being said and discussed by teachers and classmates, as he is completely immersed in his autistic world. For example, participating in class life has great value as a means of learning social rules and of feeling included in the social environment of the class and the school for high-level autistic students, in particular those with Asperger's Syndrome,

However, there are cases where it is necessary for the autistic student to work alone in a one-to-one basis with the support teacher outside the classroom. In other cases, the student can stay in the classroom for a limited time, as much as his ability to tolerate frustration can bear without acting out a problem behavior.

In general, however, there is now agreement among clinicians and researchers that the situation in which the autistic student works most of the time alone with the support teacher is not very encouraging. The new Universal Design for Learning (UDL) perspective provides for close cooperation between the classroom teacher and the support teacher, based on an integrated perspective that technically involves all the students and not just the autistic student.

The new perspective challenges the old approach to school integration that was widespread in Italy until a few years ago. This way of proceeding was to design one curriculum mainly for students with typical development and another for students with a deficit, e.g., belonging to the autistic spectrum. As Cottini (2017) has written, from this new perspective of inclusion, the autistic student is not a guest of the class, for whom an alternative modality of education and instruction is conceived and prepared in a distinct and separate assistance point of view. In all respects, he is part of the group of students in the class. Moreover, it becomes necessary from the beginning to think of sufficiently flexible forms of a curriculum prepared for all students, and then make individual adjustments for each student.

On this basis, an open and functional curriculum for all individual students is necessary from the very beginning (Olley, Reeve, 2004. From the beginning, a curriculum that integrates content and learning acquisition processes can be developed by using different codes – linguistic, visual, and iconic – in order to be generally usable by all students.

While it is true that students with Asperger's Syndrome may, in many cases, take advantage of curriculum indications for students with typical development, it is true that it becomes difficult in practice to think of forms of integration for low-functioning autistic students.

For them, teaching inevitably will require a great deal of planning and development, thinking about learning situations comparable to those of the other members of the class (Olley, 1999).

In these more complex cases, the distinction between learning a task and cultural participation in a task becomes necessary (Cottini, 2017). In these situations, it is necessary to adapt the class’s objectives to those of a low-functioning autistic student, to think about activities specifically designed for him, so as to engage him in a learning task, and involve him in the culture of class knowledge.

With a little imagination and inventiveness, however, multiple ways can be found to integrate and interconnect the curriculum points for the students in a typically developing class and for the student with autism.

Case study

For example, let us imagine the case of Anna. She is a low-functioning autistic girl, with a limited repertoire of words, but who can read, as well as perform basic arithmetic operations. What Anna, as well as many autistic subjects, is missing, is not just the motivation to carry out a task but also a capacity for narrative thought.

Following the example of this student, the curriculum can be adapted in a series of significant learning experiences relevant to the reading of fairy tales.

One specific exercise can be done using the story of Snow White. While her typically developing classmates can summarize the story and comment on the emotions that the tale has suggested to them, Anna can work on a composition of short sentences indicative of the narrative sequences of the story. In addition, another exercise can be done on the emotions relevant to the facial expressions of the story’s characters, paying attention to the images taken from the famous Walt Disney film.

Anna can thus reflect on the negative image of the stepmother, Snow White’s goodness, the different characters of each of the seven dwarfs, and Prince Charming’s appeal.

Of course, these are limited acquisitions, suitable for a low-functioning autistic individual, but it is important to underscore how working with the other students in the class cannot be impeded, with important socialization and learning experiences for even a low-functioning autistic student.

For a high-functioning autistic student – one, for example, with Asperger's syndrome, a number of more advanced school education conditions can be studied. It is well known that autistic students with Asperger's Syndrome may also excel in certain learning tasks, with major drops in performance in addition to deficits in others. They show significant deficits in empathy and in understanding the emotions of others, as well as limits in the sphere of social tasks, such as the use of money.

Even with these students, situations of dramatizing a literary story that emphasizes the emotions of the protagonists can be studied. Alternatively, recreational periods can be designed as part of a game to instruct the individual on how to use money. Another example:

Case study

Giovanni’s difficulty as a typical subject with Asperger's syndrome seems to refer to the difficulty of distinguishing how to use money, the difference between individual coins, each one indicative of a unit, and their sum depending on the total among coins of different values, e.g., 5 euros and 2 euros. If the teacher tells Giovanni "give me 7 euros", Giovanni responds by giving him 7 coins, regardless of their value, rather than for example 2 coins worth 2 and 5 euros.

Although the student was unable to overcome this important social deficit, an important step forward in the student’s learning and socialization was a game where he, together with other students, acted out a skit in which a character orders and pays for a cappuccino at the bar.

Spatio-temporal organization at school

In a chapter dedicated to the autistic student’s relationship with the school, it is important to dedicate a section to the spatio-temporal organization of the inanimate physical environment. It is well known that autistic individuals may attach importance to the inanimate environment. However, this can be a source of serious problems and distress for an autistic child.

Let us imagine the case of an autistic child who finds himself for the first time having to set foot in a classroom that has not been designed for him. The positioning of the desks, the presence of many students, and the teacher during a lesson, as well as external spaces outside the classroom, the corridors, bathrooms, and gardens – that which typically accounts for an able-bodied student’s pleasurable enjoyment of the school’s physical environment – can cause serious emotional stress in the autistic student.

In fact, autistic individuals can easily melt down in new and unknown environments or in crowded situations where they cannot tolerate aspects of the potential confusion that are beyond their control.

For this reason, the autism-oriented classroom should minimize distracting stimuli (Molteni, 2015). The fundamental concept remains to reduce as much as possible the autistic student’s anxiety, which may otherwise lead to the autistic student exhibiting problem behavior and aggression. To diminish anxiety, not only must the autistic student be acquainted with his environment, but it is also important that, to the extent possible, the area be organized in a way that is compatible with the problems posed by autism. The spatial and temporal organization of the environment must therefore always be monitored. Let us see how.

It is first necessary that the classroom where the autistic student finds himself be a fairly large classroom. This is due to the fact that there is thus an area where the autistic student can work individually. It is crucial that the autistic student become used to being in a classroom with the other classmates, as he can learn many skills regarding social interaction and curriculum from their daily work. However, the classroom must also contain a space where the student can work on a "one-to-one" basis with a support teacher (Cottini, 2011).

The well-known TEACCH program has contributed an awareness of and many clear-cut, specific strategies for organizing the spaces in which the autistic individual lives (Mesibow G.B., Victoria Shea V., Schopler E., 2004). The ideal condition in the classroom environment is to have a desk large enough to accommodate the support teacher; a table placed along wall, for example, with cupboards on either side to hold work material and to store objects.

If, as mentioned, the classroom must not contain too many stimuli, which may overwhelm the autistic student’s mind and be a harbinger of anxiety for him, it may contain a board, hung on the wall above his work area, which indicates the activities that the autistic student performs during the course of the day and the week.

All of this is also practical for an autistic individual’s sensory potentialities, notoriously unbalanced from the point of view of a visual-spatial intelligence. Designing a wall-board on which to put photos with the activities to be carried out during the autistic student’s morning of work can reassure him and reduce his anxiety. For example, activities can follow a sequence of introducing oneself, saying his own name; listening to the class lesson, sitting at a desk with a partner; psychomotor exercises; a snack break; one-to-one work on such curricular activities as mathematics exercises, reading, or writing; listening again to the lesson; and finally, lunch break.

It is important that the autistic student also learns to familiarize himself with the rest of the school building. He should be a very clear idea of which route leads to the toilet, the school canteen’s dining room, or the garden, by also taking advantage of the wall posted.

Nor should the role that the spatial organization of tasks can have for a student with autism be underestimated. Just as he may initially have a chaotic perception of space, the autistic student may not have a sufficiently structured cognition of time and thus risks becoming confused mentally. Autistic students must become accustomed to understanding how much time to devote to each activity, without abrupt and unexpected variations.

This does not mean taking the risk of encouraging an autistic student’s obsessive traits. Spatio-temporal organization as well as the activities to be performed must be tailored to each autistic subject, allowing for many variations. However, the activities should preferably be repeated daily and weekly so that the autistic student can become used to them, thus reducing his anxiety.

In some cases, it is typical to highlight to the autistic subject how much time he has available for each activity. While it may seem strange for a normal individual, repeating daily to an autistic individual that he has 15 minutes for recreation, or that physical education will take him 20 minutes, is not at all odd for an autistic student, who needs a strict time structure to be able to reduce the intense chaos of sensory stimulation by which his mind finds itself bombarded.

Temple Grandin’s well-known metaphor of "anthropologists on Mars" comes to mind here (Sacks, 1995). Autistic individuals can feel like anthropologists on Mars, being on earth with other human beings as if they were living in a land completely unknown to them. This justifies specially designing an area and an environment for them, so that they can gradually learn to experience it, appreciating the social interaction with other people.

To conclude, being in class every day with other students can be a highly meaningful experience for an autistic student. However, it requires some adjustments and a certain degree of awareness on the part of the entire school community, the support teacher, the classroom teacher, and the group of classmates.

Case study

Here we present the case of Marco, a 15-year-old autistic boy, attending the first year of middle school. He had many problems at his previous school, but he has been able to make significant progress in his new school and new class. The teachers prepared to welcome him well before his arrival. A special space was set up for him inside the classroom for storing the objects used in teaching him as well as where he can work productively at the table with the support teacher. Through a substantial group effort, Marco is now able to stay in class sitting with his classmates for a long time during a normal morning of lessons. He is also able to move effectively throughout the school environment, which has become increasingly familiar to him. This is evidence of the entire group of teachers and Mark’s classmates worked hard to do a good job of including Marco in the school.

Educational intervention models for the ASD

The models which have demonstrated more levels of effectiveness for the educational intervention in the ASD are attributable to behavioral perspective. Of particular interest are the models referable to ABA perspective, which must not be considered as specific models for the intervention, but rather as a *methodology of applied research* for to the analysis of the motivation of the behavior (Parson, Goldberg, MacLeod & Jones, 2009; Matson, 2014). From the ABA approach are derived models which provide inspiration for the special educational interventions evidence based aimed at students with ASD, like the *Pivotal Response Training*- PRT (Koegel, 2001). The better educational interventions for the ASD are characterized by appreciable levels of effectiveness according the perspective of Evidence Based Education. Some of the models, like those derived approach of the *Applied Behavior Analysis* (ABA), have demonstrated the highest levels of effectiveness in the decrease of the maladaptive behaviors associated with the disorder.

The Applied Behavior Analysis

> The *Applied Behavior Analysis* (ABA) is a research program aimed at identifying the factors which motivate an adaptive or maladaptive behavior in an environmental context (NAC, 2009; Matson et al., 2012; Matson, 2014). The behavioral analysis is oriented towards the replacing of maladaptive behaviors with others more adaptive, as these represented by the ability to *forward requests* for to the environment (Matson et al., 2012; Fixsen et al., 2013).

Behavioral strategies have a lot of benefits in the classroom, the most important is creating a structured strategy for teaching and learning and a highly structured environment that is necessary for the student with ASD. The learning outcomes as behavioral targets are defined, instructional strategies as questioning, directives or modeling are prepared in advance, the learning outcomes are permanently assessed, and progress is charted in a step-by-step manner.

The behavioral approach is not appropriate for any learning situation. Magnusen (2006) lists the following learning situations as more effective:

- In young children entering school
- In lower functioning students
- In hyperactive and with problems with attention focusing students
- When a skill or concept is initially introduced
- When a skill or concept is very complex or difficult

The behavioral approach is not considered effective in the following situations:

- For learning social/pragmatic language
- For higher-functioning students
- For developing generalization of a skill
- For learning an independent demonstration of a skill

These skills are the basis for the development of personal autonomy of the subject. The ABA approach is crucial to the educational intervention aimed at the treatment of ASD, considering its opportunities in the natural contexts, as these represented by the relationship with teacher, with peers and with parents (Parson, Guldberg, MacLeod & Jones, 2009; Fixsen et al., 2013). The approach is characterized by a series of criteria.

The *analysis of the antecedents* allows the identification of the events preceding the behavior through its measurable characteristics, such as represented by the *intensity of stereotypes* (Lubetsky, Handen & McGonigle, 2011). The *analysis of the consequences on the context* and on the subject is a further criterion for the understanding of the behavior examined. It becomes so possible the understanding of the purposes of the behavior: for example the child cries because he wants to exit from the classroom.

The *contextual analysis* is a basic component of ABA perspective. The analysis of the context allows the understanding of the functions and purposes of maladaptive behavior (Parson, Guldberg, MacLeod & Jones, 2009; Guldberg et al., 2011; Matson, 2014). The approach highlights the awareness that the best results can be pursued only if conducted in a *natural environment*, as the school and the domestic contexts. The project of intervention must so involve *all the areas of life* of the subject. Considered the application in the school context, it represents an approach for the genesis of models oriented to the development of communication skills and adaptive behaviors.

The theoretical bases of the ABA perspective present evident points of contact with the *Theory of Operant Conditioning* (Skinner, 1953). The role of *reinforcement* is dominant in the ABA perspective, which is centered on the research of the most effective reinforcements for each student, according to his interests and his Special Educational Needs (Fixsen et al., 2013; Matson, 2014). Among the various kinds of reinforcements usable in educational intervention, should be considered the *social reinforcements,* represented by the approval of the teacher or of the peers. The *materials reinforcements,* instead, allow the access to objects or activities of particular interest for the child.

The *Modeling* represents a further extension of the operating conditioning to ABA perspective (Fixsen et al., 2013; Matson, 2014). The modeling is based on imitation processes and involves the observation of a behavior model, represented by teacher or by peers, which should be imitated from the child with ASD. The reinforcements, social or material, are administered just when the imitations are successful (Matson et al., 2012; Cottini & Morganti, 2015). It must to be considered as the effectiveness of the models was derived from experimental comparison with other treatment models (Parson, Guldberg, MacLeod & Jones, 2009; Lubetsky, Handen & McGonigle, 2011; Matson et al., 2012). In the hierarchy of the effectiveness of intervention models, the upper levels are occupied by the ABA perspective and by the models from it derived, like the Pivotal Response Training (Schreibman, 2005; Koegel, 2006; Fixsen, 2013).

The pivotal response training

The *Pivotal Response Training* (PRT) developed by Koegel et al. (Koegel, 2006; Koegel et al., 2006) can to be considered as a further intervention model derived from the principles of ABA perspective. His development was originated from the works of Koegel on children with low cognitive functioning, submitted to interventions conducted in natural and interactive contexts. The PRT is characterized by the use of incidental learning techniques for to increase student autonomy during interaction. The *meta-behavior* which must to be learned is identified in the same environment in which it is normally produced, using the occasions in which it occurs naturally (Koegel, 2006; Schreibman, 2005). The PRT is based on the student initiative: the teacher asks to student to choose their favorite activity, instead of imposing. When the student has initiated the task, the educator on joins gradually to his activity, giving opportunities for the attention sharing. Reading a picture book or watching a film is examples of shared activities conducted in natural environments, and easily implementable in the educational contexts (Steiner et al., 2013).

The PRT results like a model of intervention conducted in the natural settings, such as those represented by the educational contexts and by the relationship between the support teacher and the student. The training promotes the *development of motivation* to task, which frequently is a deficient component in the cognitive profile of ASD. In the PRT, the gratification it is intrinsic to task performance, because it is chosen by the child and not imposed by the teacher (Koegel, 2006; Fixsen et al., 2013; Steiner et al., 2013). The training represents one of the most effective models for the generalization of learned skills and for the reducing of problematic behaviors (Schreibman, 2005).

The concept of *Pivotal Behaviors* (Koegel, 2006) indicates the emergent behaviors, which are prototypical for the development of other behaviors, objectives of next learning sessions. The behaviors related to the movements of the hand, for example, may be considered prototypical respect to the greeting behaviors. The Pivotal Behavior is the outcome of *simultaneous changes* in other similar behaviors, which do not require a specific teaching (Steiner et al., 2013). The teaching of pivotal behaviors conducted in naturalistic contexts could encourage the development of activities spontaneously products by child, with positive influences on his motivation to perform the task (Koegel, 2006). A distinctive feature of the PRT is represented by continuous reinforcement of all the initiatives generated *spontaneously*. The implied gratification to task configures it as a particularly promising model for the development of communication skills in students with ASD. The implementation of the PRT favors the reduction of maladaptive behaviors, often motivated by the request for to stop the activity (Schreibman, 2005; Koegel et al., 2006; NAC, 2009).

The TEACCH program

The TEACCH program is currently the most widely model of educational intervention used in the United States. It is designed as a total care model, and involves collaboration between specialists from different disciplines, which contribute to the intervention in all spheres of life of the child, such as those represented by familiar contexts.

The program provides the opportunity to follow the student in your cycle of life, also allowing the adaptation of the working environment to its cognitive and social characteristics (Mesibov et al., 2007). The initial assessment represents an integral part of the model and allows the definition of the compromised and preserved competences. The initial stage of assessment is conduct through the *Psychoeducational Profile*-PEP, which provides information of the assessment with the observation in the classroom and with semi-structured interviews with the parents.

The goal of the TEACCH program is the facilitation of the mutual adaptation between the child and the environment. This objective implies the need to *adapt the environment* to the special educational needs of the student, according to the current lines provided by biopsychosocial perspective of *International Classification of Functioning, Disability and Health*- ICF (WHO, 2001). The need to provide physical changes to the environment to adapt to the particular student's educational instances in *clearly and easily predictable ways* is a characteristic of the TEACCH, which offer an effective answer to special educational needs ASD-related. The program includes physical modification of the learning environment based on communication through images and on the visual elaboration, skills frequently preserved in the cognitive profile (SIGN, 2007; NAC, 2009; Panerai et al., 2009).

The guidelines of the TEACCH system provide for structuring the learning environment and for the organization of the tasks based on the prevalent use of the *visual scheme* (Mesibov et al., 2007; Panerai et al., 2009; Cottini & Morganti, 2015). The program guidelines include the development of *clear* and *easily detectable* contexts, for to signal the separation between play and learning areas. If the student is in the context delimited by borders, highlighted by colorful ribbons and by wall tables with iconic presentation of the activities, it can associate the task to their context. Similarly, the program provides for the prevention of distractive stimuli through the temporary isolation of the classroom with divider panels. The reduction in auditory and visual stimulation allows the student focus of attention towards the learning context. The delimitation of the physical space allows the reduction of disorientation, with positive effects on the reduction of maladaptive behaviors (Parson, Guldberg, MacLeod & Jones, 2009; Fixsen et al., 2013).

The typical learning context provides a workplace with the table facing the wall, for to minimize the sources of distraction. The relationship with the teacher is one to one, similarly to that provided by models derived from ABA perspective. The program includes the predominant use of images, and present clear points of contact with the approach of the Augmentative Alternative Communication (NAC, 2009; Cottini & Morganti, 2015).

The preliminary visualization of the daily program, presented in the form of visual table applied to the student workplace reduces the sensations of discomfort, often motivated by the deficit of temporal perception typical of ASD. The reduction of disorientation exerts positive effects on the reduction of maladaptive behaviors, which often have the function to signal the desire to stop activity (Mesibov et al., 2007; Fixsen et al., 2013). Many maladaptive behaviors, such as those represented by opposition behaviors, are attributable to such needs

(Panerai et al., 2009; NAC, 2009; Lubetsky, Handen & McGonigle, 2011).

The communication based on images suggests implicitly the term of the activities. These suggest reduce the requests relating to the end of the activity, with positive effects on the personal autonomy. A further potential implicit in the image based communication is the possibility of combination of symbols for to indicate the activities already carried out and those that need to be completed. The early organization of sequences of images gives so *predictability* to the context that represents the more effective answer for the child with ASD (NAC, 2009; Fixsen et al., 2013). The symbols allow the organization of the work material; each module is contained in a box with transparent cover containing the material, immediately viewable by the child.

According to this line, characteristic of the TEACCH program, the organization of the material *implicitly contains instructions* for its use (Mesibov et al., 2007; Parson, Guldberg, MacLeod & Jones, 2009). The containers with the materials are generally located on the left of the work place, while the work in progress is on the center and on the right are placed the containers with the tasks completed. The *left-right directionality*, in analogy with the methods of reading, providing guidance to a recursive visual feedback on the amount of work done, with positive effects on the motivation of the student .

The Denver Model

The *Denver Model* represents an ulterior developmental intervention program, characterized by empirical validation of the effectiveness according to Evidence Based Education perspective (Rogers & Dawson, 2010). It derives from the model of Rogers and Pennington, according which the *Deficit of Primary Intersubjectivity* prevents access to the experiences of socialization of the child with ASD, compromising his imitation and social communication skills.

The Denver Model is oriented to the overcoming of the deficit through early exposure of the child to structured situations of social play (Dawson, 2008; NAC, 2009). The main objective of the model is represented by the possibility of offering repeated opportunities for the social imitation and for the activities sharing with the peers. The intervention is characterized by the focus on social disability associated with the disorder, through early implementation of an intensive training (Rogers & Dawson, 2010).

The model is one of the most advanced for the educational interventions on the child in the preschool age (Schreibman, 2005). The imitative and social game play a decisive role in the model, which considers them as the most powerful tools for cognitive learning and social (NAC, 2009; Rogers & Dawson, 2010).

The training suggests the involvement of the family in the educational project of the child, and this data is testified by the opportunity to development of realistic educational goals for the child (Vivanti et al., 2014).

The model expected the division of the children in micro-groups coordinated by the teacher, to promote the development of the imitative skills. The exposure to experiences based on imitation of interactive sequences of social play encourages the development of the imitative skills and the social reciprocity (Dawson, 2008; Reichow, Steiner & Volkmar, 2013). The acquisition of interactive skills based on the concept of *alternation*, according to which the student with ASD alternates with the teacher and with peers in the conduct of a shared activity. Even the child with ASD can to share social games, picture books or communicative symbols with their peers, with positive reflexes on the social inclusion processes.

In analogy to the Pivotal Response Training, in the Denver Model are presents planned imitative modules, in which the student is invited to imitate behaviors for the acquisition of basic social skills SIGN, 2007; ISS, 2011; Fixsen et al., 2013)). The imitation of the key behaviors, thus, may facilitate the acquisition of other skills without that they are directly learned (Guldberg et al., 2011; Vivanti et al., 2014). A typical example is the greeting behavior, which could be extended to greeting in meeting or social play opportunities. The learning activities of imitative rules that guide the social interaction represent so skills whose acquisition facilitates the sharing of communication codes (Parson, Guldberg, MacLeod & Jones, 2009; Vivanti et al., 2014). The training has positive effects on the cognitive self-regulation processes and on the reduction of maladaptive behaviors (SIGN, 2007; Guldberg et al., 2011).

Case study

Corinna is a 9-year-old girl with ASD associated with low cognitive functioning (IQ = 37). He has poor vocabulary skills and expresses his discomfort with cries and crying when he is in class, especially during classroom and teacher changes.

The support teacher creates a TEACCH workstation in the classroom, with the desk facing the wall, divided by the class with dividing panels. In the workstation the teacher guide Corinna to realization of agendas with symbols, oriented towards the understanding of the temporal succession of activities and towards the signaling of changes in routines.

The educational relationship between Corinna and the teacher is based on the alternation between inclusion in the classroom and moments of study at the workstation. Every time that Corinna expresses expressions of disease, she is accompanied in the workstation for the consultation of the agendas. Corinna can leave the workstation or the class according to her preferences, and she can invite one or more child for to play on its desk.

At the end of the school year the maladaptive behaviors of Corinna have significantly decreased, with positive effects on inclusion in the peer group.

The Individualized educational plan (IEP)

The Individualized Educational Plan (IEP) represents the general framework for any educational or therapeutic intervention. IEP is an instrument for planning, structuring and monitoring all interventions applied to a child with disabilities. Developing the IEP is a continuous process, involving all parties around the child: parents, specialists and teachers.

Prior to IEP developing the assessment for intervention planning must be conducted. The assessment must address the unique needs of the individual and at the end must provide complex and useful information for intervention planning. The assessment process is carried out by different specialist and all the results must be integrated in a holistic profile of the child's needs and strengths. In the assessment team for ASD there must be a psychologist, a speech therapist, a special educator, an occupational therapist and an audiologist.

Assessment for intervention planning must gather informations from all areas of individual functioning that are affected by ASD: adaptive functioning; cognitive and academic functioning; communication; social, emotional, and behavioral functioning; comprehensive medical examination; sensory and motor functioning; and family functioning. All these information must primary take into consideration the functional aspects: what are the barriers that the child encounters in daily activities and in school-related activities such as learning, communicate, relate with others, compliance to the school curriculum and activities.

Developing the IEP consists of four processes: identifying goals, select interventions and determine procedures for monitoring progress.

The process of goal identification begins at the moment of the first contact with the child and its family. The specialists observe the child and its difficulties and starts looking for solutions. The parents express home encounter difficulties and hopes for aquiring new skills.

Goal development generaly targets three main domains: cognitive funtioning, functional social interaction and verbal communication. Each specialist develop goals related to their domain of expertize and the parents expres their needs related to home environment. They share these goals and prioritized them acording to the childs` needs. For young children with ASD the first goals can adress the intent to interact with others and to communicate. If the child master these skills the foundation for social learning and further development is established. For school-aged children the goals target skills acording the development level but if the child is mild or highly functional the new desired skills allow generalisation and transfer from learning situations to everyday life, also refer to learning and aquire social and adaptive skills. There are three levels of targets: long-term outcomes, short-time goals and current objectives. Generally the IEP is developed for one year so annualy short-time goals are formulated and reviewed periodically.

Goals and objectives for students with ASD targets specific areas (Missouri Autism Guideline Initiative, 2012):

- improving ASD symptoms in areas such as communication, social play, social skills and behavioral flexibility;
- decreasing or eliminating challenging behaviors;
- improving academic achievement;
- addressing associated attention problems, anxiety, sleep, toilet use

SELECTING OBJECTIVES AND GOALS TO IMPROVE OUTCOMES

FIGURE 2.4

(Missouri Autism Guideline Initiative, 2012, p. 23)

The second step in IEP development is to select interventions. There are many types of interventions, techniques and methods that can be used with children on the spectrum. In the following we will present the most used methods in the educational context. But how do we select the most apropriate intervention?

- Firstly, we take into consideration the individual characteristics of the child
- Secondly, the human resources are very important, very much depends on the types of therapists that are accessible to the child, school and family.
- Also, evidence-based information about each intervention can be a selection criterion.

Not all interventions are effective for any child. In many cases there is a research period for the best combination of methods and techniques that are effective and help the child to progress.

For each objective from the the IEP the plan prescribe a specific intervention or technique that will be used. Interventions are applied and combined in diverse ways to meet individual goals.

All the specicialists that will be responsible for each type of intervention is also mentioned in the IEP, including parents, considered as co-therapists.

The next step in developing the IEP is to determine procedures for monitoring progress. Periodic, assessment of the target-skills will be performed to determine the child`s progress and how effective the intervention algorithm is. The collected data is being used to determine if the student progress, regress or stay the same in each area of intervention. It is important to set achievable goals that will alow sufficient time to be reached and integrated in the child`s behavior. Each child has its own delopmental pace so it is important to reach a very good understanding of the child potential before seting realistic goals.

The IEP also function as a feed-back tool for the effectiveness of the intervention. If the results are not as good as expected few possible explanations may occur:

- The selected intervention algorith is not appropriate, in this case new twchniques will be chosen
- The team it is not efficient in working together, so new working procedures will be implemented
- External factors interfere, such as absenteism, illnesses, environmental changes, and they must be adessed and controled.
- Financial set-backs that must be overcomed.

A monitoring report is being made in which all the colected data are being presented. Also, the recomandations for improvement and future adjustments are being proposed. Based on the monitoring report new goals are developed or if the older goals were not reached they are adjusted for the next period.

Conclusion

In this chapter, we have presented a varied analysis of the problems and critical issues that the inclusion of an LD student encounters at school. Although, as we have seen, there are many serious problems to be faced, we have tried to highlight the richness of the interventions that can be directed at LD students also in the school setting.

The underlying root of autism remains a mystery. In addition, today we are used to talking about autism in the plural, rather than as a unique form of autism in the singular. Despite this, we now possess a wealth of remarkable data on autism. This awareness can be properly applied and used in a school setting. Not only is it possible to introduce into a school the wealth of knowledge that has been derived from a broad range of psycho-educational interventions, but the scholastic environment itself can act as an important training ground for the development and growth of the LD student.

However, this all requires paying special attention to the needs of the LD student and specific training for the support teachers as well as the classroom teachers, including involving his classmates in the plan to help the autistic student.

Nevertheless, the whole school environment can make a notable contribution to the autistic student's education, learning to understand him day by day, creating continuity and networking relationship with his family and his work in the rehabilitation center.

The school cannot replace the involvement of work in a rehabilitation center, but it can support this role in a relevant and meaningful way.

With courage, accountability, and a bit of imagination, classroom and school settings can become a field where the autistic student can do many things. As we have seen, these include implementing specific techniques, adapting the curriculum, undertaking the spatio-temporal organization of the room, and managing the inevitable behavior problems.

Teaching curricular skills, learning social rules, paying attention to affectivity and interaction, contributing to the student's overall education are all factors that the school can deploy to help LD students. All these elements create a successful basis for the autistic individual's life plan.

It is a life plan that someday will culminate in an attempt to gain adult autonomy, albeit with the peculiar ways that are typical, each in their own way, of people with autism.

The autonomy project can but continue over a lifetime outside of school, yet school can truly help in this endeavor. To do this, however, the school staff, primarily the teachers, have need of appropriate and specific training. Only with adequate experience, as well as a range of suitable training courses, can teachers gradually tackle the world of autism alongside the educational function of schools and rehabilitation centers in educating autistic individuals.

KEY ISSUES

The UDL approach is characterized by the development of learning environments, which can provide adequate answers to all students, including those with disabilities. The goal of the approach is the development of inclusive contexts characterized by *maximum levels of accessibility.*

The UDL approach ensures that all students may have the same opportunities for the learning and the participation in the community life.

The most effective Inclusive Contextual Strategies for the student with ASD are described by Mitchell (2008). The most relevant strategies including the wide use of the collaborative teaching, the development of a positive school culture, the promoting of positive behavior and the empowerment of the classroom climate.

KEY ISSUES

The cooperative learning processes are one of the most educational interventions for the treatment of ASD, and represent an effective inclusive strategy for the student.

The social interaction promoted by cooperative learning processes can be considered as representative of all educational goals, give its strong correlation with the decrease of maladaptive behavior.

The observation of behavioral model with typical neurodevelopment can to encrease the competences of the student with ASD.

The inclusion of student with ASD in the regular classes is crucial for the learning of social interaction rules, and both for the development of acceptance of the child with ASD in the peer's group.

KEY ISSUES

The most effective models for the educational interventions in the ASD are derived from the Applied Behavior Analysis perspective. The ABA approach is a *methodology of applied research* for to the analysis of the antecedents of the behavior.

The ABA approach is oriented towards the replacing of maladaptive behaviors with others more adaptive, as these represented by the ability to forward requests to the environment.

The Pivotal Response Training is a one of the most effective models for the generalization of learned skills and for the reducing of problematic behaviors. The PRT is based on the teaching of *Pivotal Behaviors*, which are prototypical for the development of other behaviors.

The Denver Model is an effective training based on the imitation of interactive sequences of social play, which increase the development of the imitative skills and the social reciprocity.

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Module 4: Family and Autism Spectrum Disorder

Jasmina Stošić, Ana Wagner-Jakab[5]

Introduction

Families of children with ASD face many challenges in their everyday life. They are the ones that know their family member with ASD the best and the ones that spend the most time with him, especially before the school age. Understanding parent’s perspective, communication with families and cooperation with them in building an intervention plan as well as supporting the daily life of family as a whole is an important part of every good ASD intervention. However, it is not seen as important by many practitioners and they are mostly focused on the child and teaching procedures they are using. In the education of professionals that work with children with difficulties, family support is also often overlooked.

The main focus of this module is a family of a child with ASD and the aim is to understand the specificities of families of children with ASD but also to emphasize that they too are a family like any other. It will incorporate insights into many phases families go through, from the moment they find out that their child is diagnosed with ASD; the acceptance of the diagnose; the efforts and adjustments they will have to do in order to adapt to the situation; the loss of their „perfect child” and the grieving process. It will also contain some suggestions for practitioners and explanation of different models of family support.

Module objectives

By the end of the module, you will be able to**:**

Learning outcome 1

- Define family system theory.

Learning outcome 2

- Distinct normative and nonnormative stressors.
- Distinct acute and chronic stress.
- Define the possible ways how stressors affect couples.

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- Discuss unique set of stressors which families of children with autism are faced with.

Learning outcome 3

- Define Family Resilience Theory.
- Identify specificities of resilience in the family of a child with ASD.
- Distinct protective and risk factors.

Learning outcome 4

- Define the social-ecological model.
- Describe the layers of Bronfenbrenner’s ecological model.
- Identify issues of families of children with ASD in the lifecycle.
- Identify some issues of siblings of children with ASD.
- Discuss interventions that promote resilience in families of children with ASD.

Learning outcome 5

- Identify the importance of the grieving process in families of children with ASD.
- Describe stages of grieving/adjustment of families of children with ASD.
- Discuss the role of professionals that support families with ASD in the process of grieving/adjustment.

Learning outcome 6

- Identify different family support models.
- Understand the difference between parent training and parent education.

Topics covered by this module

Family system theory
Stress in family
The social-ecological model
Family resilience theory

Family resilience theory in general and in the context of family with the child with ASD
Families of children with ASD in the lifecycle
Siblings of children with ASD
Grieving and adjustment
Supporting families

Family as a system

Family systems theory considers families as units in which members of the family impact one another in bidirectional ways, trying to maintain equilibrium (Sepulveda- Kozakowski, 2018).

According to family systems theory, subsystems exist within the family (Minuchin, 1974). Certain family members become connected by different themes or links so they may form alliances or subsystems which are often organized by different themes such as marriage, gender, disability, siblings. Each subsystem (spouses, siblings etc.) has specific goals. The subsystems are interdependent, and each family member belongs to multiple subsystems. For example mother is a part of parent subsystem with a father but also part of a female system with her daughter. Crisis could develop when the members of the subsystems have difficulties to achieve their goals. It is important that the family members acknowledge these subsystems and alliences and discuss any feelings associated with them to support closeness and togetherness within the family unit. Family system will function positively when, the system as a whole, as well as each subsystem find balance in boundaries, communication, cohesion, adaptability/flexibility and climate (Sepulveda- Kozakowski, 2018).

Stress in a family

Families try hard to achieve and maintain balance and harmony especially during time of change. Change brings imbalance and might bring disharmony. Stressor put demands on family that also might provide changes in the family system. Some stressors are normative such as those generally experienced by families in family life cycle. Non normative stressors (natural disasters, loss of family member) tend to create more stress for families then normative stressors. Stressors are as much sever as more they threaten the stability of the family unit, disrupt its functioning, place significant demands on it and tend to exhaust the family's resources and capabilities (Mc Cubbin, Mc Cubbin, 1996).

Furthermore, there is distinctions between chronic and acute stress (Karney, Story, Bradbury, 2005). Chronic stressors are relatively stable and long lasting aspects of the context (e.g. socioeconomic status, disabilities, diabetes). Acute stressors are aspects of the context that have a specific start, shift and end (e.g. transition between places of employment). Research indicate that both type of stress can affect family balance as well as marital outcomes. Acute stressors could affect variability in marital outcomes, while chronic stressors could affect the overall trend of the marriage including reactions to acute stress. Couples that face few chronic stresses may have high level or resources available to respond to that challenge. On the other hand couples who experienced high level of chronic stress should have fewer resources (e.g. less time and energy) available when an acute stressor occurs. Factors that support balance in families faced to stress protect families in difficult situations and positively influence family resilience.

Family resilience theory

The concept of family resilience refers primarily to the family's capacity to deal with and manage difficult circumstances, including the resources families possess that would enable them to face adversity and remain strong. McCubbin and Mc Cubbin (1988) defined family resilience as "characteristics, dimensions and properties of families which helps families to be resistant to disruption in the face of change and adaptive in the face of crisis situation" (p.247). On the other hand, Hawely and de Haan (1996) defined family resilience as adaptive patterns families have demonstrated both in the present and over time. The authors emphasized family resilience as developmental construct and as a process rather than static set of qualities. According to Fernandez, at al., (2013) the concept of family resilience overcomes focus on individual family members as potential resources for individual resilience to focusing more on how the family as a unit could have a role of a protective factor. Some of factors identified as protective are: family cohesion, family belief system and coping strategies. Cohesion means bonding among family members. Cohesive families are willing to work to common outcome and benefit of the family. Family belief system recognize impact of spirituality to positive outcomes of family. Family risk factors include: violence, poverty, single-parent homes, divorce, death. Family risk and protective factors refer to those characteristics that will make families either more vulnerable or buffer against the challenges. The most logical approach in examining the role of risk and protective factors in the development family resilience is socio-ecological model. Socio-ecological model recognize complex interactions between families and multiple systems.

The socio - ecological model

The social-ecological model is used as a way of working with children, young people and families that aims to keep them at the centre of anything that is assumed to help and support them. The social-ecological perspective looks at all aspects that can affect people and their lives. That means that it considers issues within the home, family, wider community and society before any attempts of solving the present issues. By assessing every aspect of a given situation, the social-ecological model aims to offer long term workable solutions. It means that we should discovered the roots/reasons of problems and try to correct them rather than only focus on solving immediate issue.

Bronfenbrenner (1986) used it as a model to look at the variety of social influences on children's lives and development and how these can affect them. In his model, Bronfenbrenner (1986) saw the child as being at the centre of any situation and everything else is placed around them in concentric circles, ordered based on how much influence he believed each factor had.

Each of the layers within the model will influence and affect children, young people, and families' lives in some way. Some layers will have a lesser affect than others and each layer will also interact with each other and can create further problems to be considered. This includes how the child's own skills, ambitions, and wishes will affect the world around them as well as how others such as siblings, parents, grandparents, teachers, and other influences such as disability, availability of services, unemployment and education may have an effect on them for good or bad.

The layers of Bronfenbrenner's ecological model (1986) are as follows:

- Individual – In this layer is the child as an individual. It shows how children's health status, sex, age, skills, resilience, personality and other personal factors have an influence on their lives.

- Microsystems – Child has direct contact with some aspects of society and life. For example, these include but are not limited to family, school, immediate neighbourhood, friends, peers, religious institutions, and social groups.
- Mesosystems – Mesosystems are connections between two or more other systems. For example: the connection between a child's parents and their teachers or relationship between the child's peers and the family.
- Ecosystem – This is a layer which contains aspects that the child may not interact with directly but that will have an influence on his/her live. These include things such as their parents workplaces and the lives of their peers' families.
- Macrosystems – Macrosystems describes the culture in which child lives. It is about identity, heritage, cultural values, customs and laws of wherever the child lives and includes the influence of provision of local services as well as wider society.
- Chronosystem: It describes patterns of environmental events and transitions over the life course, as well as sociohistorical circumstances. For example, divorces are one transition. Researchers have found that the negative effects of divorce on children are often strongest in the first year after the divorce. Two years after the divorce, family interactions are less chaotic and more stable(https://en.wikipedia.org/wiki/Ecological_systems_theory).

Within each layer there will be several influences to consider, for example each individual child's health, sex, age, knowledge, resilience and abilities will influence how they react to a situation and are able to cope and live.

Among the variety of developmental and physical disabilities that have been studied, certain of these have been known to affect families more then others. Autism spectrum disorders (ASD) is such a disability. So next chapter will describe some issues and factors of resilience in families of children with ASD.

Resilience in families of children with autism spectrum disorders

Since autism affectes number of different areas of development, families of children with ASD are faced with a unique set of stressors related to a variety of dysfunctions and behaviour characteristics. Issues faced by families of children with ASD remain constant even in those families who have children with high-functioning autism (HFA) where the degree of dysfunctions is mild (Bayat , Schuntermann, 2013). There is a lot of issues that families of children with ASD face during lifecycle. On one hand parents of children with autism seem to be tireless in their fight for cause and cure but on the other hand they are often exhausted, disappointed and depressed specially in early stages during the setting up diagnosis and identification of treatment. Because ASD has various degrees and severity it has been difficult to spot a single cause or a single treatment. Treatment options available for ASD are numerous. These options vary from biomedical, pharmacological, dietary interventions to educational and therapeutic methods. Many of these treatment options give parents a hope to a “cure” and “recovery” from ASD.

Factors influencing parental decision in choosing the treatment are complex and multidimensional. Some of these treatments (dietary interventions) are expensive and time consuming. Some of them have been recognized as dangerous to the child. Furthermore, some of educational and therapeutic interventions have empirical basis while others have no scientific evidence to support them. Some interventions require parental commitment each day all the time. To ensure treatments to be effective parents have to invest a great amount of time, energy and financial resources (Bayat, Schuntermann, 2013). Experts should acknowledge issues that families of children with ASD are faced with. In that way they will understand the concept of resilience and fine way to support it.

Issues of families of children with ASD in lifecycle

Early childhood

The experiences of the parents are different depending on time when atypical behaviours of children occur. While atypical developmental patterns might be present in some infants from the beginning or after 6 months, in other infants there is a regressive pattern that usually occurs after a period of 1 or 2 years of typical development. Parents may sense that their child’s development is not typical but still they are not aware of how disorder may change their lives (Bayat, Schuntermann, 2013). It can also happen that because of public’s increasing awareness and publicity of ASD in media, some parents suspect their children has autism although it is not so.

Some parents especially mothers report a huge amount of stress because of a lack of interactive and reciprocal behaviours in their infants. Furthermore, parents may sense exhaustion due to lack of sleep and rest because of unusual patterns of sleep in infants with ASD. Difficulties of children with ASD in coping with changes and recognizing danger often becomes huge challenges for families. Those demanding situations can lead or even force making big life decisions of family members (parents, siblings) like moving to new living places or making career decisions.

After the diagnosis a major task of the family is securing appropriate education and therapeutic services as well as establishing and maintaining relationships with service providers. Establishing relationships that is based in collaboration and partnerships requires a lot of energy and efforts from both families as well as service providers. It is unreal to expect that those qualities will always exist in both the families and service providers.

Elementary school years

This period starts with a lot of stress. Parents are struggling with school settings, trying to establish relationships with school stuff. They are also concerned about social acceptance of their children with ASD. After this first period of adjustment those parents that have a good support of school and services might experience a relatively good period. At this point they have adjusted to the demands of disorder and established some stability in daily routines. Furthermore, if they have good support and collaboration, they can relax a bit because their children are part of the system (school) for the next 8 or 9 years and have same teachers for 4 or 5 years what increase more sense of stability. During this period child could make some improvements in sociability, emotional control and/or attention span (Bayat, Schuntermann, 2013). In contrary if there is not good support of school or school even show open resistance and rejection of child with ASD this period becomes tremendously stressful for children with ASD and their and families

Adolescence

Adolescents years of children with ASD might be particularly stressful especially in families that have children with aggressive behaviour. This makes parents and siblings especially vulnerable (Gray, 2002). Children become physically larger and face hormonal changes that influence their appearance and behaviour. Openly aggressive behaviour and sexual awareness in combination od dysfunction in communication, social understanding and cognition usually appear in adolescence with severe ASD. In this period families of children with ASD become aware of the fact that disability is chronic and life-long. They also struggle to find age appropriate services and often face with depression of adolescents with ASD because of their unfilled need for friendships and peer relationships as well as romantic relations. Families of children with high functioning autism and those with Asperger syndrome are particularly concerned about the lack of friendships in their adolescents (Bayat, Schuntermann, 2013). Families are more and more concerned about the future professional or/and adult life of child with ASD. This period is emotionally very demanding for families.

Adulthood

At this time formal school years finished what changes life routine for children with ASD and their families. Families struggle with securing appropriate services, supervised living, working arrangements. One of the major family's concern is about the future of the adult with ASD because of the aging of parents. Parents become more tired, slow, could develop some diseases due to their growing age (hypertension, osteoporosis, dementia). They do not believe anymore in significant positive changes. Sometimes they start to avoid some organized daily activities for their children. They worry about their typical children and their role in future life of the child with ASD especially after they die. They think more about aging and death of themselves and their partners, friends.

In this period families could become more and more isolated. Sometimes it is not enough to offer them to come to support services then it is better to organize that support come to their home.

In addition to mentioned demands of lifecycles families are faced with different levels of other stressors. Social stigmatization cause extreme psychological stress and result with parental isolation. So parents may develop depression, anxiety and sense high level of emotional distress and anger. Social rejection more often occur if children manifest aggressive and/or obsessive behaviour. Although stigmatization usually worsens with growing age of children it seems that with time parents care less about society's perception regarding their children. Research show that mothers of children with ASD had higher degree of depression compared with fathers. Mothers often stayed at home and cared for their children what seriously influenced and limited their professional career (Gray, 2002). Important issue to families is that having child with ASD is also additional financial cost to families.

Particular issues of concern for overall adaptation of family are relationships of parents with their other children as well as sibling relationships.

Siblings of children with Autism

Research on the effects of having siblings with ASD provided variable results. Some studies report more psychosocial and peer problems in siblings of children with ASD then in siblings of children with Down syndrome (Hastings, 2003).

Other studies report higher levels of loneliness, problems with peers, attention difficulties (Bagenhol and Gillberg, 1991), reduced intimacy and less nurturance in families (Kaminsky and Dewey, 2001).

Suggestions for practitioners (Fiske, 2017)

- Share the research with parents. explaining that the stress experienced by parents of is common among all families with children with ASD, that can help them realize that what they are experiencing is normal.
- Understand that parent's mental health as well as the ability to participate in the treatment can be affected negatively by the stress. Try to find other ways to include them. If you are very concerned provide referrals to individual therapy.
- Reduce the impact of social and communication deficits and challenging behaviour of the child on parental stress by teaching them skills to address those issues.
- Identify different activities in which parents and child can enjoy together.
- Work with families to identify social activities that may reduce family isolation and help a child to develop social skills.
- Provide referrals to professionals who can analyse and intervene in problem behaviour and provide recommendations how

to address it especially at home and in the community, not just in school or centre.

- Prepare for increases in stress of parents during transitions (from early intervention to preschool, from school to adulthood). Collaborate with parents in transition planning.

Siblings might be concerned about their own physical and psychological wellbeing (Bayat and Schuntermann, 2013), may not accept that one's health and wellbeing is taken for granted (Safer, 2002). Siblings may worry about catching some of the problems from their siblings with disabilities. Siblings of children with ASD may be at risk to develop negative self-perceptions of their own social competence Particular issues of concern is parental preoccupation with children with disabilities and siblings experience of neglect (Bayat and Schuntermann, 2013).

Since ASDs have strong genetic bases siblings are at some risk for subclinical characteristics known as the "broad phenotype". These might include mind-reading difficulties, attention deficit disorder, language-based learning problems and also symptoms of anxiety and depression in adolescents (Bayat and Schuntermann, 2013). Due to a complex situation at home it can happened that those difficulties in "neurotypical" siblings go unnoticed and escape clinical attention and intervention.

Suggestions for practitioners (Fiske, 2017)

- Understand the growth of sibling's understanding of ASD, its symptoms and impact with age. This can help you to guide parents in how to effectively communicate with siblings about their brother or sister with ASD.
- Encourage parents to talk with sibling about challenging behaviour that the child with ASD expresses and how should he/she behave when that happens.

- Ask siblings about their opinion about a specific program that you conduct. Ask them both, how they feel and their thoughts about planning program. This will help them feel included.
- Try to find activities for siblings to join in together. Try to match the interest of the neurotypical child and skill level of the sibling.
- Help parents to find time to connect with sibling during the day, even for a short time. This can strengthen their relationship and help parents recognize sibling concerns before they become problematic.
- Recognize the influence of brother/sister with ASD on peer relationships of the sibling. Try to include them in peer support group.
- Encourage parents and siblings to talk about the sibling's role in caring for their sister/brother in the future.

Resilience in families and siblings of children with ASD and interventions

Understanding the process of meaning-making is central in promoting resilience in families of children with ASD (Bayat and Schuntermann, 2013). Patterson (1988 in accordance with Bayat, Schuntermann, 2013) argue that the process of meaning-making in the family is central to the family's ability to successfully cope and adapt to the demands of the disability. The way that family members make meaning out of the disability enable them to use family's resources (protective factors), arrange its structure and balance resources against demands and stressors (risk factors) of having a child with disability. Study (Bayat and Schuntermann, 2013) also showed the process of meaning-making in those families was intertwined with spirituality.

Qualities that support coping and resilience of child/sibling are: close family relationships, good boundaries, effective communication and consistent, achievable family rules, friendship attitudes, helpfulness together with the capacity to reach out for and also get support of friends, teachers and members of extended family. Positive peer relationships and good friendships are considered to be protective factors in resilience research. They increase self-esteem and coping skills and possibly decrease psychosocial risk and vulnerability (Bayat and Schuntermann, 2013).

An important goal in working with families that have child with ASD is to maintain the balance between vulnerability and resilience. Some authors (Luthar, Sawyer and Brown, 2007) state that it is needed to underback underlying processes that are linked with global risk factors because it is critical in understanding antecedents of vulnerability and resilience. It is essential to create preventive intervention with strategic timing and targeting by clinicians and communities such as schools, other agencies and policy makers. It is also important to pay attention to the factors that set into motion "cascades" that increase other protective processes. For example, when child's behaviour problems improve, there will be less negative impact on the family which results in increased positive family interactions and activities.

Since the meaning-making is central in promoting resilience in parents it is important to support them in expressing their experiences. Conversation and communication with parents about their experience, perception and feelings should help them to explore the meaning of having child with autism. Such sessions could be conducted as various times and certain periods with the family since meanings are dynamic, have multiple levels and shift over time. For example in the first level parents might make meaning about autism as a disorder and what it might mean for the child and the family. In the second level parents might construct meaning about their identity as a family and decides on family members' roles in relation with the child's treatment and demands. Finally, parents may construct meaning about their view of the world. Helping parents make global and specific meaning about having child with autism may help them cope with the situation, promote resilience and cascade successful family functioning. Professionals should respect the family's belief system. Spirituality is a key family dimension that promotes family unit adaptation and buffer the family during crisis (Bayat and Schuntermann, 2013).

Numerous studies have examined the most effective strategies for families to cope with the stressors of having a child with disability, especially regarding the impact of a child's disability on the parent-child relationship and the grieving process the entire family experiences due to the loss of "the perfect child." Although the order and description of the "stages" involved in the different models offered for this grieving process are debated, the basic components remain consistent.

The grieving processes

Grieving the loss is where healing process begins.

"Grief is a journey, often perilous and without clear direction. The experience of grieving cannot be ordered or categorized, hurried or controlled, pushed aside or ignored indefinitely. It is inevitable as breathing, as change, as love. It may be postponed, but it will not be denied." (Fumia, 2003).

Professionals need to know about the stages through which parents often pass when coping with the fact that their child has a disability. These same professionals also need to be available to support parents through the usual stages of adjustment toward “reasonable acceptance” of their child's condition and their fate. Professionals should be aware that their expectation that parents fully accept their own children disabilities is unrealistic and sometimes even arrogant Who can truly and completely accept that his/her child will be different, vulnerable with uncertain prognosis and future that sometimes looks terrifying?

Until parents who are having difficulty accepting their child's disability can cope with their own pain and frustrations, their full energies generally cannot be directed toward understanding the child's disability, level of development, readiness for instruction, or participation in the intervention process. Professionals have to be aware that when we sometimes in life grieve after important person, we lost forever this process can have it beginning and end. Through grieving process, we sense anger and sadness but are not under the stress and fear anymore and not engaged with that person in different activities and situations. Parents of children with ASD are occupied with their children in a great extend all the time and exposed to stress a lot of time. They may grieve all life to some extent, especially in the times of transition when it becomes so obvious that their children are different and vulnerable and they as parents cannot save them from life circumstances, so parents feel sad and helpless. Professionals should understand that fact and be supportive, and respect parental processes.

Stages of adjustment (Healy,1996)

The first point of providing support for parents should be during a period of uncertain diagnosis, which can cause confusion and/or insecurity. After getting a specific diagnosis, such as autism or a less definitive determination like pervasive developmental disorder, the parents' typical stages of adjustment are as follows:

Stage one

The parent may be shocked, and he or she may cry or become moody. Sometimes parents may express their feelings through physical outbursts or, occasionally, inappropriate laughter.

Stage two

This is an extension of stage one, and some parents may deny their child's disability or try to avoid that reality in some other way. Some parents will search for or try to take action as an attempt to change the reality. Some may "shop for a cure" or try to bargain for a different reality.

Stage three

At this stage, parents may feel anger. They may demonstrate their anger outwardly, in the form of rage, or become withdrawn and passive from intense feelings of guilt. It is common that parents verbally attack person who might be blamed for their unfortunate circumstance or who convey then the bad news about child delay or disability (original diagnostician or any supportive professionals). This stage could be named like famous movie “Kill the messenger”. If the parents are feeling angry, guilty, or both, professionals must understand this stage is a very positive point to reach in the process of adjustment and not become defensive if attacked. It is very important to professionals not to take parents behaviour in this stage too personal. It is important and expected phase in a process of grieving that is also process of healing.

Stage four

Parents become resigned to the fact that their child has a disability. In some situations, one or more of the family may slip into depression. Some feelings that originate from a new overwhelming burden of responsibility can become very intense. That could be feelings of shame, guilt, hopelessness, and anxiety. For some parents, withdrawing, accompanied by avoiding social gathering with friends and extended family as an attempt to hide the child may be the first sign that they have begun to accept the fact their child has a disability. However demonstration of behaviour that results in abnormal isolation of one or any family members must be prevented or stopped.

Stage five

This is the stage of acceptance, meaning the parents have achieved an positive attitudes regard for the child. They see not only deficits but also strong sides in their children. Specialists debate whether or not this stage of adjustment includes parents who show only acceptance of their child's condition, commonly called neutrality, or a very important new stage of cognition when parents not only begin to understand and appreciate their child but strengthen their skills in coping with life's trials as well as being able to help their child, themselves, and others. Reaching this stage is important point for professionals to invite parents to become team member and collaborator in a kindergarten, school, program of intervention etc.

Stage six

Parents are able to put their lives back together, continue some stuff they put on hold, begin new stuff and enjoy living, imagine a future, and talk of their child free of too intensive emotion. They can discuss and participate in designing or providing instruction objectively.

Role of professionals

Because education system (kindergarten and schools) accept students with disabilities, they have a responsibility to provide support or see that appropriate support is available to parents as they pass through these various stages. The kindergarten or school may provide parent- to-parent support groups. Those groups could be divided by disability and facilitated by school personnel such as a school psychologist, counsellor, or teacher. In case parent need individual counselling, the kindergarten/school should provide a list of counsellors with whom the parent could meet.

Reaching acceptance

Even after parents find acceptable ways to cope with their child, other complications can cause set-backs in adjustment. They could experience socially rejection by friends and strangers or being treated inappropriately by poorly informed educators. Such repeated negative experiences only worsen the difficult process of adjustment. Parents, like professionals, often perceive the inhumanity of persons who show little or no understanding and caring toward persons with disabilities or their caretakers. Peoples' actions, even more than events, cause parents, and the child, to regress into states of anger, frustration, or other earlier stages of feelings and behaviours. Most parents need support to progress positively and without delay through the stages of adjustment. Their progress toward a level of reasonable acceptance and adjustment includes an accurate understanding of reality. Professionals can help parents achieve a balance between their hopes and reality. For example, no need exists to engage in speculation about what a 4 year- old child will be able to do when s/he has reached the age of 25. Even though most parents have a need for professionals to be truthful and trustworthy persons, they do not need dark information and prognosis. The majority of parents will come to understand the realities and implications regarding their child's achievement as the various stages of development are reached and passed. It is very important for parents to believe that educators put the child's needs at first in designing educational and related services. Not every parent may experience these stages of grief, suffering, and acceptance. However, as professionals, we need to be prepared to help parents work through these stages if needed.

Supporting parents

> “…At the very least, look beyond the child with ASD in treatment and get to know the family as a whole by asking questions about their experience with their child, starting from diagnosis. Learn who they are as individuals and recognize the numerous responsibilities that they have in addition to raising their child with ASD. Work to better understand their perspective of ASD and goals they have for their child. Understand how their view of ASD is influenced by their culture and respect those views when implementing treatment. Over time practitioners should learn to let go of assumptions that they have about families’ experiences and beliefs about their child’s ASD and get to know each family as a collection of individuals wholly different from any other family they have met. Most important, practitioners should convey to families that they see them as a group of individuals with unique needs and concerns.” (Fiske,2017, page 258).

As discussed in previous chapters, ASD can have a significant impact on parents, parent relationship, siblings and all family life and functioning. Derguy et al. (2015) have interviewed 162 parents and 84 controls to assess the needs of parents with ASD. The results have shown that in both groups parents needed the support in following areas: knowledge (need for information), skills (parenting skills, daily management skills (c) need for emotional support, (d) social network (e) material resources. Parents with ASD were different form parents of typical children in that they emphasized the need for material resources, information and educational guideance and priotirezed the need for emotional and social support.

We will divide supporting parents to two areas:

- providing education support thorugh parent training and parent education
- providing psychological (emotional) support

Parent training and parent education

One of the ways to support parents of children with autism is to provide parent training. Many names for parent training can be found in the literature, for example parent-implemented intervention (Meaden, Ostrosky, Hasan, Zaghlawan, and Yu, 2009), parent-assisted training (Frankel, Myatt, Sugar, Whitham, Goropse, 2010), parent education (Schultz, Schmidt & Stichter, 2011), parent training (Ingersoll & Dvortcsak, 2006), parent mediated intervention (Ingersoll & Wainer, 2013), family implemented training (Stewart, Carr and LeBlanc, 2007).

We can divide parent trainings in two groups (Bearss et al., 2015; Preece and Trajkovski, 2017):

- *Parent support or parent education*– programs that provide support for parents, educate them about ASD and give them knowledge about characteristics of children with ASD and information about different treatments
- *Parent mediated intervention and parent training* – parent is thought different skills to be able to promote acquisition of different skills or reducing challenging behaviour in the child.

Preece and Trajkovski (2017) in their literature review found only 12 articles that evaluate parent education. However, there were many positive impacts of parent education. Stress and anxiety of parents is reduced, parent child interaction, coping, communication, understanding of ASD, efficacy and confidence of parents as well as their quality of life. Those educations had different delivery format, but similar content like information about ASD, understanding communication, social and sensory issues, understanding and dealing with challenging behaviour (Preece and Trajkovski, 2017).

There are more studies which focus on evaluation of parent training programs (see Bearss et al., 2015 for review). Those programs use naturalistic approaches that are behavioural or developmental. Programs differ in: approach to intervention (behavioural or developmental), target skills (social and communication skills, play skills, behaviour management skills), delivery format, duration and intensity. Those programs can help parents to cope with everyday challenges, to teach their child through natural routines and to feel more confident as a parent. Parent training should be carefully planned and use evidence-based methods in teaching parents. Our experience with parents and in teaching students have showed us that it is not enough to explain or even to write a detailed procedure to parents or students. Even when teaching professionals, it is not enough to provide them with books, oral or written instructions for them to be able to learn how to teach children with ASD (see for example Moore et al., 2002). Several strategies have been shown successful in teaching parents, they were driven from behavioural skills training. It was used for variety of purposes, and it has for parts: instructions, modelling, rehearsal and feedback (Stewart, Carr & LeBlanc, 2007). First part, instruction, means that the strategy is described in detail to a parent, and sometimes written instructions are also provided. After that we model how to teach a specific skill to a child. Rehearsal means that parent is trying to repeat the strategy that we have modelled him, and, in the end, we provide her/him a feedback. Some practitioners insist that parent should become a therapist for the child and work on the same goals and use the same method as in school or other therapeutic setting. When starting a parent training it is important to explain the benefits of the training to the parent, the impact that we expect it to have on everyday life so that a parent is motivated to participate. It is also valuable to provide suggestions how a parent can conduct it through everyday routines with a child.

When choosing or evaluating parent training or parent education it is very important to consider not only gains for the child, but also the impact on family life and functioning as well as well-being and resilience of the family.

Providing psychological (emotional) support

Psychological (emotional) support can be provided to parents through counselling. The perspective on client is that they are healthy persons that found themselves in a challenging situation. It has an indirect influence on person’s life and behaviour. it can be conducted in a group or individually. The goal of counselling is to help a person to understand, accept and resolve their life perspective and teach them to accomplish goals that a person has set through choices based on facts and thinking processes. It incorporates principles of mental health, psychological and human development through cognitive, behavioral, affective and systematic intervention with the goal of the personal growth of the individual (Ratkajec Gašević, 2011).

Suggestions for practitioners (Fiske, 2017):

- Provide families with the explanation of the treatment and the reason why it is implemented, that will help them to be motivated for the implementation
- Inform the parents about the challenges that you expect in the treatment, so they don’t give up when they happen
- Use role-playing and practice with the child and provide parents with opportunity to practice and give them feedback, let them try to implement the teaching strategy when they have your support.
- Discuss with parents whether they wish to get the feedback during the interaction with the child or after
- Focus on positives – what a child can do, where is he/she progressing instead on focusing on skill deficits.
- When parents have problems with the implementation non-judgmentally try to find what went wrong and try to find ways to overcome barriers for implementation.
- Direct parents to information about evidence-based treatments but caution them that even the treatment is evidence based it is not necessarily effective for every child with ASD. Help them to develop ways to evaluate the effectiveness of the specific intervention with their own child.

- Try to be understanding when parents choose the treatment that is not evidence based and be prepared to help parents to evaluate the effectiveness of those treatments.
- Provide parents with information and resources they need to advocate for their child with ASD.

As indicated in the first module on Assessment and also in the second module on Specific interventions, you need a proper training in order to conduct assessments (eq. ADOS), interventions (eq. ABA), and we will reiterate this again: to be a counselor, you also need a special training, both theoretical and practical (level Ma or Ph.D.), and at least 1-2 years of supervised practice (depends on approach). The aim of this module is to give you an insight on challenges that families of children with ASD face and the unique way of how stressors can affect each family and develop their resilience. We hope it will help you acquire a real understanding of family perspective but also help you not to be arrogant and think that you know how it is to have child with ASD. It is important not to push parents processes in line with your own expectations and give them space to parents to share their fear, anger and sadness. Try to be there even though you do not know everything, you do not understand everything or you think you would make different choices in that situation. You need to be a cheerleader, both to children and families.

Glossary

Acute stressors - aspects of the context that have a specific start, shift and end (e.g. transition between places of employment).

Chronic stressors - are relatively stable and long lasting aspects of the context (e.g. socioeconomic status, disabilities, diabetes)

Family protective factors- refer to those characteristics that will make families stronger while facing the challenges. Some of factors identified as protective are: family cohesion, family belief system and coping strategies

Family resilience -family’s capacity to deal with and manage difficult circumstances, including the resources families possess that would enable them to face adversity and remain strong.

Family risk factors- refer to those characteristics that will make families more vulnerable. Family risk factors include: violence, poverty, single-parent homes, divorce, death

Family systems theory- considers families as units in which members of the family impact one another in bidirectional ways, trying to maintain equilibrium. Subsystems exist within the family. The subsystems are interdependent and each family member belongs to multiple subsystems.

Grieving – grief is the natural psychological, behavioural, social and physical response that helps the mourner recognize the loss and get ready for the larger and often longer experience of mourning. Mourning is the process of acclimating to living without this special someone or something. It is period of adapting to the changes created by this loss. ttps://english.stackexchange.com/questions/303094/what-is-the-difference-between-mourning-and-grieving-someones-death

Normative stressors- generally experienced, predictable and expected stressful events that are common in all the families across the life cycle- like birth, marriage, retirement, death of elderly members

Non normative stressors - are unexpected, atypical life events which are not always disastrous (natural disasters, loss of family member, sudden loss of income, winning lottery, accidental death) and tend to create more stress for families then normative stressors.

Parent support or parent education– programs that provide support for parents, educate them about ASD and give them knowledge about characteristics of children with ASD and information about different treatments

Parent mediated intervention and parent training – parent is thought different skills to be able to promote acquisition of different skills or reducing challenging behaviour in the child

The social-ecological model- Bronfenbrenner (1986) saw the child as being at the centre of any situation and everything else is placed around them in concentric circles, ordered based on how much influence he believed each factor had. Each of the layers within the model will influence and affect children, young people, and families’ lives in some way.

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Appendix 1

Valuable resources for parents, tips on how to respond to parents regarding different issues

Created within the ERASMUS + project Promoting social inclusion and wellbeing for families of children with special needs – PSI_WELL as part of the Building bridges: promoting wellbeing for family. Handbook for parents (www.psiwell.eu)

What is Autism Spectrum Disorder?

ASD is a developmental disability that appears early in a child’s life. It is characterized by the presence of difficulties in two areas:

1) *social communication and social interaction and*

2) *behaviour* - repetitive behaviours or fixated interests. (for details see Frame 1)

The combination of strengths and difficulties is unique for every child with ASD. There is a famous sentence „When you meet one person with autism, you met one person with autism“ that describes the diversity of needs and challenges of persons with ASD. Some people can have a lot of difficulties in everyday challenges and some have less. That can change during the lifespan, but also can vary depending on the specific situation or setting (in school, at home, in the supermarket).

What difficulties a child with ASD can have?

- The child doesn't develop language or when he does, he is not using it in a usual way. He may have echolalia (repeats words or phrases that he heard before, or entire sentences from cartoons)
- Children can have difficulties in conversation skills, in initiating, sustaining and finishing interaction with others.
- Most children don't develop imaginative play, if some do, they may always use the same "story" and insist in their scenario, they may play with objects in repetitive manner, or explore it sensory (taste it, touch it). They often have difficulties in playing with peers.
- Some children don't imitate peers or adults
- Children can have difficulties in using eye contact. Some children don't make eye contact, some are using it only in certain situations (for example, when they are requesting), some can't make eye contact and listening to the others at the same time.
- Some children don't express a range of facial expressions and it can be hard to figure out how do they feel, or what do they want. On the other hand, they also have troubles in "reading" non-verbal communication of others. They can rely literally on what people are saying without taking into consideration of how people are using gestures, facial expressions and eye contact to convey a message. This can lead to awkward interactions and misunderstanding of another person's intent. Unfortunately, difficulty with nonverbal aspects of communication may be particularly challenging with school-aged peers, who are often less tolerant of socially inappropriate behaviours than adults and have

fewer strategies for managing difficult social interactions with a social partner.

- These children often do not spontaneously seek out other people to “share” something important they are experiencing. They may not see the value in pointing out things they like or may not share their accomplishments.
- The child may have difficulty with the social “give and take” between individuals. Some examples of how these challenges may affect social interactions include the following:
  - It may be difficult for younger children to share and take turns with toys or other preferred items.
  - Adolescents or adults may have trouble showing or expressing concern when someone is upset, or trying to offer comfort to that person. This does not necessarily mean a person on the autism spectrum doesn’t notice when others are upset or doesn’t want to support them. However, they might have difficulty understanding why someone is crying or distressed or may not be aware that their empathetic efforts might ease a difficult situation for someone else. They may simply be uncertain how to alter their behaviour to better meet the needs of others.

Repetitive behaviours or fixated interests can also have different forms in children with ASD. Children can have repetitive movements, like flicking of fingers in front of the eyes, rocking back and forth or using objects in a repetitive way. The other form can be that children are overly occupied with a single object, idea, or person. And finally, they can have difficulties with coping with changes in the environment (NAC, 2011).

Some facts about ASD

Autism spectrum disorder (ASD) and autism are both general terms for comprehensive developmental disorders that are characterized by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviours. Previously, there were different types of that disorder (autistic disorder, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger Syndrome), but since the publication of DSM – 5 (Diagnostic and Statistical Manual of Mental Disorders) (APA, 2013) they were all merged into one diagnosis of autism spectrum disorder.

Sometimes, the terms Kanner or Classic autism are used to describe the most severe form of the disorder.

For the child to receive a diagnosis of ASD he/she must have difficulties in at least six developmental and behavioural characteristics before the age of 3.

There are two domains where people with ASD show difficulties:

1) social communication and social interaction
2) restricted and repetitive patterns of behaviour

More specifically, people with ASD have difficulties in social-emotional reciprocity, deficits in nonverbal communicative behaviours used for social interaction and deficits in developing, maintaining and understanding relationships. In addition, they have repetitive patterns of behaviour, including stereotyped or repetitive motor movements, insistence on sameness or inflexible adherence to routines, highly restricted, fixated interests, hyper or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment. Symptoms can be currently present or reported in past history. The DSM-5 has an additional category called Social Communication Disorder (SCD). This allows for a diagnosis of disabilities in social communication, without the presence of repetitive behaviour. SCD is a new diagnosis and much more research and information is needed. There are currently few guidelines for the treatment of SCD. Until such guidelines become available, treatments that target social communication, including many autism-specific interventions, should be provided to individuals with SCD. (Autism Speaks, 2014)

- **prevalence of ASD is approximately 1: 100 (Fombonee et al, 2011)**
- **44% to 52% of persons with ASD may have intellectual disabilities (http://www.autism.org.uk)**
- **ASD is 4,5 times more present in boys than girls (some studies suggest 2:1, many girls are unrecognized because ASD presents different in women and girls (Gould and Ashton – Smith, 2011).**

What causes autism spectrum disorder?

The answer to that question was not known until many researchers engaged in finding it. Today, we know that there are many causes, we can't just pinpoint one. Scientists have identified gene changes and mutations connected to ASD. In 20% of persons with autism, a specific genetic cause of ASD can be identified. However, most cases involve a complex and variable combination of genetic risk and environmental factors that influence early brain development. In other words, in the presence of a genetic predisposition to ASD, a number of non-genetic or environmental influences further increase a child's risk. The clearest evidence of these environmental risk factors involves events before and during birth. They include advanced parental age at time of conception (both mom and dad), maternal illness during pregnancy, extreme prematurity, very low birth weight and certain difficulties during birth, particularly those involving periods of oxygen deprivation to the baby's brain. Mothers exposed to high levels of pesticides and air pollution may also be at higher risk of having a child with ASD. It is important to keep in mind that these factors, by themselves, do not cause autism. Rather, in combination with genetic risk factors, they appear to modestly increase risk. While the causes of autism are complex, it is abundantly clear that it is not caused by bad parenting (Autism Speaks, 2014)

Parent to parent

(the sections highlighted in green boxes in this chapter are taken over from NAC, 2011 without changes as this are valuable perspectives of parents)

Parent to parent

Years ago, few people knew about ASD, and treatment was very limited. Unfortunately, parents — particularly mothers — were often accused of causing their children's symptoms. They were labelled "refrigerator moms" who failed to respond to the needs of their children. It was much more difficult for these parents to network and get support from each other. Friends and family members who weren't familiar with autism often walked away from relationships with these families because they didn't know what to do.

Due to extensive coverage in the media, many more people know about ASD than in the past. But this coverage doesn't always convey the complexities of autism. That means that you're still likely to encounter professionals, friends, and communities with an inaccurate or incomplete understanding of your child's disorder or the impact it has on your family. Don't be afraid to become an advocate for your child and an educator for your friends and your community. Many people simply require more information, or need to understand your experiences in order to become a source of support for you and other families who have loved ones with ASD. (NAC, 2011, page 22)

How is ASD diagnosed?

There are no medical tests for diagnosing ASD, diagnosis is still based on the child behaviour in different situations.

Elements of the diagnostic assesments are usually the following:

1. Clinical interview and observation
2. Using specific tests/critera for autism spectrum disorders
3. Cognitive/developmental assessment
4. Measurement of adaptive functioning
5. Specific biomedical tests (see Filipek et all, 2000)

ADOS (Autism Diagnostic Interview-Revised; Rutter, Le Couteur i Lord, 2003) and ADI – R (Autism Diagnostic Interview-Revised; Rutter, Le Couteur i Lord, 2003) represents a golden standard for autism diagnosis and it is recommended that one of those is incorporated in the diagnostic assessment.

How to manage interventions?

The process of finding effective treatment can be overwhelming and exhausting for parents! There are numerous treatments, promises of magic cure that are offered and no clear pathway in support system. A mother of a boy with ASD writes "Above all, I learned that we parents, no matter how much we long for a panacea must allow ourselves to be guided by something other than our own panicky need for instant answers. We must allow ourselves to be guided by our own God-given reason, our gift of logic as well as our hope and our prayers…" (Maurice, 1996, page 6).

Without a doubt, you are the most important expert in your child's world. You can provide a detailed account of your child's life, strengths, the challenges he currently faces, and the obstacles he has overcome. This detailed knowledge will be important to the professionals you work with, so it is important for you to collaborate effectively with the other experts on your child's team. Experts should appreciate your unique expertise, and you can greatly benefit from their professional knowledge and experience (NAC, 2011).

There are many evidence based treatments (for information see NAC, 2011 and NAC, 2015) but they may not be easily available or recognized. Far too many treatments that exist are not conducted in line of what is called good autism practice and far too many treatments are not evaluated at all. It is important that a professional who works with your child collects data before, during, and after treatment because it can help you and her/him to assess whether the child is making progress. Without clear data showing that a treatment leads to improvements of your child's skills, you may waste a lot of time on a treatment that isn't working for your child.

What is important is that you ask every treatment provider:

What does this treatment consists of? What is it supposed to do? How will you evaluate the treatment, how will I know if this treatment is effective for my child?

And if you are offered extensive medical examinations that can be stressful or aversive for your child, you can ask the following:

Why do you need that information? What will happen when I will know the results? Is it just to have information or will there be indication for change in my child's treatment? Will there be any change in my child's life *if I will know that information? What will happen if don’t do that examination?*

Effective educators and therapists will not be afraid to have you participate in your child’s treatment process. Don’t hesitate to ask if you can do a few observations when the professional is treating your child. It is perfectly reasonable for you to observe your child’s performance and the way the treatment is being implemented. (NAC, 2011)

If your presence affects a child’s behaviour a lot, you can ask the professional to take a video of session so you can observe it.

We live in a culture that often tells us not to question the authority of healthcare providers. But keep in mind that some healthcare providers may not have a great deal of experience or comfort with providing care to a child with ASD or other special needs. It’s perfectly acceptable to take the time to identify options, talk to other families, and be honest about your concerns. You might even need to have materials ready to educate the healthcare provider! As you do with all other professionals caring for your child, be respectful, listen carefully, engage in a candid dialogue, and advocate for your child when needed (NAC, 2011).

Parent to parent

Understanding the behaviour of typically developing children is important because we sometimes hold our children with ASD to a different behavioural standard than their peers. Some parents or families set expectations too low and others may set expectations too high. Ask yourself if a typically developing child would do the same thing on the playground or at the dinner table. Would this behaviour draw attention or be perceived as inappropriate? Expectations for our children with ASD should never be so low that they do not develop skills that will allow them to reach their potential and participate in community activities. But children with ASD should also not be singled out for unreasonably high expectations — all kids occasionally make bad choices, and many of these choices do not require extensive examination.

Use structure

Structure seems to help many children with autism to manage their environment. It’s often much more difficult for parents to provide the same structure at home that a child may have at school. This is often due to other children who need care, job requirements, cooking or cleaning responsibilities, and a parent’s legitimate need for personal relaxation. Remember that it may be difficult to provide structure during holidays or other extended breaks from school. Special planning and preparation can make a big difference.

Parent to parent

Your child will likely benefit from added structure at school, at home, or in the community.

- At school, your child may need help completing larger assignments (such as book reports or science experiments) or participating in group activities that require him to interact with peers to complete a project. He may also need more time to complete tests, assistance with writing down the answers, and a testing area with reduced distractions, etc. Not all school professionals will realize that your child will benefit from these kinds of modifications. This is particularly true if you have a child who appears to be better at communicating than she actually is. This means you may need to advocate on your child’s behalf. Your child will likely benefit from added structure at school, at home, or in the community.
- At home, you might want to structure homework time, modify chores by providing specific instructions, create checklists for your child, etc. We realize it may seem overwhelming to put all sorts of new strategies in place. But if your child needs a lot of structure to be successful, remind yourself how much easier things will be once you provide that structure.

- Community outings are naturally less structured. Using Schedules and Story-based Interventions can be a great way to help your child prepare for these activities. (NAC, 2011)

Siblings

Having a brother or sister with autism can be challenging and complicated at times. Siblings of children with autism may feel neglected, embarrassed, and confused. As a parent you can listen to the concerns and fears of your children and help them understand and accept the uniqueness of your family (Timmons, Breitenbach and MacIsaac, 2006).

Siblings may need the following supports (Wheeler, 2006):

- Communication from parents that is developmentally appropriate, factual, and ongoing. They must know that communication within the family is encouraged.
- Attention from parents that is not related to their brother or sister with ASD. They may need time to engage in “normal” family activities.
- Information about how to interact with their brother or sister in ways that are similar to other sibling pairs.
- Choices about how involved they should be in the care and treatment of their brother or sister with ASD.
- To feel safe and know that they will be protected from behaviours their sibling with ASD might exhibit.
- Appropriate time and support to deal with their own feelings about their brother or sister’s diagnosis.
- Interactions with other siblings of children with ASD to share their experiences.
- Just as parents need help, siblings need guidance on how to respond to questions about their brother or sister’s disability.

Care for Yourself!

Parent to parent

Don’t feel guilty if you need to leave your child with a sitter while the rest of your family sees a movie. Sometimes this is best for the entire family! Have your child’s team help him develop the skills he needs to go to the movies with the rest of the family, but don’t make the rest of the family wait indefinitely while these skills are being developed.

Parenting is difficult. Parenting a child with ASD carries unique challenges and stressors. Parents of children with ASD often report significant stress as they manage their child’s care. Common activities, such as shopping and dinners out with the family, can be difficult.

Supporting a person with ASD can place significant strain on a family’s physical, financial, and emotional well-being. Parents may experience stress as they decide how to allocate their attention and energy across family members. Parents may feel the strength of their marriage or interpersonal relationships is challenged or feel guilty about the limited time they spend with their other children, when so much of their attention is focused on the child with ASD. It would be easy to focus all of your

energies on your child with ASD, but it’s in his or her best interest for you to have the resilience that comes from remaining connected with other adults who care about you and your child. These relationships may exist in your household, but might also exist with friends, colleagues,

or other people who have a sustained interest in your well-being.

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Module 5: Advocacy for people with ASD

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Introduction

Disability refers to any impairments of physical, sensory or mental function, which may affect person's activity at school or work, and his/her involvement and participation in community life. Disability may be due to accidents, or to genetics or disease. Disability may be a temporary or permanent state, total or partial, inherited or acquired. Some disabilities are visible (sensory disabilities, motor disabilities, etc), others are invisible (learning difficulties, for example) (Disability Discrimination Act, 1994).

The paradigms and models of interpreting disability affects its treatment and approach.

The advocacy for people with mental disorders is one of the main areas of actions to be included in mental health policies. It is part of the emancipatory paradigm which promotes and sustains the voices of different types of minority. Mental health advocacy promotes the human rights of persons with mental disorders, and aims to reduce stigma and discrimination (WHO, 2003).

The main advocacy actions are: awarness raising, information, education, training, mutual help, counselling, mediating, defending, and denouncing. The main objective of advocacy actions is the reductions of main structural and attitudinal barriers towards people on the autistic spectrum, in order to enhance the quality of their lifes.

This module investigates the key-concepts related with this topic, such as discrimination and stigma, and presents the evolution of the advocacy movement from and within the emancipatory paradigm.

Further, it identifies the roles and interests of the main advocacy groups, the specific actions of advocacy, and its impact on integration, education, and therapeutic approach of persons with mental disability, in general, and of people on the autistic spectrum, in particular.

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Module objectives

At the end of this module, students will:

4. Understand and define key-concepts like prejudice, stereotyping, stigma, and discrimination, and the relations between them;
5. Understand the main forces, motives, and resorts of the emancipatory paradigm, and its principles;
6. Understand the importance and the impact of advocacy actions on policies, agencies, integration, discrimination, etc. and on the wellbeing of people on the autistic spectrum and of theirs families;
7. Understand the rationales of advocacy measures and actions;
8. Learn how to promote, sustain, and develop advocacy actions and measures.

Topics covered by this module

This topic of this module is strongly interlink with the modules on counselling, therapy, and education of people on the autistic spectrum.

The emancipatory paradigm, and the involvment of consumers and their families, of govermental and non-govermental institutions, general and mental health specialists, and so on, in advocacy actions impacted polici and legislations regarding the rights of people with ASD, raised awerness on their needs and interests, in term of health services (dianostic procedures and protocols, treatments, therapies and interventions options and alternatives, informed and voluntary participation to intervention, relations with the health services providers, etc.), education and schooling opportunities (inclusion, curricular adaptation and environmental accesibility).

Discrimination and related concepts

Although the definitions and meanings of discrimination seem to be clear, a closer look and analisys might generate controversial discutions and perspectives. A former morally neutral term, discrimination has today mostly „a negative valence” (Wasserman, 1998, as cited by Heinrichs, 2012), representing „actions that disadvantage people or groups of people because of certain traits such as sex, race, ethnicity, religious beliefs, but also disability, weight, age or genetic constitution” (Heinrichs, 2012).

The definition of discrimination has two main meanings (Oxford Living Dictionaries):

1. A neutral one: the recognition and acknowledgement of the difference between two things. In this case, the synonyms of the discrimination would be differentiation, distinction,

and

2. A prejudicial one: the unjust or prejudicial treatment of different categories of people, due to different criteria, such as race, age, gender, state of health, etc. In this case, the synonyms are prejudice, bias, bigotism, intolerance, narrow-mindedness, unfairness, inequity, favoritism, one-sidedness, partisanship, etc.

For this second meaning, the Cambridge Dictionary defines discrimination as the action of „treating a person or particular group of people in a *worse* way from the way in which you treat other people, because of their skin colour, sex, sexuality, etc., while Collins Dictionary reffers to discrimination as the „less fairly or less well” treatment of a person or group of people.

Merriam- Webster Dictionary refines the definition of discrimination toward particular person or group of people, by making the distinction between passive and active discriminatory actions generated by bias perceptions or labelling and categorization:

1. prejudiced or prejudicial outlook, action, or treatment, and
2. the act, practice, or an instance of discriminating categorically rather than individually.

Discrimination cand be direct, when it depends on specific traits, or indirect or by proxy, when a trait is used as a proxy for another trait (Heinrichs, 2012). For example, a teacher/school could refuse to enrole a student with disability because he is seen as generally inferior or inadequated for a specific educational program, or, by proxy, because they consider he will cost more money or will negativelly interfe to the teaching process, to the development and academic progress/success of the other students.

Considering all forms of discrimination subsumed to the following principle:

„*When someone discriminates against person A he treats her differently than another person B although he should not do so because they are not different*” (Heinrichs, 2012, p. 102),

we should take into consideration that there are differences between people (person A versus person B), in terms of traits.

At first sight, the problem seems simple: it is not ethical to differenciate and treat differently people based on specific traits. But people are different, and the mere fact of distinct these differencies is not, per se, wrong or intentfully harmful (Heinrichs, 2012).

From a moral perspective, the question is what are the traits which could be used to differentiate between ”alike” and ”unlike” persons, on a morraly valid reason: all, none, or some?

If all, there’ll be no ”alike” persons, so the concept of discrimination will be empty. If none, an extreme form of egalitarianism emerges, which could be resonable in terms of fundamental rights, but „higly implausibile in all posible fields of action” (Heinrichs, 2012, p. 103). The more available understanding of discrimination consists in using some traits for different treatment. Some traists look morally valid for different treatment in different contexts/situations(for ex., level of education, qualification), other seem imorally (such as gender, race).

Another problem arises when we have to decide to which category, moral or imoral, belongs a trait, and what are the criteria to establish that. Heinrichs considers that there are three criteria which should be used to put a trait on the excluded list of criteria for discrimination: traits through no fault of one’s own, immutable traits, and traits with special relevance for personal identity.

There are two types of discrimination: fair discrimination, and unfair discrimination.

The unfair discrimination represents a policy or an action of favourism, prejudice or bias towards people, in direct or indirect manner.

Discrimination is fair, and allowed in the following circumstances:

✓ when it’s based on affirmative action;
✓ when it’s based on inherent requirement for a particular situation;
✓ when it’s compulsory by law;

- ✓ when it’s based on efficiency/productivity (at work).

Positive discrimination or affirmative action measures (a topic which will be detailed later on this module) are designed to promote equity (fairness in favour of the designated groups). Through affirmative action, equality should be achieved without lowering standards, but addressing appropriate, compensatory measures for closing the gap between normative, and disadvantaged/vulnerable group.

Equality vs. equity

In order to understand the necesity of advocacy for vulnerable group and complex relations between discrimination and equal vs. fair treatment, we should investigate two more concepts: equality and equity.

In terms of human rights, all humans are “free and equal in rights”:

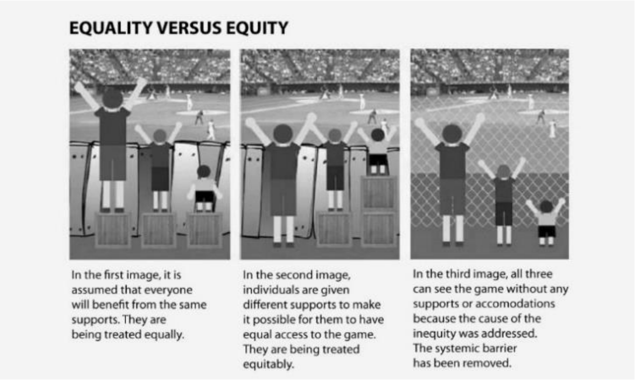
Article I *– Men are born and remain free and equal in rights. Social distinctions can be founded only on the common good.*

Article II *– The goal of any political association is the conservation of the natural and imprescriptible rights of man. These rights are liberty, property, safety and resistance against oppression.*

(Declaration of the Rights of the Men and of the Citizen, 1789, p.1)

But humans are extremely diverse, in terms of individual traits and needs, backgrounds, and upbringing and life circumstances. Thus, equal treatment is not synonymus with fair treatment in social domain. To quarantee the equality of all persons in terms of rights, society needs to implement adjustments (Fig. 1).

For example, the assurance of exactly the same educational opportunities and provisions for every students is the spirit of equality. But if a child has special conditions (low income, poverty, disability, etc.), he or she will need more to have the chance to overcome difficulties and to level to his/her collegues. Social adjustments, educational adaptations and accomodations are actions who promote equity.



EQUALITY VERSUS EQUITY

In the first image, it is assumed that everyone will benefit from the same supports. They are being treated equally.

In the second image, individuals are given different supports to make it possible for them to have equal access to the game. They are being treated equitably.

In the third image, all three can see the game without any supports or accomodations because the cause of the inequity was addressed. The systemic barrier has been removed.

Figure 1: Equality versus equity in society

While equality represents „leveling the playing field”, equity could be conceived as „more for those who need it” (Mann, 2014).

There are some important distinction between equality and equity (Tab. 1). The main characteristic of equity is the fact that it suggests the necessity and fairness of different distribution of resources and assistance, according to acknoledged individual needs.

There are many types of equality, but not all of them are appropriate in all context or for all purposes. (McCornachie, 2017). Identical, equal treatment can be inappropriate if persons have different characteristics (individual, environmental, social different characteristics).

Table 1: Differences between equality and equity

EQUALITY	EQUITY
Equality is the state or quality of being equal	Equity is the quality of being fair and impartial
Involves treating every individual in the same manner, irrespective of their differences	Involves treating each individual according to his or her needs
Does not consider requirements or needs of people	Consider individual needs of people

Especialy in education, equality, the „sameness” for all could be detrimental for the students with special needs. There are more valuable types of equality valuable for educational context. They are called „substantive” equality.

These substantive equality in school are translated in the following principles (McCornachie, 2017:

- It is important that all learners receive a basic education
- School should promote understanding and tolerance, and understand that equality consists in accommodation and valorization of differences, not in uniformizations
- Equality in school can break down old patterns of group disadvantage, and to prevent the development of new ones.

Equity is the aim of most affirmative actions or positive discrimination.

Stigma, prejudice and stereotype

At the base of any discrimination act resides a complex system of personal and cultural values, which mold own's mindset. This mindset further influence the ways of perceiving reality, of interpreting it through personal lenses of beliefs, rules, assumptions, and attitude. A distorted, narowed perception would generate faulse interpretations, and negative emotional and behavioral reactions.

Based on irrational beliefs, distorted perceptions, and cognitive distortions, people might missinterstand, missjudge, and misstreat other persons, who do not seem to be similar to them.

Prejudice is one type of cognitive error in assessing others. It represents a negative oppinion about a person or a group of persons. pre-formed oppinion is used to guide the reactions towards that person or groups of persons, even without meeting the, and prior to have the chance to know, observe, and gain knowledge about them.

Due to prejudicial thinking**, steoretypes** tend to be use in assessing and describing each member of a specific community. The stereotype is a overall generalizations about all the members of a culture, religion, gender, etc. Usually stereotype is a negative belief about a group.

This steoretypes and preconception cast a stigma or a label on person or on an entire group of persons. Stigma represents a negative perception/disapproval of a person.

Figure 2: Stigma and related concepts (by Brayden Habben)

Labeling theory, based on the idea of the social construction of reality, affirms that people tend to identify themself and behave in a manner that reflect the label attached to them by others.

Labelling a person or a group means to define that person/group based on their condition. Labelling will generate a stereotypic assessment of a member of the group, only as a consequence of apartenence to that group. Stigmatized social groups are izolated, separated, devalued, and discriminated (Link et al., 2004).

Discrimination is the behavioral response to prejudice, and might consist in avoidance, withhold educational or job opportunity, withholld help, etc.

Anti-discrimination acts

Fundamental human rights, and all civil, cultural, economic, political and social rights are universal, indivisible, interdependent and interrelated. The efforts must consist not only on measure against the violation of these rights, but also on actively promoting and protecting them. Anti-discrimination acts aim to empower discriminated persons or groups of persons.

Discrimination Act -1991– racial 75, age, sex 75

Disability Discrimination Act – 1995, 2005

These principles of equity for persons with special needs, , applied to educational system, are stressed in The Salamanca Statement (1994):

„2 . We believe and proclaim that :

- *every child has a fundamental right to education , and must be given the opportunity to achieve and maintain an acceptable level of learning,*
- *every child has unique characteristics , interests , abilities and learning needs,*
- *education systems should be designed and educational programmes implemented to take into account the wide diversity of these characteristics and needs,*
- *those with special educational needs must have access to regular schools which should accommodate them within a childcentred pedagogy capable of meeting these needs,*
- *regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes , creating welcoming communities , building an inclusive society and achieving education for all; more over, they provide an effective education to the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system."*

(The Salamanca Statement, 1994)

The actions against disctimination, called affirmative action or positive discrimination, intend to provide access to different systems (education, work, health and care welfare, etc.) to people traditionally discriminated, to creat a more egalitarian society

„It is no longer about support and ideas of inclusion, it's about the law"

„The terms affirmative action and positive discrimination originate in law, where it is common for lawyers to speak of affirmative or positive remedies that command the wrongdoer to do something. In contrast, negative remedies command the wrongdoer to not do something or to stop doing something." (Mooney, 2007, p.9).

Emancipation and Advocacy

Mental disability, like many other types of disability, represents a vulnerability per se, but constitues a great factor of vulnerabilizations through prejudice, stigma, and discrimination.

Mental health and mental disability do not receive the same importance as physical health, in many cases being neglected and/or ignored (WHO, 2001).

WHO (2001) presents the main barriers which become risk factors to mental health:

- Lack of mental health services or, at least, not entirely effective and comprehensive treatment;
- Unaffordable cost of mental health;
- Lack of parity between mental health and physical health in terms of governments and health insurance companies' investments
- Poor quality of care in mental hospitals and other psychiatric facilities.
- Absence of alternative services run by consumers.
- Paternalistic services, dominated by the views of service providers and not of the consumers
- Violations of human rights of persons with mental disorders.
- Lack of housing and employment for persons with mental disorders.
- Stigma associated with mental disorders, resulting in exclusion.
- Absence of programs for the promotion of mental health and the prevention of mental disorders in schools, workplaces and neighborhoods.
- Lack or insufficient implementation of mental health policies, plans, programmers and legislation.

To overcome these shortcomings, to promote the rights of persons with mental disability, and improve their quality of life, persons with mental disabilities and their allies had to raise their voice to be heard. They had to emancipate. These are the main objectives of advocacy.

The medical model sees the disabilities as a disease, a medical condition, and the person with disability as a "problem", unable to do some things. The main effects of this approach consist in creating “special” schools and shelters workshops for people with disabilities.

The ‘medical model’ of disability focuses on the person’s impairment or physical or mental medical condition and regards the person as the ‘problem’ and unable to do certain things. This thinking has been fundamental in approaches like sending children to ‘special’ schools or employing people with disability only in sheltered workshops.

The “charity” model considers persons with disabilities as persons in need of “help”, unable to do things for themselves, so it offers support. In this model, helplessness of persons with disabilities is highlighted and used as main purpose for fundraising campaigns. This model, often adopted by mainstream media, risks to undermine the autonomy, independence and rights of people with disabilities.

The most empowering model is the “social” one, which stresses the distinction between impairment and disability, and aims to remove barriers and restrictions of life choices for people with disabilities. This model shows that disability is a social construct, the effect of society’s inability to offer solutions for impairments.

The emancipatory/transformative movement aims to make heard the voices of those who were overruled, stigmatized, ignored, and excluded by society. The emancipatory paradigms affirms the right of vulnerable groups to be listened, their wishes to be respected, and their interests to be protected. Thus, these marginalyzed persons/groupd become more active members of their communities (Citizen Advocacy, Information and Training, 2000).

The advocacy movement encourages the support of vulnerable people, speaks on behalf of anyone who’s rights and wishes are overruled or ignored: persons with intellectual disability, gay men and lesbians, the elderly, homeless people, children (especially those in care) and people in jail.

The main objective of advocacy are equity and social justice through empowering disadvantage groups, such as persons with disabilities, promoting and supporting their active participation and direct involvement in decision making processes concerning their lives. Advocacy could change mentalities and attitudes toward people with disabilities, challenge barriers to their inclusion, improve policies. Through advocacy, persons with disabilities are supported, enabled, included, and empowered.

In the case of persons with mental disorders, more and more organizations and families become involved in advocacy, and, eventually, even the persons with mental disability themselves get involved, acting on their own behalf. People's ability to act and advocate on behalf of themselves and their families are known as self-advocacy.

Disability advocacy acknowledges the aspects that may have negative effects on a person's or a group with disability life and activity. Disability advocacy acts for raising public awareness, empowering, and reducing inequities, unequal opportunities and barriers in life choices for people with disabilities.

Initially, persons with disabilities, the consumers and their families begin to organize and to make their voice heard. Non-governmental organizations, professionals from general and mental health services, and some government agencies joined to them.

Consumers started to affirm and to solicit the needed and adequate services, made informed decisions about treatments and life choices.

Advocacy aims to change mental health policy and legislation for the benefit of consumers and families. Advocacy consists in raising awareness, disseminating information, educating, counselling, mediating, defending and denouncing

Advocacy actions

There are two main methods of advocacy:

- **Lobbying or direct communication** refers to influencing decision makers, policy makers through direct, private communications, and personal meetings.
- **Campaigning –** public actions raising attention on a specific issue, to generate a response from a wider audience. Campaigns use various techniques, such as chain e-mail or letter, editorials, newsletters, celebrity endorsements, media partnerships with newspapers, journalists and film-makers, web-based bulletins and online discussions, public events, large-scale advertising campaigns.

Disability advocacy may have different types.

It could be **self-advocacy**, when a person with disability speaks and represents his/herself.

An **individual advocacy** represents a one-on-one approach, when a professional advocate, a family member, friend or volunteer takes position to prevent unfair treatment or abuse or report it to the justice system.

Group advocacy represents the interest of a group of people with disabilities or specific type of disability.

When community volunteers become to advocate for the rights of a person/group of persons with disability, over a long period of time, we talk about **citizen advocacy.**

Systemic advocacy refers to long-term actions and efforts for social change, for promoting and supporting collective rights, and interests of people with disabilities.

Legal advocacy is performed by a lawyer, who offers legal representation in the justice system, tries to positively change the legislation, or gives legal advice in for cases of discrimination or violation of human rights.

Disability advocacy includes the following actions:

- Providing information to people with disability about their human rights and identifying cases of discrimination.
- Assisting people with disability to uphold their rights by speaking with and writing to people and organizations to raise awareness of problems and seek solutions.
- Helping people with disability negotiate complaints processes or legal action to enforce their human rights.
- Writing submissions and lobbying government to make changes that promote and protect the rights of people with disability.
- Campaigning for social change by speaking to the media to raise awareness and highlight situations where people with disability are treated unfairly.

However, disability advocacy do not imply providing counselling, making decisions for another person, providing mediation or providing case management.

Advocacy campaign - development and implementation

Disability advocacy requires special skills, such as: the ability to communicate and support people with disabilities, knowing and understanding laws, legal instruments and jurisdictions, knowing and adapting human rights approach to advocacy, negotiation skills, and lobbying and running campaigns skills.

An advocacy plan should factor in all the elements described in the previous sections – goals and objectives, target groups and the specific activities to be undertaken, as well as set out stakeholder roles and responsibilities, time frames, expected short-term and long-term outcomes, and available and needed resources.

In planning and developing an advocacy action, it is important to use a logic model of steps (Fig. 1) (WHO, 2008):

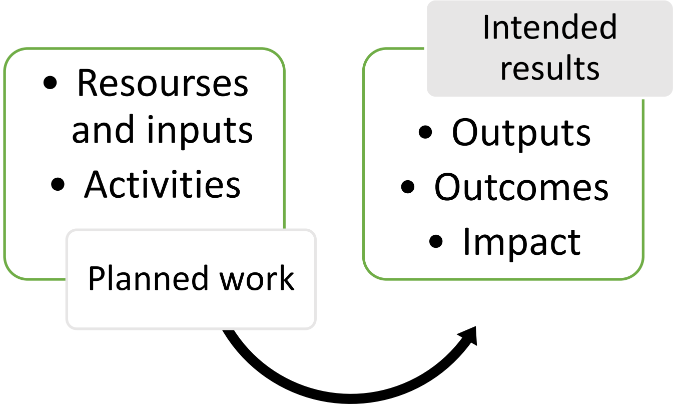


Figure 1: A logic model of planning advocacy actions (WHO, 2008)

A logic model is a visual presentation of steps to follow in developing and implementing an advocacy campaign. The relations between the model components are conditional, „if-then".

There are some suggestions to be consider when beginning an advocacy campaign:

- There may be controversies, but they are not fear of but to try to be turned into an advantage for the campaign.
- Any illegal or unethical activities should be avoided.
- Policy-makers should be held accountable to their commitments.
- A record of successes and failures helps in assessing progress and planning further measures.
- Advocacy group members should be kept on track, informed and motivated, at least monthly.

- Monitor public opinion and publicize positive developments.
- Acknowledge and credit the role of policy-makers and coalition partners.

„One voice calling for change is more powerful when combined with many others”

The following list of actions suggests a possible sequence of steps to take when implementing the advocacy plan:

- Define the current national or regional advocacy needs.
- Identify, categorize and map the affiliations and influence of the stakeholder community.
- Decide on and document the current goals and objectives to raise awareness for the topic, and the need for a comprehensive plan among key political decision-makers within one year.
- Assess and document the advocacy methods used (e.g. the media used, the network of contacts, communications vehicles, government relations).
- Assess the quantity and quality of services available at the time (e.g. education, information dissemination and new legislation).
- Assess and document the available collective resources (e.g. financial resources, human resources (staff, professional, volunteer), social capital (trust, understanding, communications).
- Consult and cultivate a network of champions/leaders/charismatic persons who lead by example and demonstrate the values and goals of comprehensive approach of the topic.
- Engage members and stakeholders by building common ground through shared visioning, planning, actions and learning.
- Enable and mobilize the stakeholder network to act collectively with a unified voice and vision.
- Measure the impact of action to date, modify the advocacy methods as necessary, and expand the network through community outreach and public engagement, leveraging the collaborative momentum created.

Advocacy groups – roles and interests

The advocacy movement and the advocacy specific actions are initiated and developed by different specifc groups, inspired and motivated by specific interests and aims.

The main groups interested and involved in the advocacy movement for the persons with mental disorders are:

- Consumers and their families
- Communities – therapeutic community?
- Nongovernmental organizations
- Professionals in mental health system
- Policy-makers
- Mass-media

Consumers and their families

Persons with mental disorders tend to organize in different types of organizations, from informal ones to legally established associations.

Initially, their main motivations for associating are to give and get mutual help by sharing personal experiences and challenges with the disorders, but also to redefine their relations with health services (treatments, specialists, etc.), and to identify efficient ways of improving social, school and job inclusion. The emancipated attitudes of the consumers denounciated some aspects of treatments, considered negative: poor service delivery, poor access to care, involuntary tretment, etc. (WHO, 2003).

The effects of consumers' involvement in advocacy movement consists in modifications of policies and legislations regarding their rights, raising awarness and sensitized the general public for their cause

The motivations and interests of the families are, at some degree, similar with those of the consumers.

WHO (2003, p.18) presents the most important roles of consumers and their families in advocacy:

- Raising awareness about the importance of mental health and mental disorders for the quality of life of populations.
- Information, education and training on consumer and family needs and rights, mental disorders and methods of combating stigma.

- Contribution to the development, improvement and implementation of policies and legislation.
- Involvement in the development, planning, management, monitoring and evaluation of services.
- Counselling, mediating and defending other consumers and families through service utilization and treatment decision processes.
- Developing support networks: mutual help for information exchange; emotional and instrumental support.
- Denouncing poor access to and quality of services, violations of rights, and stigmatizing behaviors.
- Denouncing socioeconomic and cultural conditions that have adverse influences on the mental health of populations.
- Developing alternative services run by consumers and/or families.

Case study – The Son-rise program

A clear case of consumers and their families's affirmative actions is the foundation of the Son-Rise program (see Chapter 2?). Barry ("Bears") Neil Kaufman and Samahria Lyte Kaufman, parents of Raun, received the diagnostic of their son being severely and incurably autistic. They were advised to institutionalyze their son, considered to have ahead a rather "hopeless, lifelong condition."

The Kaufmans dfind themselves another way to approach and reach theirs son, and thus created and developed an innovative home-based, child-centered program, completelly different from existing methods of treatment, called The Son-Rise program. The program was consists in a complete different interpretation, and, subsequently, interventions to this special condition.

Started as a family endeavour, this program rose into an internationally acknowledge, and important alternative to traditional recommendations, treatments, and interventions.

In the last decades, the Kaufmans structured this program, created a training center, and trained staff in this methods, in order to help other parents, but also professionals to work and connect with children with autism. It is considered that the programs from the Autism Treatment Center of America in Massachusetts and various international outreach programs were attended by persons from 130 different countries.

The importance and prestige of this program is demonstrated by numerous books authored by the Kaufmans, translated in 22 languages, by the articles and chronicles from major media, and reckognision from well-known and well-respected personalities.

More than this, Raun, their son, an obviuos evidence of the efficacy of this program, became an inspirational, motivational voice, and advocate for the rights and needs of people on the autistic spectrum.

The principles of Son-Rise Program (https://www.autismtreatmentcenter.org/contents/about_son-rise/) are clear examples of taking into account the voices and perspectives of consumers and their families, and assuming of responsibility for own destiny and decisions. Son-Rise Program expresses the trust in consumers and families' strengths and potential and empowers them to become actively and purposefully involved in intervention, in establishing objectives, planning and developing strategies.

Nongovermental organizations

Different types of nongovermental organizations are involved in promoting people's with disability rights, changing community and society's attitudes towards them, and improving health services for them. The interests of nongovermental organizations are diverse, from promoting better health services, human rights, civic liberties, to sustain social inclusion.

Nongovernmantal organizations can be stricltly professional, including only specialists in mental health, or can be interdisciplinary, including different categories of stake-holders.

The main interest and the most important contributions of these organizations consist in supporting and empowering consumers and their families.

These are the specific advocacy actions of nongovermental organizations WHO, 2001):

- reinforce and complement consumer and family advocacy positions with the views of mental health professionals;
- train consumers and families in mental health issues and leadership;
- help consumers and/or families to create their own organizations;

- provide professional support to consumers and families at times of crisis (consumers and families working in advocacy are often exposed to high levels of stress that can precipitate crises);
- provide mental health services to consumers and families.

Autism Speaks is an organization founded in 2005 by Bob and Suzanne Wright, grandparents of a child with autism. This organization carries the legacy of three leading autism organizations, Autism Coalition for Research and Education (ACRE), the National Alliance for Autism Research (NAAR) and Cure Autism Now (CAN).

Its main objectives are:

- To promote solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families through advocacy and support;
- To increase the understanding and acceptance of people with autism spectrum disorder;
- To support researches into causes and better interventions for autism spectrum disorder and related conditions.

Autism Speaks invests and develops strategies for significant progress toward the following outcomes:

- A better understanding of the causes and typology of ASD
- Children with an autism spectrum disorder being diagnosed before the age of 2
- Children having access to appropriate intervention, services and resources immediately following diagnosis
- The availability of better treatments both for underlying pathology as well as co-existing conditions that decrease quality of life for those with autism
- People with ASD and their families have transition plans that result in more independent adult life that is meaningful to the individual
- Individuals with ASD will have effective interventions, services and supports throughout their lifetime.

The main advocacy priorities of organizations militating for people on the autistic spectrum's rights are (Autism Speaks, https://www.autismspeaks.org/our-advocacy-priorities):

- **Increasing global understanding and acceptance of autism** by educating legislators and regulators on autism spectrum disorder to ensure policymaking that benefits people across the spectrum.
- **Being a catalyst for life enhancing research breakthroughs** by increasing funding for autism research at federal agencies, including the National Institutes of Health and the Department of Education, and by reauthorization of the ***Autism CARES Act*[7].**
- **Increasing early-childhood screening & timely intervention** by ensuring that people with autism have **access to the healthcare** they need, irrespective of payer (Medicaid, private insurance, etc.).
- **Improving outcomes for transition age youth across the spectrum** by
  - increasing access to housing and community-based services (HCBS) for individuals and increasing HCBS capacity to provide meaningful services for people with autism and their families.
  - Improving the quality and accessibility of employment-focused training systems for individuals with autism as well as advocating for increased employment opportunities.
  - Increasing equitable access to high-quality postsecondary education opportunities for students with autism.
  - Expanding support for resources and practices that keep our community safe, including ***Kevin and Avonte's Law*[8]**.

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[7] The Autism Collaboration, Accountability, Research, Education and Support Act (Autism CARES) is the **primary source of federal funding for autism** research, services, training, and monitoring. Autism CARES became law in 2006 when it was originally called the Combating Autism Act. It was reauthorized in 2011. In 2014, it was renamed and reauthorized again.

[8] This bill amends the Violent Crime Control and Law Enforcement Act of 1994 to reauthorize the Missing Alzheimer's Disease Patient Alert Program and promote initiatives intended to reduce the risk of injury or death relating to the wandering or elopement of children and adults with autism, other developmental l disabilities or dementia. The bill honors the memory of Kevin Willis and Avonte Oquendo, two boys with autism who drowned after wandering from a supervised setting.

- Making ***ABLE accounts***[9] widely available.
- Ensuring staff across settings have appropriate training, particularly related to challenging behaviors, safety, sensory needs, and augmentative and alternative communication.

Autism CARES requires and supports:

- Autism prevalence monitoring.
- Training of medical professionals to detect and diagnose autism.
- Development of treatments for medical conditions associated with autism.
- The Interagency Autism Coordinating Committee (IACC) and its annual strategic plan.
- Centers of Excellence in autism surveillance and epidemiology
- Countless programs and research grants to benefit individuals with autism.

Due to Autism CARES Act, there have beem made significant scientific progress and breakthrough in understanding and approaching people on the autistic spectrum:

- Set a reliable diagnosis age of 18-24 months
- Established that timely interventions makes a lifetime of difference
- Identified co-morbidities
- Increased understanding of biological causes of autism
- Identified genes and possible medication targets

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[9] ABLE Accounts, which are tax-advantaged savings accounts for individuals with disabilities and their families, were created as a result of the passage of the Stephen Beck Jr., Achieving a Better Life Experience Act of 2014 or better known as the ABLE Act. The beneficiary of the account is the account owner, and income earned by the accounts will not be taxed. Contributions to the account, which can be made by any person (the account beneficiary, family and friends), must be made using post-taxed dollars and will not be tax deductible for purposes of federal taxes, however some states may allow for state income tax deductions for contribution made to an ABLE account.

- Developed early career autism researchers.

Professionals in general and mental health

Usually, general health workers and mental health workers are less involved in advocacy initiatives than consumers, families and nongovernmental organizations.

The advocacy from general and mental health providers is more represented and active in places where paradigm shifted from psychiatric hospitals to community services. The main roles of mental health workers are to protect their consumers' rights, and to raise awareness about their needs for improved services (Cohen & Natella, 1995; García et al., 1998; Leff, 1997).

Implication of mental health workers is motivated by different factors, such as empathy for persons with mental disorders, compassion.

Also, mental health workers often experience similar discrimination and stigmatization to those experienced by persons with mental disorders, have lower wages than professionals from general medical services, worse working conditions, etc.

They may benefit themselves from advocating for the rights of people with mental disabilities.

Sometimes, conflicts of interest can occur between mental health workers and consumers, when the requests for higher wages are contrasted with the requests of consumers' campaigns for their rights to be respected, for improvements in mental health services. Mental health workers may feel targeted in campaigns requesting fair and respectful treatment for people with mental disabilities or campaigns denunciating stigma or violations of rights during treatments or interventions.

As first steps in involving in advocacy for mental health, professionals in mental health services should use and apply to their patients the methodology of informed consent, least restrictive care alternative, and confidentiality, whenever possible and relevant for treatment. Mental health consumers, as any other citizens, should be informed and consulted about any clinical decision during the different stages of the treatment process.

Mental health professionals could also participate in activities of consumer groups and family groups, support the development of consumer groups and family groups, and plan and evaluate together with the family suggested mental health services.

Policy-makers

Policy-makers can play important roles in advocacy, by implementing advocacy actions for improving the mental health of population.

Ministries of health may act directly or may indirectly promote advocacy by supporting other advocacy organizations (consumers, families, nongovernmental organizations, mental health workers), convincing other policy-makers and planners (executive branch of government, ministries of finance and other ministries, (the judiciary, the legislature and political parties) to be involved and to invest in mental health or creating advocacy activities in partnership with media.

As in the case of mental health professionals, there could be conflict of interest or contradictions between health ministries and other advocacy groups, as some of the measures or situation advocated against are in the responsibility of ministry.

Contradictions may arise between ministries, in terms of their motivations and measures, and opposition parties, trade unions in the health sector, and even consumers and family organizations.

Impact of Advocacy for mental health services and providers

Advocacy may change mentalities, attitudes and behaviors towards people with disabilities.

Consumers raises voices and express their own vision and opinion about the health services and about the conduct of health services providers, making informed decisions about medical intervention, treatment, and important aspects of daily life. Through advocacy, people behind labels and diagnoses are revealed.

> *„Those who have been diagnosed with mental illness are not different from other people, and want the same basic things out of life:* adequate incomes; decent places to live; educational opportunities; job training leading to real, meaningful jobs; participation in the lives of their communities; friends and social relationships; and loving personal relationships*"*
>
> (Chamberlin, 2001)

Advocacy generates positive effects for consumers and their families:

- the decreases in the duration of inpatient treatment and in the number of visits to health services.;
- a reinforcement of consumers and families' knowledge and skills acquired through contact with services;
- the building of self-esteem, feelings of well-being, enhanced coping skills of the consumers and their families,
- the strengthening of social support networks;
- and the improvement of family relationships.

Advocacy can improve people's access to mental health services and can stimulate the development and implementation of programs on mental health promotion and mental illness prevention, at national level.

Also, it can help in developing treatment programs and rehabilitation strategies for people with mental disability, improving and implementing mental health legislation, and stimulating the financing of mental health services and provisions.

Impact of Advocacy in education and counseling

In education field, advocacy promotes inclusion, the necessity to provide to all students, with or without disabilities, equitable opportunity to quality education, to effective educational services., to needed supplementary aids and support services. It sustains that classroom should be age apropriate, in every students' neighborhood schools. Schools' main goal should be to prepare students for productive lives as full members of society.

Inclusive education, that is the practice of educating all children of all abilities in one classroom, is the goal standard.

Although IDEA (The Individuals with Disabilities Education Act, 1975), many times revised along the years, provides guidance to educating children with disabilities, especially in the least restricted environment, many children with disabilities are educated in segregated classroom or even school still.

WHO (2001, 2003, 2007) offers suggestions for efficient and succesful advocacy for inclusive education, relevant for parents, and for any persons involved in promoting it:

1. It is important to know the definition of inclusive education.
2. It is important to identify the specific law that support the education of students with disabilities.
3. Gather researches, studies and study cases that supports inclusive education, and prove its positive effects. Inclusive education has been proven to be beneficial to the social, academic, physical and emotional growth for both students with and without disabilities.
4. Find out the position of school/educational system regarding inclusive education.
5. Contact national organizations who support the inclusion of people with disabilities in all areas of life, including school.
6. Families and school should develop and maintain a good, honest and efficient communication, sharing the relevant information about the child with special needs, his/her strengths and weaknesses. This type of communication help to decide what types of supports are needed in and around the school for successful inclusion.
7. Parents and teachers could identify and share few inclusive education resources (hand-outs, books, video, etc.), to help undestand the inclusion.
8. Find-out resources in your community, find opportunities for training and support for inclusion, and any extra materials and expertise available.
9. Find people with similar experiences and ask for their ideas and suggestions. Learn from their experiences, take notes, and ask questions, face-to-face or on-line.
10. Inclusive education is a program who requires a system of support from all school personel (from the principal to the teacher, bus driver, lunch supervisor and recess monitor, etc.). Also, inclusive education requires parents participation, availability for meetings, response to corespondence, regularly communication with child’s teachers.

Annexes: Barriers and solutions for advocacy

WHO, 2001:

Barriers	Solutions
Resistance to advocacy issues from policy-makers and planners. They consider that the defense of consumer rights or the plea for better mental health is either critical of their work or not relevant in the country or region concerned.	Formulate advocacy issues from a technical point of view, demonstrating that the defense of consumer rights and the improvement of mental health have positive health outcomes and cost-benefits.
2. Division and friction between different mental health advocacy groups. The conflict results in the advocacy groups losing strength and the ability to get their messages to the general population and policy-makers.	Help the different mental health advocacy groups in the country concerned to find common issues and goals. Facilitate the formation of large alliances or coalitions.
3. Resistance and antagonism from general health workers and mental health workers to advocacy for consumers' rights and better quality of mental health services.	Do not become involved in conflict with health workers' unions. Try to find common ground on advocacy issues, e.g. by establishing how working conditions would improve with the upgrading of the quality of services.
4. Very few people seem interested in mental health advocacy and proposals are not receiving support from the general population at the national or regional level.	Local actions are necessary. Implement pilot experiences or demonstration areas where advocacy proposals can be tested.
5. There is confusion about the theory and rationale of mental health advocacy. Stakeholders do not seem to believe the soundness of the ideas presented to them.	Organize a seminar on mental health advocacy in the country or region concerned with the participation of international experts and the main stakeholders.
6. Few or no consumer groups, family groups and nongovernmental organizations are dedicated to mental health advocacy in the country or region concerned.	Help to organize advocacy groups, identify and support stakeholders that have an interest in advocacy, and/or empower existing groups.

Conclusions and recommendations

Advocacy represents a responsible and assumed action for defending the human rights of different groups of minority, once ignored and overlooked. It is an important social response, for promoting the rights, expressing the voice and the needs, and for improving the attitudes and the behaviors towards different minoritary/special groups. Advocacy aims to enhance and improve their inclusion, and, finally, has impact on their wellbeing.

The advocacy movement and actions are very diverse and differ from country to contry in terms of organization, power and influence.

The recommendations differ, depending of the level of strenghts and structure of the advocacy movement in specific regions.

6.1 Countries with no advocacy group (WHO, 2007)

1. Set priorities for advocacy actions from the ministry of health, based on interviews with key informants and focus groups.

2. Draw up a brief document showing the priority mental health advocacy issues in the country (e.g. conditions in psychiatric institutions, inaccessible primary care services, discrimination and stigma against people with mental disorders). Support the document the country’s policies, legislation, programs or guidelines relating to these issues.

3. Disseminate the above document throughout the country via the supporting organization for mental health at the levels of health districts, community mental health teams and primary care teams.

4. Identify one or two psychiatric services with the best practices in the country and negotiate a joint demonstration project. This should involve the ministry of health and the psychiatric services. It should have the goal of forming consumer groups and/or family groups with advocacy functions. Technical support and funding are necessary.

5. Identify one or two stakeholder groups interested in the rights of people with mental disorders or in the promotion of mental health and the prevention of mental disorders.

Carry out advocacy activities with them cooperatively on a small scale. These small projects can be used as a basis for attracting greater funding and for the expansion of advocacy activities in subsequent years.

6.2 Countries with a few advocacy groups (WHO, 2007)

1. Empower the advocacy groups by providing them with information, training and funding. Focus on consumer organizations.

2. Carry out external evaluation of the advocacy groups, identify best practices among them and demonstrate them to the rest of the country as models.

3. Organize a seminar on mental health advocacy and patients' rights, inviting the advocacy groups and national and international experts on these matters.

4. Lobby the health minister and other health authorities so as to obtain explicit support for advocacy in mental health.

5. Conduct a small campaign, e.g. using radio and leaflets, in order to inform the population about the advocacy groups.

6.3 **Countries with several advocacy groups ((WHO, 2007)**

1. Maintain an updated census of the mental health advocacy groups, and particularly of the consumer groups, in the country. Periodically distribute a directory of these groups.

2. Invite representatives from advocacy groups to participate in some activities at the ministry of health, especially on the formulation, implementation and evaluation of policies and programs. Try to disseminate this model to all health districts.

3. Co-opt representatives of consumer groups and other advocacy groups on to the visiting board for mental health facilities or any other board that protects the rights of people with mental disorders.

4. Train mental health and primary care teams to work with consumer groups.

5. Conduct an educational campaign on stigma and the rights of people with mental disorders. Try to incorporate issues about the promotion of mental health and the prevention of mental disorders.

6. Help advocacy and consumer groups to form large alliances and coalitions.

The implementation of some of these recommendations can help ministries of health to support advocacy in their countries or regions. The development of an advocacy movement can facilitate the implementation of policies and legislation on mental health.

Authorship statement

The authors of this paper take public responsibility for the content and have had equal contribution in concept development, design, analysis, writing, or revision of the manuscript.

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