ABC'S OF
Autism

The ABC's of Autism: Mobilising diverse approaches to training ASD professionals

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ABC'S OF
Autism

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General Disclaimer

It's important to clarify that this handbook serves as an educational and intervention tool rather than a therapeutic one. Its primary objectives revolve around improving social awareness, educating and supporting families, and enhancing social and communication skills.

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Autism

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Content

Introduction

The American Psychological Association (APA) describes Autism Spectrum Disorder (ASD) as a neurodevelopmental disorder typified by significantly poor verbal and nonverbal communication, restricted interests, and repetitive behaviour (DSM-5; American Psychological Association, 2013). Before the age of three, the disorder begins to show symptoms, but these vary considerably among children depending on their chronological age, language ability, and developmental stage (Andersson, Maniscalco and Gillberg, 2014).

The effects of these behaviours can be minimal or disabling. Autism's defining characteristic is inadequate social interaction. Typically, parents are the ones who initially identify their child's autistic symptoms (Glascoe, 2003). An increasing need for education and support for that population is evident for making physical, social and attitudinal environments more accessible, inclusive and supportive for them; also, for developing their social and life skills to be integrated into society and live independently (Keen, 2009). Differences in the social communication skills of the autistic population include difficulties in initiating and responding to joint attention,

Since every child or adult with autism has different strengths and challenges, there is no one-size-fits-all strategy for autism therapy and intervention. Every autism intervention or treatment strategy should, therefore, be customised to meet the needs of the individual. (autismspeaks.org). For this reason, it is crucial that professionals who work with ASD (such as occupational therapists, speech and language therapists, physical therapists, behaviour support professionals (such as BCBAs, RBTs, and behaviour analysts), counsellors, and psychologists) are trained in a variety of interventions and treatments.

The aim of this project, ABCs of Autism, is the delivery of a series of trainings focusing on social skills, functional communication, and communicating with parents. Among the project's objectives is the bridging of the gaps that exist between professionals and mapping the current good practices related to ASD interventions. In addition, another objective is the creation of a network between ASD professionals who can exchange good practices at a European level.

Introduction

The project's main direct target group is professionals and paraprofessionals supporting individuals with autism and/or other neurodevelopmental disorders. These can include among others: Occupational therapists (OTs), Speech and Language Therapists, Physical Therapists, Psychologists, etc. The ASD professionals will be able to share their insights, experiences, and knowledge with others and at the same time upgrade their own skill set. Groups affected indirectly by the project will be among others: educators and trainers, governmental departments, policymakers, and ASD or SEN associations, in the partners' countries.

In the following training guide, a summary of the training activities will be presented based on four themes: Teaching Social Skills through the teaching Interaction Procedure, 2. How to talk, empower and educate parents of children with ASD, 3. Supporting families of children with autism, and 4. ASD Communication Training.

Overview of Social skills in Autism

Social skills are an essential tool for successful communication in everyday life. They are often goal-oriented, they depend on the situation, who it involves, and where it occurs. For example, the same scenario taking place at home may produce a very different reaction than the same scenario taking place at work. Our social skills include certain types of behaviour that get judged by other people and these behaviours get evaluated to determine our level of social skill. However, these behaviours can be taught, practised, and learned. Four of the main social skills categories include verbal social skills, written social skills, and non-verbal social skills – which comprise 60-65% of our communication and empathetic social skills.

Social impairment in social functioning is a central feature of ASD (O'Keeffe & McNally, 2021). Research suggests that those impairments in social skills may impact negatively autistic children as they are affected by their ability to develop interpersonal relationships with their peers (Reichow and Volkmar, 2010). Autism in young children may be exhibited in behaviours (but not strictly) such as: not responding to their name, avoiding eye contact, not reciprocating a smile, not talking as much as other children or repeating the same phrases (echolalia).

Older children with a diagnosis on the spectrum may seem to not understand what others are thinking or feeling, they may find it hard to say how they feel or to make friends or they may prefer to be on their own. Another sign is taking things very literally – for example, they may not understand phrases like "break a leg".

Notably, an under-diagnosis is observed in girls, mainly because autism can be harder to spot in girls known as the female protective effect theory (FPE theory). There could be several explanations for this phenomenon. One possibility is that girls might be inclined to conceal their emotions, requiring more demanding or stimulating environments to reveal their autistic traits. Alternatively, they might seem to manage social situations more effectively (Robinson et al. 2013).

Early intervention is key when taking into consideration that autistic individuals who are older or have a late diagnosis may struggle to relearn healthy social skills (O'Keeffe & McNally, 2021). Learning a new skill set can take quite a bit of time, often because they also have to let go of their old habits. Having good social skills can help autistic individuals determine how to act appropriately in any social situation, make new friends, discover personal interests, develop new hobbies and learn from their peers.

Overview of Social skills in Autism

A robust set of social skills is essential for autistic children given the significant positive impact on their mental health. It contributes to their mental well-being by enabling them to communicate their needs, express their emotions to others, boost their self-esteem and assist in a better quality of life. To acquire and develop their own social skills effectively, they must possess a thorough understanding of these skills, the ability to recognize them in everyday situations, and full cognitive control over their application without external direction on when and how to use them (Koegel, Koegel, Frea, & Green-Hopkins, 2003).

Some of the most crucial and valuable social skills that can be taught to children with autism include interaction skills, affective skills, cognitive skills, and foundation skills (Canney & Byrne, 2006). Achieving this can involve the implementation of Applied Behavior Therapy (ABA) techniques, which target unwanted behaviours associated with social skills, define them, collect baseline behaviour data, reinforce desirable behaviours, and work to extinguish undesirable behaviours (Landa, 2007). Alternatively, social skills can also be taught using methods like the Teaching Interaction Procedure (TIP) or through the use of social stories (Oppenheim-Leaf et al., 2012)."

In this part is essential to identify that ABA and TIP are both techniques used in the field of education and behavioral therapy, particularly for individuals with autism spectrum disorder (ASD), however, they are two district educational approaches that share common goals and methods. Moreover, the connection between ABA therapy and TIP lies in the fact that TIP is a specific teaching strategy that is often employed within the broader framework of ABA. ABA is a comprehensive approach that encompasses a wide range of techniques and interventions, while TIP is a more focused method for teaching communication and language skills, particularly in individuals with communication challenges.

Guidelines

The training guide, comprising four modules, is a comprehensive resource designed to equip ASD professionals with actionable strategies acquired from four distinct training activities.

To provide a clearer overview, the handbook includes training activities grouped into four main themes:

1. Teaching Social Skills through the Teaching Interaction Procedure: This section focuses on strategies for teaching social skills using the Teaching Interaction Procedure, an ABA-based approach.
2. How to Talk, Empower, and Educate Parents of Children with ASD: Here, the handbook offers guidance on effectively communicating with and supporting parents of children with ASD, empowering them with knowledge and resources.
3. Supporting Families of Children with Autism: This section provides tools and insights for professionals to offer comprehensive support to families dealing with autism, considering the unique needs and challenges they face.
4. ASD Communication Training: This part of the handbook concentrates on communication training specifically tailored to individuals with ASD.

All the activities included in this handbook have been developed, pilot-tested, and reviewed by ASD professionals. They have also been implemented in carefully designed meetings and sessions to ensure their effectiveness and relevance.

Overall, this booklet serves as a valuable resource for both ASD professionals and paraprofessionals seeking to enhance their knowledge and skills in the application of ABA techniques and interventions. It offers a comprehensive guide to adapting well-established activities to align with ABA principles and focuses on empowering professionals to better serve individuals with Autism Spectrum Disorder. Whether you are a seasoned ASD expert or just starting your career in the field, this handbook provides valuable insights and practical tools for improving your practice and supporting individuals with ASD and their families.

Modules

During the project, 4 educational activities were carried out with trainers and experts in the field of autism. During the activities, the material used, the interaction between trainers and trainees and the feedback given led to the creation of four Modules bearing the same names as the training.

Module 1: Teaching social skills through the teaching interaction procedure

Module 2: How to talk, empower and educate parents of children with autism spectrum disorder

Module 3: Supporting families of children with autism

Module 4: ASD communication training

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MODULE 1

Teaching Social Skills through the teaching Interaction Procedure

UNIT1: 1.1 Functions of Behaviour; Examples

Short description of module:

The current Module is thoughtfully designed to encompass a variety of ABA and TIP techniques. It offers essential background information necessary for the proper understanding and application of these techniques. Simultaneously, it presents well-structured training methods that have been developed as part of the ABCs of Autism project.

1.1. Objectives and Skills

The main objective of this activity is to help professionals identify the 4 main functions of behaviour sensory, escape, attention, and tangible.

Recognising, understanding and identifying these behaviours is crucial for implementing and intervening with various educational techniques and activities.

1.2 Introduction

Understanding why a behaviour is occurring is a crucial component of effective intervention, helping to prevent negative behaviours and manage them when they occur. Determining the function of a behaviour aids in developing treatment plans for unwanted behaviours and, more broadly, informs the design of intervention procedures. There are four main functions of behaviour: sensory, escape, attention, and tangible. It's worth noting that some behaviours can serve multiple functions.

Teaching Social Skills through the teaching Interaction Procedure

1.3. Background

The four primary functions of behaviour are sensory stimulations, escape and access to attention, and tangible. Here are their main characteristics:

Sensory stimulation:

Also referred to as sensory needs, occurs when children seek pleasant sensations or alleviate discomfort. Depending on their sensory needs, children may either crave stimulation or attempt to reduce sensitivity. Sensory stimulation can manifest in various forms, including activities like jumping, skipping, hand-flapping, tapping feet, and rocking back and forth.

Escape behaviours:

These are commonly observed when a learner seeks to evade or "escape" a particular task or situation. This phenomenon is frequently encountered during instructional periods in ABA therapy sessions.

Access to Attention:

This type of behaviour arises when an individual craves feedback or a reaction from someone else. Classic instances of attention-seeking behaviours in children include crying and throwing tantrums. To discourage attention-seeking behaviour, it's crucial to withhold attention from problematic behaviours, signalling that these negative actions will not be reinforced. Attention seekers may accept any form of attention, whether it's positive or negative.

Access to tangible:

Children may exhibit specific behaviours because they aim to obtain something, like a treat or a toy. For the child, the treat or the toy acts as a significant reward, leading them to exhibit disruptive behaviours in their efforts to obtain it. At this part is important to mention that it's completely acceptable to use tangible rewards to reinforce a child's positive behaviors, but it's essential to acknowledge that this falls under one of the functions of behavior."

MODULE 1

Teaching Social Skills through the teaching Interaction Procedure

1.4. Content

The following examples illustrate the four primary behavioural functions within real-life scenarios. It provides four instances for each behavioural function while also emphasizing the potential outcomes associated with each function.

EXAMPLE Sensory stimulation

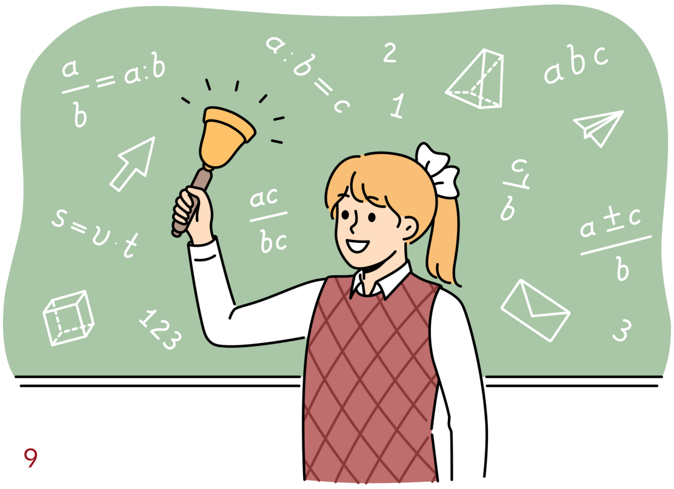
P**rimary Behavior:** John engages in hand flapping in the absence of any specific antecedent or consequence stimulus.

Behavioural Function: The function of this behaviour is to provide automatic sensory stimulation for John.

EXAMPLE escape

Primary Behavior: Every time Ms. Smith puts a maths worksheet on Johnny's desk, he rips up the paper and throws it on the floor. As a result, Ms Smith does not make him do his maths homework. In the future, Johnny continues to engage in this behaviour every time he receives a maths worksheet because it results in escaping the behaviour of doing the maths worksheet.

Behavioural Function: Every time Johnny rips up the paper he gets out of doing the maths homework. Given that this keeps working, Johnny will most likely keep engaging in this behaviour to avoid doing any maths homework. Johnny's behaviour facilitates escape.



Teaching Social Skills through the teaching Interaction Procedure

EXAMPLE Attention-maintained behavior

Primary Behavior: Johnny screams every time his mother walks away from him. When he engages in this behaviour, his mother returns to him and asks, “What’s wrong Johnny?”

Behavioural Function: This behaviour is attention-maintained because the behaviour consistently results in attention. When Johnny “wants” attention, he screams. Therefore, the main function of this behaviour is to get the attention of the parent.

EXAMPLE Access to tangible

Primary Behavior: When Stevie cries, his mother gives him a pacifier. In the future, Stevie cries because it consistently results in access to the pacifier**.**

Behavioural Function: The function of this behaviour is access to a tangible item.

MODULE 1

Teaching Social Skills through the teaching Interaction Procedure

UNIT2: ABC’s of Behavior

2.1. Objectives and Skills

By examining a behaviour within a logical sequence of events, it becomes simpler to identify the purpose of the behaviour and gain a deeper understanding of why a child is behaving in a particular manner.

2.2 Introduction

The Antecedent-Behavior-Consequence (ABC) model plays a crucial role in comprehending the function of behaviour. When a child is receiving ABA therapy or attending a therapeutic preschool program to address behavioural challenges, their teachers and therapists frequently analyze these behaviour components.

The following three steps – the **“A-B-Cs”** – help us teach and understand several behaviours:

Antecedent: This denotes the stimuli or activity occurring just before a child displays the behaviour. In some instances, the antecedent may also be the underlying cause of the behaviour in the child.

Behaviour: This pertains to the action that occurs following the antecedent.

Consequence: This pertains to the event or results that ensues after the behaviour.

2.3 Background

By dissecting the specific behaviour into smaller components, particularly with the assistance of the A-B-C steps, we can closely observe, interpret, and document each aspect of the behaviour. These procedures are essential for the identification of each behaviour and provide essential feedback regarding the effectiveness of the cognitive approaches and techniques.
ABA practitioners employ ABC charts to document specific behaviours and analyze their functions in children. These techniques offer a comprehensive perspective on each component of behavior and its function, aiding at the same time in the development of a comprehensive treatment plan

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2.4 Content

In this section, a preliminary version of the ABC chart is provided for each behavioural element. For practice, it is strongly recommended that you watch the demonstration video at this link: [https://www.youtube.com/watch?v=EgMVCX586eQ]. After viewing the video, you can fill in the gaps with the necessary information based on your observations.

Date	Time	Duration/ Frequency	Antecedent	Behavior	Consequence	Function/ Comment

MODULE 1

Teaching Social Skills through the teaching Interaction Procedure

UNIT3: TIP: Greet a friend in public

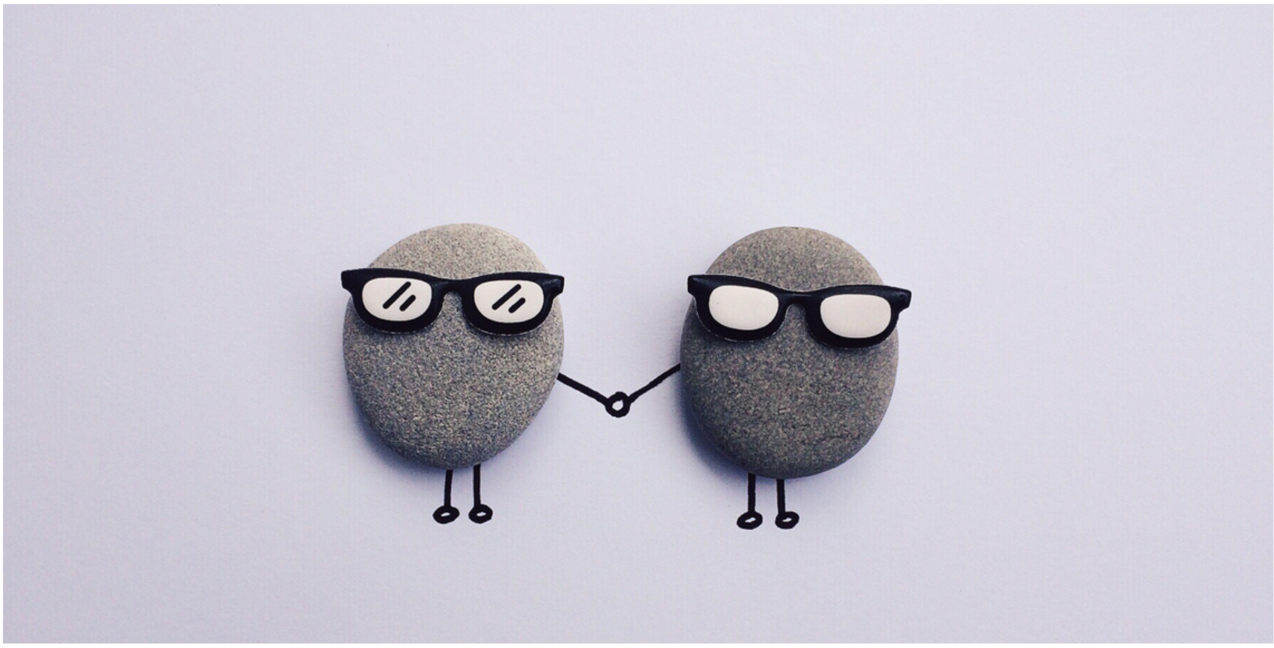
3.1. Objectives and Skills

The primary aim of this activity is to boost social consciousness and to fortify soft social skills. By utilizing the Teaching Interaction Procedure (TIP), interventionists can assist learners in cultivating essential social abilities, such as knowing how to politely acknowledge and greet someone in public. These skills are crucial for effective peer interaction and communication.

3.2 Introduction

The TIP techniques have undergone extensive examination over the past decade, with research conducted in various settings, such as one-on-one scenarios (for example, Leaf et al., 2009), group contexts (for example, Leaf, Dotson, Oppeneheim, Sheldon, & Sherman, 2010), and educational institutions (Tullis & Gallagher, 2016). TIP is applicable in various environments, including natural settings. In clinical settings, there might be minor adjustments in the number of steps, but the fundamental elements of the procedure are consistently applied.

It can be easily implemented for different scenarios and can be used as an intervention technique by several professionals.



Teaching Social Skills through the teaching Interaction Procedure

3.3 Background

The TIP techniques are based on a six-step model, where the targeted behaviour is broken down into smaller steps.

Facilitating the TIP:

At first is important to identify and label the skill to be acquired. The interventionist should assign a name to the desired skill that is descriptive and appropriate, taking into account the skill set and language level of the learners. Subsequently, each learner should describe how they understand the skill. Learners must respond actively at this stage as it familiarizes them with the rationale of the activity.

The next step is to provide meaningful rationales to the learners, again concerning their age and language level. The main aim of this step is to inform learners of the appropriate use of the acquired skill. Then, the interventionist should break down the targeted behaviour into smaller steps and guide the learner to verbally state each of the steps.

The fifth and most important step is to provide appropriate and inappropriate demonstrations of the targeted behaviours, concerning the specific skills under focus.

Lastly, the interventionist should provide feedback and explanations to the learners.

3.4 Content

The following content demonstrates a scenario (within a classroom) of TIP interventions by breaking down the same time the six main steps of the procedures.

Step 1 - Label and Identify the skill to be learned.

EXAMPLE

·Interventionist: “Greeting a friend when seen in public is essential for social communication” (verbal social skill).
·Learners: ‘’It’s important to say ‘hi’ to others”

MODULE 1

Teaching Social Skills through the teaching Interaction Procedure

Step 2 - Provide meaningful rationales.

EXAMPLE

·Interventionist: "It's a good idea to say hello to your friends when you see them at the mall because it will make them feel good, remember when you saw Maria at the mall the other time...".

·Learners: "So we can develop a friendship in the future"

Step 3 - Break down the targeted behaviour into smaller steps and guide the learner to verbally state each of the steps

EXAMPLE

·Interventionist: "When it's time to say 'hi' to a friend, you should look at your friend, smile, and say 'hi' in a friendly voice. How do you say 'hi' to a friend?"

·Learners: "I look at the person, smile and say 'hi' with a friendly voice to my friend"

Step 4 - Break down the targeted behaviour into smaller steps and guide the learner to verbally state each of the steps

EXAMPLE

- Interventionist's appropriate demonstration: "When it's time to say 'hi' to a friend, you should look at your friend, smile, and say 'hi' in a friendly voice. How do you say 'hi' to a friend? Did I do it the right way?"

- Learner response: Understanding the interventionist's actions and the way greeting is performed, like saying hi, smiling, and using of friendly voice.

- Interventionist's Inappropriate demonstration: e.g. standing too close (not responding to physical boundaries), talking too loud etc.
- Learner response: "Understanding the interventionist's actions is not socially accepted and can cause discomfort".

Teaching Social Skills through the teaching Interaction Procedure

Step 5 - skill practice or role-playing with either the interventionist or another learner

EXAMPLE

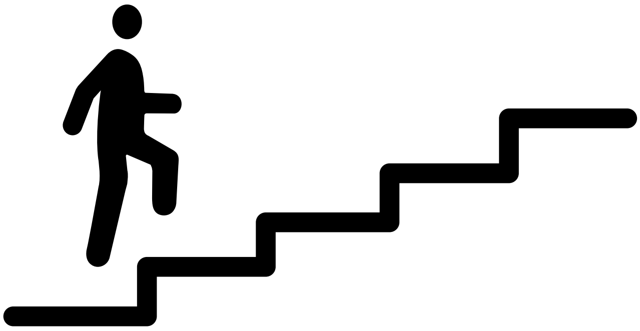
·Interventionist: ''Someone is coming to the room, how do you say 'hi' to him?"

Learner's response: ''Show how to express greetings through observation, smiling, and saying 'hi' as you have learned"

Step 6 - Feedback should be offered throughout the entire process.

During the Teaching Interaction Procedure, it is important for the students to be acknowledged and positively reinforced for accurate responses, usually through descriptive praise and some form of reward, while also receiving constructive feedback for any mistakes made.

Note: The final step can be proceeded with the use of open questions and follow-up discussions.



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MODULE 1

Teaching Social Skills through the teaching Interaction Procedure

UNIT4: Social Story

4.1. Objectives and Skills

The primary objective of this activity is to enhance communication skills in children, utilizing the effective tool of social stories. Social stories serve as a valuable resource for educating autistic children on various social behaviours, such as those encountered in settings like the supermarket, school, playground, and more. Through the use of social stories, children can develop skills such as empathy, appropriate social

4.2 Introduction

Traditionally social stories are used as a communication and exchange information tool. Starting from the early 1990s, Social Story interventions have been recommended as a way to promote the social development of children with Autism Spectrum Disorder (ASD). These Social Stories were originally developed by Gray in 1991 as an efficient means of communication for children with autism, and their widespread acceptance extends throughout academic communities worldwide.

More specifically, a social Story is an individualized short story specifically designed to aid individuals with Autism Spectrum Disorder (ASD) in comprehending and making sense of complex or confusing to social scenarios.

4.3 Background

Social Stories can either be created by a professional after identifying specific areas of concern, or they can be sourced from sources such as fairy tales or educational activity books. Commonly is based on illustrations or photos that contain everyday scenarios and demonstrate different communication styles or cues. The story should be written with respect to children's cognitive abilities and age.

Social stories can cover a range of subjects, including personal care tasks like dressing, putting on shoes, or handwashing. They can also address social skills, such as fostering friendships, engaging in cooperative play, and comprehending others' reactions.

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Teaching Social Skills through the teaching Interaction Procedure

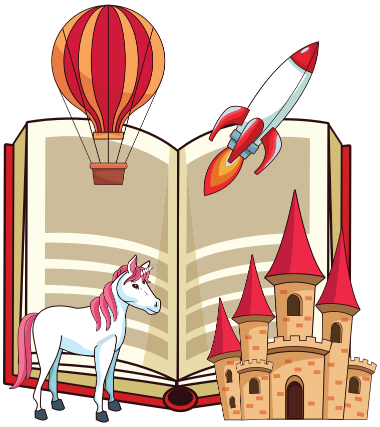
An effective social story should meet the following criteria:

- It should have a clear and specific objective, focusing on the desired behaviour.
- It should be thoroughly researched, ensuring accuracy, relevance, and reader engagement.
- The narrative should be descriptive and employ positive language, addressing the questions of where, when, who, what, how, and why while using straightforward and encouraging words.
- These are the essential components of a social story.

Social stories can be used in different aspects of everyday life as bedtime stories, and school materials by educators, teachers, psychologists, and speech therapists.
It is important to choose a social story based on the skills you want to teach. They must consist of interesting illustrations and a short description of the picture, commonly one sentence.
The choice of topics for a social story should be influenced by your target audience and their particular requirements. The intervention should consider what would be beneficial or crucial for them to acquire.

Key Recommendations for Creating Social Stories:

1. Always try to conclude the social stories on a positive note, perhaps with a happy expression.
2. Choose to write in either the first or third person, avoiding the use of “you“ to prevent it from feeling too targeted. Generally, older children prefer the third person.
3. Refrain from using the word “change“ and other potentially confusing terms. Instead of “different“ or “new,“ consider using positive alternatives like “better“ or “more.“
4. Ensure that the language you use is comprehensible to the individual.
5. Provide reassurance that all emotions and feelings are acceptable by emphasizing that “IT IS OK!!“



MODULE 1

Teaching Social Skills through the teaching Interaction Procedure

Facilitating the social stories:
The interventionist should present the social stories in a way that inherits the interest of the learners.

It is crucial to utilize social stories for positive reinforcement in at least 50% of instances, rather than exclusively focusing on behaviours that require modification. They should also be employed to celebrate accomplishments and successes.

After a brief introduction of the materials, is essential the debriefing with the use of open questions and follow-up conversations.

For example:

·Interventionist: ‘Can you think why is important to say ‘hi’ to someone?’, ‘How we say ‘hi’ to someone’.

Materials

Teaching Social Skills through the teaching Interaction Procedure

UNIT 5: Teaching cooperation

5.1. Objectives and Skills

The primary objective of this game is to promote cooperation, mutual understanding, and tolerance. To effectively carry out this exercise, requires mutual collaboration, peer interaction, and non-verbal communication. In essence, it is a structured, cooperative activity designed for children with autism spectrum conditions.

5.2 Introduction

The 'Draw a pizza together' activity is based on peer interaction approaches to non-verbal communication.

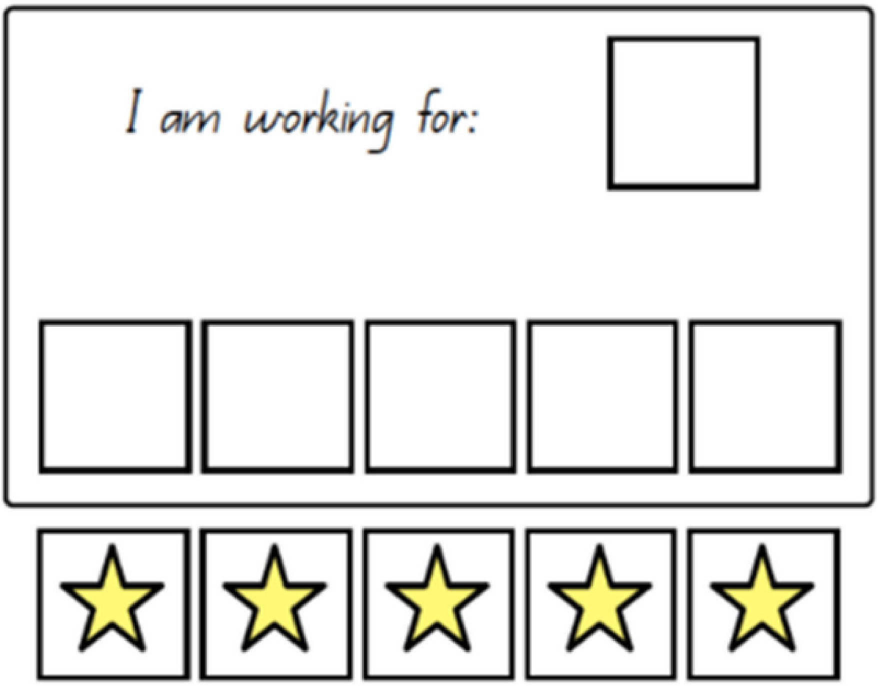
By initiating those games the learners will be educated on how to:

- respond to social interactions,
- hold a conversation with another person, which includes staying on topic and taking turns speaking,
- reading the non-verbal cues of others or unspoken social rules,
- learning to play or work together,
- and sharing enjoyment.

Teaching Social Skills through the teaching Interaction Procedure

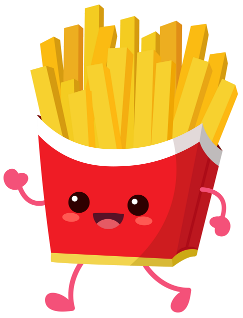
5.3 Background

Group-based social skills training is particularly attractive for autistic children because it provides them with the chance to apply recently acquired skills naturally while engaging with their peers (White et al., 2006). This activity could be enhanced using additional ABA teachings and principles, for example with the addition of a token economy board.



As outlined by Cooper and colleagues at Ohio State University (Cooper et al., 2007), setting up a token economy involves six key steps:

1. Choose the tokens.
2. Define the target behaviours or rules.
3. Decide on the backup reinforcers.
4. Determine the exchange ratio.
5. Create a procedure for the distribution and exchange of tokens.
6. Test the system through practical application.



Teaching Social Skills through the teaching Interaction Procedure

5.4 Content

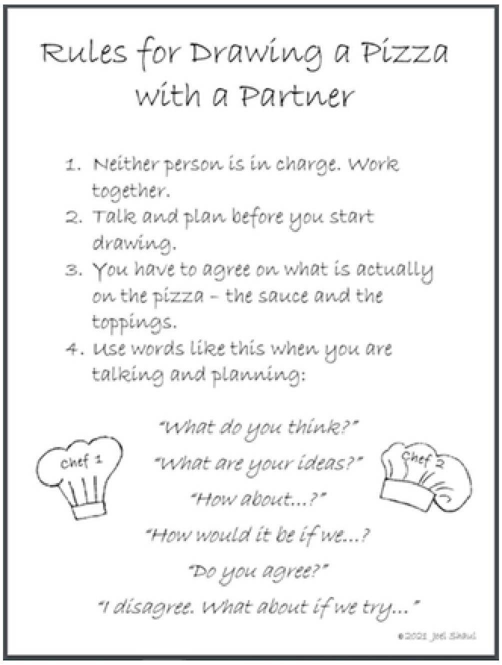
The interventionist starts by explaining that each group or pair of learners has an image of a pizza template without any ingredients on it as well as written “Rules for Drawing a Pizza with a Partner(s)”.

It is highly recommended the use of short role-play demonstration of how to use supportive words and questions.

Here are some recommendations for introducing this activity:

1. Organize the participants into pairs.
2. Offer a clear introduction before distributing the drawing materials.
3. Read aloud the “Guidelines for Collaborative Pizza Drawing“ and provide each pair with a copy of these guidelines.
4. Conduct a brief role-play demonstration illustrating the use of supportive language and questions.
5. It is strongly advised to conclude the activity with a debriefing session involving open-ended questions and the utilization of a token economy board to reward cooperation and supportive behaviours.

Illustrations:


Rules for Drawing a Pizza with a Partner

1. Neither person is in charge. Work together.
2. Talk and plan before you start drawing.
3. You have to agree on what is actually on the pizza - the sauce and the toppings.
4. Use words like this when you are talking and planning:

"What do you think?"
"What are your ideas?"
"How about...?"
"How would it be if we...?
"Do you agree?"
"I disagree. What about if we try..."

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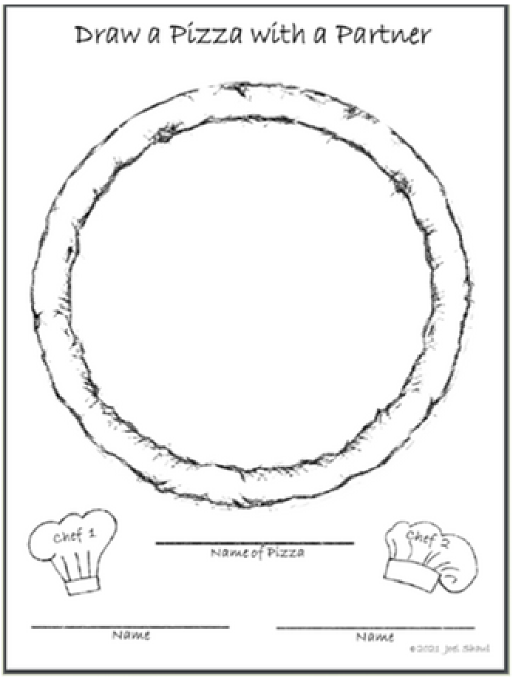

Teaching Social Skills through the teaching Interaction Procedure

UNIT6: Conversation cards

6.1. Objectives and Skills

The main objective of this exercise is to help learners develop communication and conversational skills with the use of flash cards.

Conversation cards are specially designed to assist individuals with autism in starting or maintaining conversations with peers, family members, or members of the community. These cards are tailored for those who require additional support in initiating organic conversations and staying on topic.

6.2 Introduction

Children with autism frequently experience delayed or disrupted speech development. They might engage in activities such as reciting scripted lines from television shows without understanding the meaning of the sentences, producing nonsensical sounds, or even repeating the same sentence again and again.
Hence, in many cases, it is necessary for the intervention of speech and behavioral therapists to acquire knowledge of using spoken language correctly and to understand how to employ language in a suitable and interactive manner (Paul, 2008).

Additionally, social skills therapists and coaches concentrate on enhancing speech and conversational abilities. Some of the specific skills they aim to impart include:

1. Learning how to ask and respond to questions.
2. Selecting appropriate conversation topics.
3. Developing the ability to establish and maintain eye contact.
4. Becoming proficient in recognizing and utilizing body language cues.

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Teaching Social Skills through the teaching Interaction Procedure

6.3 Background

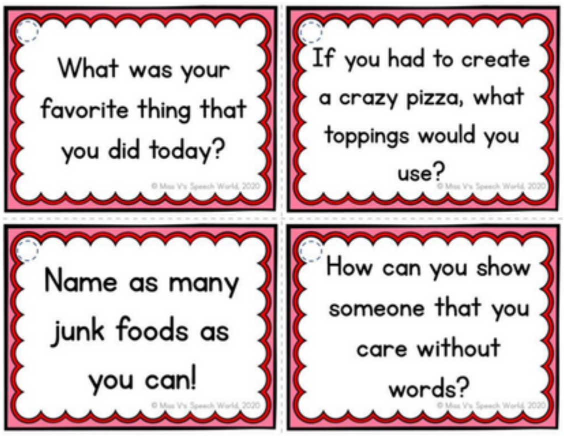
Children with autism spectrum conditions often encounter challenges in developing effective conversation skills. Many of these difficulties can include generating original questions, maintaining the conversation's focus, and asking follow-up questions in a reciprocal manner. A highly effective method for teaching and acquiring conversation skills is through the use of communication starter cards. These cards are specially designed to assist learners in initiating a conversation.

6.4 Content

Facilitating the cards:

Each Topic Card includes an image and /or a question for the learner to use during a conversation. It is highly advisable, when providing instructions, to involve a third-party individual, whether it's an adult or a peer, as the conversation partner. This allows your learner to recognize and express the appropriate statements and questions within the conversation.
In accordance with ABA (Applied Behavior Analysis) principles, it is essential to evaluate which skills are needed for development or advancement. This evaluation will help the interventionist choose the suitable cards for each conversation.

Illustrations:

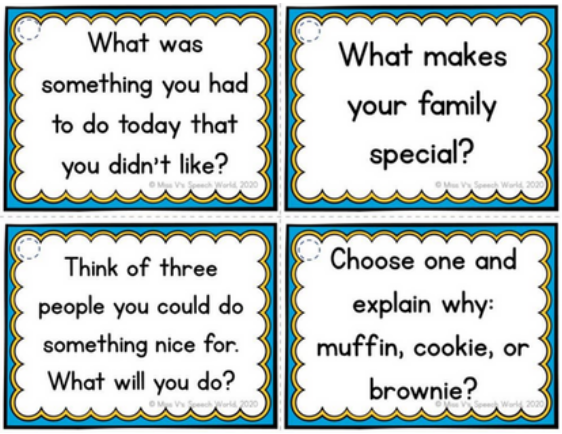


What was your favorite thing that you did today?

If you had to create a crazy pizza, what toppings would you use?

Name as many junk foods as you can!

How can you show someone that you care without words?



What was something you had to do today that you didn't like?

What makes your family special?

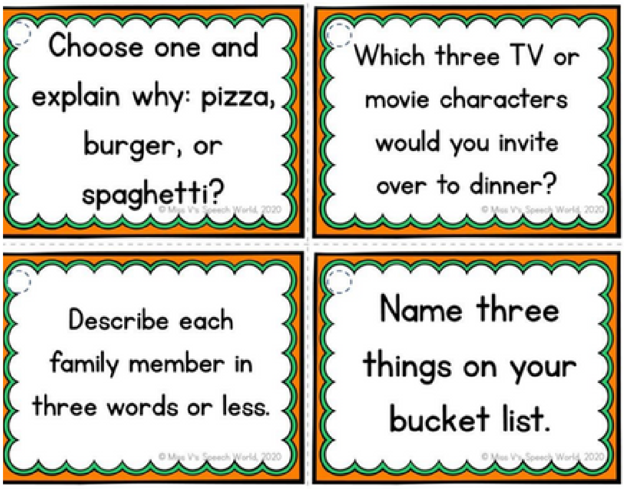
Think of three people you could do something nice for. What will you do?

Choose one and explain why: muffin, cookie, or brownie?

MODULE 1

Teaching Social Skills through the teaching Interaction Procedure

Illustrations:

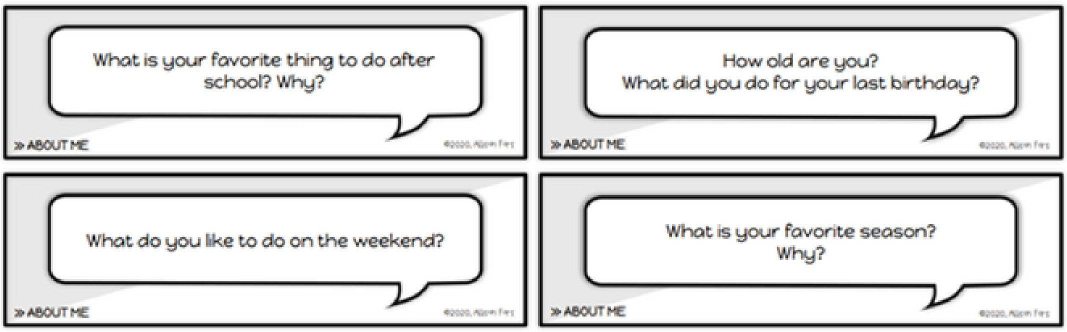


Choose one and explain why: pizza, burger, or spaghetti?

Which three TV or movie characters would you invite over to dinner?

Describe each family member in three words or less.

Name three things on your bucket list.

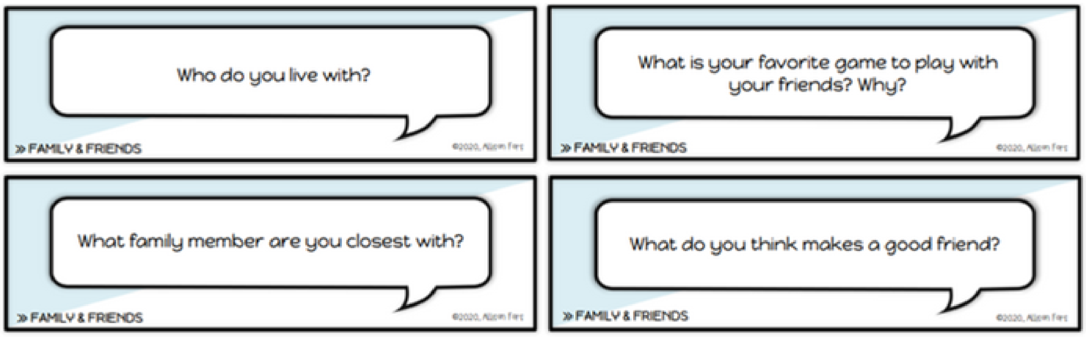


What is your favorite thing to do after school? Why?

How old are you? What did you do for your last birthday?

What do you like to do on the weekend?

What is your favorite season? Why?



Who do you live with?

What is your favorite game to play with your friends? Why?

What family member are you closest with?

What do you think makes a good friend?

Teaching Social Skills through the teaching Interaction Procedure

UNIT 7: Identifying emotions (EQ)

7.1. Objectives and Skills

The primary objectives of these activities are to boost emotional awareness, identification, and communication among participants. By engaging in shared scenarios and conversations, participants enhance their ability to identify, understand, and express emotions.

The skills emphasized in this section primarily revolve around self-monitoring and self-awareness, social perception, perspective-taking, and grasping another person's point of view (empathy).

7.2 Introduction

Identifying another's person's emotion is essential for cognitive abilities and communication. As autistic children face difficulties on such skills, those activities will help them recognise and express their emotions.

Emotional intelligence, often referred to as EI or EQ, denotes the capacity to identify, interpret, and manage both your own emotions and those of others. These skills associated with emotional intelligence enable a deeper understanding and better handling of emotions.

Having high emotional intelligence has been correlated with numerous advantages, including enhanced academic performance, as indicated by research, improved decision-making abilities, and greater overall life success. Some experts even propose that EQ might hold more significance than IQ, which pertains to intellectual intelligence (Goleman, 1998).

MODULE 1

Teaching Social Skills through the teaching Interaction Procedure

7.3 Background

This activity is based on the movie 'Inside Out' (Pixar, 2015) and can readily be seen as a modified version of educational card games."

'Inside Out' is a famous animated film created with the mindset of teaching both children and adults about emotions and feelings, while imparting the same time concept of emotional intelligence to both children and their families.

As a result, a card game was developed in alignment with the principles of ABA techniques, aimed at teaching children various emotional states and how to identify them.

7.4 Content

The interventionist should place all the cards with the emotional states face down.

Then each learner should pick one card at a time and decide which emotion it goes with.

The goal is to ignite a discussion about emotions and the things that they associate with each emotion.

Photo credits: **Momendeavors.com**

How to talk, empower and educate parents of children with autism spectrum disorder

Short description of module:

For professionals who work with children with ASD and their parents, it's very important to be aware not only of the children's needs but also of their parent's needs for support. This training can give you valid, based on research, information on what parents of children with ASD need and how professionals can help them. It will help professionals feel confident to empower and educate parents to better understand the context of family functioning, to recognize their needs for support, and how to provide support and assistance.

At this training, experts will have the opportunity to learn the theoretical foundations of parenting and the difficulties that imply parenting a child with an autism spectrum disorder. What are the biggest challenges that parents face at different stages of a child's life? One of the goals is to raise awareness of experts what is the importance of educating and empowering parents, for a better quality of life for a child with autism spectrum disorder, but also for his entire family. Experts will have the opportunity to learn how to assess the strengths and needs of family support and how to provide them with adequate support. One part of the lecture will also focus on siblings and how experts can work with them on empowerment. Also, this training will include workshops where experts will have an opportunity to practice to apply the learned knowledge. Active participation of all participants is necessary in order to acquire skills that can be applied in practice and daily work with families. The main objective of the training is that experts feel confident to empower and educate parents, to better understand the context of family functioning, and to recognize parents' needs for support and how they can provide that support and assistance from their roles.

UNIT1: Registration, welcome and introduction activity

1.1. Objectives and Skills

The first activity was getting to know each other and the main goal was to relax and create a positive and fun atmosphere where everyone felt good and accepted.

1.2 Introduction

Getting to know each other was realized through a workshop method, each participant introduced himself and said what he wanted about himself. The participants listened to each other and got to know each other.

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MODULE 2

How to talk, empower and educate parents of children with autism spectrum disorder

UNIT2: What is autism spectrum disorder? How to explain parents diagnosis, professional terms, different perspectives

2.1 Objectives and Skills

In this unit, the goal was to come to an understanding through the discussion that autism has a different meaning for people depending on their perspective. How professionals should explain the spectrum to parents, some common myths, and the basics of etiology and epidemiology.

2.2 Introduction

What is autism?
Everyone gives a word that is for their first association with autism. Everyone gets the opportunity to say it and then we discuss it.

2.3 Background

What is autism?

Autism spectrum disorder (ASD) is a developmental disability caused by differences in the brain. The Diagnostic and Statistical Manual of mental disorders lists signs and characteristics of autism spectrum disorder. For an autism diagnosis, children must have social communication difficulties, and restricted, repetitive, and/or sensory behaviors or interests. It is important to note that some people without ASD might also have some of these symptoms. But for people with ASD, these characteristics can make life very challenging. Today, the current DSM-5 classification issued in 2013 introduced major changes - it accepted the concept of the autism spectrum of disorders, in Serbia experts still use the International Statistical Classification of Diseases and Related Health Problems 10 (ICD-10) so the official term is still pervasive developmental disorder.

How to talk, empower and educate parents of children with autism spectrum disorder

Deficit of reciprocal social interactions and communication

Difficulties in social communication and interaction with other people in different environments are cited as the first group of symptoms in people with ASD, and it includes three diagnostic criteria:

- deficit in social-emotional reciprocity,
- deficit in non-verbal communicative behaviour and
- deficit in the development, maintenance and understanding of relationships

Restricted, repetitive patterns of behaviour, interests and activities

For the second group of symptoms, there are four criteria:

- stereotyped or repetitive motor movements, use of objects or speech,
- insistence on sameness, inflexible adherence to routines or ritualized patterns of verbal or nonverbal behaviour,
- highly restricted, fixed interests that are abnormal in intensity or focus, and
- hyper or hypo reactivity to sensory input or unusual interest in sensory aspects of the environment.

However, in order for a child/person to be diagnosed with ASD, they must meet the presence of only two of the four criteria, currently or during their lifetime (DSM-5; American Psychiatric Association, 2013).

What is hardest for parents to understand?

Usually, the biggest mistake is the equalization of one symptom with the whole diagnosis. Most often they think or say:

- He looks me in the eyes, he can’t have autism.
- He likes to cuddle.
- He is smart, he knows numbers and letters at the age of 3.
- He just likes to play that way, it’s just the way he is.
- He is just like his father, he also didn’t speak until 4.
- He understands everything, he just needs to start speaking.
- He was okay until he got the vaccine.
- It’s all from smartphones and tablets, we are going to stop using them.
- They are all smart, Nikola Tesla and Albert Einstein had autism.

MODULE 2

How to talk, empower and educate parents of children with autism spectrum disorder

Why is it a challenge to explain autism to parents?

When parents get the diagnosis the biggest job for experts is explaining the complexity and heterogeneity of autism spectrum disorder.
Our explanation depends on:

- the specific child and his symptoms,
- educational level and prior knowledge of the parents.

There are several meanings of the term “spectrum“ in relation to autism:

“Spectrum“ can refer to the dimensional nature of the basic characteristics of autism within the clinical population, to emphasize differences in symptom severity and presentation among those diagnosed with ASD this was suggested as early as the 1970s by Lorna Wing to highlight the diversity among major domains within autism. However, the term “spectrum“ can also be used in the context of the autism subgroup that DSM-5 attempted to move away from and instead recognize underlying commonalities while attempting to individualize diagnosis through dimensional descriptors. It is important to remember that autism is not homogeneous, and defining it using the umbrella term ASD risks whitewashing the evident heterogeneity, which also has a significant impact on research into this condition. Also, the word “spectrum“ emphasizes that autistic features vary in severity and extend to levels of non-clinical significance in the general population (Lai MC, Lombardo MV, Chakrabarti B, Baron-Cohen S, 2013).

What all people with autism spectrum disorder have in common is that their symptoms are clinically significant, limit them in their daily functioning, and affect their quality of life, as well as that these symptoms must be present in the early development period (but they do not have to become completely obvious until social demands overwhelm limited abilities or can be masked by learned strategies in later life) (DSM–5; American Psychiatric Association, 2013).

How to talk, empower and educate parents of children with autism spectrum disorder

Etiology and epidemiology

The etiology of the disorder is still unknown, although it is likely that there are several different causes that give a similar clinical picture with dominant symptoms of disorders of verbal and non-verbal communication, social interaction, and stereotypic behavior. Today, the majority of experts believe that autism spectrum disorder is a multi-causal disorder and that it is a behaviorally described syndrome of diverse etiology (Guidelines, 2018).

As for the epidemiology when autism was first described, it was considered a rare childhood disorder because the first studies, conducted during the 1960s and 1970s in the United States and Great Britain, estimated the frequency at 2-4 cases per 10,000 children. The World Health Organization (WHO) estimates that 1 in 160 children worldwide has ASD (0.7–1%). The lack of records in most countries, especially in those with low or medium incomes, indicates the need to standardize the criteria for diagnostic and research methodology (Guidelines, 2018).

2.4 Content

Before every slide on powerpoint presentation we open with a question, where participants give answers for what they think, we all discuss it and then we go on to the theoretical part.

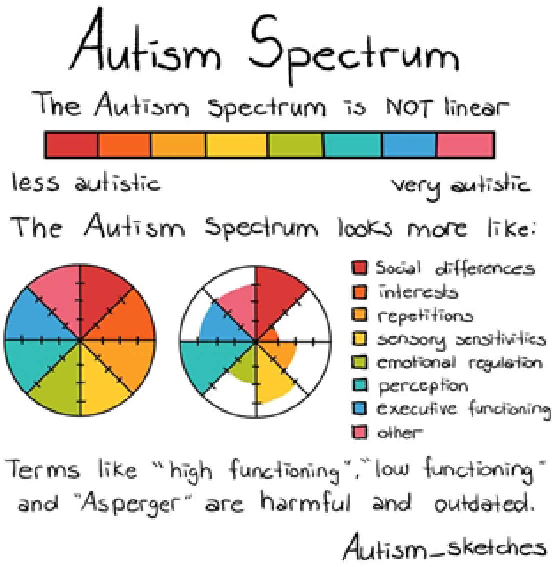
1. Why is it a challenge to explain autism to parents?

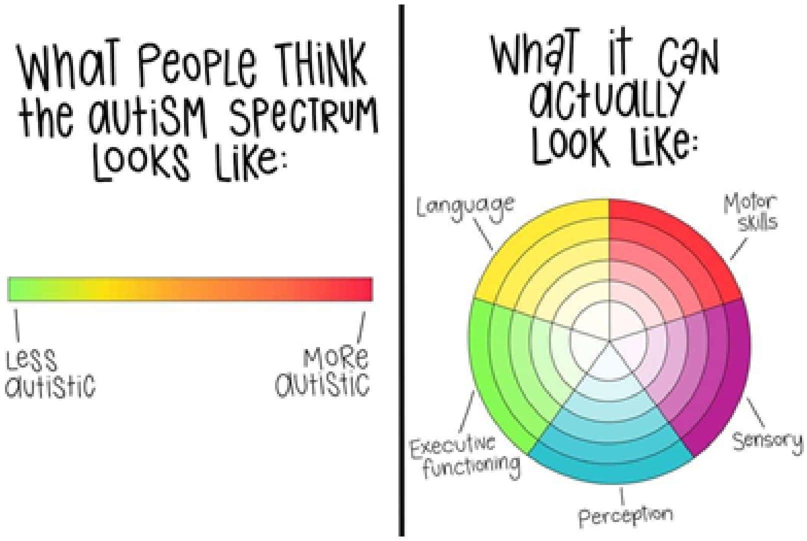
2. What is hardest for parents to understand?

3. What is the word “spectrum” in ASD diagnosis?

MODULE 2

How to talk, empower and educate parents of children with autism spectrum disorder





Workshop, where every participant for themselves writes ten sentences about someone with autism spectrum disorder, that you know. Sentences should be about their ASD symptoms or characteristics so we can discuss how ASD can look in different people... It should contain information such as age, communication and social skills (verbal and nonverbal), routines, repetitive behaviors, special interests, difficulties in everyday situations, some joint conditions...

The goal of the workshop is to realize how very different each person with ASD will be and that we see once again how everyone is different.

How to talk, empower and educate parents of children with autism spectrum disorder

UNIT3: Phases of acceptance diagnosis by parents + siblings

3.1 Objectives and Skills

In this unit, the goal was for participants to understand some basic phases of acceptance diagnosis by parents, family's roles and functions, and how they can be different when we have a child with ASD. One part is dedicated to siblings and support they need in different families.

3.2 Introduction

As part of this training block, in addition to presenting presentations, interactive tasks were organized with the participants. Within family roles and functions, the participants worked in pairs for a particular family function and analyzed what challenges families have within a certain function. A special focus was placed on the challenges of siblings in the family, but their strengths were highlighted as well.

3.3 Background

Phases of acceptance diagnosis by parents + siblings
"Different" families

Recommendation for the text of Emily Perl Kingsley, she wrote "Welcome to Holland" in 1987 and described the experience of raising a child with a disability.

1. PRODUCT OF THE ART WORKSHOPS IN DPOSA WITH ART TEACHER MAJA STOJANOVIĆ , TULIPS 2015.

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MODULE 2

How to talk, empower and educate parents of children with autism spectrum disorder

Each family is unique according to structure, dynamics, functioning, and life cycle (Velišek-Braško i Svilar, 2017). Family structure is comprised of members, their number, and their role within it (father, mother, son, daughter, grandmother, grandfather, and other close relatives). Family dynamics are determined by family subsystems, the relations within the same subsystem, and those between different subsystems (spouse - spouse, parent - child/children, brother/sister - brother/sister i.e. siblings, and the relations with other family members). Different life cycles characterize the family in relation to defining roles within the unit.

Parents' reactions to the fact that their child is different from other children can be different because they depend on many factors, but there is a list of "common reactions" created based on parents' feelings, which are: shock, sadness, anger, denial, loneliness and eventually acceptance. The quality of relationships within the family and their construction are of special importance (Velišek-Braško, 2015), primarily considering the relationship with a child with developmental disabilities, relationships with and between siblings, mutual relationships between partners, as well as relationships with other members of the extended family. Perception and building of the relationship between parents and siblings with the child with developmental disabilities depends more on family experiences and the quality of relationships within the family, and less on the severity of the condition of the child with developmental disabilities.

How to talk, empower and educate parents of children with autism spectrum disorder

Reactions and path to the acceptance of diagnosis for parents

Reactions of parents when they find out the fact that their child has autism per Kubler-Ross (Autism Speak, 2013):

I Shock - astonishment, confusion, and inability to accept it.
II Sadness - grief for the hope and dreams that the parents had for their child, possibly extreme sadness.
III Anger - a natural part of the grieving process can be anger directed towards those closest to them and manifest, e.g., on a child, partner, or friends. Parents look for someone to blame in their environment, they blame others for their family troubles and child’s problems.
IV Denial - by refusing to believe what is happening to him and his child, the parent is often unable to accept the facts of the child’s condition.
V Loneliness - isolation, solitude, which can have two reasons for losing contact with friends: because of obligations or because of lack of understanding and help from others.
VI Acceptance - follows when a parent accepts their child with a disability, as opposed to accepting the diagnosis itself. Acceptance means that a parent is willing to advocate for their child.

Examples of comments - Which reaction do they belong to?

- “No, my child doesn’t do that at home“ or “Really, he can do that at home.“
- “What kind of expert are you to tell me that!“ or “A real expert can teach him that.“
- “I did something wrong during pregnancy“ or “I took care of the baby wrongly.“
- “It will be better not to go to the birthday parties“ or “We’ll go for a walk in the evening, alone.“
- “It’s the doctors’ fault“ or “The gynecologist made a mistake during the delivery.“
- “Uh, what did they say to me, I didn’t understand anything.“ or “Are they saying that to me!?“
- “It is what it is, he’s mine and I love him.“ or “We’re going on rehabilitation treatments and I’m seeing progress.“

MODULE 2

How to talk, empower and educate parents of children with autism spectrum disorder

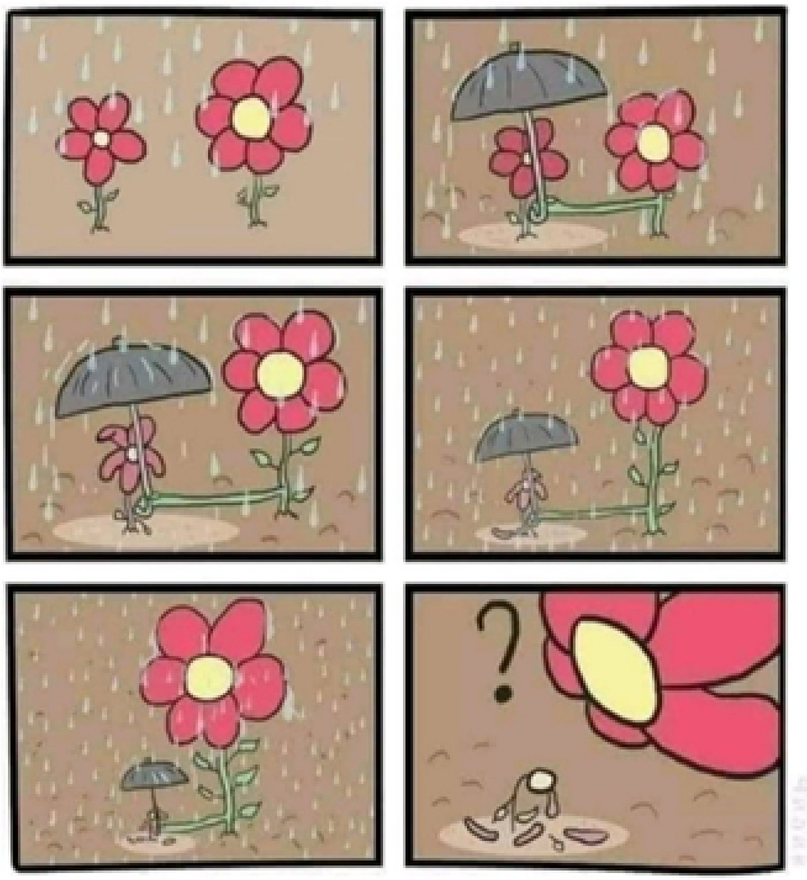
The Family Roles and Functions

The roles of the modern family are realized through (Velišek-Braško, 2015) reproductive function – which is reflected in the continuation of the species by means of producing offspring; emotional function – which is the fullest expression of the contemporary family and is completely detached from the reproductive function, it represents the pillar in preserving harmonious family relations and family integrity and is thus the most important function, which affects psychological stability of each family member; economical function – in modern world it is reflected in consumer society, where family income affects its stability; function of providing protection – which encompasses social, moral, legal and economic protection; educational function – considering that education is the right of every child, this function is realized by means of state-implemented systemic solutions, the result of which is the inclusion of children in the educational system, through various forms and levels of education; leisure function – which takes place in different forms, within the family circle but also outside of it, such as outings, vacations, events, meetings, social gatherings. This role implies family members spending quality time together, thus enriching experiences. The specifics of the realization of family functions and their combinations depend on priority areas, value systems, and family approach, which gives each family its authenticity.

Families of children with autism are atypical, in terms of internal relationships and dynamics. Such families have specific challenges in all roles: reproductive, economic, emotional, protective, educational, and leisure role (Velišek-Braško, 2015). This affects the stability of the whole family, due to the stated aggravating circumstances that these families have, there is a high probability that the family will become dysfunctional. That is why the role of the state and society, and especially of the educational system is important, as it is up to them to provide all the necessary help and support so that every role is fulfilled and the family is maintained. But in stable, functional, and accepting families of children with disabilities, parents and siblings, due to their specificity, strengthen certain characteristics, skills, and competencies such as persistence, resourcefulness, perseverance, patience, but also problem-solving skills, compassion, understanding of the situation and the feelings of others, accepting and respecting diversity, providing support to others. The path of parents to accept the fact that their child is different from other children is difficult and can take a long period of time.

How to talk, empower and educate parents of children with autism spectrum disorder

Within the family, parents are the foundations of the “institution of the family” and the key implementers of family functions. Special understanding needs to be provided to them, especially when it comes to the families of children with disabilities. Support for parents, those who ensure the quality of functioning within it, is of great importance for the entire family and its immediate members. The specific situation, the fact that the child has a diagnosis, sets unique requirements and roles for all family members. Parental knowledge of the fact that their child has developmental disabilities is a powerful event in the family environment. The specific situation, the fact that the child has a diagnosis, sets unique requirements and roles for all family members (Zaidman-Zait, Yechezkiely & Regev, 2020).



3. Story in pictures about over-caring parents

How to talk, empower and educate parents of children with autism spectrum disorder

Siblings to “different” persons (a person with autism)

Being a brother or sister to “different“ persons is a very specific situation. Siblings are a special subsystem of the family, there is a special relationship with each member. Siblings are the closest family members to parents and regardless of the nature of their relationship, it is one of the deepest and longest bonds in life.

A brother or sister of a child who is “different“ goes through all these stages just like the parents, that is, lives and grows in a family that goes through the various reactions described, which of course also affects their development. Unfavorable consequences of these reactions and relationships within the family for siblings are premature maturation, and exposure to excessive tasks and expectations.

4. My brother and I by Hunor Velišek, 2015.

How to talk, empower and educate parents of children with autism spectrum disorder

Brothers and sisters are very important for children's interaction from an early period, it is a possibility for peer relationships in the family environment. Questions opened up about the gender (of the differences) have an impact on the position and relationships between siblings. Or the birth order of a (different) child?

Siblings of "different ones" have a very specific situation and it is important because it influences in a positive and negative way the development and relationships. In this topic it is necessary to overview from the point of view of a child who has different positive and negative aspects, and from the point of view of a sibling of "different ones" also from the positive and the negative aspects.

Children who have a brother or sister with developmental disabilities in their family showed a statistically significantly lower level of hostile behavior and feelings of shame towards their siblings and showed a higher level of acceptance and support than the siblings of typical children (Velišek-Braško & Svilar, 2017). Positive experiences of growing up with a brother or sister who is different contribute to the development of altruism and tolerance and develop more patience, understanding, sensibility, and awareness of persons from sensitive groups. In addition, they often develop deep and tender feelings of loyalty and pride towards children from vulnerable groups and develop advocacy and self-advocacy skills for them. The positive outcomes that siblings often mention are the acquisition of patience, tolerance, and compassion, as well as the opportunity to cope with difficult situations (Autism Speaks, 2013).

We have to support siblings who have sister or brother who is different with workshops and through books or media. A group of authors of the Autism Society's brochure for supporting people with autism called "From the point of view of brothers and sisters" (2013) highlighted many important needs and tips for providing and supporting them.

MODULE 2

How to talk, empower and educate parents of children with autism spectrum disorder

UNIT3: Phases of acceptance diagnosis by parents + siblings

3.4 Content

The workshop task was within the topic of stages of parents to the child's diagnosis: each participant got a paper with a stage, ie. reaction. The participants were to organize themselves and put themselves in order of the stages/reactions of the parents. Playful activity with movement enriched this task and contributed to the quality of the discussion that the participants conducted with each other.

The second part of the task is to identify some example sentences to which phase and reaction they belong

Reactions and path to the acceptance of diagnosis for parents

Workshop where participants get papers with phases of acceptance and they have to agree on the sequence of phases.

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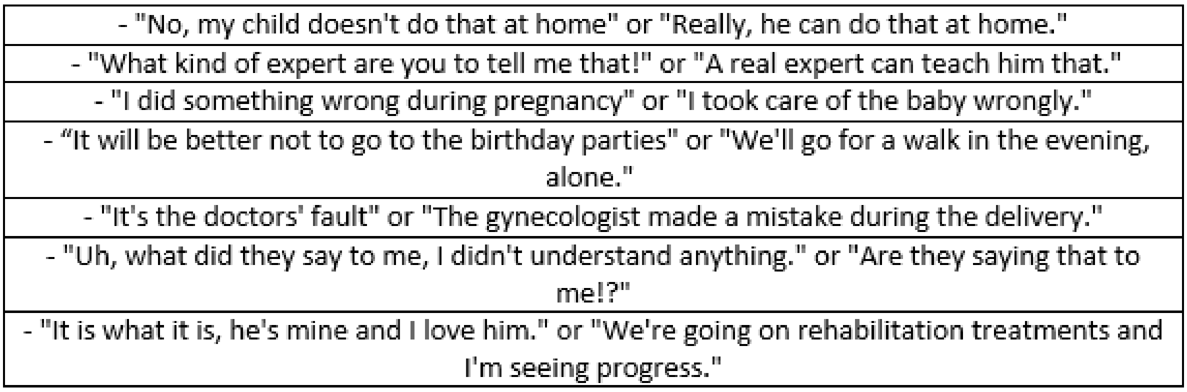
Workshop to connect statements to phases of acceptance



- "No, my child doesn't do that at home" or "Really, he can do that at home."
- "What kind of expert are you to tell me that!" or "A real expert can teach him that."
- "I did something wrong during pregnancy" or "I took care of the baby wrongly."
- "It will be better not to go to the birthday parties" or "We'll go for a walk in the evening, alone."
- "It's the doctors' fault" or "The gynecologist made a mistake during the delivery."
- "Uh, what did they say to me, I didn't understand anything." or "Are they saying that to me!?"
- "It is what it is, he's mine and I love him." or "We're going on rehabilitation treatments and I'm seeing progress."

MODULE 2

How to talk, empower and educate parents of children with autism spectrum disorder

UNIT4: The challenge in getting a diagnosis/recognizing the key elements of ASD

4.1 Objectives and Skills

In this unit, our aim was to understand different challenges in getting a diagnosis in different countries. What is the golden standard for the diagnosis of autism what do we know in theory and what do we have in practice?

4.2 Introduction

Before every slide on power point presentation we open with a question, where participants give answers for what they think, we all discuss it and then we go on to the theoretical part.

4.3 Background

The challenge in getting a diagnosis/recognizing the key elements of ASD

Monitoring the growth and development of all infants and young children (including developmental screening), as well as early detection of signs of atypical development, constitute the essence that are in the domain of the advisory work of every pediatrician. Early recognition of symptoms of ASD is of great importance because it allows a more detailed assessment to be carried out in a timely manner and/or referring the child, when necessary, to additional diagnostics in the secondary and tertiary institutional level of health care (Guidelines, 2018).

Families may have very different experiences, emotions, and expectations that they bring with them to the assessment. Incorporating family experiences and input into the assessment from the initial point of entry is critical for establishing a productive working relationship (ASD, Oxford). Parents of young children with ASD often find themselves serving in the role of advocate and resource specialist for their child. Many families seeking a diagnostic evaluation for ASD have already had numerous formal and informal experiences, opinions, and/or evaluations offered by professionals, family, and friends that impact their desire for a formal diagnosis of ASD.

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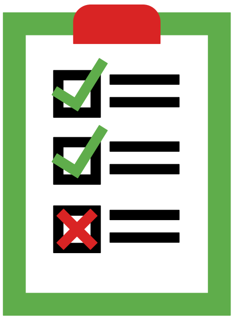
How to talk, empower and educate parents of children with autism spectrum disorder

Optimally, caregivers have expressed concerns to professionals and individuals within their support networks who have, in turn, been sensitive and supportive in listening to and validating their concerns as well as assisting them in securing a comprehensive diagnostic assessment explicitly for ASD. Even in this ideal circumstance, such support and validation do not eliminate the often intense distress and anxiety that caregivers experience in anticipating an evaluation that might confirm the fears they have about their child. Regrettably, many caregivers do not receive support for their concerns and instead are met with dismissive attitudes by professionals and individuals within family support systems. In other circumstances, caregivers may in fact have very limited knowledge or specific concerns about ASD, but have been asked to pursue services by professionals in their care systems. Although concerns about ASD are often noticed in the first years of life and professional groups consistently advocate for early screening and intervention, numerous barriers contribute to a significant time gap between the first concern and diagnosis (ASD, Oxford).

ASD can sometimes be detected at 18 months of age or younger. There are unique challenges in generating definitive diagnoses of ASD for very young children (i.e., children under 2 years of age). By age 2, a diagnosis by an experienced professional can be considered reliable. However, many children do not receive a final diagnosis until much older. Some people are not diagnosed until they are adolescents or adults. This delay means that people with ASD might not get the early help they need. Diagnosing children with ASD as early as possible is important to make sure children receive the services and support they need to reach their full potential. Developmental counselling centres at health centres should be reference places where children with developmental delays, as well as children with suspected ASD, would be referred. The developmental counselling centre team (paediatrician, psychologist, defectologist, and speech therapist), in cooperation with the parents, conducts detailed assessments (Guidelines,2018).



MODULE 2

How to talk, empower and educate parents of children with autism spectrum disorder

When ASD is suspected, within developmental counseling centers in addition to a more detailed clinical and developmental assessment, the application of specific screening M-CHAT-R/F and/or the application of other assessment instruments for ASD for which experts are trained - (e.g. CARS- 1, CARS-2, GARS-3). After the assessment within the developmental counseling centers, and in the period until the implementation of a specific targeted ASD diagnostic assessment in specialized centers, the child and the family should be included in an intervention that involves the application of developmental stimulation measures, aimed at areas where delays are manifested (Guidelines,2018).

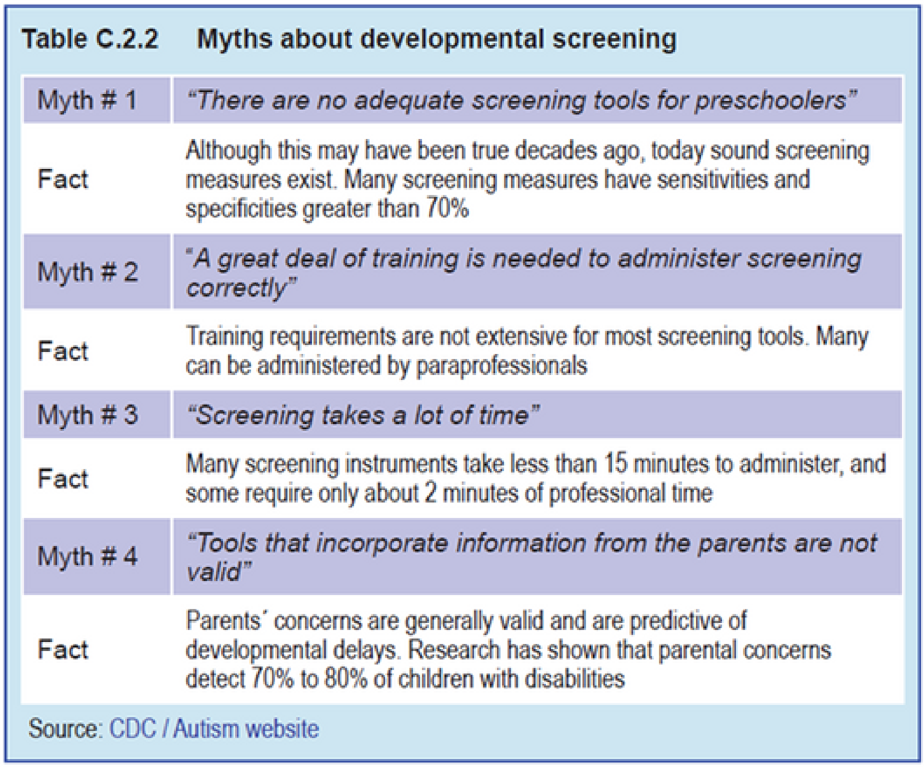


Table C.2.2 Myths about developmental screening

Myth # 1	*"There are no adequate screening tools for preschoolers"*
Fact	Although this may have been true decades ago, today sound screening measures exist. Many screening measures have sensitivities and specificities greater than 70%
Myth # 2	*"A great deal of training is needed to administer screening correctly"*
Fact	Training requirements are not extensive for most screening tools. Many can be administered by paraprofessionals
Myth # 3	*"Screening takes a lot of time"*
Fact	Many screening instruments take less than 15 minutes to administer, and some require only about 2 minutes of professional time
Myth # 4	*"Tools that incorporate information from the parents are not valid"*
Fact	Parents´ concerns are generally valid and are predictive of developmental delays. Research has shown that parental concerns detect 70% to 80% of children with disabilities

Source: CDC / Autism website

MCHAT link https://mchatscreen.com

How to talk, empower and educate parents of children with autism spectrum disorder

In practice, on average, the diagnosis of autism is made after the third year of a child’s life, and the age of diagnosis is influenced by a number of social factors. It is important to note two large time gaps that affect the final age at which a child will receive a diagnosis, namely the period between the onset of parents’ concern and performing the assessment, but also between the first assessment of the child and receiving the diagnosis of ASD. This long time period of “waiting“ is a reflection of the complexity of the diagnostic process, the insufficient availability of diagnostic services, but also the reduced recognition of ASD at an early age (Cepanec M, Šimleša S, Stošić J, 2015).

Diagnosing autism spectrum disorder (ASD) can be difficult because there is no medical test, like a blood test, to diagnose the disorder. Doctors look at the child’s developmental history and behavior to make a diagnosis (ASD, Oxford). A general and serious problem in the ASD diagnostic procedure is the great subjectivity in the interpretation of the diagnostic criteria, regardless of which diagnostic manual is used. Namely, both manuals, to a greater or lesser extent, pose equal challenges to the diagnostician (Cepanec M, Šimleša S, Stošić J, 2015).

In recent years, a large number of scales and measuring instruments have been developed all over the world, which are used in the screening and diagnosis process of ASD. By analyzing the literature on instrumentation used in clinical practice and scientific research, instruments that are systematically applied in a large number of countries can be singled out, which have proven good validity and reliability and which have become the standard of recommended measuring instruments within the framework of the thorough assessment of ASD (Cepanec M, Šimleša S, Stošić J, 2015).

Today, with the application of diagnostic criteria from diagnostic manuals, the “gold standard“ in the diagnosis of ASD is the use of the following:

- ADOS (Autism Diagnostic Observation Schedule), instruments, standardized behavioral observation form and
- ADI-R (Autism Diagnostic Interview-Revised;), standardized structured interview with parent or caregiver.

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The Autism Diagnostic Observation Schedule - Generic (ADOS-G) is a proven reliable diagnostic tool, which can also be used as an adjunct to taking anamnestic data. In Serbia, this instrument is available in tertiary healthcare institutions. By comparing the instruments, it was concluded that the use of a combination of instruments (ADOS + ADI-R) had similar accuracy to the "gold standard" in establishing the diagnosis (multidisciplinary assessment). It is not recommended that the diagnosis of ASD be made solely on the basis of autism-specific diagnostic instruments. Physicians involved in the specialist assessment should take a developmental history specific to ASD, as well as directly observe and assess the patient's behaviour, and social and communication skills (Guidelines,2018).

The Childhood Autism Rating Scale (CARS) is an older questionnaire that includes a brief medical history and observation of spontaneous behaviour patterns relevant to ASD. It was recently updated to CARS-2. In Serbia, this instrument is also available in tertiary healthcare institutions (Guidelines,2018).

The experience of interacting with a child with ASD, in order to gather clinical evidence for ASD that is consistent with the ICD-10 or DSM-5 classifications, is a task that cannot be undertaken without significant clinical experience. Crucial elements for achieving these skills are education, training and experience gained during specializations and sub-specializations. Assessing a child with ASD must not be quick. Sometimes it is impossible to collect a sufficient amount of information and evidence during one examination, and observation of the child in a different environment is required, e.g. in kindergarten, school or clinic. The ADI-R has been shown to be a reliable diagnostic instrument but should be used with particular caution in children under two years of age. ADI-R was translated in Serbia and is used in tertiary health centres (Guidelines,2018).

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Specialist assessment or diagnosis is carried out only by professionals who have sufficient experience and skills to diagnose ASD. At this moment in Serbia, autism is diagnosed by a diagnostic team consisting of a child psychiatrist, a clinical psychologist and a special education teacher. In some countries, the diagnosis is made by paediatricians with sub-specialization in developmental paediatrics, that is, child neurologists with their teams, which include clinical psychologists and special education teachers. The goal of a specialist assessment is to collect and record information that enables diagnosis, a diagnosis of ASD can be seen as lifelong, therefore, it is important to make a precise diagnosis (Guidelines,2018). It needs to be recognized, however, that the vast majority of child and adolescent mental health services worldwide do not have these instruments used in specialized clinics in wealthy countries.

Here are some of the concerns of parents in the diagnostic process:

Many caregivers are concerned about how their child will behave in the assessment environment. For example, they may be worried that their child's behaviour will be different than it is in more familiar settings, or that the assessment results may either over- or underestimate the child's true level of skills.
Likewise, caregivers may be concerned or embarrassed if the child exhibits challenging behaviors and they may be uncertain about what role they should play in these situations. It is often helpful to let caregivers know that the assessment will be done in such a way as to obtain optimal performance from the child.

Further, it can be beneficial to let caregivers know that all observed behaviour will be matched with information from the caregivers themselves about whether these observations are consistent across circumstances that the caretaker observes.

Finally, when challenging behaviours manifest themselves, it is helpful to reassure caregivers that the assessment team is comfortable with and adept at addressing these behaviours, and, moreover, that the opportunity to observe such behaviours provides valuable information to the assessment team.

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In many circumstances, immediate feedback subsequent to the assessment itself is thought to be ideal. Certainly, long delays – and the resulting uncertainty and discomfort associated with waiting – may be extremely difficult to tolerate, and should be minimized whenever possible. However, there may be a number of circumstances under which it might be appropriate to delay feedback.

Questions regarding the level of functioning, including ideas of “recovery” and overcoming challenges, are often driven by projections about the child’s future, and the fundamental parental hope for the most positive outcome possible for their child. As such, these questions are ultimately some of the most important for parents but are very difficult for clinicians to answer for individual children. The ability to predict long-term outcomes for very young children with ASD is quite limited.

Another important aspect of the diagnostic process is the implication a diagnosis holds for obtaining access to desired services. In many instances, a specific ASD diagnosis is required for access to specialized programs, funding, and intervention opportunities. Conversely, the inability to provide a definitive diagnosis because of limitations in our diagnostic methods and understanding at very young ages may prevent families from obtaining certain services. Unfortunately, there is often a gap between the guidelines and laws surrounding interventions and the availability of community resources and services. As such, families often face significant barriers to accessing interventions. Caregivers are often placed in the extremely difficult role of having to act as expert advocates and resource specialists for their child to secure services that their child needs.

In Serbia diagnosis is most commonly given by a psychiatrist so parents often come to the therapist with a paper with a diagnosis on it but they don’t have a clue what that means for their child.

How to talk, empower and educate parents of children with autism spectrum disorder

UNIT5: Partnership, what constitutes cooperation, obstacles in cooperation between different actors

5.1 Objectives and Skills

When we talk about professionals and parents we have to talk about partnership. In this unit, we talked about what constitutes cooperation, obstacles in cooperation between different actors, and what we should do to have a good working relationship with the whole family.

5.2 Introduction

At the beginning of the day, a review of the previous day was made and the plan for the day ahead was presented.

Discussions were held with the participants about the understanding of key terms such as: What is different between participant and partner?

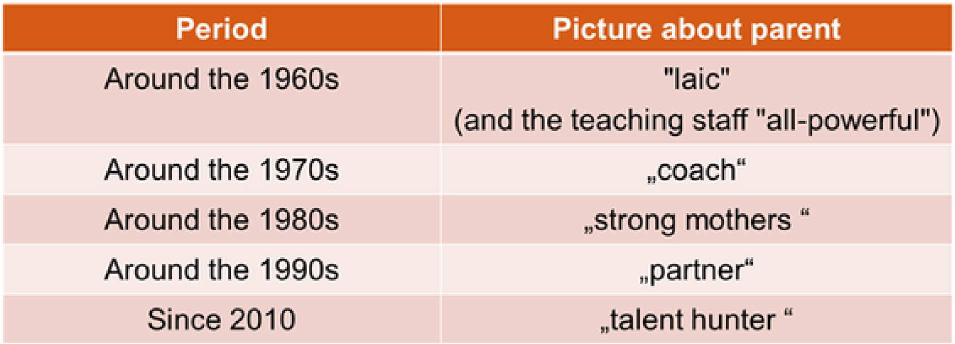
One of the challenging tasks for the participants was to guess the “magic formula“ for a successful partnership, i.e. to find out what the ingredients are, i.e. elements of the partnership.

5.3 Background

Understanding parents and the whole family in the process of coping to accept having a child with autism is critical for building an open relationship and cooperation between parents and the main bearers of the institutionalized educational process, i.e. preschool teachers, school teachers, and counselors. Cooperation with the family in the period of providing additional support to a child with developmental disabilities, especially during treatments and interventions of special pedagogues (special education teachers, speech therapists...) is crucial, but the approach and attitude towards parents have changed, as well as their role over the years.

MODULE 2

How to talk, empower and educate parents of children with autism spectrum disorder



Period	Picture about parent
Around the 1960s	"laic" (and the teaching staff "all-powerful")
Around the 1970s	„coach“
Around the 1980s	„strong mothers “
Around the 1990s	„partner“
Since 2010	„talent hunter “

Presentation of different approaches to parents in treatments and education over several decades (Czeizel és Kemény, 2015)

Different approaches and roles of parents have changed in the process of providing additional support to the child’s learning and development and interventions over the last six to seven decades: the parent was seen as a “laic”; then the parents were associates in therapy; afterward they encouraged and supported “strong mothers”; after that, they noticed partners in parents, and in recent years, parents have become “talent hunters”. Although the trend in the 21st century is to identify talent for certain areas in a child with developmental disabilities, in Serbia and according to the current educational paradigm, partnership with parents is sought and promoted. The partnership and teamwork of experts and parents in providing additional support in children’s learning and development is the “formula“ that provides the greatest opportunities for the child’s progress in order to achieve the child’s well-being in all dimensions.

Partnership is a very complex relationship between partners and it is not simple to achieve and maintain partnership relations between two persons or institutions. Partnership relationship in the context of upbringing and education relationships to all participants of that process - to children, parents, and employees in educational institutions. In the best interest of the child, it is necessary to realize a partnership between the educational institution and the family and work to achieve a high-quality educational process and child development. According to the model of the US Department of Education, the partnership with.

Partnership building model (from USA Ministry of Education)
I Counselor
II Co-speaker
III Participant
IV Partner

Counselor - the phase when the family is advised by experts and professionals learning process, educational work, and ways and methods that are required for work. At that stage, the role is divided so that the pedagogue is the one who initiates, proposes measures, and has a more dominant position than the parents, but is ready for suggestion and cooperation.

Co-speaker, in this phase, the positions of parents and pedagogues are rotated: the pedagogue leaves the leading role to the parent, with respect and confidentiality of private data about the family and the child. At this stage, the pedagogue must possess the necessary good communication skills and compassion, with complete elimination of critical thinking or evaluation in relation to parents.

Participant - on the basis of the interview phase, the participant phase is upgraded, because the parent becomes a part of life in the kindergarten and school with his clear role created by the pedagogue based on the results from the previous phase. At this stage, the parent receives the most information and insight into work and education - the questioning process. In that period, the parent's role is clearly defined and in which period of the child's development is it most important?

Partner - as the crown of cooperation comes the partnership of family and institution. This is achieved when the parent is guided and informed about the process of education and upbringing, and when the pedagogue knows all the details well in connection with the child and is adequately informed for working with him. Those relations are based on deep respect and trust, with a common goal. It is impossible to build such a partnership if the kindergarten or school does not respect its family, and vice versa. That level of cooperation and appreciation is achieved through frequent and open conversations, as well as constant maintenance of communication. Partnership with the family is achieved by going through it together through important previous stages if the parent is active and involved in the work. The team participates together in planning, implementation, and division of responsibilities in child education.

For the relationship;

Very important to understand what is different between participant and partner. The partnership and teamwork of experts and parents in providing additional support in children’s learning and development is the “formula“ that provides the greatest opportunities for the child’s progress in order to achieve the child’s well-being in all dimensions.

<u>What does partnership entail?</u>
“A magical scheme“ for the parentship: **AC E DC**
For success in partnership, we need to include:
A – authenticity
C – competence
E – equality
D – Democracy
C – complementarity

Partnership the relationship between upbringing and education is based on the principles of equality, authenticity, competence, complementarity, and democracy (Pavlović-Breneselović and Pavlovski, 2000 to Velišek-Braško, 2015). In order for a partner relationship to exist, it is necessary that the partners have the same rights and respect the rights of the other, that is, that they are equal, that they accept and respect each other and its differences, i.e. the authenticity of your partner. In partnership relations, recognition of strengths and abilities, i.e. competencies, is important in oneself and in one’s partner, on the basis of which they should complement each other - and that means achieving complementarity. Mutual respect for opinions, using arguments during conversations, discussions, and agreements, and joint decision-making in a democratic way - they do democracy in partnership relations.

How to talk, empower and educate parents of children with autism spectrum disorder

Identified risk factors that make it difficult to cooperate with parents are:

1) Lack of communication skills
2) Misunderstanding the purpose and meaning of cooperation
3) Lack of time
4) Cultural differences
5) Criticizing each other
6) Prejudice, stereotypes and discrimination
7) Stress
8) Bad past experiences
9) Fear of change
10) Differences in seeing the child's needs

It is necessary to eliminate risks in the communication and cooperation between parents teachers staff.

Tips for developing partnerships with parents

Organization of space (because space speaks to us). What is telling us about the space organization in the left and in the right picture? How does it determine our relationships and roles?

Pictures for talking with space

1. Space - The organization of all objects in space is important, but the position of the table and chair is especially important:

-take care of the distance
-pay attention to the angle at which they stand.

2. Time - organization of time

-respect the time scheduled for the meeting
- provide enough time to talk
-without answering the phone
- and ensure privacy without the entry of other persons

3. Communication - It is necessary to reflect on the content and feelings in the conversation. An example of reflective communication:

Parent: This lasts too long, I’m very tired.
Expert: You are exhausted.
Parent: Yes. I don’t sleep well. I’m worried, we need help.

* * *

Parent: Imagine, the teacher said, that my child is late in speaking. How dare she!

Expert: That made you angry.

Parent: Yes, of course. What does she think, who is she?

Expert: Let’s do a questionnaire together about the speech development of your child.

How to talk, empower and educate parents of children with autism spectrum disorder

UNIT6: The most common questions of parents, problems of parents in practice, how to answer them

6.1 Objectives and Skills

In this unit, we dealt with topics such as the most common questions of parents, problems of parents in practice, and how to answer them. Also, we discussed different kinds of formal or informal support parents need and have.

6.2 Introduction

Before every slide on powerpoint presentation we open with a question, where participants give answers for what they think, we all discuss it and then we go on to the theoretical part.

6.3 Background

The most common questions of parents, problems of parents in practice, and how to answer them

In terms of diagnosis and treatment

As ASD professionals, persons who are working with these families we know that it is extremely important to establish a meaningful working relationship with families from the initial point of contact and to nurture this relationship throughout the assessment process, the discussion of clinical impressions and recommendations, and the follow-up (ASD, Oxford).

In addition to informational support, parents should also receive psychological support through support and meeting groups; health workers who work with children should include parents in the intervention, train them for similar behavior at home, and work with parents to overcome existing personal problems/dilemmas, that is, work to empower parents. Caring for a parent is caring for a child. Parents and guardians of a child with ASD should be provided with continuous information and assistance in understanding the diagnosis, as well as empowerment in the decision-making process when choosing interventions (Guidelines,2018).

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Treatment of ASDs depends on factors that make a description of "the treatment" inadequate. Differences in age, degree of impairment, comorbid disorders, family and social situation, level of resources and community development, provision of education (or lack of it), health and welfare assistance, opportunities for sheltered employment, and availability for inclusive living in the community in adult life will make a huge difference. If there are two words that would underline what should be done for children with ASD, those two concepts would be "to **personalize**" and "to **contextualize**" (Ray, 2013).

Helping parents navigate through a "sea" of different treatment options is a big and important part of our job. Also, directing them to evidence-based treatment. Parents often say: "When a child gets cancer dg, no one expects you to help the child get better, when he gets ASD dg, it's up to the parents to figure out how to make the child better.“

Despite accepting these common sense ideas, there is a tendency to search for a "cure" for ASD, as if there was a single cause, a unique mechanism, and a single condition underlying the syndrome that, if identified, would lead to a cure for all the ASD. The Internet allows families and professionals to hear about many "treatments" – some based on current knowledge but others based on sheer superstition or false beliefs – that most people feel confused about what to do. The worst aspect is that families (and professionals) feel that there is something else they should be doing and by not doing it, they are not providing the best treatment for the child with ASD.

Programs developed over the years in wealthy countries are copied or applied in completely different areas of the world without regard for the local circumstances, opportunities, and feasibility of future maintenance. While there is no cure for ASDs, there is strong evidence that appropriate, lifelong educational approaches, support for families and professionals, and provision of high-quality community services can dramatically improve the lives of persons with ASD and their families (Ray, 2013).

In providing feedback about interventions, it must be recognized that in addition to the behavioral and educational interventions recommended in current practice parameters, most parents have questions about complementary and alternative medical (CAM) treatments as well. At present, a majority of children with ASD participate in CAM treatments, with the number of different treatments and their rate of use growing over time (Guidelines,2018).

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As more children with ASD become involved with CAM treatments, it is important for clinicians to be familiar with these interventions and address them within the context of the assessment. If clinicians hope to assist families more fully in making autonomous, empirically informed decisions about treatments, then they must address questions about CAM treatments in a manner that allows families to feel comfortable reproaching this issue on an ongoing basis (Guidelines,2018).

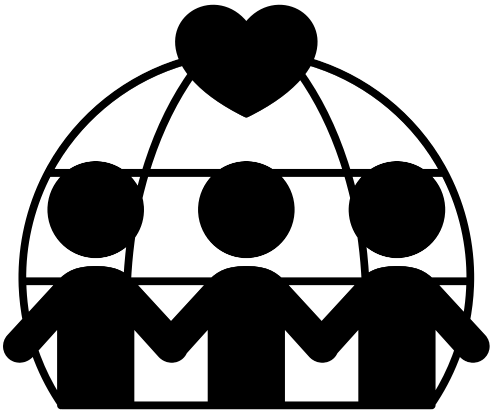
Education of parents

Parental education is the process of systematically providing the necessary information to parents and guardians of the child, which will provide them with specific knowledge and skills for caring for children and help them to encourage the child's development and competence.

For parents of children who have recently been diagnosed with ASD, education and mastering specific skills significantly improve their mental health and the process of adapting to new conditions. Parents' education has a positive effect on:

a) improving the child's social and communication skills;
b) causes a positive effect on the child's social behavior and communication and on more successful parenting and improvement of the parent-child relationship.

One of the most recognized parent education programs in the world is Parental Skill Training (PST). This educational program is intended for parents whose children have developmental problems, and it was developed by the organization Autism Speaks and the World Health Organization. Parents and guardians of preschool children with ASD are recommended to attend preschool programs (Guidelines,2018).



MODULE 2

How to talk, empower and educate parents of children with autism spectrum disorder

Social support

Every individual and family that needs social assistance and support in order to overcome social and life difficulties and create conditions for meeting basic life needs has the right to social protection, in accordance with the law.
"The rights to social protection are ensured by the provision of social protection services and material support".

Families with children with developmental disabilities are among the most sensitive user groups in the social protection system, not only because of the child's difficulties, which require additional strain on the family but also because of the need for support that is long-term, continuous, comprehensive and requires the coordination of various departments, services, institutions and organization (Guidelines,2018).

Support within the community

In addition to the support of immediate and extended family, and formalized forms of health, educational, and social support, parents and guardians of children with ASD can also request support from other sources within the community. For example, the main objective of "self-help groups" (which are voluntary organizations) is to provide social support and necessary information and to advocate the interests of beneficiaries. These groups can help parents deal with the challenges of getting a diagnosis and allow them to not feel alone in the process. ASD affects all aspects of the life of the child and his family, so the importance of social support and the existence of networking of families with the same problems is very great. Help and support for parents and guardians that come from the family and the community in which they live significantly reduces the level of stress that accompanies caring for a child with ASD. Informal social support is important for absorbing stress in the family of a child with autism (Guidelines,2018).

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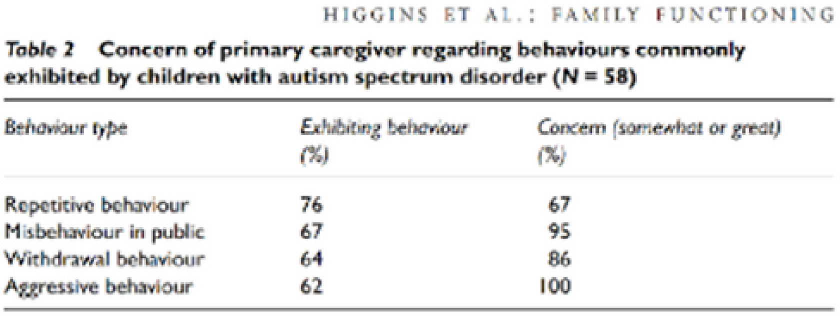
Associations have different informal forms of support, of which we highlight

- Helpline – a reliable service led by staff trained in ASD
- answers general questions about ASD
- informs about the options available to people with ASD
- informs about support options available to family members
- refers parents from other cities of Serbia to local associations
- sends brief information on legal interpretations and procedures (Guidelines,2018)

Advisory work, as an example of good practice, involves the formation of groups of parents (from 10 to 15 members) included in the support program. The groups are closed and meet twice a week for 120 minutes. The activities are organized in the form of workshops where, in addition to the exchange of practical knowledge and skills, interaction between the participants is encouraged. Thematic workshops are led by experts and are divided into two parts: the first part consists of a presentation by an expert on a topic (for 30 minutes), and the second part is dedicated to parents' experiences and strategies for overcoming problems. Workshop topics are usually suggested by parents (Guidelines,2018).

Counseling work in the form of meetings with parents is carried out by parents who have been trained in group counseling workshops. This activity takes place on the premises of the Association of Associations of Serbia to help people with autism if the parents are from Belgrade or visiting parents from other cities of Serbia who are at clinics for diagnosis. This support system includes basic information about the disorder itself (brochures, informants, flyers, and institution contacts) (Guidelines,2018).

What worries parents the most?
- perspective trough time -



HIGGINS ET AL.: FAMILY FUNCTIONING

Table 2 **Concern of primary caregiver regarding behaviours commonly exhibited by children with autism spectrum disorder (*N* = 58)**

Behaviour type	*Exhibiting behaviour (%)*	*Concern (somewhat or great) (%)*
Repetitive behaviour	76	67
Misbehaviour in public	67	95
Withdrawal behaviour	64	86
Aggressive behaviour	62	100

MODULE 2

How to talk, empower and educate parents of children with autism spectrum disorder

UNIT7: Family stages through the ages, different challenges, growing up, maintaining functionality

7.1 Objectives and Skills

In this unit we finished with family stages through the ages, how different challenges arise when children with ASD grow up, and how those new challenges affect the whole family.

7.2 Introduction

The workshop task was for the participants to express themselves through drawings, i.e. to draw a family with its members. The presented families introduced themselves to each other, and the workshop emphasized that each child has its own specific family context and that together with the child, we get to know the child's family with all its specificities.

7.3 Background

Family stages through the ages

The family structure consists of members, their number, and their role within it: (father, mother, children (son, daughter), grandmother, grandfather, other members or close relatives. Family dynamics are determined by family subsystems, relationships within the subsystem, and relationships between subsystems (partner-partner, parent-child/children, brother/sister-brother/sister, i.e. siblings, and relationships with other family members.) From the child's point of view, the family is the first and most important social group that has a determining role in the child's development.

Toy happy family of the student from PTTC Novi Sad

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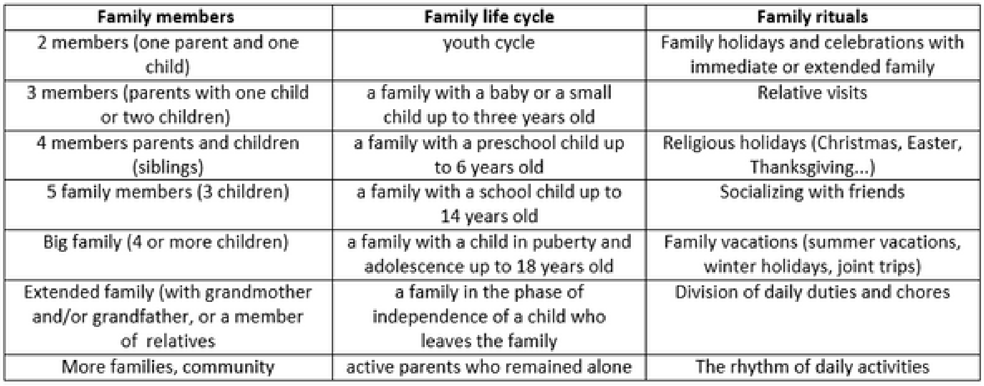
Every family is different (Bánlaky, 2009) in terms of the number of members, structure, number of adults and number of children, roles within the family..., family rituals... life cycle. Families can be very different in structure: by the number of members, the number of children in the family, the gender of the children... Siblings have specific positions in relationships which depend on the number of children, sex of children, order of birth, or the same specifics. Every family has some authentic events in the family (different child, loss, moving, living conditions...). The life period of the family is related to the age of the children (early period, school age, adolescence...).



Family members	Family life cycle	Family rituals
2 members (one parent and one child)	youth cycle	Family holidays and celebrations with immediate or extended family
3 members (parents with one child or two children)	a family with a baby or a small child up to three years old	Relative visits
4 members parents and children (siblings)	a family with a preschool child up to 6 years old	Religious holidays (Christmas, Easter, Thanksgiving...)
5 family members (3 children)	a family with a school child up to 14 years old	Socializing with friends
Big family (4 or more children)	a family with a child in puberty and adolescence up to 18 years old	Family vacations (summer vacations, winter holidays, joint trips)
Extended family (with grandmother and/or grandfather, or a member of relatives	a family in the phase of independence of a child who leaves the family	Division of daily duties and chores
More families, community	active parents who remained alone	The rhythm of daily activities

Family structures and dynamics

Family stages through the life cycle with different challenges, growing up and maintaining functionality:

1) Newlyweds: coordination of different performance expectations, models, samples, the creation of joint schemes, and the creation of one’s own family model.

2) Families with infants and small children (0-3 years): parents must find each other in their relations between the new balance, in which there is a natural place for thirdly, the children.

3) Family with small children (3-6 years): the mother-child and father-child relationship becoming more similar, at the same time, of the content of the mother role and the father role modification, i.e. the filling of the husband role and the wife role with new contents, and thus the further formation of the relationship between the couple, a new balance design.

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4) Family with a school-aged child (6-14 years old): the relative equilibrium situation is a new design that meets the conditions and incorporates the changes into the internal family system.

5) Adolescent child (14-18 years) in the family: the complete reorganization of the network of relationships results, and the previous asymmetry of relations must be gradually rebuilt into a more symmetrical relationship system.

6) Family issuing adult children: parent-child during the period of issuance the symmetrical relations of the relationship are fundamentally rearranged and the original internal of the family and its relationship system must be transformed accordingly.

7) Active parents are left to themselves: transformation of the couple’s relationship duration, new development of relationship content

8) Family of inactive elderly parents: staying alone, death of spouse, couple

The life period of the family with the child with autism:

A family with a baby or a small child up to three years old - characterized by difficulties in feeding the baby, establishing the rhythm of the day, problems with the baby sleeping, difficulties in soothing the child, parents physically completely exhausted and lost.

A family with a child of preschool age - more difficulty with adaptation of the child to kindergarten, difficulties in establishing a relationship with the kindergarten teacher and other children, challenges in peer interaction, in the children’s play, noticing deviations in development, seeking advice and experts.
Period of starting elementary school - searching for an accepting school, and teacher, stress due to enrollment and testing, challenges with the transition to a new environment, and accepting new situations and new roles.

Period of the lower grades of primary school (classroom teaching) – learning new material at school, doing the school and homework, accepting new student obligations, following classroom rules, and establishing relationships with peers.

Transition to higher grades of primary school (subject teaching) - transition to classroom teaching, changing classrooms, new subjects, new teachers, and more than 10 people.

The higher grades of primary school (subject teaching) - different requirements from different teachers, volume, and complexity of learning materials, and puberty changes.

Enrollment in secondary/high school- professional orientation, identifying personal potential for choosing a profession, searching for a new accepting school, stress about enrolling in high school.

Attending high school - more subjects about 15, new subjects, professional subjects, a new way of working with new teachers, high-risk groups, puberty, and sexuality.

Employment - having a diploma, applying to the labor market and health insurance, many administrative procedures, searching for an accepting employer, going to an interview, starting business obligations, searching for a mentor at work, inconvenient working hours, difficult jobs, and low salary.

What after high school / Daycare period - difficulties with independence in everyday life, necessary constant support for everyday life, residences with insufficient capacity and in poor conditions for residence and work.

Period of adulthood - insufficiently organized and structured day, loneliness, psychological problems, and health problems. Living with siblings or relatives, often in institutions.

Period of old age - mental and physical problems, health problems due to a passive lifestyle, living with siblings or relatives, often in institutions. According to statistics, they live shorter than typical people, on average less than 18-30 years.

The life period of the family with the child with autism - Every life period for the different families or cycles has some specific, challenge or problems.

MODULE 3

ACTIVITY-BASED SUPPORT FOR FAMILIES OF CHILDREN WITH AUTISM

UNIT1: What causes Autism - Relevant studies for families;

Short description of module:

Module 3 is based on showing support activities for families with children with autism. To begin with this module, families are offered information about autism, and later, support tools for families are shown, as well as the importance of implementing a family-centred model to deal with children with autism.

1.1. Objectives and Skills

The objective of this first unit is to provide readers with information and knowledge about autism through published studies and tools that help them understand what autism is.

1.2 Introduction

In 1924 the Austrian psychiatrist Leo Kanner emigrated to the United States, where he was later commissioned to set up a child psychiatry service - probably the first in the world - at Johns Hopkins Hospital in Baltimore. There he treated several children in whom he observed a pattern of behaviour that did not correspond to any of the disorders known at the time. This led him to publish, in 1943, a work entitled Autistic Disturbances of Affective Contact. The term autism was already used to describe one of the symptoms of schizophrenia (with which until then it was confused), and it referred to the isolation of the person in his inner world.

At the same time, the pediatrician Hans Asperger, also Austrian, was working at the Vienna University Children's Hospital. Although it seems that neither Kanner nor Asperger had any knowledge of the other's work, their research maintains many parallels, even in the common use of the term autism. However, Asperger observes in some of his patients' cognitive abilities that allow them, with appropriate help, to partly compensate for their difficulties.

His work was summarised in the article Die Autististischen Psychopathen im Kindesalter (Autistic Psychopathen in Childhood), published in 1944, although due to the isolation caused by World War II it went largely unnoticed, and was not widely known until an English translation of it was published in 1991. Since Kanner's foundational study was published 70 years ago, researchers have tried to **answer two questions about autism spectrum** disorders: what causes them, and above all, **¿what are they really?**

The first of these two questions has been, and partly still is, the cause of several controversies. In the beginning, it was believed that autism was due to the lack of affection from mothers (Kanner spoke of “the lack of maternal warmth“). The progressive increase in the number of diagnosed cases (largely due to improved means of detection) has led to suspicions about the harmful effect of certain chemicals, such as pesticides or food additives, and since 1998 in some places vaccines have been blamed, leading to campaigns against childhood vaccination. The truth is that autism has mainly genetic causes (siblings, parents and children of an autistic person have more possibilities of being within the spectrum) or related to circumstances of pregnancy or birth.

1.3 Background

The second question leads us to the aim of this article: ¿what is autism in reality? We can try to approach the answer by proceeding at different levels:

- The first level is the “official“ criterion, the one used to establish a diagnosis, which is set by the Diagnostic and Statistical Manual of Mental Disorders (DSM (3)). In the 2013 version of the DSM-5, only two types of symptoms are included: persistent deficits in communication and social interaction, and restricted and repetitive patterns of behavior, activities, or interests.

- On a second level, we see that in general, people with these disorders not only present these two diagnostic symptoms but also other characteristics which, although they are not the same in all cases and do not always occur with the same intensity, tend to belong to a specific group of apparently unrelated manifestations. An interesting phenomenon to note is the variability of IQ across the spectrum, and even in the same person there may be high ability in one area and deficits in other areas.

- The third level is offered by professionals who have accumulated a long experience, who, after years of dealing with very different people, acquire the intuition that underneath the observed variability there is something unique and common in autism.

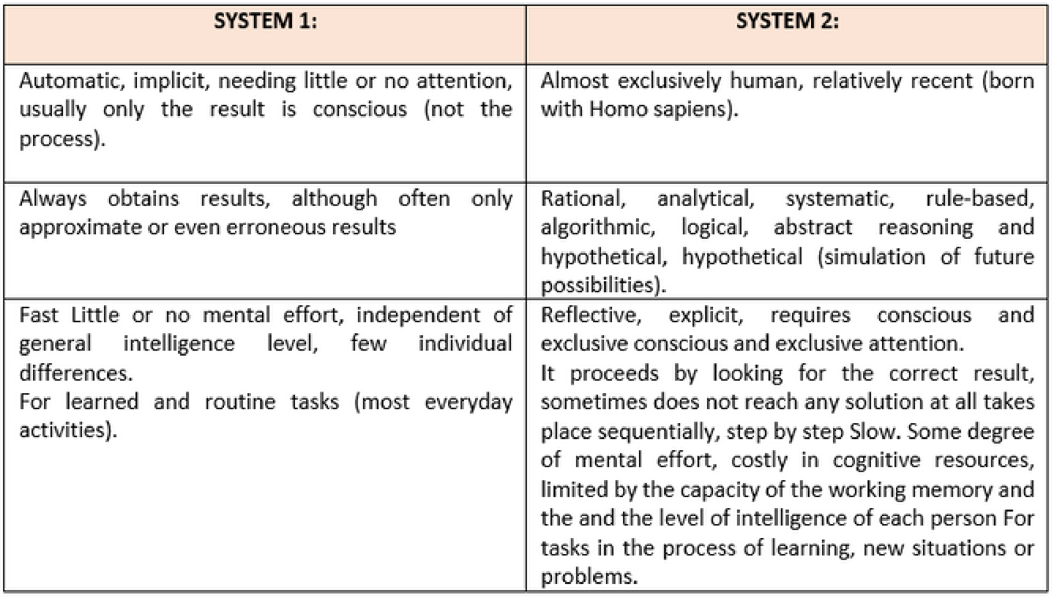
Several theories have attempted to find this basic core that could explain all the features observed along the spectrum. The most widely accepted have been weak central coherence, theory of mind deficits, executive dysfunction deficits, and the emphasis/systematization imbalance. However, each of these only explains part of the symptoms.

It is possible to think that, if autism has repercussions in such varied fields, it cannot be due to an anomaly in a specific brain function (a cognitive module), but it is a different global functioning of the brain, which modifies the way the brain processes information in all its different activities. But to understand what this different functioning may be, it is useful to review what normal functioning is like.

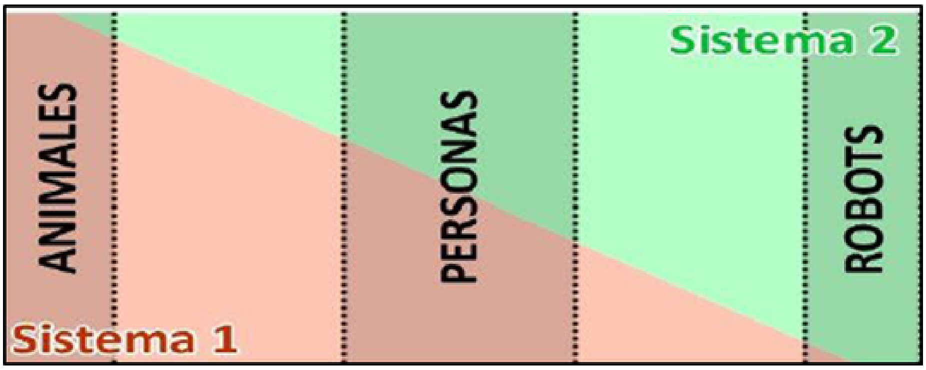
1.4 Content

Two minds in one brain: As early as the 4th century BC, Aristotle defined human beings as "rational animals", thus indicating that our reasoning, our decisions, and our social relations are guided partly by the same impulses that govern the activity of animals, and partly by our reason.
In recent decades, some cognitive scientists have come to the conclusion that there are actually two cognitive systems in our brains with very different - usually opposing - characteristics, which they have come to call System 1 and System.

System 1:
Universal, similar to other animals, evolutionarily ancient. Heuristic, associative, intuitive, instinctive, global, derived from experience, proceeds according to the result obtained in previous similar cases.



SYSTEM 1:	SYSTEM 2:
Automatic, implicit, needing little or no attention, usually only the result is conscious (not the process).	Almost exclusively human, relatively recent (born with Homo sapiens).
Always obtains results, although often only approximate or even erroneous results	Rational, analytical, systematic, rule-based, algorithmic, logical, abstract reasoning and hypothetical, hypothetical (simulation of future possibilities).
Fast Little or no mental effort, independent of general intelligence level, few individual differences. For learned and routine tasks (most everyday activities).	Reflective, explicit, requires conscious and exclusive conscious and exclusive attention. It proceeds by looking for the correct result, sometimes does not reach any solution at all takes place sequentially, step by step Slow. Some degree of mental effort, costly in cognitive resources, limited by the capacity of the working memory and the and the level of intelligence of each person For tasks in the process of learning, new situations or problems.



Although each of the two systems is often used specifically for certain types of activities, they often interfere with each other, with sometimes beneficial and sometimes detrimental effects. The psychologist and economist Daniel Kahneman, winner of the 2002 Nobel Prize in Economics, has shown that this cognitive bias effect allows people’s decisions to be subtly but significantly influenced, even when they believe they are acting rationally, and without them being aware of this manipulation. A disturbing example is the experiment with a group of German judges who were given a detailed description of a case of robbery. They were then asked to roll a pair of dice and say whether the number of months’ imprisonment for the thief was more or less than the sum of the two dice.

Finally, they were to indicate the exact sentence they thought was appropriate. What the judges didn’t know was that the dice were rigged so that in half of the cases they added up to 3, and in the other half to 9. Well, on average, the judges who had rolled a 9 said they would sentence the thief to 8 months in prison, while those who had rolled a 3 only sentenced him to 5 months.

But at the same time, the symbiosis of both systems provides humans with unique capabilities that neither of them separately can achieve (creativity, culture, progress, art). Thus, despite advances in computing and robotics, we see that these System 2-only devices suffer from specific limitations:

Electronic translators can store complete dictionaries in multiple languages, but even so, the translations they produce contain many errors, as they are unable to interpret the meaning of sentences, which requires deducing the speaker’s intention, picking up on irony and double meanings, and “reading between the lines“. To communicate with the computer, programmers must use a systematic language, with strict and unambiguous rules.

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In manufacturing processes, it is becoming increasingly common to use robots that repeat the same movements over and over again with precision. Computers, too, are increasingly finding solutions to problems by invariably following a fixed list of instructions. But neither have the creativity to adapt themselves to new situations or to unforeseen changes. They are simply blocked in front of them.

More and more surveillance cameras are recording activity in outdoor and public places. Most of these images are stored on computers, which can store an enormous amount of hours of video (even allowing details to be seen that went unnoticed by the people watching live). However, the interpretation of these images (e.g. to detect a criminal actor or the causes of an accident) is beyond the capacity of the computer, which cannot extract the overall meaning from the details it records.

In recent decades, universities, companies, and organizations around the world have been working to develop humanoid robots. The most advanced ones can walk on flat surfaces, pick up certain objects, detect obstacles, and some are even able to climb stairs, but their movements do not even reach the flexibility of a toddler. There is a long way to go before they can compare to this child at the age of a few years, playing ball with friends, riding a bicycle, or climbing a tree. At this point, something may strike us: those areas in which robots perform less well correspond to the areas in which difficulties are often observed in people with autistic spectrum disorders (difficulties that seem to be unrelated). Is this just a coincidence or is there a deeper cause for this? If we recall the graph on the previous page, the band occupied by humans has a certain width, which means that the relative importance of each of the two cognitive systems is not the same for all of us. In fact, this is something we perceive when we look at the way people are: some people are more intuitive, instinctive, and global (with a greater predominance of System 1) while others are more reflective, methodical, and detail-oriented (dominated by System 2).

The differences between the two systems are usually relatively small, but they contribute greatly to defining a person’s character. Of the main theories that have tried to explain autism over the years, one has a certain similarity to the one proposed here, since it is also based on an imbalance between two trends. This is the so-called theory of Empathization-Systematization, by the British professor Simon Baron-Cohen.

What is proposed here is that autism consists of a predominance of System 2 beyond the usual variations. Since this is due to a certain structure of the brain that affects all its parts, its effects are manifested in areas as diverse as those observed in these disorders: difficulties in the interpretation of social signs, non-explicit communication, or figurative language; tendency to repetitive or routine activities; bad adaptation to changes, especially unexpected ones; attention to detail over global sense; psychomotor problems; specific abilities, etc. This hypothesis is also consistent with the higher incidence of these disorders in males since System 1 is statistically predominant in females.

However, the two extremes are not two cognitive systems that encompass all brain activities, but two partial aspects of them: empathy and systematization. This explains only part of the observed symptoms.

These are the core symptoms that could manifest themselves:

SOCIAL	Less eye contact, use of gestures or facial expression Difficulty in understanding others' emotions and feelings
	Less sharing of interests with others.
	Difficulty in playing with children of the same age
	Problems making and keeping friends

COMUNICATION	Slow to learn to speak
	Unusual speech (repeats things, speech sounds unusual)
	Difficulty in engaging in conversation
	Less imitation and symbolic play.

REPETITIVE BEHAVIOURS	Repeats activities or movements (rocks, turns, waves hand, shakes fingers).
	(i.e., spins the wheels of the toy car).
	Unusual, strong, limited interests (often talks about the same topic or plays with the same item, knows a lot of information about the topic).
	Plays with parts of a toy rather than with the whole toy.

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UNIT2: LEARNING ABOUT AUTISM FOR THE FAMILY / RESPONSE TO DIAGNOSIS

2.1 Objectives and Skills

The main objective of this unit is to guide families when receiving a diagnosis. How to face the situation at all levels and obtain the necessary information so that they can face it in the best possible way.

2.2 Introduction

When we find out that my child is diagnosed with autism, it is a very difficult moment in the life of the family, mostly due to the little information about the disorder or the false myths that are still prevalent in clinical consultations, and society in general. This means that suddenly, family life changes, becomes distorted, and can feel very different from what they expected it to be.

First of all, it highlights the concern about what we are going to do now with the child, as well as worrying about whether this will affect the child's day-to-day life and what it will mean for their daily life experiences, at school, with other children, with their own immediate family. You worry about how you and your family will adapt to this in the years to come. You worry about the day-to-day challenges of caring for your child with autism.

This is an important turning point in your family's life, as well as in your child's life and for other family members. Getting emotional support and factual information is essential to help you cope and fostering a positive future for your child and your family will be critical during this period.

2.3 Background

Common reactions to diagnosis:

It is important to keep in mind that each family's reaction to the diagnosis will be different depending on a number of factors. The list of "Common Reactions" is intended to be a summary of the feelings that families may or may not experience.

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When a child is diagnosed with autism, parents and other family members often experience a variety of uncomfortable emotions that are considered a grief reaction. We can learn more through: On Grief and Grieving, Dr. Elisabeth Kubler-Ross describes stages or types of grief reactions that make sense of what most people experience.
She is careful to point out that we can move randomly between the stages, although there tends to be a clear progression towards resolution.

1. Shock: "I don't remember how I drove home after I first heard the diagnosis". "How can this be happening to my child?" Immediately after the diagnosis you may feel stunned. The reality of the diagnosis may be so overwhelming that you may feel confused and unable to accept it.

2. Sadness or distress: "I have no energy". "I can't do what I normally do for my family. "I find that I cry a lot. "I feel overwhelmed by sadness".

3. Before they can move on, many parents grieve for the hopes and dreams they had for their child. There will probably be times when you feel extremely sad. It is important to remember that there is a difference between sadness and depression. Depression often gets in the way of moving forward. Allowing yourself to feel sad can help you grow. You have every right to feel sad and to express it comfortably.

4. Anger: "We didn't deserve this". "It makes me so angry that this is happening to those I love. "I wish my neighbor wouldn't interfere".

5. Anger is a natural part of the grieving process, and you may find that it is directed at the people closest to you: your child, your spouse or a close friend. Anger is a healthy and expected reaction to the feelings of loss and stress that come with your child's diagnosis. Expressing your anger is natural and sometimes healthy.

6. Denial: "You'll get over it". "I can fix it.

7. You may go through periods when you refuse to believe that this is happening to your child. During this time, you may not be able to hear the facts about your child. Denial is a way of coping. It may get you through a particularly difficult period. It is important to realize that you may be experiencing denial so that it does not interfere with making good decisions about your child's treatment.

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8. Loneliness: “I have never felt so lonely“. “I wish I had a friend who understood my situation“. “It is so difficult to get close to other people. These feelings come from a variety of sources when you experience a loss. Loneliness may also be due to the fact that you simply do not feel you have time to seek the company of friends or family. You may also feel that, if you approach others, they may not understand or support you.

9. Acceptance: “I feel we can get through this“. “My family will be fine. Finally, you will probably feel a sense of acceptance. It is helpful to distinguish between accepting that your child has been diagnosed with autism and accepting autism. Accepting the diagnosis simply means that you are ready to be an advocate for your child.

2.4 Content

WHEN TO SEEK PROFESSIONAL HELP?

The most common feeling; is when we have difficulty managing our emotions within a reasonable time frame or if we feel that we cannot function in the usual way, then seeking professional help may be a good idea.

ACTIVITY-BASED SUPPORT FOR FAMILIES OF CHILDREN WITH AUTISM

Professional help can prevent serious problems from developing in the near future. It can help strengthen us to deal with challenges more effectively and empower us in the face of a situation that may at first appear to be a dead end.

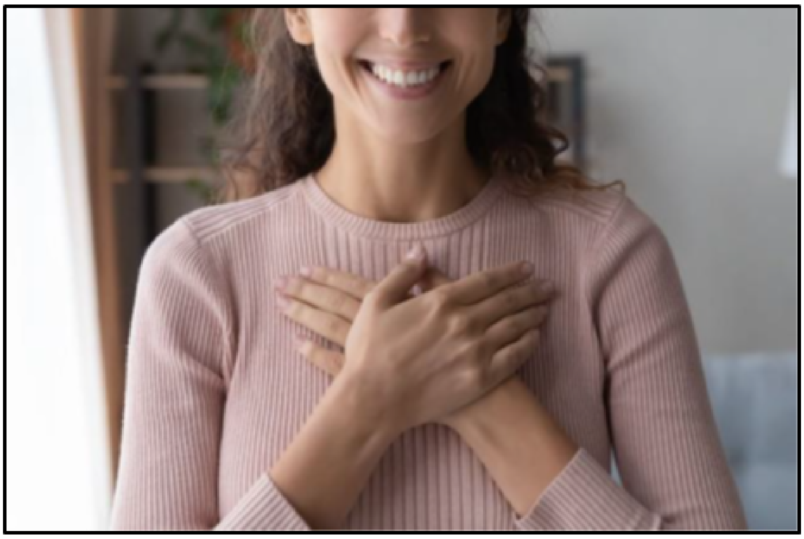
There are several of the following signs and symptoms over a period of time, you may wish to seek professional advice:

- You have difficulty sleeping and do not feel rested when you sleep.
- You cannot control your negative thoughts, no matter how hard you try.
- You have lost your appetite or cannot stop eating.
- Other people report that you seem irritable, moody or more aggressive than usual.
- You are drinking more alcohol than usual or engaging in other reckless behaviour.
- You have thoughts that life is not worth living.

What tools we give to Families: "What you can do for yourself at this moment".

1. Practice self-care.

Even if it is only 15 minutes a day, take a break, make a plan of activities where you have time to do what you need, like or consider motivating in your daily life. You need to take care of yourself in order to take care of others.



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2. Recognize what you have achieved (Set short-term goals).

At the end of the day, it is easy to think about all the things you didn't get done that day. But this discourages us from trying again later. Instead, think about all the things you did accomplish that day. You will be surprised how long the list is and you will feel better at the start of the next day, especially with your child with Autism, remember that goals should be set weekly in the short term, otherwise, both of you will be stressed and it will be detrimental to your understanding and daily tasks.

3. Focus on the positive.

Nothing in life is perfect. Every situation has positive and negative aspects. Focusing on the positive, such as the progress your child is making or the amazing speech therapist you found, will give you the energy you need to keep going.

4. Continue family rituals.

When possible, continue with your family's routines or rituals. This will be useful for your whole family. It could be a trip to the movies on Friday night or lunch in the park on Sunday. Tradition and rituals give your family a greater sense of stability and create fun times to enjoy together and remember.
Remember that we will need the anticipation of what we will do, so the child with Autism will find it easier to communicate and space-time orientation.

5. Give yourself time to adjust.

Be patient with yourself. It will take some time to understand your child's disorder and the impact it has on you and your family. Difficult emotions may resurface from time to time. There may be times when you feel helpless and angry because autism has resulted in a very different life than you had planned. Remember that you will also experience feelings of hope as your child begins to make progress.

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BELONGING TO A COMMUNITY... THE ROLE OF SOCIAL ENTITIES...GET INVOLVED WITH THE AUTISM COMMUNITY!

Sometimes families of people with autism feel isolated from others. It is important to connect with families who share similar experiences and seek support from others. We encourage you to reach out to other families in social entities that not only offer activities, but also training programs, meetings, and events where they take place and this will make you feel more understood and share with more families your fears and progress.

For more information on how to get involved, please visit www.asociacionmihijoyyo.org.

MODULE 3

ACTIVITY-BASED SUPPORT FOR FAMILIES OF CHILDREN WITH AUTISM

WHAT THEIR ROLE IS AS A PARENT:

This moment is stressful in the life of any family, especially if the process has been long, in most cases, it usually happens because they did not expect and do not know well what Autism is and how to face it with their child and their close social environment.

Knowing that your child has autism will affect everyone in your family and circle of friends. It is probably no surprise that your role as a parent will change and you will go through many positive and negative experiences in your new role.

Below are examples of new experiences you may face:

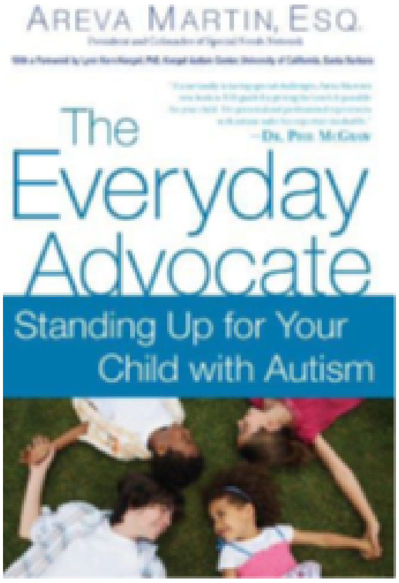
MOTHER	FATHER
Feeling overwhelmed by the daily responsibility of caring for a child with autism. May feel pressured to become an autism expert and learn everything overnight.	May feel less inclined to share feelings.
She may worry about the future of the family.	May be stressed by family finances and questions about the situation.
May have difficulty finding balance and time to manage household chores, other children, daily activities, etc.	May worry about the child's long-term future.
	May develop other problems such as stress and anxiety that can affect work life.

ACTIVITY-BASED SUPPORT FOR FAMILIES OF CHILDREN WITH AUTISM

Your child's BEST advocate IS YOU:

When your child is first diagnosed, you will probably find yourself in many roles: care coordinator, therapist, parent, teacher, etc. One of the most important roles you will have is to be your child's advocate. Acting as such will be a lifelong journey that will require different skills depending on your child's needs.

In her book, Everyday Advocate: Standing Up for Your Child with Autism, Areva Martin describes seven principles that can be applied to serve as an effective advocate for your child.



Martin's book provides examples of each principle in relation to real-world activities that parents can do to be advocates for their child with autism.

1. Take Responsibility: Be a Leader
2. Learn - be an expert
3. Think critically: Be discerning.
4. Speak with authority: be proactive
5. Be documented - be prepared
6. Collaborate: foster team spirit.
7. Educate - be a voice for your child

ACTIVITY-BASED SUPPORT FOR FAMILIES OF CHILDREN WITH AUTISM

HOW TO BUILD A SUPPORT NETWORK:

In today's world, there are a variety of family models, and this may be especially true for parents or guardians of children with autism.
Regardless of your family structure, you can expect that in your journey as a parent of a child with autism, you will need support and help on many occasions. We will remember that it is important to maintain relationships with your family, friends and community so that your support network is there when you need it most. So ideally keep your marriage strong.

It is important to stay as connected as possible with your spouse and keep the lines of communication open, it is normal to not always agree on the best decisions, treatments, therapists, doctors, and even daily life at home with the rules to be used for your children with Autism.

In addition to the normal demands of marriage, parents of a child with autism may also experience:

- Additional stress in navigating the maze of agencies, funding sources and paperwork to help their child.
- Loss of income due to one parent not working to care for their child and the additional expense of hiring and managing specialised caregivers.
- Different views about your child's disabilities and decisions about treatment and interventions.
- Loss of friendships or loss of time and energy to maintain outside friendships.
- Concerns about your family's long-term future.
- Changes in your retirement plans, your ability to take holidays or explore enrichment activities, etc.

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ACTIVITY-BASED SUPPORT FOR FAMILIES OF CHILDREN WITH AUTISM

What you can do to keep your marriage strong as you face the daily challenges of living with autism:

- Communicate! The more you can communicate in challenging times, the stronger you will be as a couple. You and your spouse may not react the same way to your child’s diagnosis but try to explain how you feel and listen carefully when your spouse shares his or her feelings as well.
- Talk openly about problems as they occur.
- Be kind to yourself and your spouse during this difficult time.
- Work together to learn all you can about autism.
- Help each other focus on the present and what you can do to make things better today.
- Spend time together. Plan to spend time alone, even if it’s just a few hours a week, to relax and have fun together. Try to do and enjoy the recreational activities you did before your child was diagnosed with autism.
- Share responsibilities at home whenever possible. Work together on chores, childcare, homework, and other household tasks.
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- Get help if you need it. A marriage therapist can help you and your spouse sort out your feelings and maintain a healthy marriage.
- Choose what is important and what is not important to both of you. Carefully discuss the best ways to have a good life for you and your family.

Support for single parents:

While stress affects all parents, single parents who have a child with autism may experience even more challenges. Single parents often face multiple challenges and are forced to take on multiple roles. They may be responsible for both the emotional and financial needs of their families, while at the same time having to care for a child with special needs.

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• Reach an agreement that involves both parents.

Start with your child’s mother/father and try to establish “agreements“ that support everyone. The best situation is for your child to have frequent contact with the non-custodial parent so that your child interacts with both parents. This also gives the custodial parent a break or time to relax.

• Build a support network of friends and family.

If you do not have family in your local community, you may consider moving closer to family or friends where you and your child have a support network to turn to.

• Take time for yourself.

If you cannot rely on family or friends, seek respite care in the area where you live so that you can recharge and focus on yourself for even a short time each week.

• Social networking: ¡Find support online!

Many parents turn to the internet to avoid feeling isolated. Today, social networking sites will make it easier for you to find support from like-minded parents on the web. Social networking sites such as Facebook, Twitter and blogs about autism will allow you to:

- Connect with parents who are in similar situations and facing the same challenges.
- Ask specific questions and get immediate feedback.
- Receive support from other parents without having to travel or leave home.
- Read information from trusted health organisations.

ACTIVITY-BASED SUPPORT FOR FAMILIES OF CHILDREN WITH AUTISM

FAMILY NETWORK - SIBLING SUPPORT

Parents of children with autism can be under tremendous stress. There never seems to be enough time to do everything that needs to be done. So much attention and energy are given to the child with autism that parents often have little time or energy left to focus on their other children.

Brothers and sisters of children with autism often face their own challenges. Too much may be expected of them. They often need help in understanding the emotional reactions they have as a result of the many changes that occur in their lives. This support is essential for their future well-being.

Some of the things your other children may have difficulty with are:

- Young children may not understand what is happening to their brother or sister. They may feel confused and unable to fully understand the implications of the diagnosis.
- They may have feelings of jealousy and resentment if they see that their parents spend less time with them compared to their brother or sister with autism.
- They may feel angry that their brother or sister with autism is not disciplined in the same way or is not assigned similar chores.
- They may feel embarrassed with friends or in community settings where strangers react negatively to their brother or sister’s unusual and sometimes aggressive behaviour.
- They are often frustrated by the fact that they cannot get their brother or sister to respond or interact with them in a “normal“ way.
- Silently, and sometimes secretly, siblings worry about their brothers and sisters and their parents, as everyone in the family is affected by the disorder in some way.
- Many children are unable to express their feelings, so they sometimes resort to misbehaving. For example, they may misbehave when they defy their parents or get into trouble at school.

ACTIVITY-BASED SUPPORT FOR FAMILIES OF CHILDREN WITH AUTISM

Strategies for supporting your other children:

It is important that your other children understand what autism is and what is happening to their brother or sister. Talk to them as early and often as possible.
Here are some recommendations of books that can help you
www.autismspeaks.org/family-services/resource-library/books#siblings

Help your children learn to play and build relationships with their siblings with autism. There are some simple things you can do to facilitate this, including teaching them how to get their sibling's attention and giving them simple instructions. It is also important to praise all your children when they play well together.

- Find sibling support groups that can help them form friendships and connect with other peers who have a sibling with autism. www.siblingsupport.org
- Don't hesitate to consult a professional if you think your child is internalising most of his or her feelings or is starting to misbehave. The sooner you address this, the better. It is not a failure to ask for this kind of help. Rather, it is a sign of strength and evidence of good parenting.

TAKING CARE OF YOURSELF:

Caring for a child with autism can be physically and emotionally exhausting. Parenting responsibilities can create extraordinary stress. It is not easy trying to balance your time and energy with the needs of your other children, the needs of your marriage and your own personal needs. It takes time to find a good balance and put it into practice.

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ACTIVITY-BASED SUPPORT FOR FAMILIES OF CHILDREN WITH AUTISM

Some helpful things you can do are:
Take time for yourself.

If you don't have a family member or friend who can care for your child, find respite care in the area where you live so that you can recharge and focus on yourself for even a short time each week. Respite time allows you to run errands, relax or enjoy time with your partner or other family members. Establishing a relationship with a respite provider means having a trusted person who can care for your child if a family emergency arises.

Make time for friends.

Many parents report that lasting friendships have given them strength and comfort during the most difficult times. If you feel isolated, it's time to take action.
Explore creative interests outside of autism.

Try exercising or exploring some creative interests. Take the time to realise that you are important and are more than just the parent of a child with autism.

Respite care

Respite care is short-term temporary care provided to people with disabilities at home, either for a few hours or in another licensed setting for a longer period of time. Respite care allows caregivers to take a break from stress and fatigue.

When you are ready to interview respite care providers:

Keep in mind that the most important step is to observe how the respite worker interacts with your child with autism and your family. If possible, have the worker spend supervised time with your family member. It is true that it may take a few weeks for respite workers and family members to get to know each other, but do not allow an uncomfortable situation to continue by thinking that it will eventually resolve itself.

Below is a checklist of what you will want to discuss with the potential relief worker:

- **Previous work experience with people with autism.**

A respite worker does not necessarily need to have previous experience with autism in order to be successful in the job. Because people with autism are so unique, some families prefer that the respite worker have no prior experience so that they can teach the respite worker the best ways to interact specifically with their child. ©2011 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks of Autism Speaks Inc. All rights reserved.

- **Background Checks**

Examples include DMV traffic records, insurance, criminal records, and other certifications such as CPR, first aid certification, etc. Today, many agencies require background checks on workers. If you are receiving services through an agency, ask them to share with you the information they request from their workers. Agencies differ in what they require for background checks.

- **Training sessions:**

Many community agencies offer free workshops on autism. Agencies that provide respite services may also offer training. This may vary from agency to agency. It is reasonable to pay your respite worker less to attend training sessions than to provide respite services directly.

- **Behavioural concerns:**

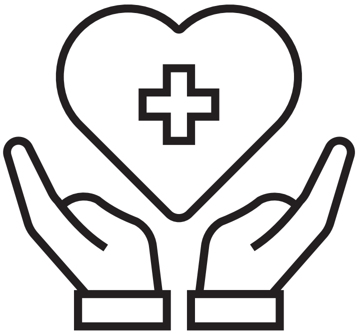
Behavioural problems, such as tantrums, biting, scratching, etc., can discourage anyone, so you can expect the worker to have the same reaction. This is an area where you or a professional should train the worker. A behavioural plan written by a professional will include an intervention plan. The worker should fully understand their role in managing the specific behaviours of the child with autism.

- **Safety issues:**

The issue of safety should be discussed with the worker. Safety issues are highly individualised, so it is best to document your concerns. More than anything else, the worker must demonstrate common sense and good judgement based on the needs of their family member.

- **Availability and flexibility:**

Let the applicant know exactly what your needs are. It is helpful if they have some flexibility in their schedule so that you can take a break when you need it most.



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MODULE 3

ACTIVITY-BASED SUPPORT FOR FAMILIES OF CHILDREN WITH AUTISM

UNIT3: FREQUENTLY ASKED QUESTIONS FROM PARENTS

3.1 Objectives and Skills

In this unit, families/readers will be able to obtain answers to the most normal questions that they may have when a person in their environment is diagnosed with autism. The main objective is to resolve all those doubts and obtain knowledge on how to deal with the situation.

3.2 Introduction

When the time comes, every father, mother, sibling, grandparent, friend, etc. They have doubts and questions about how to act, how to treat or what to do with a person diagnosed with autism. In this sense, having knowledge and adequate information can ensure that that person has as normal a life as possible. Below are the issues and small practical cases to understand this situation.

3.3 Background & Content

Q: My daughter is 2 years old and has recently been diagnosed with autism. Some family members insist that she is just developmentally delayed.

<u>Can you give me some suggestions on how to respond to them?</u>

- Your situation is very common in families of children diagnosed with special needs, especially autism. After receiving this diagnosis many emotional processes occur in the family as a unit and in each individual family member. Of course, there is the initial shock that can send you into the actual grieving process, and each family member will go through this at his or her own pace. Part of that process includes a stage of denial, as is seen particularly in family members who do not live with their child on a day-to-day basis. It is likely to take longer for them to accept the diagnosis. In addition to all that you are already doing, you must also be patient for this to happen. Family members who love your child will benefit most from learning about autism so that they can adapt their interactions and expectations to more appropriate levels.

There are also effective professionals and support groups in your community who have a great deal of experience and expertise in understanding this process. They may be able to provide support for you and your extended family.

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ACTIVITY-BASED SUPPORT FOR FAMILIES OF CHILDREN WITH AUTISM

Q: My husband refuses to accept the diagnosis and does not keep appointments with our doctor. What can I do?

- It is not uncommon for one parent to accept the diagnosis and the other parent to be in denial. Denial happens to fathers as well as mothers. Although the situation is very difficult for you at this time, you must be patient and understanding. Your spouse will eventually overcome his or her denial. In the meantime, you can recommend a book or share an article about autism, but be careful not to push. Most people need to do this at their own pace.

Q: Since my son's diagnosis, I feel overwhelmed and can't even motivate myself to read anything about autism.

- Being an advocate for your child with autism is probably a lifelong activity. From the moment they are confronted with the diagnosis, parents feel overwhelmed by the news. They feel confused, fearful and angry. Many tire easily as they try to cope. It is helpful to remember that you are not alone, that ©2011 Autism Speaks Inc, Autism Speaks and Autism Speaks It's Time To Listen & Design are registered trademarks of Autism Speaks Inc. All rights reserved.

- Other people are going through this and therefore support is available to you. Keep a folder of articles and other information material so that when you are ready to read them you have them available. Go at your own pace and in time you will do what you need to do and, in the long run, your efforts will make a difference.

Q: My family's involvement in the church is important to us. How do I get my church to be more accepting of my child?

Members almost always seem uncomfortable when I try to talk to them about our son and his diagnosis. My expectation is that they will be supportive and supportive because I really need them on my side. My son also needs to relate to other families in our congregation.

ACTIVITY-BASED SUPPORT FOR FAMILIES OF CHILDREN WITH AUTISM

For many people, including members of your church, autism is not something they have had experience with or adequate information about, so you need to educate them. A good way to start doing this is with your pastor or minister. See how much you know and provide information as needed. Sometimes the leader can incorporate related topics into a sermon or lesson. He or she may also suggest people you can approach because they may be more open to learning about autism. Then, you might suggest that the church invite a professional to give a workshop on children with special needs, with an emphasis on the challenges associated with autism. Suggest that the church develop a plan that includes children with special needs in its various activities, such as Sunday classes, worship service, choir, etc. At some point, it may be helpful to invite a behavioural specialist to work with and train staff. This may mean asking teachers, parents and other trained professionals in the church to volunteer their time to help in Sunday school, modify lessons, etc. Involve your community and they will thank you later!

Once members of your congregation receive accurate information, they will become more open and understanding. You may need to suggest ways in which they can become involved with your child and with advocacy organisations. There are many opportunities for the faith community to get involved and partner with parents. As advocates, parents have a unique opportunity to lead the way.

Q: ¿How do I know that everything possible is being done for my child? Sometimes it seems that not enough progress is being made.

Almost every day, every parent of a child with autism asks this question: ¿Is there more that can be done to help my child? We work as hard as we can and very often feel that we are not doing enough. It is also very easy for us to project this onto others involved in our child's life. In fact, historically, not enough has been done and in many ways, more needs to be done in today's world. This is what being an advocate is all about. We must continue to push for the best treatments and services available.

ACTIVITY-BASED SUPPORT FOR FAMILIES OF CHILDREN WITH AUTISM

In the meantime, we must recognise that there are some limits that we must accept. The treatments currently available have limits. We are learning a lot, but we have a long way to go. 2011 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are trademarks of Autism Speaks Inc. All rights reserved.

In addition, your family's health insurance may reimburse you for autism services, such as speech therapy or behavioural health treatment, such as applied behavioural analysis. Start by talking to the human resources department where you or your spouse works, and ask about insurance reimbursement for autism services. Many states now have government agencies that oversee the health insurance industry, so this can be a backup resource for you to explore benefits as needed.

It is important to continue to advocate for increased funding from the government and the insurance industry. For more information on autism insurance reform in your state, visit www.AutismVotes.org. 2011 Autism Speaks Inc. Autism Speaks and Autism Speaks It's Time To Listen & Design are registered trademarks of Autism Speaks Inc. All rights reserved.

Q: My wife and I worry that over time our other children will feel deep resentment for all the special attention and treatment their sibling receives and that this may affect their lives in a negative way.

¿Do you have any suggestions for raising our other children so that they don't feel resentful? Sibling rivalry occurs in all families with more than one child and can be especially complex when dealing with a child with special needs. There is no way to avoid giving extra attention and treatment to a child with autism. For siblings, you can make sure life is great for your child, and I can't guarantee that or fix the future.

My next priority was to learn as much as I could. Oh, what hard work it was, it was a bit overwhelming. Like other people, I "knew" about autism, but I didn't really understand it.

ACTIVITY-BASED SUPPORT FOR FAMILIES OF CHILDREN WITH AUTISM

In his assessment, the psychological report had mentioned that he had the potential to be extremely intelligent, but could be socially awkward. We are big fans of the show “The Big Bang Theory“ and after reading that, my first thought was, “Oh boy, we’re raising Sheldon!“

It was nice to be able to laugh at the situation, but obviously, research was needed. After doing a search on autism on the internet, I was at a loss. There were so many websites, books and blogs that I didn’t know where to start - who was I supposed to believe when the sites contradicted each other? Then I remembered that the teachers at my son’s school had done the Autism Speaks Walk and our family had made a donation. So that’s where I started. I contacted the Autism Speaks Family Team for support.

I needed to talk to someone who would listen and relate to my situation. It was only the first week and I already knew I needed others who knew what I was going through.

As a result of my contact with Autism Speaks, I found an amazing online community of parents. The past experience online made me hesitant at first, making me feel like I might be getting the wrong information. But, this was not the case. I found parents like me, who were there to support each other and stick together. We were able to get accurate and useful information. When you think no one will understand you, someone will. Every time I asked a question, I got answers from people who had been in my shoes. If I sent an update on something good my son had done, I got cheers from people who had experienced the same thing. They understood me and I understood them. *2011 Autism Speaks Inc, Autism Speaks and Autism Speaks It’s Time To Listen & Design are registered trademarks of Autism Speaks Inc. All rights reserved.*

ASD Communication Training Activator Workshop

Short description of module:

An interactive workshop to learn how to create engagement, assessment, and education in an inclusive environment using a series of tools that may be adapted to any topic or situation.

1.1. Objectives and Skills

Workshop Outcomes
1. Better understanding of how to deliver activities inclusively;
2. Be more aware of the difference between inclusion and accessibility;
3. Gain better awareness that everyone is different, with different skills and abilities, but all can participate together;
4. Better understand how to use simple tools to engage people with different backgrounds at the same time.

Equipment:

- 10 of each red, yellow and green domes
- 10 of each red, yellow and green cones
- 30 Balls of different, shapes, sizes, colours, textures and weights from different sports including balls with bells for blind football and tennis.
- 20 Bats of different, shapes, sizes, colours, textures and weights from different sports.
- 30 Cardboard boxes of different, shapes, sizes, colours, textures and weights
- 50 Sheets of flipchart paper
- Flipchart stand
- 1 pack of white or blue tack
- 3 rolls of sellotape
- 6 pairs of blunt-ended school scissors
- Notebook for each participant
- 50 ballpoint pens
- 50 chisel point felt tip markers for paper in at least six different colours
- Laptop, Projector, Projector screen, 10m extension lead (all optional, depending on workshop delivery method.
- Large wall clock

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ASD Communication Training Activator Workshop

1.2. Introduction

The workshop is organised using the following methodology

Space:

- The workshop venue should be an accessible enriched environment:
- Appropriate lighting and colours;
- Sufficient space;
- A comfortable seating area;
- A work area set up with tables and chairs;
- An activity area set up with equipment;
- Healthy, good quality food and drink with inclusive options for culture, allergies and dietary preferences.
- Accessible toilets.

Task:

- An InfoPack should be created with:
- High-contrast, minimum 12pt, easy-read, sans serif font such as Calibri or Arial;
- High-contrast text boxes over pictures;
- Summary/context of the workshop;
- Venue of the workshop and/or accommodation;
- Travel instructions, maps and a link to Google Maps should be provided to assist timely arrivals. Preferably, the InfoPack should also contain instructions on how to use Google Maps;
- A WhatsApp group for participants to communicate;
- Dates and a timetable for all activities including breaks.
- Email, phone and website details of the organiser and/or staff involved.

ASD Communication Training Activator Workshop

1.2. Introduction

Equipment:

- 10 of each red, yellow and green domes
- 10 of each red, yellow and green cones
- 30 Balls of different, shapes, sizes, colours, textures and weights from different sports including balls with bells for blind football and tennis.
- 20 Bats of different, shapes, sizes, colours, textures and weights from different sports.
- 10 Balloons of different colours.
- 30 Cardboard boxes of different, shapes, sizes, colours, textures and weights
- 50 Sheets of flipchart paper with some previously prepared materials.
- Flipchart stand
- 1 pack of white or blue tack
- 3 rolls of sellotape
- 6 pairs of blunt-ended school scissors
- Notebook for each participant
- 50 ballpoint pens
- 50 chisel point felt tip markers for paper in at least six different colours
- Laptop, Projector, Projector screen, 10m extension lead
- Workshop presentation slides
- Large wall clock
- Large tables for people to gather around and work on flipchart paper.
- Chairs
- Comfy chairs and/or sofas

People:

- Minimum of 16 participants

MODULE 4

ASD Communication Training Activator Workshop

1.3. Background

Created by the internationally recognised inclusion expert, Ken Black, the Inclusion Spectrum and STEP modifications (also known as TREE), are commonly used tools in the delivery of inclusive physical activity and sport. The tools have been adapted by UEIF as methodologies to engage, empower and educate people in other settings.

1.4. Activities

Day 1:

Arrivals and registrations

People are welcomed and invited to take a coffee or drink and sit in the comfortable area, table area or stand. Each person completes a registration form with their contact details. The flip chart stand has a previously prepared flipchart paper with the Activator (presenter) name, organisation name, and contact details so that everyone can see it. The first slide is shown on the projector screen.

ABCs of Autism

Project Number
2021-2-CY01-KA210-VET-000048730

Mobilising diverse approaches to training ASD professionals

UEIF

ABC'S OF Autism

Stockholm, SWEDEN
11-13 JULY 2023

The Venue:
Ridvägen 24A
174 57 Sundbyberg
Rissne Centrum

https://www.google.com/search?client=firefox-b-d&q=ridv%C3%A4gen+24a

Take the Blue line to Rissne

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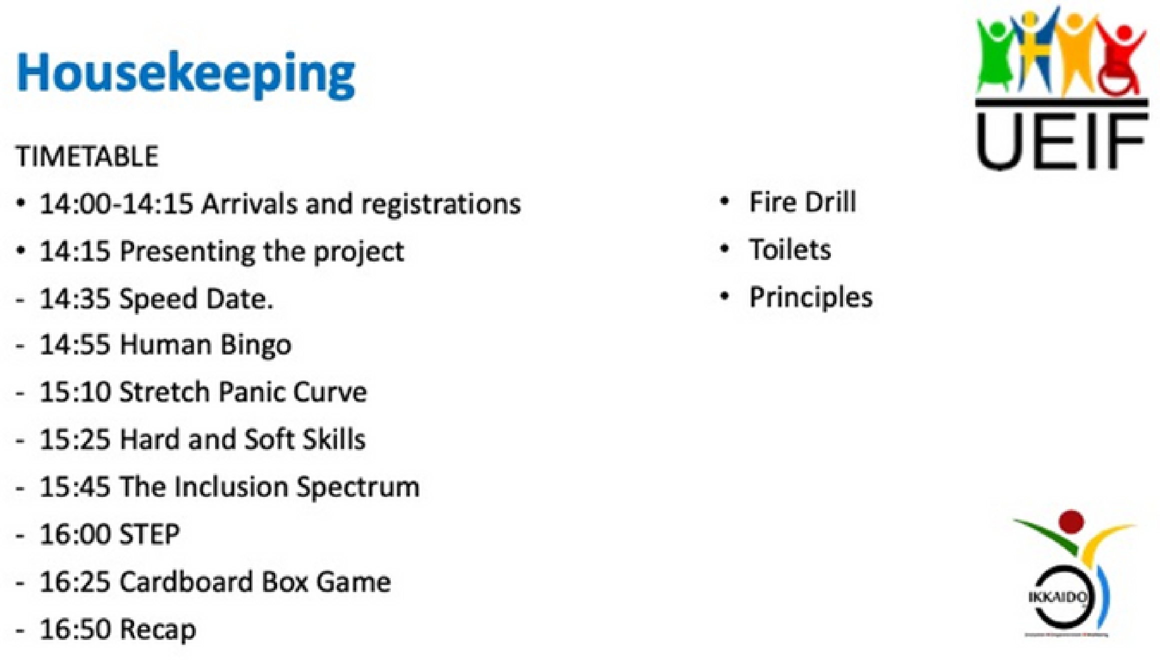
Presenting the Workshop Using Different Tools

Using the information in the presentation slides, the Activator (presenter) introduces themself and shows the timetable and Housekeeping slide.



Housekeeping

TIMETABLE

- 14:00-14:15 Arrivals and registrations
- 14:15 Presenting the project
- 14:35 Speed Date.
- 14:55 Human Bingo
- 15:10 Stretch Panic Curve
- 15:25 Hard and Soft Skills
- 15:45 The Inclusion Spectrum
- 16:00 STEP
- 16:25 Cardboard Box Game
- 16:50 Recap

- Fire Drill
- Toilets
- Principles

The timetable is the default slide when other slides are not being used.

The Activator explains that there is a large clock on the wall so that participants can understand where we are in the timetable. Participants are told where the toilets are and that they do not need to notify anyone to use the toilet, because everyone is an adult. The Activator explains that no fire drills are planned, so, if an alarm is heard, participants should calmly leave the building through one of the fire exits and assemble in an open space in the car park away from cars and trees.
It is explained that coffee and drinks are available whenever they want and that a snack break will be taken at 3:30 p.m.

In front of the flipchart stand, the Activator asks what rules the participants would like for the workshop, and people call the rules out. Each rule is written on the flipchart paper and then it is stuck to the wall with blue tack. Rules that should be encouraged are:

MODULE 4

ASD Communication Training Activator Workshop

- Listen
- Respect other people’s opinions
- Mobiles on silent
- Don’t interrupt people
- Have fun
- Be polite

In the case of “ mobile phones off” it should be explained that perhaps some people might be expecting an important message or call, so maybe it is better that mobile phones are on, but silent, and if someone needs to take a call they can go outside.

It is explained that the participants had created the rules, so therefore, they should abide by them.

The Activator introduces their organisation using the About Us slide, pointing out the contact details on a flipchart paper, and describes the reason for the workshop on the summary slide. It is explained that each person has several contemporaneous roles in the workshop as a teacher, activator, facilitator, participant, assessor and evaluator and that every smallest part of the action in the workshop is there for a reason. The flipchart paper with contact details is put on the wall.

About Us

- UEIF stands for "Ung European Internationella Forening" or "European Youth International Association" in English. We work with organisations in Europe to strengthen solidarity and inclusion, both in local communities and within Europe as a whole. We also work to improve the quality, availability and inclusiveness of Vocational Education and Training (VET).

- We have a special focus on young people with disabilities who may need help or extra support to engage in education and employment or to overcome obstacles in their community.

Project Summary

The objectives of the ABCs project are:

- To take the gaps identified among the professional partners and map current good practices related to interventions for autism.
- To deliver training courses to directly train the ASD professionals, in evidence-based approaches they can incorporate into their work.
- to create a network of ASD professionals, who can exchange good practices, at European level
- the professional development of ASD professionals

The Activator explains that accessibility is where someone has access to something, such as a wheelchair user having a ramp to get into a building where an activity opportunity is taking place with other wheelchair users. This is accessible but exclusive.

Inclusion considers every aspect needed to ensure that the wheelchair user receives the exact same experience as any other person, at the same time. Inclusion is about access to the community, not just an opportunity.

A previously prepared flipchart shows steps arranged as follows

- S
- T
- E
- P

and the Activator expands it to:

- Space
- Task
- Equipment
- People

The Activator explains how STEP was used in the design of the Workshop as described in the methodology in the Introduction section above.
The workshop outcomes are explained using the presentation slides.

MODULE 4

ASD Communication Training Activator Workshop

Workshop Outcomes

1. Better understand how to deliver activities inclusively;
2. Be more aware of the difference between inclusion and accessibility;
3. Gain better awareness that everyone is different, with different skills and abilities, but all can participate together;
4. Better understand how to use simple tools to engage people with different backgrounds at the same time.

Icebreaker Tools

Icebreakers are a great way to get people to know each other and build rapport.

Speed Date

A Speed Date consists of two lines of people facing each other. It is explained that every person in Line 1 has greater skills than Line 2. They approach each other and are given three questions to ask each other:

1. What is your name?
2. How was your journey to get here?
3. What is your favourite sport?

After a few minutes of talking, the person at the end of Line 1 (the line with the greater skills) is asked to move to the beginning of Line 1, and all participants in Line 1 shift down one place. The participants in Line 1 with the higher skills are the people who move positions.

Repeat or add new questions, or allow longer times for people to talk as the "ice" is broken.

Participants are asked, "Why did we play this game".

Answer: To learn a little about each other in a quick easy and fun way.

Human Bingo

Human Bingo

Someone who has children	Someone who has a pet	Someone wearing black socks	Someone who likes the same music you do	Someone who can sing a song to you
Someone who can speak three languages	Someone who does not have a GRCC Library card	Someone who walks or takes the bus to school	Someone who has dreamed in English	Someone who has been in a casino
Someone who has a birthday this month	Someone who doesn't like to fly in a plane.	Free Space	Someone who has worked in a store	Someone who has visited more than 3 countries
Someone who likes to cook	Someone who is the oldest child	Someone born in the same month as you	Someone who drives and American car	Someone who likes to exercise
Someone who plays a musical instrument	Someone who will be going on vacation within 3 months	Someone who has been to Mt. Rainier	Someone who has lived in California	Someone who likes American food

ASD Communication Training Activator Workshop

Each person is given a sheet of paper set out in a grid-like a bingo card. However, instead of numbers, each box contains a phrase relating to hobbies, interests or other personal information. A time limit is given and everyone asks each other questions. When they find someone who fits one of the categories, they ask that person to write their name in the box.

The winner is the first person to get a signature in every box or to gather the most names within the time limit. If you want, you can make it a rule that each person can only sign one or two boxes on someone else's card. You will need to prepare the cards in advance and choose around 12 to 20 categories to suit the characteristics of the group members.

Participants are asked, "Why did we play this game".

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ASD Communication Training Activator Workshop

Stretch-Panic Tool

Participants are invited to stand outside a curved line of domes, green on one side, yellow in the middle, and red at the end.

Green cones mean I am very comfortable or skilled, yellow means I am neither comfortable nor uncomfortable, and red means I am uncomfortable. By standing further along a coloured section of the domes participants can indicate how comfortable or uncomfortable they feel.

Questions are asked and the participants are asked to move to a position to indicate how they feel or how skilled they are:

Stretch-Panic Questions:

- How do you feel about singing at home when no one is around?
- How do you feel about singing karaoke in the pub?
- How would you feel about singing in front of an audience?
- How would you feel about singing on stage?

Topic Targeted Stretch-Panic Questions:

How would you feel about delivering an activity to children with autism?

How would you feel about delivering an activity to children with mixed abilities?

How would you feel about teaching mixed ages, mixed abilities and different disabilities all at the same time?

The Activator asks, “Why did we do this activity?”

The message being looked for is: everyone is different – everyone has different skills and abilities – and everyone has different levels of confidence.

The activity enables each person to learn about other people and what their skills and confidence levels are like. More importantly, it also enables the Activator to assess the participants, including whether they have a disability and their ability levels in any field which might be chosen.

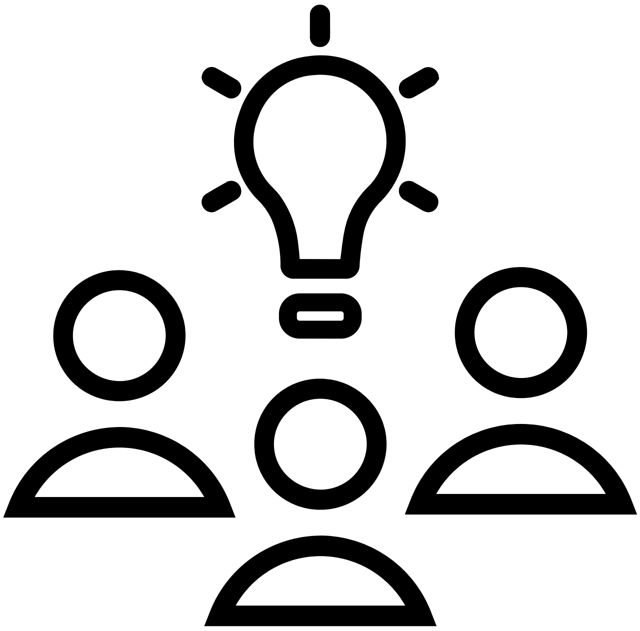
ASD Communication Training Activator Workshop

Group Dynamics and Team Buiding Tool

Participants are asked to listen and remember the number they are given. Each participant is given a number, for example, 1 to 5 and then all numbers are asked to get into a group together, number twos together and so on.

Each participant group is given a flipchart sheet and some coloured felt tip pens. Each group is asked to write at the top of the paper:

1. Group 1 “Activity Leader”
2. Group 2 “Parent”
3. Group 3 “Teacher”
4. Group 4 “Disabled Person”



ASD Communication Training
Activator Workshop

The groups are asked to draw a picture and add text to it to answer the following questions:

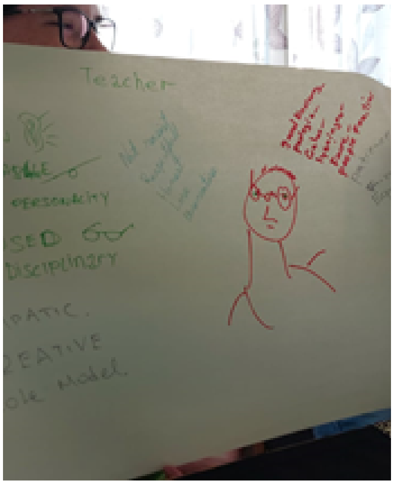
1. What hard and soft skills does a good activity leader have?
2. What hard and soft skills and competences can a good parent have?
3. What hard and soft skills and competences can a good teacher have?
4. Can you draw a picture of a disabled person?

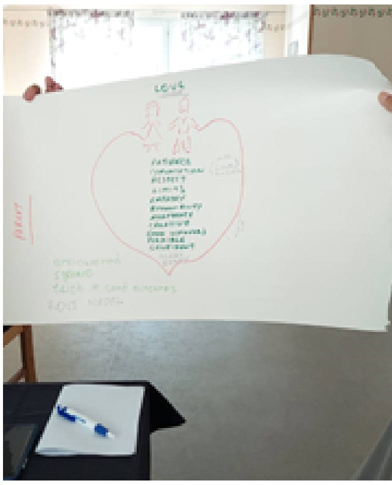
The Activator allocates a time, perhaps 15 minutes and walks around the groups helping them to expand their ideas and provide feedback. They are told when 5 minutes and two minutes are left.

Each group presents their flipcharts to the other groups and then discusses the results through open questions.

Results in ABC's included:

- Patience
- Good communication
- Mutual respect
- Define limits/rules and stick to them
- Empathy
- Mutual responsibility
- Acceptance
- Adaptable
- Creativity
- Fun
- Play
- Good listeners
- Flexible
- Confident
- Alert
- Ready
- Empowering and empowered
- Optimistic
- Being a good role model
- Passionate





Groups may be asked to exchange flipcharts a few times to see if they can add more information to each task.

ASD Communication Training
Activator Workshop

The Inclusion Spectrum

In order to provide an inclusive physical activity environment there are a number of tools available to help you. The Inclusion Spectrum is:

- A structure for inclusion
- A flexible tool for use with a wide range of activities and abilities
- A continuum of participation
- A social-environmental approach
- Emphasis on ability, not disability
- Varying rates of progression and development

How to use each aspect:

Open Activity

A simple activity based on what the entire group can do with little or no modifications. Can also be used as an assessment tool.

Modified Activity

Everyone does the same activity with modifications to challenge and support all abilities. Can also be used for progressive learning in “stations” in the same room.

Parallel Activity

Participants are grouped according to ability—each does the same activity but at appropriate levels. Can also be used for progressive learning in “stations” in the same room.

Separate Activity

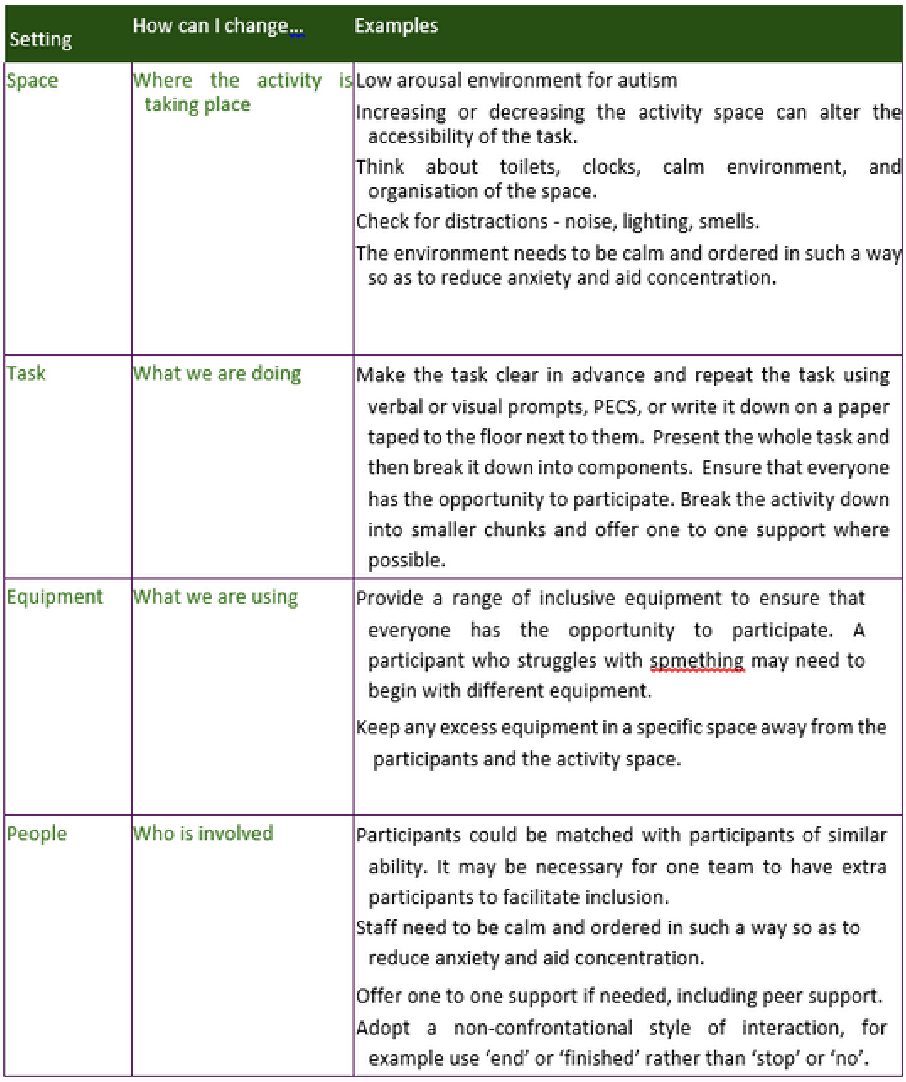
An individual or group does a purposefully planned different activity.

A participant who is hypersensitive to noise may be unable to participate in activities in a sports hall due to the loud nature of the environment. They may instead require a personalised program which combines sensory integration activities with physical activity. Examples include rocking activities or practising gripping activities with different types of balls and inclusive equipment.

Activities for all participants based on aspects of a disability or target group can be included in all approaches—reverse integration. An example might include men attending female empowerment courses.

STEP Modifications

The STEP tool is a simple system for making changes to activities so that everyone can be included and participate together. It can also be used to help organise thinking around activity adaptation and modification in support or as a stand-alone tool. For example, changes can be made to an activity where there are: children and young people of different ages, or disabled and non-disabled people in a group. Changes in the way the activity is delivered can be made in one or more of the STEP areas (Space, Task, Equipment, People). This simple system helps practitioners to adapt the activity for different abilities and ages. In The ABCs of Autism, we used STEP to educate participants about inclusive practice and as a tool to engage and empower people.



Setting	How can I change…	Examples
Space	Where the activity is taking place	Low arousal environment for autism Increasing or decreasing the activity space can alter the accessibility of the task. Think about toilets, clocks, calm environment, and organisation of the space. Check for distractions - noise, lighting, smells. The environment needs to be calm and ordered in such a way so as to reduce anxiety and aid concentration.
Task	What we are doing	Make the task clear in advance and repeat the task using verbal or visual prompts, PECS, or write it down on a paper taped to the floor next to them. Present the whole task and then break it down into components. Ensure that everyone has the opportunity to participate. Break the activity down into smaller chunks and offer one to one support where possible.
Equipment	What we are using	Provide a range of inclusive equipment to ensure that everyone has the opportunity to participate. A participant who struggles with spmething may need to begin with different equipment. Keep any excess equipment in a specific space away from the participants and the activity space.
People	Who is involved	Participants could be matched with participants of similar ability. It may be necessary for one team to have extra participants to facilitate inclusion. Staff need to be calm and ordered in such a way so as to reduce anxiety and aid concentration. Offer one to one support if needed, including peer support. Adopt a non-confrontational style of interaction, for example use 'end' or 'finished' rather than 'stop' or 'no'.

ASD Communication Training Activator Workshop

- In addition to the strategies suggested in the table, it is also important to consider the following:

- Respect the sensory differences – we all experience sensory differences in one way or another but for someone on the autism spectrum the experience may be heightened

- Avoid the cause of the sensory discomfort where possible. We know that this isn't always a realistic suggestion, but in some cases, it may be possible

- Gradually expose the participant to the sensory discomfort whilst simultaneously ensuring that you build positive experiences. For example, if the participant knows that once they arrive in the noisy sports hall they are going to enjoy the activity, they may be more inclined to gradually spend longer in the space

- Conduct an audit of the environment in which the activity will be taking place; similar to a risk assessment but instead, looking for potentially overbearing sensory stimuli

- Some participants may experience synaesthesia; a rare condition whereby a sensory experience goes in through one system and out through another. So a person might hear a sound but experience it as a colour. In other words, they will 'hear' the colour blue.

ASD Communication Training Activator Workshop

The Cardboard Box Game

This tool reinforces how to use STEP and the Inclusion Spectrum in a gamified way.

A line of cardboard boxes of different sizes, shapes and colours are placed along the centre of the room. 30 Balls of different, shapes, sizes, colours, textures and weights from different sports including balls with bells for blind football and tennis are placed on the walls on each side of the line of boxes.

Each participant is told they are a number 1 or 2. Number ones are told to go to one wall behind the balls and number twos on the other wall, facing each other. Participants are instructed that the game will be to underarm-throw the balls at the boxes to try to move the boxes to the other side of the room.

After a few minutes, participants are asked if it was easy or difficult for them. Then they are asked how to modify it to make it more difficult or easy using STEP so that everyone can have an achievable challenge.

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ASD Communication Training Activator Workshop

Open Activity Tool
Domes and Dishes

Red and Yellow cones are randomly set out inside a 5x5 or 10x10m grid
Half of the cones are laid out facing upwards and are Dishes. Half of the cones are laid out facing down and are Domes. Two teams are randomly selected using the 1, 2 methodology, changed to Tea Domes or Team Dishes.

The aim is for Team Dishes to turn the domes over into dishes and Team Domes to turn the dishes into domes.

After some time, the participants are asked if the game is inclusive and what adaptations they could make using the STEP tool. More colours and more teams could be involved.

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Inclusive Running

Three concentric circles are created in different colours, a smaller red circle, a larger green circle and a very large yellow circle. Each one is a running track for participants with different abilities so that everyone can participate in the same activity at the same time. Participants can choose where to run and the Activator will encourage people with greater skills to take part in one of the greater challenge tracks. Swimming strokes can be added whilst participants are running.

Skill Development Tools

Speed Date

As previously described, a Speed Date consists of two lines of people facing each other. It is explained that every person in Line 1 has greater skills than Line 2 and they will learn to underarm throw and catch with both hands. To meet their disability needs, people in Line 1 are each given a ball of a different shape, size, colour, texture or weight, or with bells, from different sports and a balloon.

Participants throw the ball to the person opposite them and try to catch it. The Activator makes comments, gives tips and praises participants during the activity.

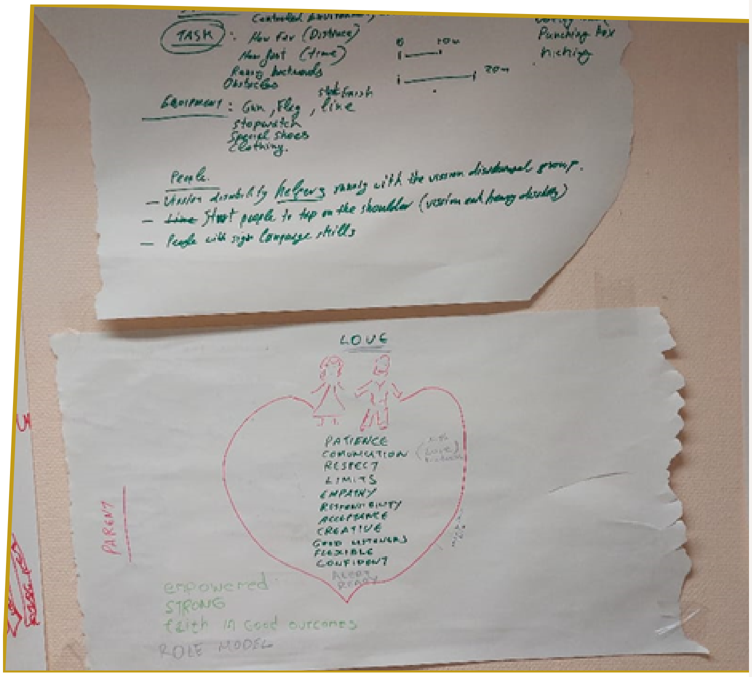
MODULE 4

ASD Communication Training Activator Workshop

After a few minutes, the person at the end of Line 1 (the line with the greater skills) is asked move to the beginning of Line 1, and all participants in Line 1 shift down one place. The participants in Line 1 with the higher skills are the people that move position and Line 2 maintains hold of the ball.

Participants are asked how the game can be modified using STEP, so that people can be included. ie Moving a person closer so it is easier, using a larger ball, changing the ball colour, or using a balloon. Participants are asked how we might use STEP to create a greater challenge or improve skills for some participants ie group more highly skilled participants together, move farther away, smaller ball, throw and catch with only one hand, or the less dominant hand.

Participants used the problem Solving Tool to explore further adaptations for other activities.



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Work Stations

The Work Station is a perfect vehicle for modifications and inclusive practice. Work stations may be set up in the four corners of a room with participants carrying out the same activity but broken down into smaller bite-sized chunks using STEP, so that each station provides an ever greater challenge (parallel activity). The workstation allows the Activator to move between the stations offering constructive feedback. The Activator can ask students to move to more or less challenging stations if they wish. Workstations are a great way to build up to full participation in small steps.

Empowerment with STEP

Problem Solving Tool

During all of the activities the Activator continuously assesses the participants and their roles, as well as barriers, abilities, knowledge, competence and skills. The Activator nominates three topics for the participants to explore based on their assessment. Alternatively, the Activator might request participants to name challenges that they face and wish to resolve.
Participants are again given a number and are asked to join the group with the same number.

Each group is given a flipchart sheet and some coloured felt tip pens.

In ABCs, three groups investigated the chosen topics:

1. How to engage and empower teachers in special schools
2. How to engage and empower parents of autistic children
3. How to build and strengthen communities for autistic children

The Activator allocates a time suitable for the task and walks around the groups helping them to expand their ideas and provide feedback. They are told when 5 minutes and two minutes are left.
Each group presents their flipcharts to the other groups and then discusses the results through open questions.

ASD Communication Training
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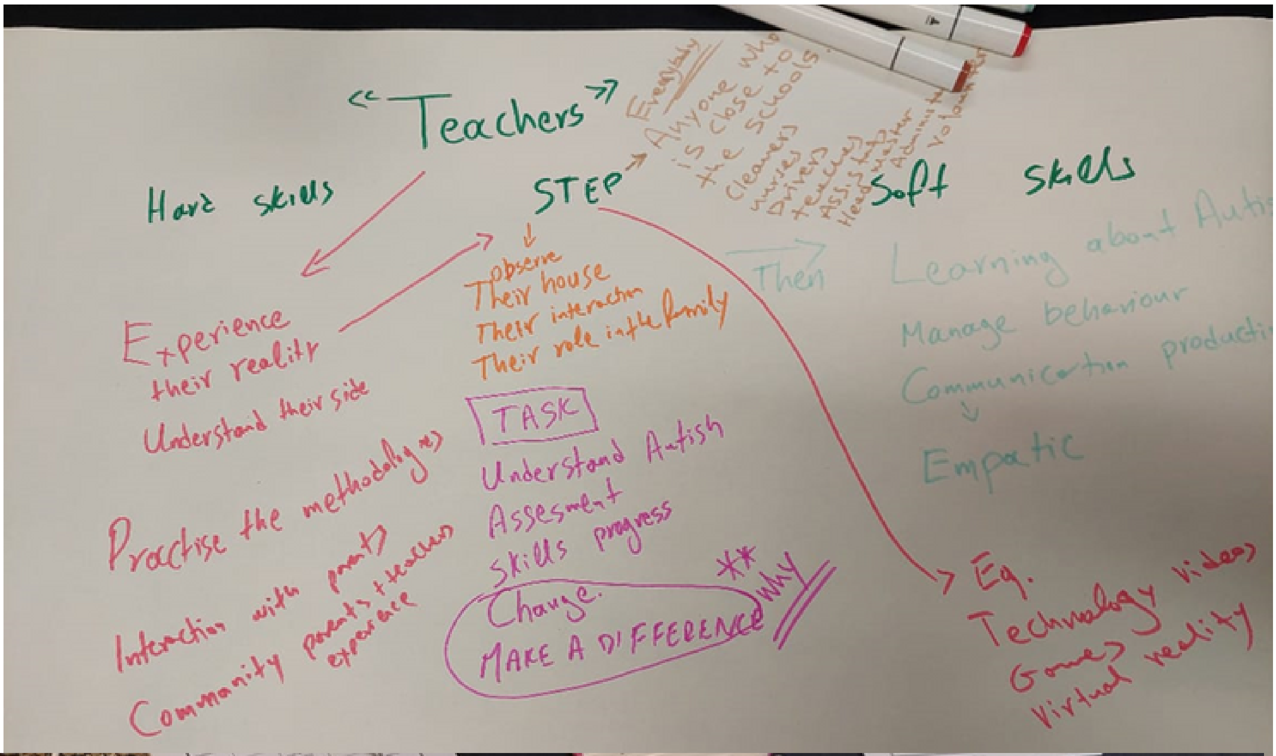
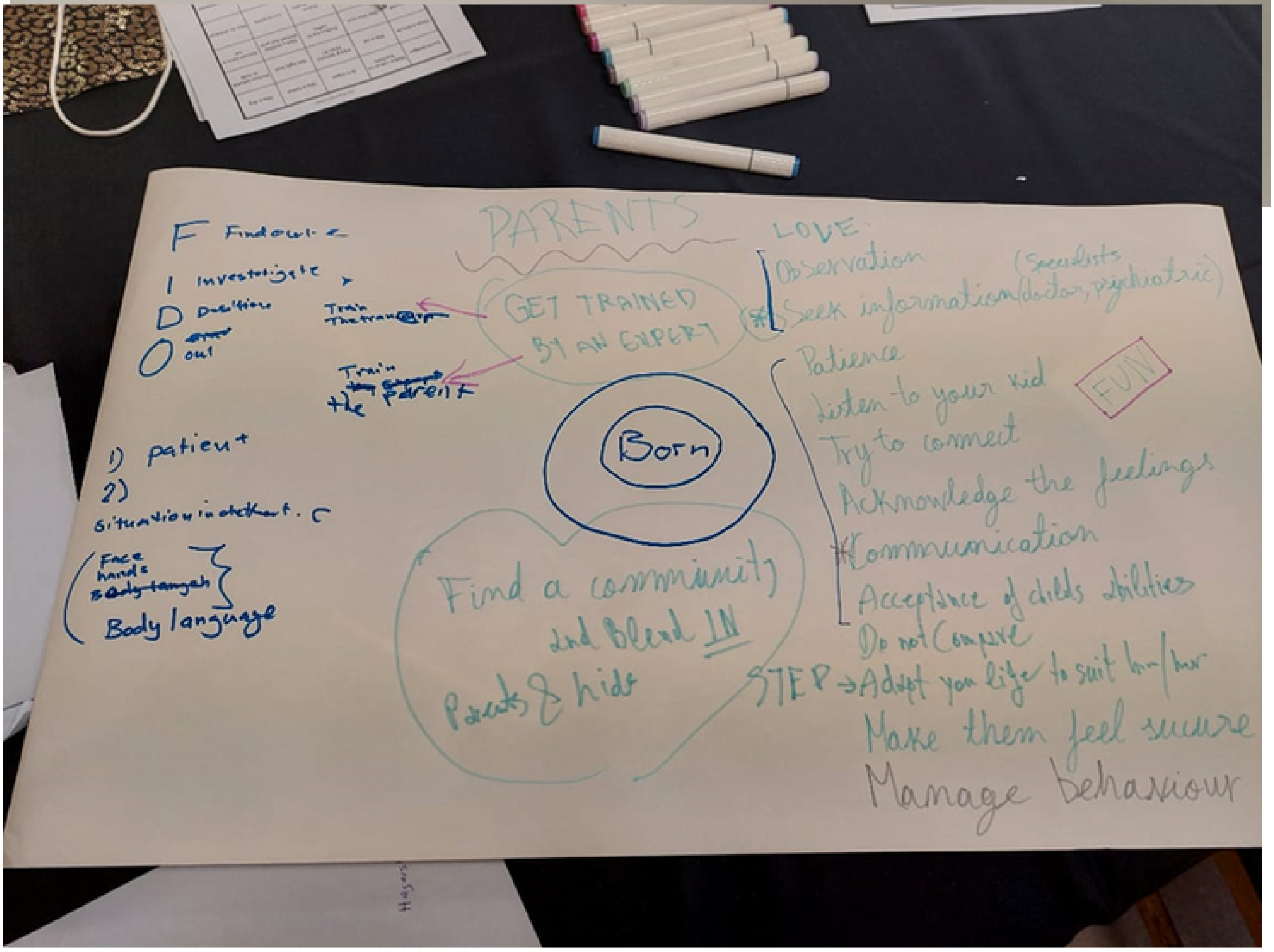
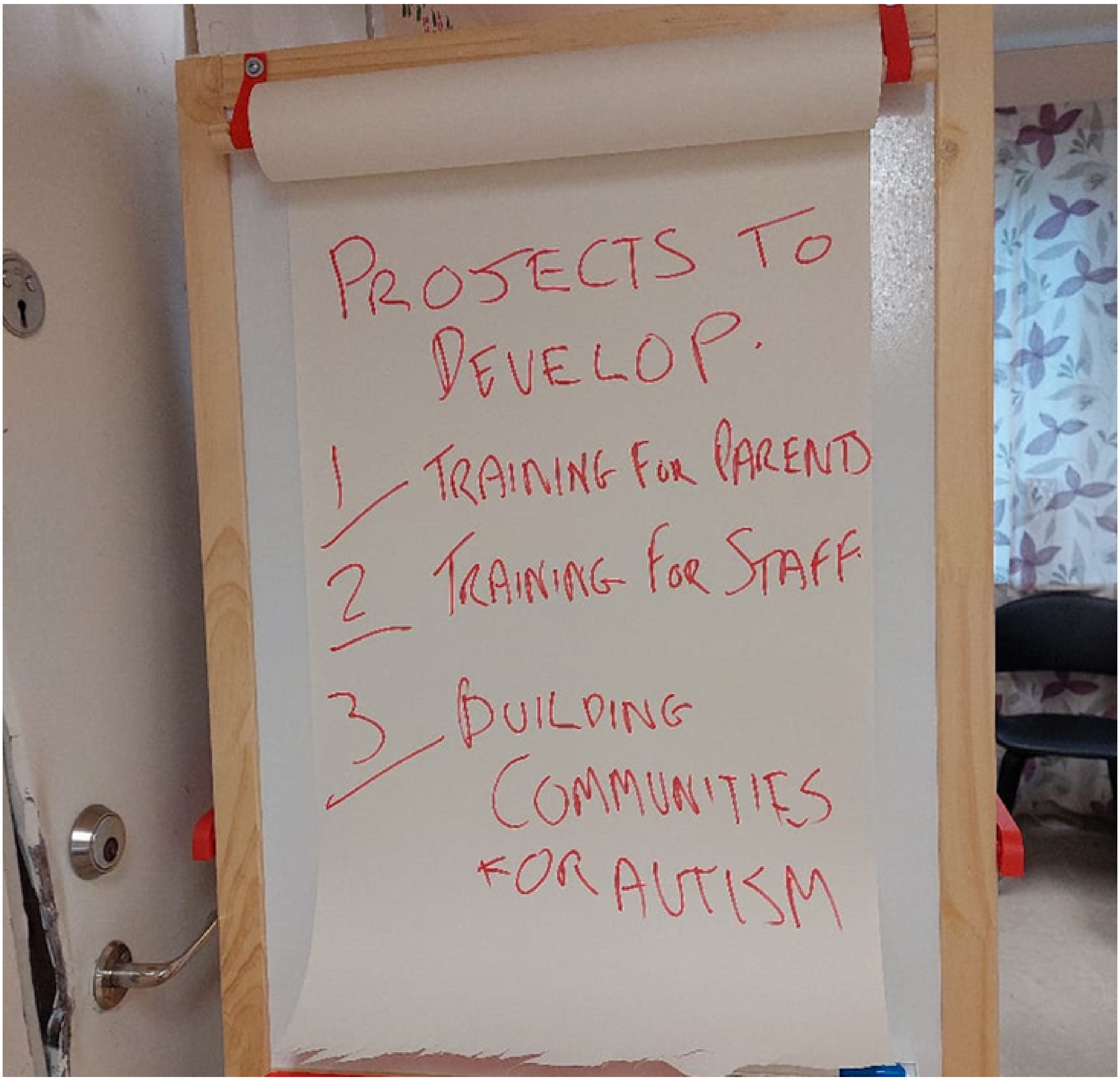




ASD Communication Training Activator Workshop

The activator explained the Erasmus+ Programme and suggested that the partners might wish to implement their ideas in further projects.



ASD Communication Training
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Recap and Review Tools

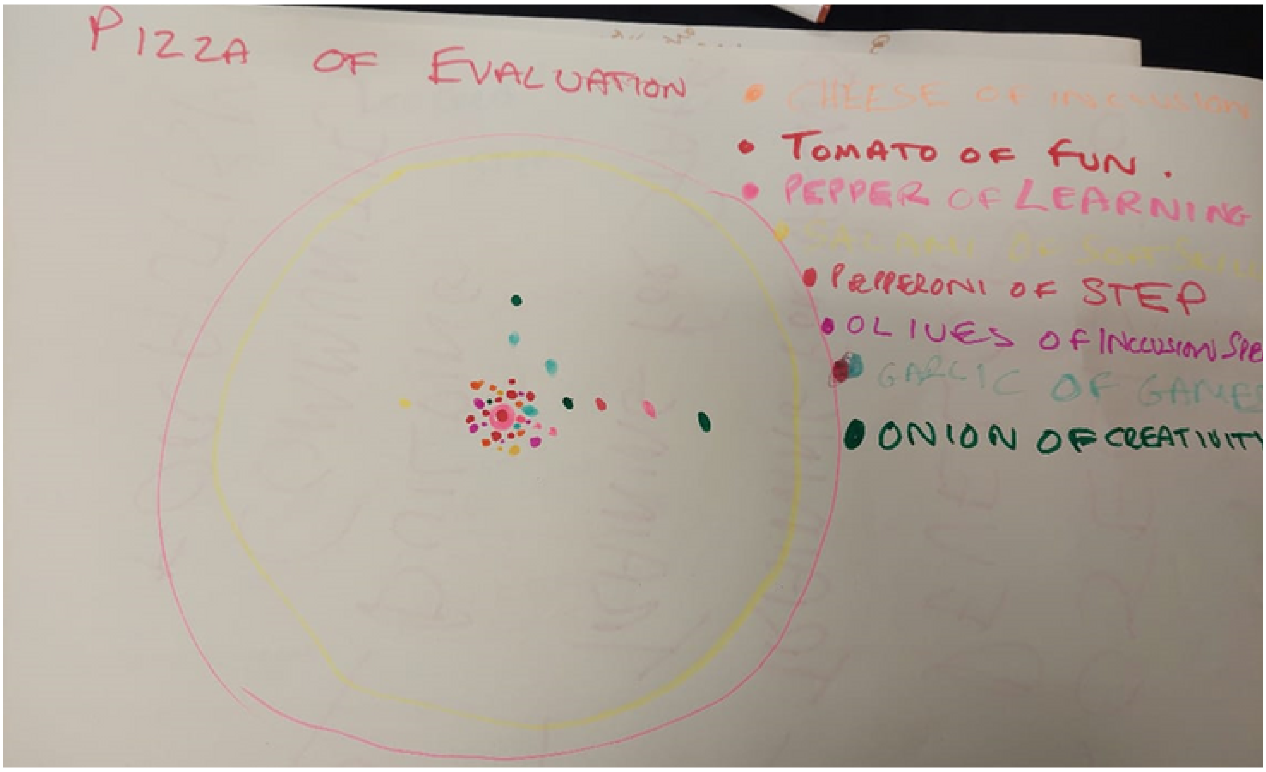
The Activator explains that Recap and reviews are to check for the Activator to check knowledge, understanding and skill acquisition and reinforce the learning. Feedback and reflection are for participants to understand what they would like to do next, and for the Activator to understand how they might improve the workshop.

Days 2 and 3 began with a recap of the previous day and at the end of each of the three days of the project, there was a reflection, review and feedback session.

Evaluation Tool

The Pizza of Evaluation

On the final day, there was a gamified evaluation. Ingredient colours were chosen to represent the tools and delivery of the workshop. The closer to the centre, the more important the ingredient was seen to be, and the more of the dots, the more they liked the ingredient.



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