

# **Guide for youth organizations on structures and strategies for the inclusion of people with Autism Spectrum Disorder (ASD)**



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## Chapter 1 – What is ASD?

### Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder on a biological basis, which manifests itself in the first 3 years of life but whose characteristics evolve over the years. ASD is a condition of being, reasoning, perceiving and functioning.

In 2013, APA (American Psychiatric Association, 2013) published a new version of the DSM, the most important Diagnostic and Statistical Manual of Mental Disorders, introducing DSM-5. Important changes to the definition of ASD have been introduced in this new version of the manual. The most notable one was precisely the introduction of the term Autism Spectrum Disorders, which constitutes a single macro category, introducing the dimensional aspect of the disorder. Today, in fact, there is no longer any talk of a diagnosis of “Autistic Disorder”, “Asperger's Syndrome” and “Pervasive developmental disorder not otherwise specified”. ASD is a single diagnostic category- a spectrum- within which we can find different levels of functioning along a continuum.

In terms of prevalence, ASD occurs more frequently in boys than girls, with a 4:1 male-to-female ratio.

### 1. ASD core deficits

ASD is characterized by two core deficits (Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, DSM-5, 2013):

- **Persistent deficits in social communication and social interaction;**
- **Restricted and repetitive patterns of behaviour, interests or activities.**

These characteristics are variable in range and severity and often change with the acquisition of other developmental skills.

#### 1.1 Social communication and social interaction in ASD

People with ASD have persistent difficulties in **social communication** across multiple contexts. In fact, they have difficulty interpreting and utilising non-verbal communication in social interactions, which plays a crucial role in understanding the interlocutor's



intentions and internal emotional and mental states. This also leads to difficulties in understanding irony and jokes. When communicating with people with ASD it is therefore important to make everything explicit.

Another core deficit of ASD concerns social-emotional reciprocity in **social interaction**.

It is closely linked to the difficulty in processing, interpreting and using non-verbal communication. This has an impact on their ability to develop and nurture relationships and understand their dynamics. This deficit can range from a difficulty in modulating one's own behaviour on the basis of feedback from the interlocutor or on the basis of the social context; to difficulties in shared attention, symbolic play, making friends and playing with peers; to an apparent disinterest in other people. It is as if the social cues speak a language unknown to them, therefore, it is important to “subtitle” the dialogues we have with them explaining all our intentions and emotions and to provide them with clear instructions and procedures, accompanied by pictures, on how to behave and what to do in different social situations.

### 1.2 Restricted, repetitive and stereotyped behaviours, activities or interests

People with ASD might show **stereotyped and repetitive patterns of movements, use of objects and speech**, which may appear bizarre and inappropriate to the context and may interfere with the person's functioning (Lewis & Boucher, 1988).

These stereotypes can be:

- body-rocking, rhythmically moving the torso back and forth;
- simple motor stereotypes;
- strong need to put things in order or perfectly aligned;
- repetitive manipulation of objects;
- echolalia, automatic repetition of words and/or sentences said by someone else, may concern single words, conversations, film scenes, songs...;
- idiosyncratic phrases, i.e. the unconventional repetition of words or phrases.



People with ASD tend to adhere to **rigid and fixed routines**, appreciating everything that is predictable and follows fixed patterns. From this perspective, even small changes can create great distress in the person with ASD. They may have difficulties with transitions from one environment to another or from one context to another.

This insistence on sameness can also manifest itself in the choice of food. It is important to help the person with ASD predict what will happen in their day by means of a calendar enriched with visual aids, but it is also important to help them get used to uncertainty, e.g. within the visual calendar it is possible to insert an icon with a question mark and call it “unexpected event”.

Another central aspect in the ASD is the presence of **highly restricted interests** that are unusual for intensity or focus, e.g. they may have a strong passion for insects and know every single detail of them.

Finally, ASD can also involve **hyper- or hypo reactivity to sensory input**, or an uncommon interest in certain sensory characteristics of the environment (they could be fascinated by lights, colours, movements...). There may be sounds, lights, smells or textures that create a particular discomfort in people with ASD, or conversely, they may be insensitive to pain or temperature.

## 2. Areas of difference in ASD

With the publication of the DSM-5 (2013), it was decided to speak of autism by bringing together all the previous subcategories under an umbrella definition of “Autism Spectrum Disorder”. This definition emphasises the importance of considering autism according to key characteristics that are common to all individuals with ASD. Each characteristic, symptom or deficit is thus defined as being along a dimensional continuum within which its intensity and severity must be placed.

We believe that it is fundamental to speak of autism as a life condition, a way of functioning that accompanies people from the earliest stages of development to adulthood. Since it is a condition of life, interventions must also meet the specific needs of the person at that time in their life and their individual characteristics.



## 2.1 Functioning

The very definition of Autism Spectrum Disorder invokes the idea of heterogeneity. In fact, there are multiple and heterogeneous manifestations of the clinical condition (Lai, Lombardo, Chakrabarti, & Baron, 2013). In the diagnostic manual that is used as a reference (Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, DSM-5, 2013), in addition to the core symptoms, specifiers are described to help us better define each case. These are:

- With or without concomitant intellectual impairment;
- With or without language impairment;
- Associated with a known medical or genetic condition or environmental factor;
- Associated with another neurodevelopmental, mental, or behavioural problem.

Further specification is made with reference to the severity of symptoms and the support needed. This allows us to describe the level of impairment in through the description of the two main dimensions (core symptoms) on the 3 degrees of severity:

- Level 1 - Support needed
- Level 2 - Significant support needed
- Level 3 - Very significant support needed.

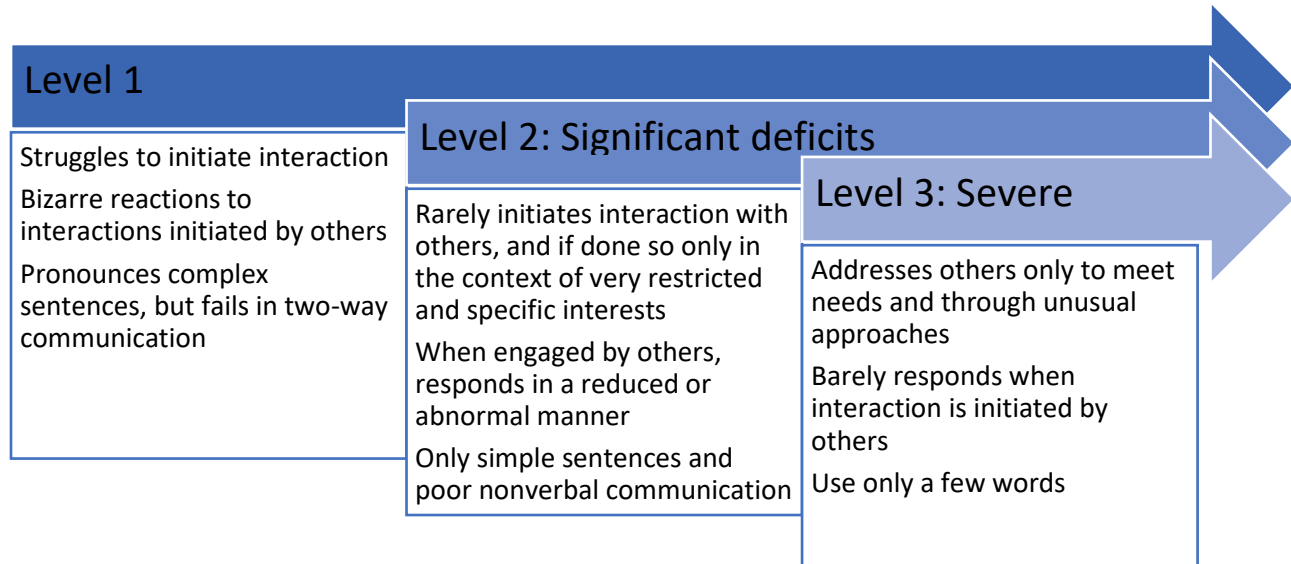
This gives us an idea that the degree of these core symptoms and related symptoms are highly subjective and can change from person to person, although the diagnosis is the same. So, when we approach a person with ASD, we have to think that this person might show very different strengths and difficulties than another (Vivanti, Hudry, Trembath, & Barbaro, 2013). Also, the same person might present symptoms of different severity depending on the context or time of life.

Let's look at some examples of how the two symptomatologic dimensions appear according to a continuum of increasing severity and needed support.



## 2.2 Social communication and social interaction

As seen above, a person with ASD may have challenges in socialisation and communication, which may vary depending on the level of severity. Each level may in fact have its own peculiarities and the following have been identified with regard to communication and social interaction:



Below is a depiction inspired by an early classification of ASD made by Wing (1988). While outdated and limiting, it gives us an idea of the many facets that can occur in terms of difficulties in the area of communication and social interaction.



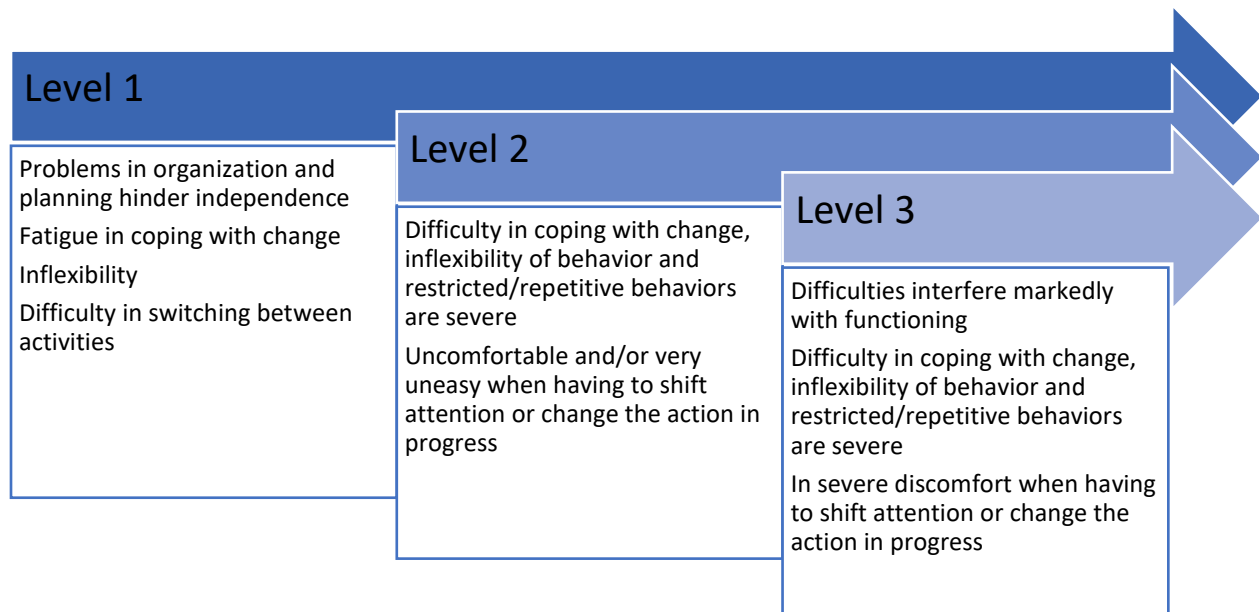
Figure 1 Wing and Gould 1979, Wing 1988





### 2.3 Restricted and repetitive patterns of behaviour, interests or activities

The other key point in the description of ASD symptoms is a restricted and repetitive pattern of behaviour, interests or activities. So, let's try to see together how they may change in this area according to severity:



These are examples of the main difficulties a young person with ASD may have. We must remember, however, that each individual is different. Address them or the family directly to find out what their difficulties and strengths may be.



## Chapter 2 – Communication with people with ASD

### Introduction

In this chapter we will not explain the core aspects of autism, as they were previously explained. However, we must highlight that the current definition of autism only focuses on social communication and not on language *per se*, as this aspect of development is not always affected and therefore it cannot be considered a diagnostic criterion for all people with ASD. Within the autism spectrum we can find people with no oral language at all and with a very developed oral language. In all cases, what should be present are social communication difficulties and we should think of the most suitable type of support in order to facilitate social interaction.

To identify the most functional degree and type of support for people with ASD, a holistic and comprehensive approach is needed. This means that each support must be individualised, designed according to all the factors included in that given situation and capable of involving different contexts. Finally, each individual should be able to express their needs and what kind of support they require.

### 1. Support and social communication needs

Taking the above into account, support needs for social communication should be understood from at least two different perspectives. The first perspective should deal with the communicative skills and competences of the person with autism with the aim of expanding his/her language and communicative resources. The second perspective should focus on reflecting on the demands placed on the individual person in the different contexts in which he/she actively participates; then, these should be eased so the gap between competences and demands is reduced as much as possible.

As we mentioned above, the cases found within the Autism Spectrum Disorder are very different both in terms of social communication and language capabilities.

We already said we can see people with autism with or without oral language capabilities. Within the latter category (with language capabilities), we could also find people with a



language deficit (approximately 25-30% of people with ASD) and people without language deficit.

Taking the above into account, talking about communication and language in autism is even more complicated if space is also limited. Even so, we will try to find a practical and functional approach that is useful for dealing with people with autism for monitors and educators of youth organisations. To do this, we will divide the text for people with ASD with language deficit on one hand, and for people without language deficit on the other.

## 2. People with ASD with language deficits

The first thing to consider is that every person has the right to be able to communicate beyond their verbal (both oral and written) capabilities and skills. From this starting point, support people must be responsible for delivering support and teaching people with autism a functional communicative system adapted to their needs and expectations. Any agent that interacts in a meaningful way with people with autism should respect and know their own communication systems. For this purpose, we will offer a brief presentation of the systems most commonly used nowadays. It is important to emphasise that before knowing all the technical tools, it is important to approach people with ASD with sensitivity and empathy, to be available and to adapt.

### Alternative and augmentative communication systems

Alternative and augmentative communication systems (AACs) can be defined as those methods used to complement or replace speech or writing for people with difficulties to produce or understand oral and/or written language.

Amongst others, AACs have the following benefits:

- They enable the socialisation of the individual by improving interpersonal relationships.
- They improve attention during communicative interactions.
- They reduce the anxiety of the individual.
- They can be used in real-life environments.
- They can reduce the likelihood of challenging behaviours.



Here are some of the methods currently used:

### 2.1 Gestures and sign language

Gesture-based communication systems and sign languages are widely used models when people do not use spoken language or their spoken language must be supported by other communicative modalities.

We can highlight as an example Benson Schaeffer's (Schaeffer, Musil, & Kollinzas, 1980) total communication programme; which goal is to promote spontaneous non-verbal communication by using signs by both interlocutors. These signs are accompanied by speech.



Figure 2 Example of signs used in sign language

### 2.2 Low-tech exchange systems

Low-tech AAC exchange systems consist of communicators and/or selection panels for requests in which an image is delivered to a receiver to communicate what the person desires to achieve.

The most recognised image exchange system is [PECS](#) (Bondy & Frost, 1998). It consists in teaching to give a symbol to another person in order to get an object or initiate a desired activity.



Figure 3 Analogue communicator for pictogram exchange

The teaching of this system is divided in different phases that increase in difficulty aligned to communication. In the first phase the only objective is to deliver an isolated element, image or pictogram to make a request. Then, different images are presented to teach how to discriminate different images and movements are also introduced to make the requests.

We recommend starting with a low-tech system and keep using it until the user has mastered at least levels I, II and III of the PECS programmes (functional use, spontaneous use, adequate discrimination of symbols) and then assess the usage of a high-tech exchange system.

### 2.3 High-tech exchange systems

High-tech exchange systems are specific applications for non-dedicated (general purpose, non-exclusive) devices like iOS, Android and Windows smartphones and tablets. Having in mind the current technological landscape, this type of system is emerging as a valuable and highly demanded alternative to ease the communication of people with intellectual disabilities and communication and language difficulties (Lorah, Parnell, Whitby, & Hantul, 2015).



Some of these apps are [Proloquo2go](#); [Eneso Verbo](#) or [TD Snap Core First](#). All of them are based on the usage of pictograms as the basis for daily communication and the development of language skills in some cases. Through these apps it is possible to compose even complex sentences, they will be automatically spoken by the device instead of the person, facilitating social interaction. The level of communication can be adapted according to age. The advantage of these tools is that they are understandable even by those who are not experienced, easily transportable and generalizable to different contexts (Shic & Goodwin, 2015).

When thinking about using a pictogram exchange system, we may have doubts as to which model we should use, low-tech or high-tech. The final decision may be influenced by different factors such as price, durability or previous use of this type of support.

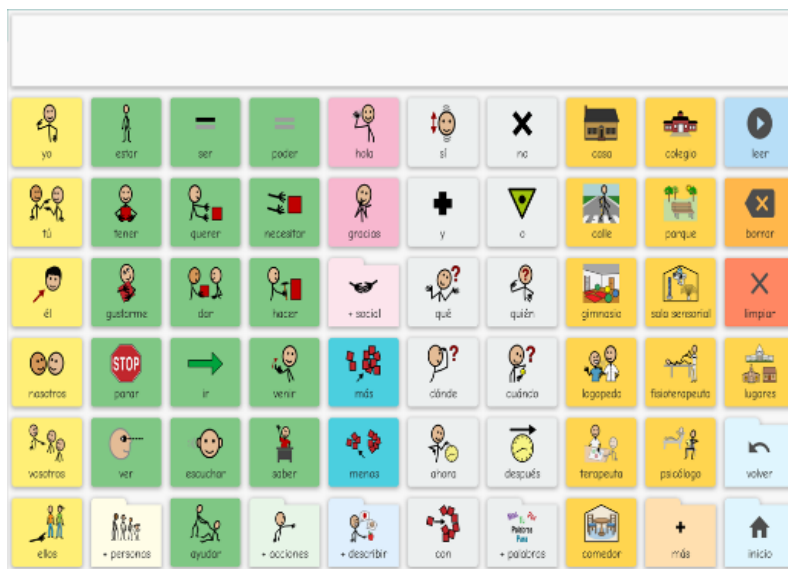


Figure 4 Landing screen of a communicator based on pictograms

Here are some tips that we think are useful for communicating with people with ASD who have some language deficit:



### 3. People without language deficit

On the other hand, if we talk about people with autism without an oral language deficit, we will surely find difficulties very different from those of the people who have it.

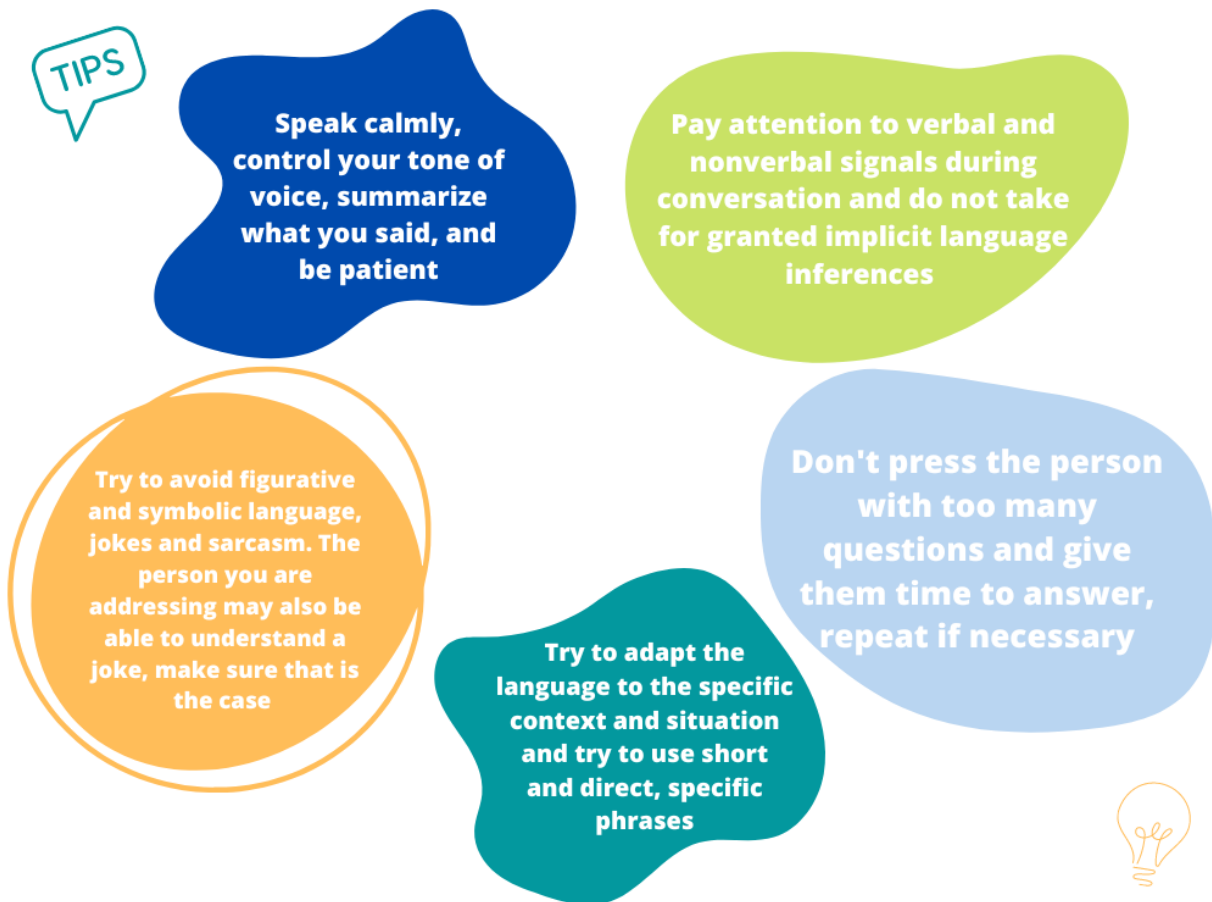
First of all, it is important to consider that they are people with difficulties to initiate, maintain or end conversations; to understand the meaning of communication at a social level; to understand jokes, sarcasm, figurative language and double meanings; to infer implicit points in language or to use and understand non-verbal language.

Sometimes we will see repetition of phrases, phrases out of context or strange verbalisation in terms of tone, speed or volume. These issues are quite frequent in people with autism. Just like we noted in the previous section, please get information from the family and other professionals that will help and give you some advice to communicate



and interact with that person. These people are part of his/her support team and will have a vast knowledge about him/her.

Here are some tips we think are useful for communicating with people with ASD without language deficit:







On a final note, some general tips to keep in mind when you want to communicate with people with ASD:

**Try to catch their attention during communication**

**Keep calm, use a calm tone of voice and adapt to their skills and competences**

**The language used and the context must be predictable**

**Do not base your communication just in requests. Communication means sharing information, let that person express his/her desires and intentions**

**Don't force eye contact**





## Chapter 3 – Creating a safe and inclusive Environment – Inclusive Organisational Structures

### Introduction

In the following material, all of the suggestions will focus around creating a safe and inclusive environment in the organisational structure for people with ASD. The hints provided may also be useful more generally, as it is not only important for the young person with a diagnosis to feel comfortable and included, but for everyone.

How to build an environment that is autism-friendly has been a question that more individuals have been asking themselves over the past several years. It is obvious that those who suffer from an Autism Spectrum Disorder (ASD) may view the world significantly differently from others. This can be both empowering and challenging. You must work to lessen the negative effects of sensory differences and increase the good benefits while building an environment that is welcoming to people with autism (DIALOGICA - Creators of Autism Dialogue). The quality of life for those with autism spectrum disorders can be improved by creating a supportive atmosphere.

Every person on the autism spectrum will have a unique sensory experience of the environment. It might be difficult to address diversity, especially disability, within an inclusive framework. Although it will never be easy to accommodate everyone's preferences, some thought and care can go a long way for certain people, especially for young people with autism spectrum disorder (ASD). A setting that is welcoming and makes people feel at ease should have clear, well-defined spaces, as well as activities that are well-timed and well communicated from the start. Consider the sensory abilities or limitations of young people with ASD when designing an inclusive environment. Help them navigate and comprehend the place via explanations and illustrations. The surroundings need not be devoid of obstacles, but they must be introduced gradually lest they find it too challenging and upsetting.



## 1. Inclusive Organisational Structures

A key characteristic of people with ASD to consider when thinking about an environment is sensory sensitivity. We can classify the difficulties in modulating sensory sensitivity found in people with autism (Miller, Anzalone, Shelly, Cermak, & Osten, 2007) as follows:

- Hyper-sensitivity: an exaggerated, negative or avoidance behavioural reaction of sudden onset and/or prolonged duration to sensory stimuli such as noises, lights and smells in the environment;
- Hypo-sensitivity: lack of or reduced response to sensory stimuli such as pain (frequent falls, cuts, etc.), temperature (burns, scalds) and taste (reduced taste abilities).
- Compulsive seeking (sensory seeking/craving) and unusual, absorbing and excessive interest in a specific sensory experience that is abnormal in intensity or duration (specific lights, movements, smells and tactile textures).

This sensitivity can vary from person to person in severity and frequency and may even be present to a small degree.

To assist us choose how to make adjustments that will be beneficial for people with autism, we should consider different factors before we start remodelling a space or planning a construction project. We need to pay attention to all seven of the senses – visual, auditory, olfactory, taste, touch, vestibular and proprioceptive. We also need to pay attention to space and how it is used.

### 1.1 Sensory areas

When we design an environment that can be inclusive for people with ASD, we need to consider several sensory aspects (AsIAM.ie - Ireland's National Autism Charity, 2012).

Below is a list of the main ones:

1. Visual sense (Sight)
2. Auditory sense (Hearing)
3. Touch and pressure sense

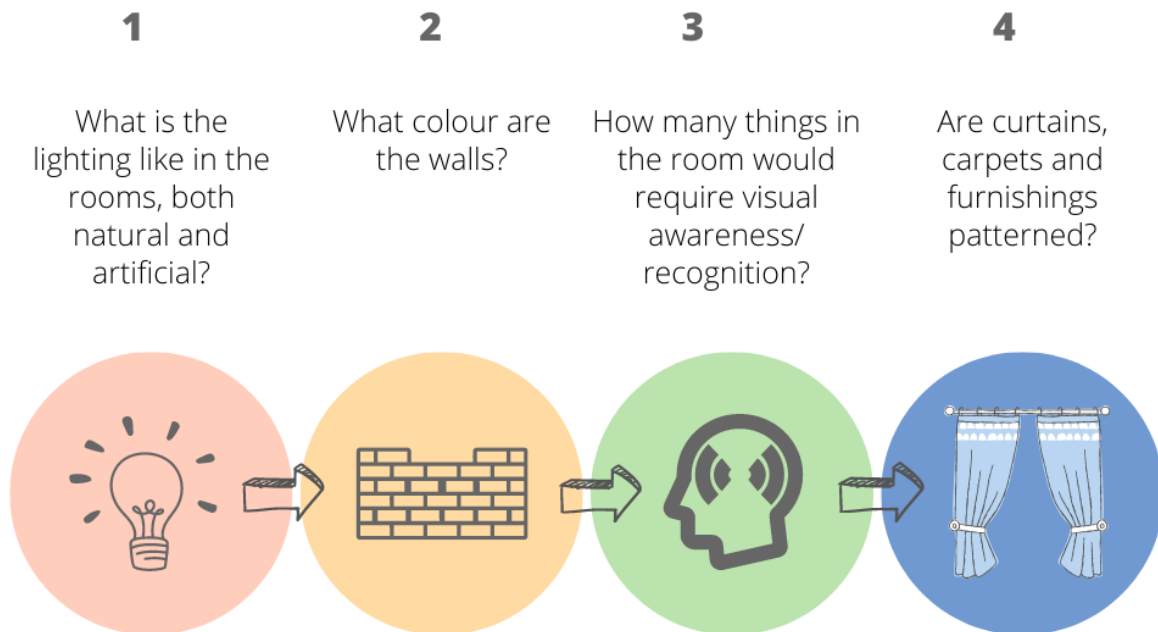


4. Olfactory sense (Smell)
5. Taste sense
6. Vestibular sense (Balance)
7. Proprioceptive sense (Space)

Since the sense of sight and hearing are the senses with the greatest impact on the activities and setting of the environment for an organisation, we will discuss them in more detail below and provide some suggestions.

### Visual sense

Here are some questions that relate to visual sense we should ask ourselves when designing an environment:





Lighting plays a large part in the sensory experiences of many autistic people. In general, very bright lights (especially office strip lights) or moving light sources nearly always have a negative effect on an autistic person (Matusiak, 2019). Other factors regarding lights to consider: fluorescent or harsh lighting and reflective surfaces. One suggestion might be to avoid these types of lights and/or to use lamps with the option to adjust the light by intensity and/or colour.

Paying attention to colour is also essential. Different colours have different effects on us (DIALOGICA - Creators of Autism Dialogue). Think about the room you are designing – are you trying to create a stimulating or calming environment? Generally, the color green has a relaxing effect, light blue aids concentration while yellow and red have stimulating power.

The degree of clutter or minimalism in the spaces should also be considered. Many autistic individuals are especially attentive to every detail and can become overloaded with too much visual information. Others require greater stimulus from images. In addition, having too much space in any direction could make them anxious. It might be useful to design environments with furniture and equipment that can be moved according to the task at hand or the particular sensitivity of the person involved.

Patterned fabrics can be particularly distressing to some individuals with an autistic spectrum condition. Patterns can be distracting and overwhelming and can even cause visual distortion (DIALOGICA - Creators of Autism Dialogue).

### *Auditory sense*

An additional sense to pay attention to when thinking about how to create an inclusive environment is hearing. People with ASD may be particularly sensitive to some specific noises (e.g., ticking clocks, phones, printers) or to the intensity of these noises. In fact, if these are very loud or sudden they may annoy people on the spectrum. Pay attention to possible background noise such as road noises or building/gardening work in the distance. In addition, be aware of one person pointing at someone else or using a



dominant voice (especially talking over others or for a long time), this can be overwhelming for an autistic person (DIALOGICA - Creators of Autism Dialogue).

What to do? One suggestion would be to set possible noises to a low level and to keep noise-cancelling headphones at hand, in case of noises over which we have no control. In addition, it might be helpful to think of an extra space that can be quieter than where you normally are, so that people can choose according to what they need most at that moment.



## Essential Information to Know When Creating an Autism-Friendly E N V I R O N M E N T

- 01 People on the autism spectrum **experience life very differently** from others.
- 02 An autism-friendly environment should **reduce the negative effects and enhance the positivity of sensory differences**.
- 03 **People with autism can be hypersensitive or hyposensitive**, requiring more or less stimulus at times.
- 04 **Fluorescent lighting can be distracting** and debilitating for some autistic people.
- 05 Darkness is **essential** for treating sleep problems.
- 06 Different colors have different effects on people with autism. **Green is restful, light blue aids concentration, yellow and red are stimulating**.
- 07 **Clutter can cause overstimulation** for some people with autism.
- 08 **Patterned fabrics can be distressing and overwhelming** to some people living with autism.
- 09 Autistic people can hear sounds many decibels above those others can hear. **Sound intensive can be deafening**.
- 10 Some autistic people **find touch distressing** unless they are in control of it.
- 11 Some hyposensitive people **need additional stimulation** to feel.
- 12 **Smells can cause extreme nausea** in some autistic people.
- 13 **Distaste** for a particular food can be caused by the texture or appearance of the food, rather than the taste.
- 14 Some autistic people rock, balance, and swing to help gain a sense of self. **Too much space can cause anxiety and disorientation**.
- 15 Many autistic people **need space around them** and cannot handle clutter and crowds, including narrow corridors and passageways.
- 16 **Ask yourself** if the space will be used by individuals or groups, and is the space transitional?
- 17 Pay attention to all seven senses: **hearing, sight, taste, smell, proprioceptive, touch, and vestibular**.

LIVING autism

Figure 5 Matusiak, M. (2019, August 29). How to create an autism-friendly environment. Living Autism. <https://livingautism.com/create-autism-friendly-environment/>

### 1.2 Who will use the space?

This might seem an obvious question to ask; however, it is important to think the answer through. The environment might need to be different for children or adults. You might also need to consider whether the same environment will be used by others who might have sensory differences, or by a group with very differing sensory needs. If there is a risk of sensory overload; is there somewhere else a person can go to escape from the overload? On the basis of this it might be useful to have an environment where the person can go



in case he finds the environment too overloaded and that allows him to familiarise himself with that overload gradually.

### 1.3 What will the space be used for?

Some spaces are used for large groups of people, such as school halls or open-plan offices. Other spaces are for single use or small groups. Yet, other spaces are intended for transition, e.g. corridors or lifts.

Transition spaces can be complex for people on the autism spectrum because it can sometimes be difficult to move from one space to another or one activity to another.

Therefore, consideration needs to be made as to how to make transition spaces easier to deal with. Some questions you can ask are:

- Can there be a natural flow from one space to another without using a corridor? Are there fewer claustrophobic ways to go up or down a building than the use of lifts?
- If spaces are being used for large numbers of people, are there smaller spaces available for retreat if necessary?
- If spaces are small and intimate, are there opportunities to go easily to a more open space?
- Can you create a map of where individuals with autism seem to become most anxious? Are there alternative routes?

A last question we might ask ourselves, when creating an autism friendly environment, is “what can be easily visualised” instead of being overexplained. A great tip for this is to create pictures on the door of every room, on drawers, closets etc. An example is, instead of writing “WC” and “Toilet” you can put a picture of a toilet. Instead of writing “Teachers room” or “Entrance” you can visualise this with a picture instead. The same procedure can also be applied to the material to indicate where to find it.





## 2. Safe spaces – physically and mentally

### 2.1 What is a safe space?

A safe space is a place (physical or mental) where people feel comfortable, seen/heard, able to express themselves (or not, if that is what they wish) and feel like their presence is as valuable as anyone else's. It is important to feel this way, if a person wishes to develop and thrive. 'Personal space is the area individuals maintain around themselves and into which intrusion by others may cause discomfort or even anxiety. People closely monitor and appropriately regulate their interpersonal space to obtain a comfortable distance of interaction with others' (Gessaroli, Santelli, Di Pellegrino, & Frassinetti, 2013). It is important to keep in mind that people with ASD may have a different perception of personal space than we do; we have to respect that.

The focus of this module is to enable institutions to create and facilitate this kind of environment, so that the people in it e.g. young people with ASD can take part in a beneficial way in the institutional life.

#### 2.1.1 *The physical safe space*

People with ASD have just as many different needs as everyone else. Therefore, there is not specific solution to the task of creating a safe space, but there can be certain actions that will enable most people to participate. One thing that is important, is to be aware of one's own and other people's situation/mood/capabilities/resources for the day. Not everyone would have the same ways of expressing that with words or actions which is why the "Welcome Board" comes in handy.

#### **The Welcome Board**

The aim of this board is to welcome everyone into the institution every day and give people the chance to see who is here and how are they feeling today. This gives everyone an overview and if a person is low on energy, people will be aware, before the person is being overstimulated. The board starts with a welcoming sentence and a question about "How are you today?" just as anyone else would ask when entering. Everyone has their face on a sticker/poster on the board, which they will place on the line of people who are



present in the institution today. Afterwards, depending on the capabilities of the target group, the person has to choose three items that describe their mood today. If the target group is able, there are posters with words like “happy”, “sad”, “tired”, “smiling” etc. If it suits the target group better, the questions would be “What is your weather forecast?” and they could then choose pictures/posters/stickers with “rain”, “sun”, “cloudy” instead and put them next to their picture, to show how their inner self is feeling. Another alternative is to use pictures that express emotions or weathering instead of words.

This gives everyone the possibility to take care of their friends and colleagues, if they see they feel “rainy” they know this person today is not in his/her best mood, so they can help them and not expect too much of them. If they see that a person has chosen the words “funny”, then other people can see the board and know that this person is up for a game or a talk. This is a way of easily creating a space, where everyone is seen and heard in a manner that fits them, and as people with ASD often have a sensitive reaction behaviour, this is a great way of foreseeing a challenge.

### *2.1.2 The psychological/mental safe space*

The welcome board is a way to visually portray people's feelings, so that everyone can help meet this person and meet themselves in the best possible way. Another important factor is that people have a set of rules and safe ways of interacting with each other. Therefore, it can be beneficial to create a set of “Norms and Rules” and perhaps finding an appropriate name or headline of norms and rules are too vague.

#### **Norms and Rules**

In order to secure a safe and inclusive environment, it is important to establish a set of norms, so that everyone is interacting and participating in a way that suits them. This is kind of the ground rules for the institution, that will help people feel acknowledged in different situations. A great way of doing this is having a session where everyone can wish for norms and rules they find important. This could be everything! And will vary according to the cognitive capabilities and needs of the persons that will use the norms. Some examples:



- Everyone put their name and words/weather on the welcome board when they arrive
- You always ask “How are you today?” or “Did you have a good day?”
- If you need a break, you can go to the “silent room” “pause place” anytime you need to
- Everyone has to respect the needs and feelings of people in the organisation
- Everyone says goodbye when they leave

When the norms are set, they might not always be met by everyone, but it is a way of facilitating dialogue to someone who might not seek it themselves e.g. with how was your day? And it is a way of ensuring that everyone's needs are met and people can feel safe and comfortable. It might be useful to create a poster board with the rules that have been chosen by the group, so that they are always visible during the activities. You can also associate a picture with each rule or simulate each rule and take a picture of them to attach to the billboard. This facilitates interiorization of the rule.



## Further Resources

- See this video on how to create an inclusive classroom for Autistic children:  
<https://www.youtube.com/watch?v=UM5NA2fPBvU>
- This article addresses the benefits of inclusion for students on the Autism Spectrum <https://files.eric.ed.gov/fulltext/EJ1304391.pdf>
- This document provides some useful ideas on Autism Friendly Environment Guidelines  
[https://education.gov.mt/en/NSSS/Documents/ASD%20friendly%20guidelines\\_pr  
inting.pdf](https://education.gov.mt/en/NSSS/Documents/ASD%20friendly%20guidelines_printing.pdf)
- This is a useful checklist for Autism-Friendly Environments  
[https://www.southwestyorkshire.nhs.uk/wp-content/uploads/2014/10/Checklist-  
for-autism-friendly-environments.pdf](https://www.southwestyorkshire.nhs.uk/wp-content/uploads/2014/10/Checklist-for-autism-friendly-environments.pdf)



## Chapter 4 – Supporting your staff in ASD-related skills development

### Introduction

With acceleration of the prevalence of Autism Spectrum Disorder (ASD) has come the imperative to provide effective interventions that aim to promote the inclusion of people with ASD. First of all, it is important to highlight that inclusion is about offering the same activities to everyone, while providing support and services to accommodate people's differences. Inclusive organizations actively reach out to people with disabilities and seek to understand and appreciate their differences, while fostering a sense of belonging (Autism speaks, 2018). To build activities on a good foundation, commitment to the success of an inclusion program must come from the top. The board and staff must recognize and support the program. Teamwork among program staff, family members, caregivers, and the child's team is crucial and parents should be actively involved in planning for inclusion.

Considering that ASD consists of a wide range of clinical characteristics, individualised approaches and interventions should occur. Indeed, one of the basic rules is that you must focus on the participant's strengths and then implement ad hoc activities. However, general guidelines and specific tips could facilitate the inclusion of youth ASD in peer groups and organisations (Anthony & Campbell, 2020).



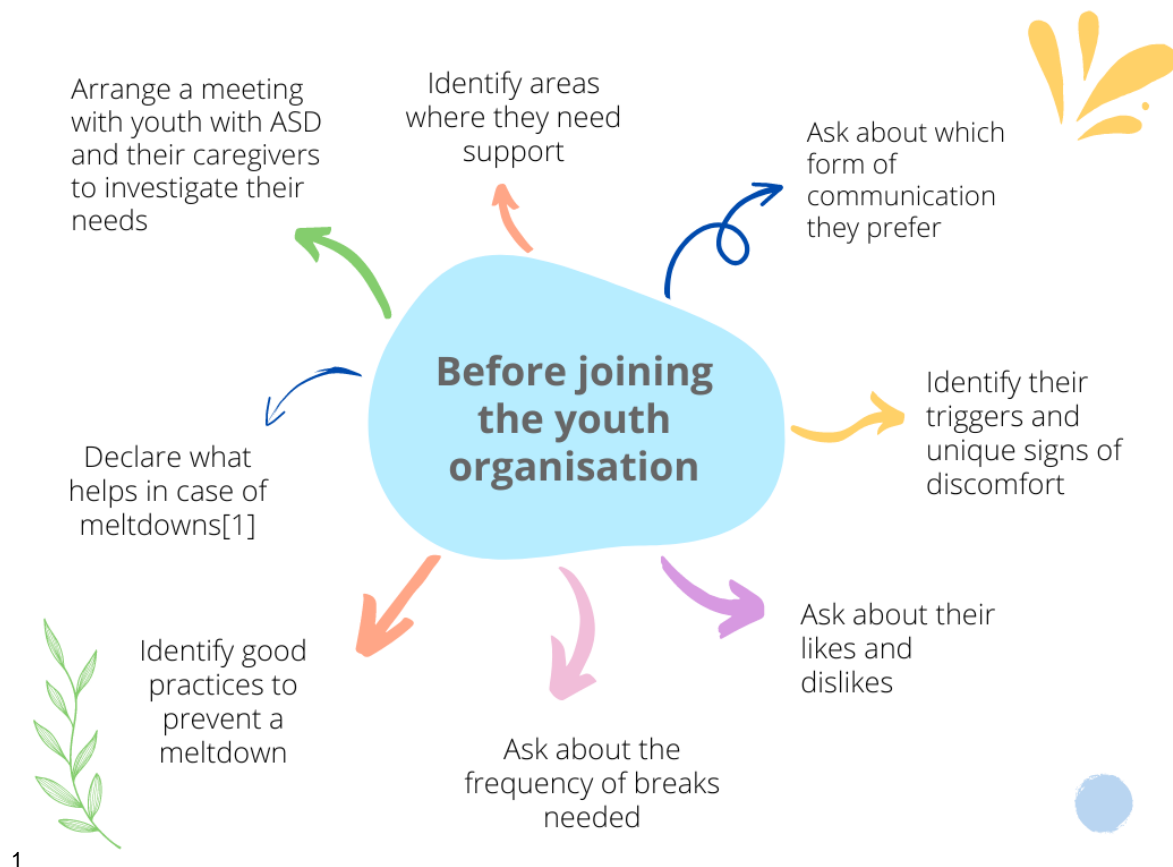
Figure 6 Source: Freepik



## 1. The three phases of inclusion

We will focus on three important steps to help your organization's staff in creating inclusive activities and engaging youth with Autism Spectrum Disorder as effectively as possible (Sridhar, Drahota, & Walsworth, 2021). Particular attention will therefore be paid to three key moments: before youth with ASD join the youth organization, during the inclusion procedure, and after the first session. Here are some suggestions that we think you might find useful.

Before young people with ASD join the youth organisation:



1

<sup>1</sup> A meltdown is the appearance of problem behaviours that may be verbal or physical, due to sensory overload or difficulty coping with intense emotional states, cognitive overstimulation or over-socialization, suppression of stereotypes, and unexpected changes.

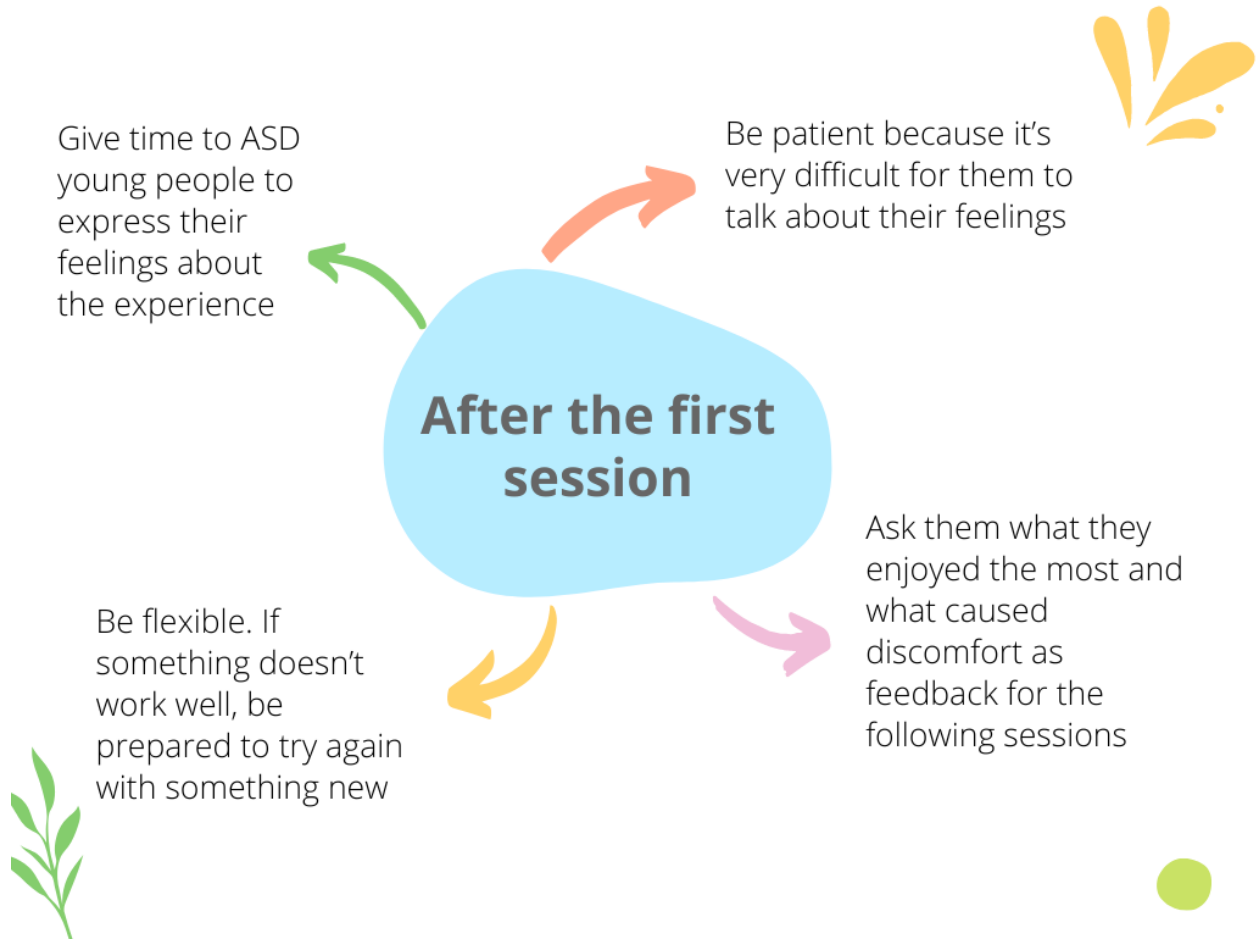


In their inclusion procedure:

- Support individuals with ASD to talk to their peers about their specific strengths and difficulties, in the time and manner they prefer. Make sure if they are willing to disclose their diagnosis;
- There are four areas of difference to be considered:
  1. Social interaction: Social interaction can often be complex and tiring for young people on the spectrum. Keep in mind that they need more time;
  2. Social communication: Discrimination between verbal and non-verbal individuals should be done in order to adopt the most suitable communication method. Consider the use of visualised communication tools. Evaluate the different types of communication through words, sounds, signs or gestures;
  3. Routines and repetition: Young people with ASD need to know what will happen and when changes will occur;
  4. Sensory Issues: Keep in mind that some sounds, lights, smells and physical touch could cause discomfort to people with ASD. Suggest sunglasses or ear defenders when needed.



After the first session:







## 2. Our guidelines for fostering inclusion

In order to create and implement inclusive activities there are certain elements that must be taken into consideration (Wong, et al., 2015). It may be helpful to create a good initial atmosphere, and icebreaker activities are very effective for this purpose. Next, it will be necessary to take care of the creation of the groups, which will be mixed groups with youth with ASD and normo-typical youth; organize the schedule of activities and transitions between activities; set goals; think about the most useful communication strategies depending on the context; prepare the peer group; and last but not least, involve the family in the planning stages.



Figure 7 Source: Freepik

### Icebreakers

These are activities that precede the main session help group members relax and get to know each other. For autism-friendly icebreakers:

- Avoid physical touch activities;
- Prefer non-verbal sorting games, including all group members, but always considering ways to facilitate communication based on the method used;
- Choose activities suitable for the particular age group- young people with autism are not children.

### Create the main activities and groups



The main activities are those that involve the true involvement of youth with ASD. There are many activities that may be suitable, the important thing is that they have certain characteristics, below we provide some hints. Also, keep in mind to provide alternatives taking into consideration the ASD young people's individual needs. In order to offer services adjusted to people's strengths and difficulties we suggest to:

- Create groups, avoiding putting too many people together (3-5 are ok) and balancing groups by age and abilities;
- Involve both people with ASD and neurotypical people in the groups;
- Prefer activities with clear goals and structure;
- Be flexible and run different activities at parallel times, giving ASD individuals the chance to choose the field they want to be involved;
- Keep the possibility of doing different activities than the group, in case of need of one-to-one support.

### Organization and transitions

For people with ASD, it is critical to know exactly what will happen because of the difficulty in dealing with the unexpected. ASD individuals usually depend on routine and structure. Any changes should be explained in advance in order to avoid distress. For this reason, it is crucial to plan activities in advance so that we can provide them with a schedule and a timeline, so they can know what to expect. In addition, it is important to support ASD young people joining and leaving a youth group. For this purpose:

- Arrange a pre-session meeting with individuals to describe the activities which will take place in the new peer group
- Organise an agenda (with pictures if useful) to indicate the steps in the activity and/or the sequence of activities (which activities are done at what time)
- Introduce the faces involved in this procedure- schedule an appointment with the new leader before the first official session.
- Provide time for individuals to ask questions and share their feelings about the upcoming changes.



- Try to indicate real photos of the new places and activities in advance.
- Adapt a functional session plan with five particular aspects:
  1. Space: where the activity will take place;
  2. Time: when this is going to happen;
  3. Task: what is going to happen – detailed description of the activity;
  4. Equipment: what tools and instruments will be used;
  5. People: who is involved in this activity.

## Goals

The particular benefits individuals could gain from each activity should be identified before the session. Consider:

- What skills young people on the spectrum could build by completing the activity?
- What challenges could they face in this process?
- How will you know that the goal is achieved?
- How is their confidence boosted throughout this procedure?

Try to set *goals* with the following *characteristics*:

- ✓ Specific
- ✓ Measurable
- ✓ Attainable
- ✓ Relevant
- ✓ Time-based- Prefer short-term goals

## Communication

As mentioned above, individuals with ASD communicate differently. In order to facilitate communication, it should be useful to use visual supports such as stickers or badges and agree with individuals on the intention of each badge. For example, a red badge could possibly mean that young people on the spectrum need to be left alone for a while, a yellow badge could be the sign that only close people can talk to them, and finally, a green



badge could be interpreted as willingness for interaction. Agree with ASD individuals a specific word or signal to let you know that they need a break. If you want to learn more about communication and potential strategies to implement, read Chapter 2 – Communication with people with ASD.

## The peer

Since true inclusion is only possible when the same activities are offered to all, it is advisable to prepare the normo-typical peer group before including youth with ASD in activities. Here are some tips that you might find useful:

- Encourage them to ask questions about the characteristics of ASD;
- Explain to them that specific repetitive movements- stimming- intend to allay ASD individuals' distress;
- Suggest to them to ask what is best to do in cases of meltdowns and shutdowns<sup>2</sup>;
- Declare that young people with ASD have unique strengths and difficulties. Explain that when ASD young people don't talk, they don't try to ignore peers but just need time alone;
- Tell them that young people on the spectrum have really focused hobbies, which they like to talk about and don't realise that other people might not be as interested;
- Encourage the peer group to interact and support youth with ASD respecting their dignity and individuality.

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<sup>2</sup> Shutdown is an implosive reaction of shutting down toward external stimuli that may manifest in immobility, not responding if called, cowering, hiding, etc. Like meltdowns, it is due to sensory overload or difficulty coping with intense emotional states, cognitive overstimulation or over-socialization, suppression of stereotypes, and unexpected changes.



Figure 8 Source: Freepik

## Cooperation with Family

Parents should be actively involved in planning for inclusion since they can give you very valuable information. For this purpose, we suggest you to:

- ✓ Arrange an advance telephone conference with individuals' caregivers and advise them to give a clear history of individuals, considering their triggers and strong characteristics;
- ✓ Be willing to listen to them and familiarise yourself with peoples' individualised peculiarities;
- ✓ Propose scheduling individuals' first meeting with the staff of your organisation a few weeks or months ahead of time;
- ✓ Suggest the use of a visually supported calendar that demonstrates activities, including the sessions in youth organisations;
- ✓ Arrange appointments with individuals' caregivers on a frequent and regular basis to discuss emerging needs and challenges.



Figure 9 Source: Freepik



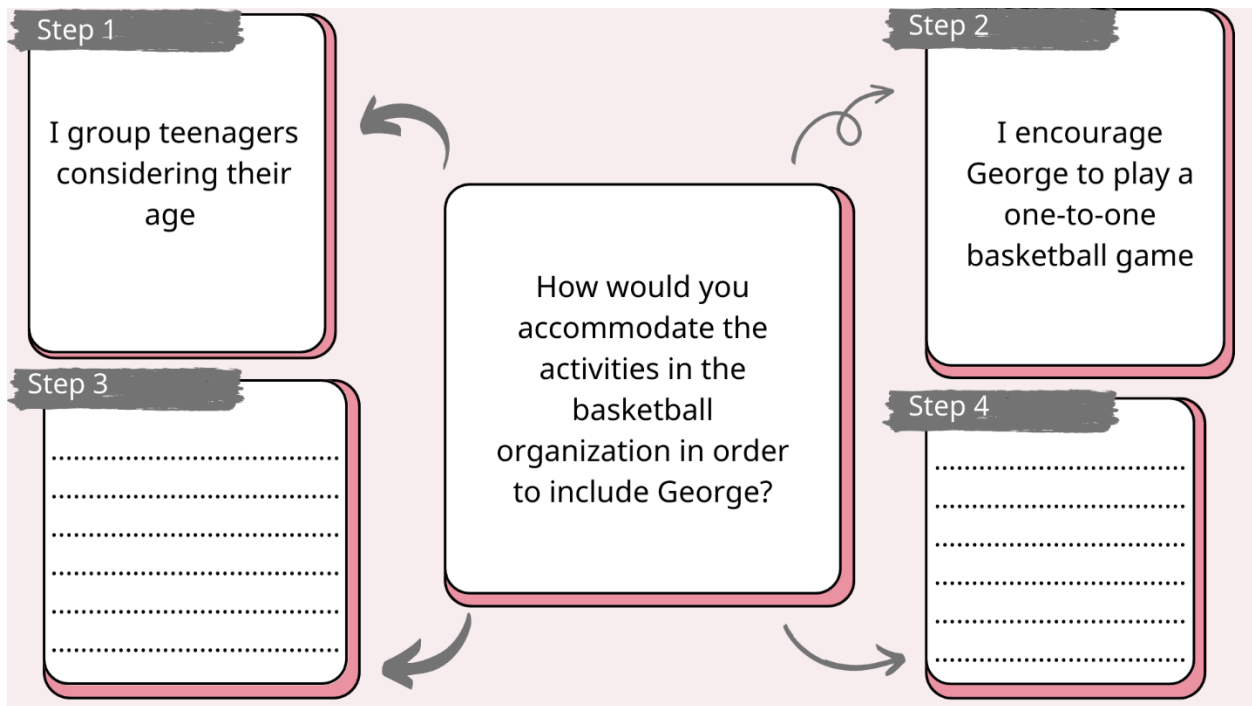
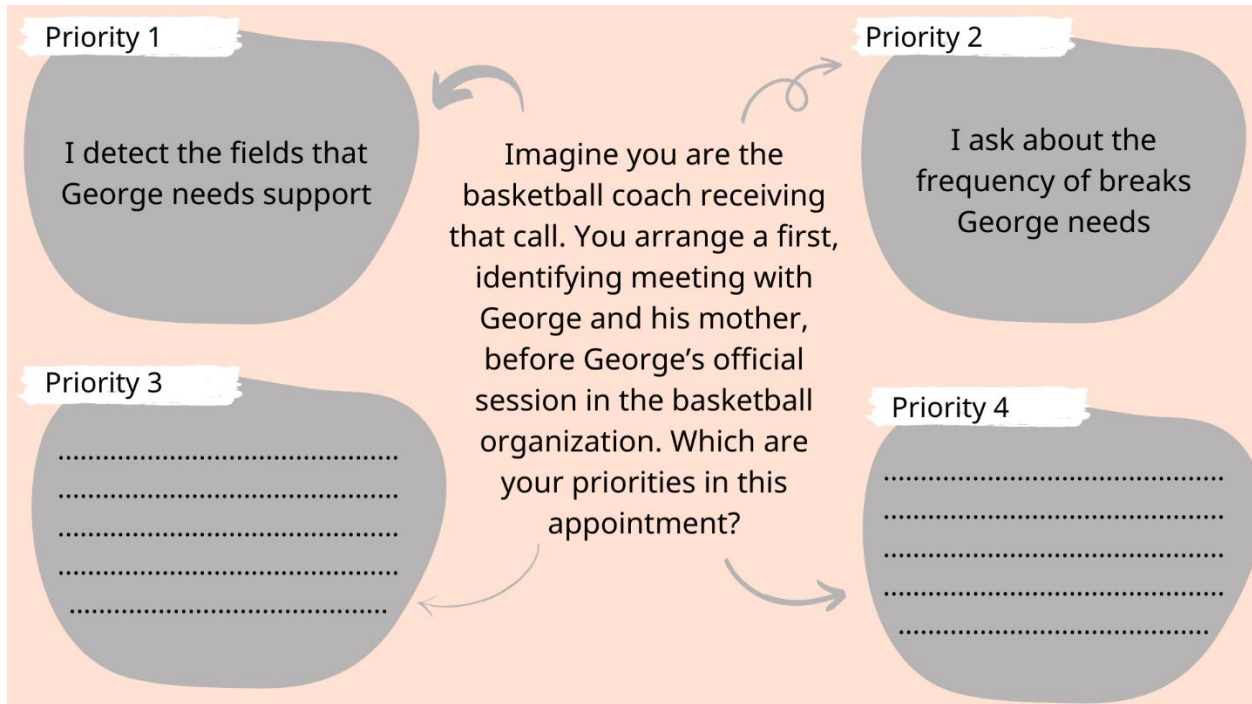
### 3. Let's think...

After the theoretical preparation and suggestions provided up to this point, we think it might be useful to put yourself to the test with a practical exercise. Try thinking about what you would do in the scenario presented below to foster George's inclusion on the local basketball team, keeping in mind everything you have read in this Guide.



*George is a 15-years-old boy who was diagnosed with ASD at the age of 1,5 years old. He is living with his mother in a suburb of Athens, Greece. He is a verbal autistic teenager and he experiences discomfort when changes in his regular daily program occur. He enjoys playing basketball, but only by himself shooting the ball in the basket. The last two months he expresses the desire to communicate with other teenagers and play basketball together. Although he has the ability to follow rules and instructions, he needs more time to digest them. Moreover, he experiences distress when he doesn't manage to put the ball into the basket and in order to relax he moves his head back and front. His mother decides to contact the local basketball organization and describe the situation.*







## Chapter 5 – Best practices and initiatives

What emerges from the most recent research on the quality of life and general well-being of young people with ASD is that increased participation and integration in the community has important benefits for young people with ASD and is closely correlated with improvements in their quality of life.

To address this problem, there is a need to increase the focus on community initiatives aimed at the inclusion of young people with ASD and the social resources to support them. To this end, it is particularly relevant to equip local and community youth organisations with knowledge and skills appropriate to the inclusion of young people with ASD in their communities, in order to be able to adapt their services to this present and future need to support the psychosocial development and independence of persons with ASD.

That is why this Guide was created, to provide youth organisations with the fundamental knowledge and tools to renovate their organisational and environmental structures and allow their proposed activities to be enjoyed by youth with ASD.

In the framework of the research prior to the development of this Guide, several best practices and initiatives were identified, all with the aim of fostering and encouraging the inclusion of youth with Autism Spectrum Disorder within the community.

We think it is useful and important to provide you with these best practices and initiatives, which can be an inspiration for your own context. Therefore, the following are a few examples we leave you with. The best practices and initiatives identified can be divided into three macro categories:

- best practices and initiatives focusing on social inclusion;
- best practices and initiatives focusing on school inclusion;
- best practices and initiatives focusing on work inclusion of youth with ASD.

In addition, at the end there will also be an example of a multidimensional programme specific for people with ASD.





## 1. Best practices and initiatives focusing on social inclusion

### Rulli Frulli – Italy

“Rulli Frulli” is a band that grew up in difficult circumstances: the earthquake that hit Emilia Romagna in 2012. Around seventy young people between the ages of eight and thirty are members. Fifteen of them are young people with disabilities (autism and down syndrome). The members of the band Rulli Frulli search for new sounds and their nuances by building and playing musical instruments using recycled materials (pipes, tiles, pots and pans, washing machine baskets, etc.). Music serves as a tool to unite all the different band members and allows each person to make his or her own unique contribution.

### Famiglia Ludica – Italy

The Famiglia Ludica project focuses on integrating young people with ASD with their family members and peer group using board games. The project was born out of the need to create a more engaging space that would strengthen the bonds between family members in an effective way, through a tool that was accessible to all, even economically, such as board games. It seeks to promote through play the knowledge and mutual recognition of skills to create closer ties; the acquisition of notions and skills such as mental organisation, flexibility and self-control; the development of cognitive and socio-relational skills, competencies and behaviours such as the ability to stay and work in a group, conflict and frustration management; the improvement in the family and in groups of psychological closeness, mutual respect and solidarity and the ability to adapt and problem-solving.

### “Servicio de Ocio Comunitario” – Spain

This initiative is based on personal interests and leisure with an emphasis on community. The main objective of this service is to provide support for people with ASD so they can enjoy leisure activities, regardless of their condition. Therefore, the service contributes to enhancing personal autonomy and social inclusion within the community. The programme



comprises general sports, community, leisure, aquatic and transport activities, and also special activities according to the preferences of the association's users.

## 2. Best practices and initiatives focusing on school inclusion

### Gli Insuperabili – Italy

This initiative, called “Gli insuperabili” (The unbeatable), developed in a high school in Modena, creates the possibility of knowing and seeing disability in a different way through cooperation and sharing a single goal, namely the creation of a play that will be put on in the municipal theatre of the city of Modena. The play serves as a tool to realise a school and extracurricular environment of genuine inclusion between youth with different disabilities and their classmates.

### Specially designed youth education – Denmark

The Danish practice “Specially designed youth education- STU” consists of a three-year youth education for young people up to age 25, targeted to people with intellectual disabilities and other young people with special needs who cannot complete another youth education. The training is based on a personal developed curriculum and may consist of:

1. A general part that includes subjects on social conditions, housekeeping, economics and self-care;
2. A specifically targeted part, which, based on interests and abilities, includes training in industrial relations and training in employability;
3. Traineeships in companies and institutions to give young people experience of working conditions and cooperation in a workplace.

### Special classes at High schools for young people with ASD – Denmark

This Danish educational model involves the establishment of special classes, created to encourage children with ASD to continue their studies in high school. The classes consist of only 12 students (instead of 25-30 as usual). The teachers have participated in ASD-specific courses and teach with students’ specific needs and difficulties in mind. What is



different is the mode of teaching; the curriculum and teaching are the same as in all other classes. Special attention is also paid to the physical setting: the class has the same normal classroom as others (so plenty of space for 12 people) and in addition there is a specially designed group room with the possibility of extra peace and relaxation. Lastly, the high school offers conversations with a mentor who is a trained special educator.

### 3. Best practices and initiatives focusing on work inclusion

#### ErgAxia – Greece

The purpose of this project is to train and support young adults with developmental, intellectual disorders and autism spectrum disorders in the workplace to find and keep their desired work position. The service was established to respond to every person's fundamental right to employment and eliminate the vocational exclusion of people with disabilities from the labour market.

#### TheSpecialisterne – Denmark

The Specialisterne is a company founded by Thorkild Sonne, a father of an autistic boy. This company offers services to other companies based on the specific & unique competences of many young people and adults challenged by autism. Today Specialisterne is a company established in many countries employing more than 10.000 people challenged by autism. The Specialisterne also offers training and developing programs for people with ASD and acts as an employment office finding competent people with ASD – but having specific and unique competencies required by other big companies – such as airports – pharmaceutical companies.

#### Il Tortellante – Italy

Il Tortellante is a therapeutic - habilitative workshop where youth and adults with autism spectrum disorder learn to make fresh handmade pasta which is then sold to the public. The project is led and supervised by a neuropsychiatrist and with the collaboration of coordinating psychologists and educators and the help of chef Massimo Bottura. The specific activity of making fresh handmade pasta is used as a tool to work with young people with autism spectrum disorder on the main areas that are lacking in this disorder: communication, social relationship with peers and autonomy and offers the opportunity



to learn a specialised skill that can make young people with ASD independent in the future.

#### 4. Multidimensional programmes specific for people with ASD

“Center for family intervention and support of persons with autism”- Cyprus

Multidimensional programmes specific for people with ASD is a practice identified in most countries, these programmes include different types of specialised services and supports specifically aimed at persons with autism or other disabilities and their families. This centre is specifically for people with Autism Spectrum Disorder in early childhood and their families. This practice includes, among other, psychological support services and counselling, homeschooling and educational support services as well as social support services.



## References

- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, DSM-5*.
- Anthony, N., & Campbell, E. (2020). Promoting Collaboration Among Special Educators, Social Workers, and Families Impacted by Autism Spectrum Disorders. *Advances in Neurodevelopmental Disorders*. doi:10.1007/s41252-020-00171-w
- AsIAM.ie - Ireland's National Autism Charity. (2012). *What Does Autism Friendly Mean?* Retrieved from ASIAM.IE: <https://asiam.ie/advice-guidance/community-inclusion/what-does-autism-friendly-mean/>
- Autism speaks. (2018). *Inclusion: Ensuring Access for Everyone*. Retrieved from Autism Speaks: <https://www.autismspeaks.org/tool-kit-excerpt/inclusion-ensuring-access-everyone>
- Bondy, A., & Frost, L. (1998). The picture exchange communication system. *Semin Speech Lang., 19*(4), 373-424. doi:10.1055/s-2008-1064055
- DIALOGICA - Creators of Autism Dialogue. (n.d.). *Creating an Autism Friendly Environment*. Retrieved from Autism dialogue: <https://autismdialogue.wordpress.com/creating-an-autism-friendly-environment/>
- Gessaroli, E., Santelli, E., Di Pellegrino, G., & Frassinetti, F. (2013). Personal Space Regulation in Childhood Autism Spectrum Disorders. *PLoS ONE, 8*(9). doi:<https://doi.org/10.1371/journal.pone.0074959>
- Ingersoll, B., & Dvortcsak, A. (2019). *Teaching Social Communication to Children with Autism and Other Developmental Delays - The Project ImPACT Guide to Coaching Parents and The Project ImPACT Manual for Parents*.
- Lai, M.-C., Lombardo, M., Chakrabarti, B., & Baron. (2013). Subgrouping the Autism "Spectrum": Reflections on DSM-5. *PLoS Biol, 11*(4). doi:<https://doi.org/10.1371/journal.pbio.1001544>



- Lewis, V., & Boucher, J. (1988). Spontaneous, instructed and elicited play in relatively able autistic children. *British journal of developmental psychology*.  
doi:doi:https://doi.org/10.1111/j.2044-835X.1988.tb01105.x
- Lorah, E., Parnell, A., Whitby, P., & Hantul. (2015). A systematic review of tablet computers and portable media players as speech generating devices for individuals with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 45(12). doi:10.1007/s10803-014-2314-4.
- Matusiak, M. (2019). *How to create an autism-friendly environment*. Retrieved from Living Autism: <https://livingautism.com/create-autism-friendly-environment/>
- Miller, L., Anzalone, M., Shelly, J., Cermak, S., & Osten, E. (2007). Concept evolution in sensory integration: a proposed nosology for diagnosis. *The American Journal of Occupational Therapy*, 61(2), 135-140. doi:https://doi.org/10.5014/ajot.61.2.135
- Ohrberg, J. (2013). Autism Spectrum Disorder and Youth Sports: The Role of the Sports Manager and Coach. *Journal of Physical Education, Recreation & Dance*, 84(9). doi:https://doi.org/10.1080/07303084.2013.838118
- Schaeffer, Musil, & Kollinzas. (1980). *Total Communication: A signed speech program for non-verbal children*. Champaign: Illinois Research Press.
- Shic, F., & Goodwin, M. (2015). Introduction to Technologies in the Daily Lives of Individuals with Autism. *Journal of Autism and Developmental Disorders*, 45(10), 3773-3776. doi:1007/s10803-015-2640-1
- Sridhar, A., Drahota, A., & Walsworth, K. (2021). Facilitators and barriers to the utilization of the ACT SMART Implementation Toolkit in community-based organizations: a qualitative study. *Implement Sci Commun*, 55. doi:https://doi.org/10.1186/s43058-021-00158-1



- Vivanti, G., Hudry, K., Trembath, D., & Barbaro, J. (2013). Towards the DSM-5 Criteria for Autism: Clinical, Cultural, and Research Implications. *Australian Psychologist*, *48*, 258-261. doi:<https://doi.org/10.1111/ap.12008>
- Wong, C., Odom, S., Hume, K., Cox, A., Fettig, A., Kucharczyk, S., . . . Schultz, T. (2015). Evidence-Based Practices for Children, Youth, and Young Adults with Autism Spectrum Disorder: A Comprehensive Review. *Journal of Autism and Developmental Disorders*, *45*, 1951-1966. doi:<https://doi.org/10.1007/s10803-014-2351-z>