

Guide for youth organizations on structures and strategies for the inclusion of people with ASD

Summary



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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 a way of being, reasoning, perceiving and functioning.

ASD is a spectrum within which we can find different levels of functioning along a continuum.

ASD occurs more frequently in boys than girls, with 4:1 male-to-female ratio.

ASD core deficits

ASD is characterized by two core deficits (American Psychiatric Association, 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 changes with the acquisition of other developmental skills.

2.1 Social communication and social interaction in ASD

People with ASD have persistent difficulties in **social communication and social interaction**. 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.

2.2 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).

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.

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. 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.

Areas of difference in ASD

The definition of 'Autism Spectrum Disorder' emphasises the importance of considering each characteristic, symptom or deficit along a dimensional continuum within which its intensity and severity must be placed.

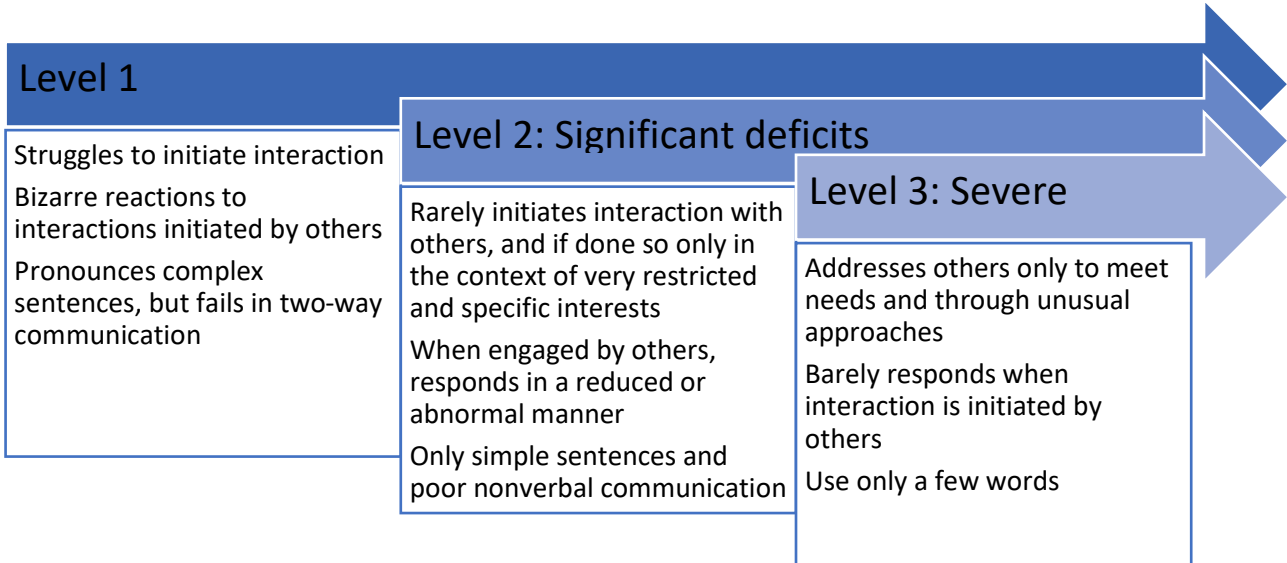
ASD is a condition of life, a way of functioning that accompanies people from the earliest stages of development to adulthood.

1. Functioning

There are different specifications to the diagnosis depending on the severity of the symptoms and the 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, et al., 2013). Also, the same person might present symptoms of different severity depending on the context or time of life.

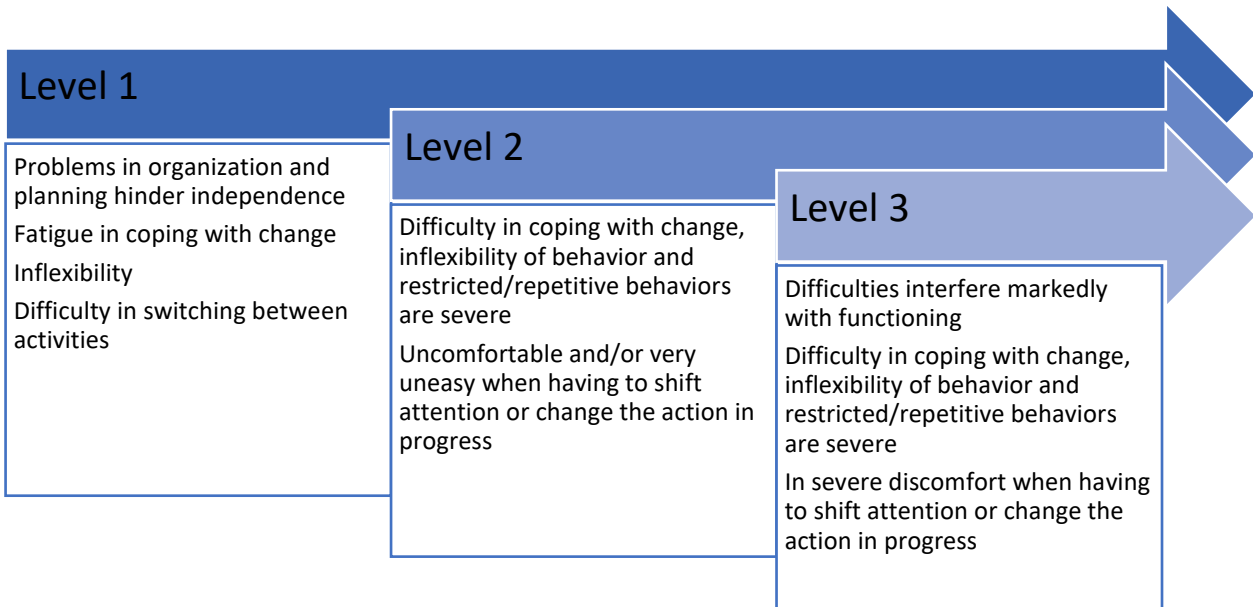
1.1 Social communication and social interaction

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:



1.2 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:



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 is social communication difficulties.

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

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 will 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. Here is a brief list of the tools that are used to facilitate communication:

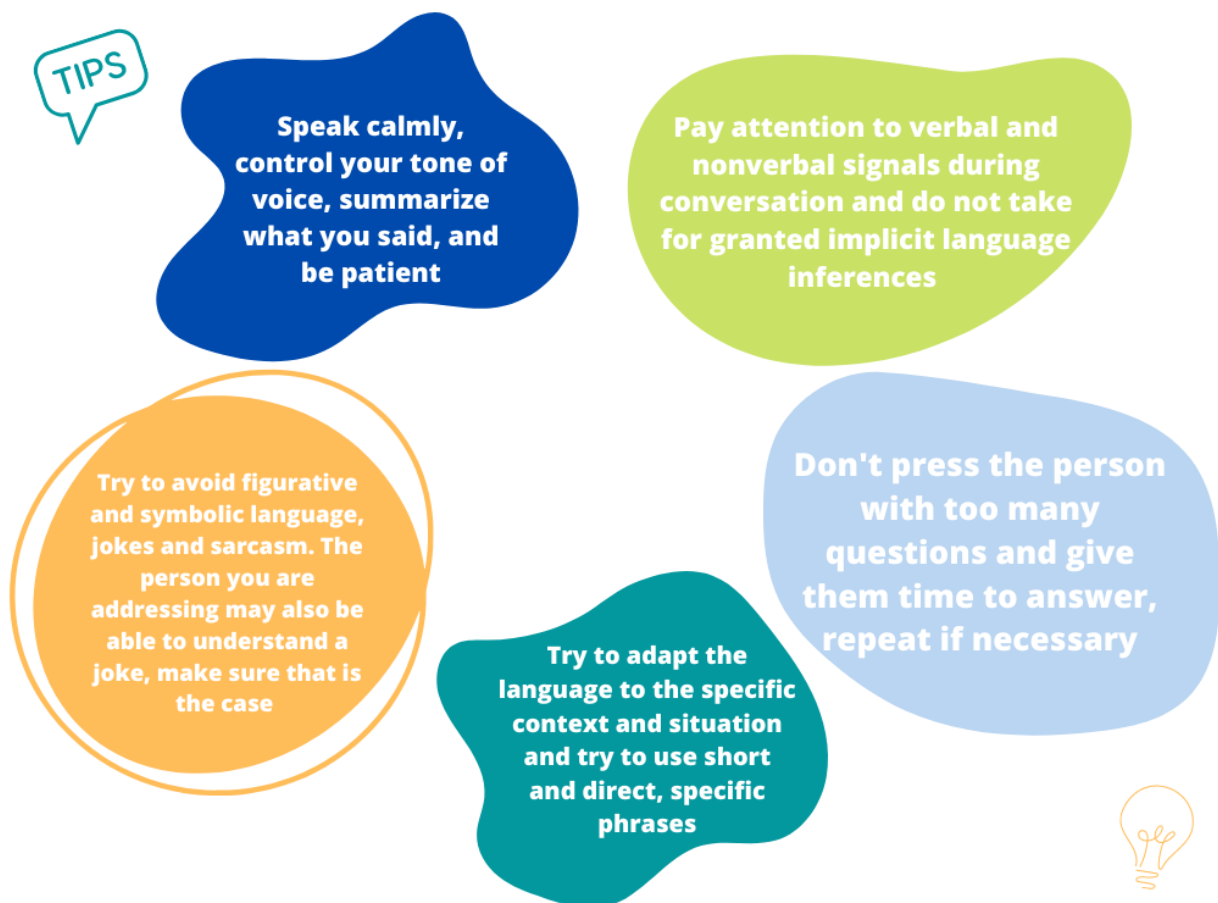
- Alternative and augmentative communication systems
- Gestures and sign language
- Low-tech exchange systems
- High-tech exchange systems

3. People without language deficit

On the other hand, if we talk about people with autism without 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.

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





Final considerations and tips

Despite we difference between people with language difficulties and people who only have difficulties in social communication, here are some final tips that we hope you will find useful in communicating with that people:



We hope that all the points above are useful to raise your awareness about communication with people with autism.

Create a safe and inclusive environment – Inclusive organisational structures

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.

1. Inclusive Organizational 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 et al., 2007) as follows:

- Hyper-sensitivity
- Hypo-sensitivity
- Compulsive seeking (sensory seeking/craving)

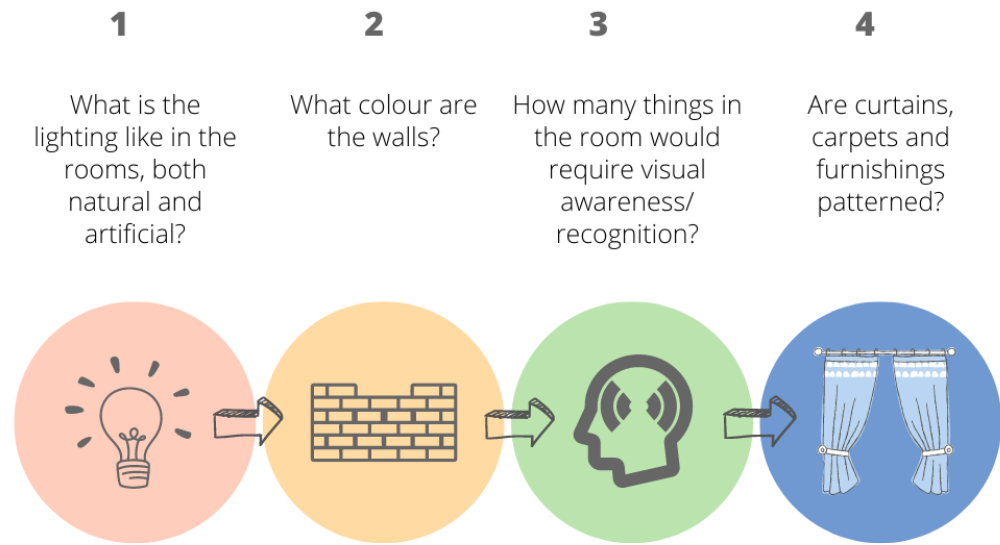
This sensitivity can vary from person to person in severity and frequency and may even be present to a small degree.

Since the sense of sight and hearing are the senses with the greatest impact on the activities and setting of the environment for an organization, here is some information on these topics.

Visual sense

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.

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



Auditory sense

People with ASD may be particularly sensitive to some specific noises (eg. 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.

Who will use the space?

It is very important that the space to be created is designed for those who will use it, and therefore an individualized and personalized approach should be used.

What will the space be used for?

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?

Safe spaces – physically and mentally

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.

Supporting your staff in ASD-related skills development

Considering that ASD consists of a wide range of clinical characteristics, individualized approaches and interventions should occur. However, general guidelines and specific tips could facilitate the inclusion of youth ASD in peer groups and organizations.

1. The three phases of inclusion

- 1) **Before** young people with ASD join the youth organization: Fields in that young people need support, communication preferences, triggers and methods avoiding meltdowns
- 2) **In their inclusion** procedure: Aspects of diagnosis' disclosure and the four areas that young people with ASD differ from their peers: Social interaction, social communication, routines and sensory issues
- 3) **After** the first sessions: Likes and dislikes, feelings and feedback

2. Our guidelines for fostering inclusion

- Autism friendly *icebreakers*: Non-physical and non-verbal activities
- Inclusive *activities*: Flexible and different activities with clear goals and structure running at parallel times
- *Transitions*: Pre-session meetings and functional session plans describing different aspects of activities: time, space people etc.
- *Goals*: Skills that individuals could build and challenges they may face setting specific and measurable goals
- *Communication*: Alternative methods of communication and use of specific tools and methods

Preparation of the **peers**:

- ❖ Answering peer group's questions
- ❖ Promoting respect among people
- ❖ Familiarization of the peer group with ASD's characteristics

Co-operation with **family**:

- ❖ Familiarizing with people's individualized peculiarities
- ❖ Considering the impact of autism on the entire family
- ❖ Arranging frequent and regular appointments with caregivers

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