

# MANUAL



**AHA4AUTISM**

**EXCHANGING GOOD PRACTICES  
ON ACTIVE AND HEALTHY AGEING  
FOR ADULTS WITH AUTISM  
AND THEIR CAREGIVERS**

ERASMUS+ ADULT EDUCATION PROJECT | REF: 2023-1-ES01-KA210-VET-000166128

## PARTNERS



[www.aha4autism.eu](http://www.aha4autism.eu)

# Table of contents

<b>1. Introduction</b>	<b>03</b>
<b>2. Diagnostic characteristics</b>	<b>04</b>
<b>3. State of the art</b>	<b>10</b>
<b>4. Quality of life of people with Autism Spectrum Disorder (ASD)</b>	<b>14</b>
<b>5. Selection process of good practices</b>	<b>18</b>
5.1 Good practices in social inclusion of people with autism	20
5.2 Good practices in health of people with autism	41
<b>6. Results of the Expert Committee</b>	<b>63</b>
6.1 Implementation of best practices	72
<b>7. Bibliography</b>	<b>92</b>

## 1. Introduction

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition that influences how individuals interact with others, communicate, and perceive the world around them. It is characterized by persistent difficulties in social reciprocity and communication, along with restricted and repetitive patterns of behavior, interests, or activities. Additionally, individuals with ASD often exhibit sensory processing differences, which may include hypersensitivity or hyposensitivity to certain stimuli, such as sounds, lights, or pain (American Psychiatric Association, 2023).

ASD is highly heterogeneous, meaning that its symptoms and manifestations vary significantly from person to person. The term “spectrum” reflects this wide variation in strengths and challenges, as individuals with ASD can experience a broad range of cognitive abilities, language skills, and adaptive behaviors. While some individuals may have intellectual disabilities and require significant support in daily life, others may possess average or above-average intelligence and demonstrate remarkable strengths in areas such as logical reasoning, pattern recognition, and creative problem-solving. Many individuals with autism lead highly independent and successful lives, particularly when provided with the appropriate accommodations and resources tailored to their unique needs.

Over the years, extensive research has been conducted to better understand the underlying causes of ASD. While significant progress has been made in identifying potential contributing factors, the complexity of its etiology has not yet been fully elucidated. Current scientific consensus suggests that ASD arises from a multifactorial interplay between genetic predisposition and environmental influences, including maternal infections during pregnancy, maternal-fetal immune status, exposure to medications or toxic agents during pregnancy, and advanced parental age at conception. Scientific evidence regarding the presence of specific biological markers, as well as morphological and biochemical alterations, is still not interpretable in a univocal manner (Frith, 2009).



## 2. Diagnostic characteristics

In Autism Spectrum Disorder, clinical symptoms can vary widely in both complexity and severity and may change over time. Moreover, individuals with Autism Spectrum Disorder often present with multiple comorbidities, which must be carefully considered when planning interventions (Matson & Cervantes, 2014).

The diagnosis of the disorder is primarily based on a clinical assessment, supported by a specific structured evaluation. The diagnostic framework proposed by the DSM-5-TR (APA, 2023) outlines the five criteria on which a diagnosis of **Autism Spectrum Disorder (ASD)** must be based.

**A: Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following factors, present currently or in the past:**

- Deficits in social-emotional reciprocity, ranging, for example, from an abnormal social approach and failure in normal back-and-forth conversation to reduced sharing of interests, emotions, and feelings; to a lack of initiation or response to social interactions.
- Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poor integration of verbal and nonverbal communication to abnormalities in eye contact and body language, or deficits in understanding and using gestures, up to a total lack of facial expressions and gestures.
- Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties in adapting behavior to different social contexts, to challenges in sharing imaginative play and making friends, up to an apparent lack of interest in peers.

**B: Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following criteria, present currently or in the past:**

- Stereotyped or repetitive motor movements, use of objects, or speech, such as simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases.
- Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior, including difficulties with transitions, rigid thinking patterns, ritualized greetings, insistence on taking the same route or eating the same food, and extreme distress over small changes.
- Highly restricted, fixated interests that are abnormal in intensity or focus, such as a strong attachment to or preoccupation with unusual objects, or excessively circumscribed or perseverative interests.
- Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment, such as apparent indifference to temperature or pain, adverse response to specific sounds or textures, excessive smelling or touching of objects, or fascination with lights or movement.

**C. Symptoms must be present in early childhood (However, they may not become fully apparent until social demands exceed the individual's capacities, or they may be masked by learned strategies in later life.)**

**D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of functioning.**

**E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay.**

This does not mean that Intellectual Disability and Autism Spectrum Disorder cannot coexist. Comorbidity between these two disorders is, in fact, common. The two diagnoses can be made simultaneously: social communication must be more impaired than expected, given the overall level of development.

Thus, these DSM-5-TR criteria define autism as a unique condition that spans a broad spectrum, emphasizing significant individual variations. For each case, specific specifiers are identified to assess the severity of the disorder and the level of support required, which may change over time depending on contextual factors.

The diagnosis is based on Criteria A and B, supplemented by the presence of certain specifiers, which help to provide a more detailed evaluation of the individual's condition.

1. With or without intellectual impairment.
2. With or without language impairment.
3. Associated with a known medical, genetic, or environmental condition.
4. Associated with a neurodevelopmental, mental, or behavioral disorder.



However, scientific research emphasizes the importance of expanding the approach to autism, going beyond the DSM-5-TR criteria to embrace a more comprehensive view of the individual.

From this perspective, it is suggested to integrate the DSM-5-TR model with the bio-psycho-social approach of the International Classification of Functioning, Disability, and Health (ICF) by the World Health Organization (WHO, 2001). This framework interprets functioning and disability as the result of a complex interaction between individual conditions (bodily functions and structures) and environmental and personal factors.

It is therefore considered essential to take into account the interaction between the individual and the environment. In this perspective, the concept of functioning is not limited to describing an individual's behavior within their context but also seeks to explain the motivations and conditions that influence it.

A supportive environment, free of barriers and enriched with facilitators, can promote participation and autonomy, even in the presence of physical or cognitive limitations. Conversely, a negative interaction between an individual's health condition and their environment can transform a deficit into a disability.

Thus, disability is not solely dependent on organic impairments but also on activity limitations or participation restrictions determined by the environment, as highlighted by the ICF approach.

## 3. The state of art

In recent decades, research on autism has increasingly focused on adulthood. In a recent study, Cottini (2024) examines autism in adults, emphasizing that while scientific literature has traditionally centered on children, autism is a lifelong condition.

Moreover, Keller and colleagues (2023) highlight the importance of an accurate and rigorous diagnosis of autism spectrum disorder in adults. They stress the need for a diagnostic process that not only considers an individual's unique characteristics but also takes into account their family and environmental context. This comprehensive approach enhances the accuracy of the diagnosis, providing a solid foundation for developing a tailored support network and personalized intervention plan.

Building on this perspective, Keller (2023) also underscores the growing awareness in recent years of the need to diagnose autism in adults who were not identified earlier. Many individuals receive a diagnosis only later in life—often in their twenties, thirties, or even forties—after enduring years of uncertainty, confusion, and isolation. For many, finally understanding their autism proves to be a transformative experience, allowing them to embrace both their strengths and challenges.

This growing recognition of autism in adulthood aligns with scientific evidence on the stability of autism's core characteristics over time. Various studies (Matson, Wilkins, Ancona, 2008; Howlin et al., 2013; Magiati, Tay, Howlin, 2014; Gotham et al., 2015; Lever, Geurts, 2016a; Steinhausen, Mohr Jensen, Lauritsen, 2016) have consistently documented how autism-related challenges—such as difficulties in social interaction and communication, along with a wide range of restricted and specific behaviors and interests—tend to persist throughout life.

In other words, even as individuals grow older, the defining characteristics of autism do not disappear but remain stable, although they may evolve in certain cases. This further highlights the importance of recognizing and diagnosing autism in adults, ensuring that appropriate support is available at every stage of life to improve well-being and quality of life.

## 3.1 Developmental Trajectories of Autism

Building on these considerations, it is essential to analyze the developmental trajectories of autism, particularly regarding behavioral aspects. These elements are fundamental to understanding how autism manifests and evolves over time.

Shattuck et al. (2007) conducted a study involving 241 adolescents and adults with autism, aged between 10 and 52 years, monitoring them over a period of four and a half years. The results showed that while many participants exhibited no significant changes in symptoms, a high percentage demonstrated improvements in their challenges, with a reduction in maladaptive behaviors and an increase in communication (excluding nonverbal communication) and social reciprocity.

Similarly, Esbensen et al. (2009) studied 712 individuals with autism, aged between 2 and 62 years, focusing on age-related differences in obsessive and repetitive behaviors. Their findings indicated that these behaviors tend to decrease in frequency and severity with age.

Subsequent studies (Chowdhury, Benson, Hillier, 2010; Gillespie-Lynch et al., 2012; Gray et al., 2012; Howlin et al., 2014; Lord, Bishop, Anderson, 2015) have confirmed that certain core symptoms of autism, particularly repetitive and stereotyped behaviors, tend to lessen over time. However, the extent of this improvement is often smaller in individuals with lower intellectual quotient (IQ) scores. For example, Gray et al. (2012) found that individuals with a verbal IQ below 70 showed a less significant reduction in symptoms compared to those with a verbal IQ above 70. Nevertheless, having an average or above-average IQ does not necessarily guarantee successful social adaptation in adulthood.

These findings underscore the complexity of autism's developmental trajectory and the need for long-term support tailored to the evolving needs of autistic individuals.

Taking these findings into account, Jordan and Powell (2003) emphasize the importance of considering these factors, which are crucial for designing effective support programs for adults with autism. These include:

- **Difficulty Managing Change:** Many people with autism struggle with transitions and changes in routine or environment, which can cause anxiety and stress. Although this rigidity may lessen with experience, it remains an important factor to consider in support strategies.
- **Lack of Spontaneity and Initiative:** People with autism often follow instructions well but may find it challenging to engage in activities beyond their specific interests. Their actions are frequently tied to learned patterns rather than intrinsic motivation.
- **Limited Creativity and Imagination:** Due to cognitive rigidity and a lack of spontaneity, people with autism may have difficulty generating new ideas. While they may excel in replicating what they observe, they often struggle to interpret or imagine scenarios beyond their direct experience.
- **Repetitive and Circular Thinking:** Many people with autism engage in repetitive thought patterns and behaviors, which can serve as coping mechanisms for stress but may limit social engagement and adaptability. While these tendencies are characteristic of autism, they are not unchangeable. An enriched educational and social environment can encourage greater flexibility and responsiveness to external stimuli.

Although rigidity and repetitive behaviors are central characteristics of autism, they can be positively influenced by supportive environments that encourage flexibility. At the same time, it is important to recognize and value these cognitive styles, as they can be effective in certain contexts. A balanced approach—one that promotes adaptability while respecting individual strengths—can enhance quality of life and social integration for people with autism.

These insights further reinforce the importance of recognizing autism across the lifespan and ensuring that individuals receive the necessary support at every stage of their development.

# QUALITY OF LIFE

## 4. Quality of Life of people with Autism Spectrum Disorder

The quality of life of people with Autism Spectrum Disorder (ASD) is an increasingly important topic, both theoretically and practically, as it should represent both the goal of any intervention and the parameter against which the effectiveness and efficiency of various interventions are measured.

According to Parmenter T.R. (1988), quality of life:

“represents the extent to which a person has met their needs in order to give meaning to their life and maintain a positive self-image in a social context.”

The quality of life is linked to individual needs and expectations. An individual's needs may vary based on age, interests, time of day, social interactions, and the presence of a motivating operation (Gottschalk, J. M., Libby, M. E., & Graff, R. B., 2000). Despite the difficulties associated with the disorder, people with autism can achieve a good quality of life if adequately supported. However, achieving a satisfactory life for adults with autism depends on several factors, including psycho-social support, education, employment and recreational opportunities, as well as the personalization of support pathways (ISS, 2023).

Among the key aspects that determine well-being are autonomy in daily activities, social participation, inclusion in recreational activities, and access to work experiences (Cottini, 2019). Autonomy is one of the main indicators of quality of life, as it allows individuals to feel more fulfilled and satisfied. Adults with autism who can independently manage daily activities such as household chores, financial management, and employment tend to experience greater personal satisfaction (Hedley & Uljarević, 2018). However, the promotion of independence must be accompanied by appropriate support strategies, especially in the initial stages of autonomy, in order to address the practical difficulties associated with the disorder.

# QUALITY OF LIFE

Another crucial aspect of well-being for adults with autism is participation in social relationships. People with autism may struggle to establish and maintain friendships, but social relationships remain one of the fundamental elements for improving well-being. Adults with autism who have a social support network, including friends, family, and colleagues, generally experience a better quality of life while reducing the risks of loneliness and isolation (Howlin, 2013).

Active participation in social life is, therefore, an important goal of support programs. Creating social environments that promote inclusion and respect for differences is essential for the emotional well-being of people with autism. Studies conducted by Brown et al. (2002) have highlighted that active participation in social groups, recreational activities, and community projects can help adults with autism develop and maintain satisfying interpersonal relationships, reducing feelings of loneliness and isolation.

Activities that do not require advanced social skills, such as swimming or photography, can be particularly suitable for encouraging social interaction in a gradual and non-invasive way. Additionally, support from family and community groups can facilitate the integration of people with autism into social and supportive contexts (Brown et al., 2002). Inclusion in leisure, cultural, and sports activities helps reduce stress, improve mood, and promote socialization.

However, many available recreational activities are not designed with the specific needs of people with autism in mind, particularly regarding sensory, behavioral, and relational difficulties. Creating opportunities for participation in inclusive and structured activities that cater to individual needs is essential to ensure that these experiences are positive and fulfilling (Cottini, 2021a).

# QUALITY OF LIFE

Work plays a central role in the lives of adults, as it not only represents a source of financial independence but also contributes to self-esteem and personal fulfillment. However, the employment inclusion of adults with autism is often hindered by difficulties in communication and social interactions, as well as the lack of specific training and workplace support. Despite these challenges, numerous studies indicate that employment, if adequately supported, can significantly improve quality of life by increasing the perception of usefulness and satisfaction (START AUTISMO, 2014).

According to Autism Europe (2023), policies aimed at creating training and professional inclusion opportunities are crucial for improving the quality of life of adults with autism. Specific work support programs, which include training, mentoring, and workplace adaptations, have been shown to be effective in improving the professional and social integration of adults with ASD (Autism Europe, 2023). Therefore, targeted support is needed to facilitate entry into the workforce, focusing on personalized training pathways and direct support in the workplace (Lai et al., 2016).

Regarding support, it is essential that it is designed to meet the specific needs of adults with autism. This requires a personalized approach that considers their skills, preferences, strengths, and individual challenges. Support plans should include strategies that promote self-determination, meaning the ability of individuals with autism to make autonomous choices about their own lives. In this sense, promoting self-determination does not only mean fostering independence but also respecting individual preferences, creating pathways that allow them to make informed decisions regarding work, relationships, and leisure activities (Hedley & Uljarević, 2018). The training of family members and educators is another crucial element.

These individuals must be adequately prepared to meet the needs of adults with autism through training that includes not only behavioral management techniques but also those related to communication, social skills, and workplace support. Additionally, the importance of targeted psychological support cannot be underestimated, as many adults with autism may face emotional difficulties such as anxiety, depression, and stress, requiring specialized intervention to prevent the worsening of psychological conditions.



# QUALITY OF LIFE

Finally, best practices for supporting adults with autism must focus on their social inclusion in everyday life. Creating inclusive environments that encourage active participation in all areas of life is essential. This involves not only adapting existing structures and services but also promoting a culture of acceptance and understanding of diversity. In this sense, practices must be based on listening to people with autism and respecting their choices and needs (Badia et al., 2013).

It is also essential to remember that the approach to supporting adults with autism must be based on scientific evidence, as demonstrated by international guidelines (NICE, 2016). Effective interventions, such as those aimed at improving social skills, stress management, and emotional self-regulation, are crucial to enabling people with autism to face daily challenges with greater confidence.

The adoption of individualized support techniques, monitored and adapted according to evolving needs, ensures a continuous improvement in quality of life (NICE, 2016). In summary, improving the quality of life of adults with autism requires a holistic approach that includes psycho-social support, education, professional training, assistance in daily activities, and participation in social and recreational activities. Only through an adequate personalization of support **pathways** can it be ensured that adults with autism lead a fulfilling life, characterized by autonomy, positive social relationships, and participation in meaningful experiences.

# PROCESS OF SELECTING

This chapter is part of the work carried out within the AHA4AUTISM project and represents a concrete and operational continuation of the theoretical framework explored in the previous chapters. After analysing the diagnostic foundations, developmental characteristics, and relational challenges faced by people with autism, this section now offers a structured overview of European and international good practices aimed at improving the physical and psychological well-being, as well as the social inclusion, of individuals on the spectrum.

The AHA4AUTISM – Active and Healthy Ageing for Autism project, funded by the European Erasmus+ programme under Key Action 2 for Small-scale Partnerships, aims to promote the exchange of good international practices to support the active and healthy ageing of autistic people and their caregivers. The initiative, which runs from 1 November 2023 to 31 October 2025, involves four European organisations: Fundación Miradas (Spain), Greek Carers Network EPIONI (Greece), University of Calabria (Italy), and Autism Praxis Infinity Solutions (APIS) Ltd (Cyprus).

Coordinated by Fundación Miradas, the project develops and shares innovative practices to improve the quality of life of autistic people through research, training, awareness-raising, and dissemination. One of the key events is the European meeting in Limassol (Cyprus) on 22-23 May 2025, where selected good practices will be presented, discussed, and operational training sessions will be held to ensure their implementation in local contexts.

The term "Good Practice" (from the Greek πράξις, meaning "action, way of acting") generally refers to a habitual procedure or action taken to carry out a particular activity effectively. These practices are deemed "good" because they are structured, coherent solutions aimed at promoting skills and improving quality of life.

# PROCESS OF SELECTING

Planning a good practice must consider personal history, the environmental and relational context, the degree of impairment (including social communication, interaction, repetitive behaviours, sensory perception), and the severity and support levels (Level 1 to Level 3).

## **Core elements include:**

- A methodological plan starting from daily routines to complex skill generalization.
- A context-specific action plan.
- Simulated activity design for learning.

## **Key characteristics:**

1. Lifelong learning orientation.
2. Personalisation based on individual needs and experiences.
3. Active participation in learning and community.
4. Social support and mentoring.
5. Recognition of existing competencies.
6. Technological upskilling.

Good practices aim to create environments that value and support autistic adults, enabling them to grow, learn and live with dignity.

A total of 18 good practices were identified and analysed by partners, covering the domains of social inclusion and health. These were field-tested and evaluated based on criteria such as effectiveness, innovation, replicability, and impact on quality of life.

**The following 18 good practices will be presented, divided in GOOD PRACTICES IN SOCIAL INCLUSION OF AUTISTIC PEOPLE and GOOD PRACTICES IN HEALTH OF AUTISTIC PEOPLE**

# GOOD PRACTICES IN SOCIAL INCLUSION OF AUTISTIC PEOPLE



# TRAINING WORK-RELATED SOCIAL SKILLS USING A TABLET-BASED INTERVENTION

This practice addresses the need to strengthen social competencies in adults with autism to support their inclusion in the workforce. By using tablet-based technology, it delivers personalized, accessible, and flexible training in social interaction.



## Implemented

Paris-Saclay University CNRS, Interdisciplinary Laboratory of Digital Sciences (France)



## Description

The digital app on tablets is used for developing work-related social skills in adults with Autism. It consists of quizzes about 66 social scenarios which illustrate 28 social skills, such as interacting with others, that the participants must answer. The participants must select at least one correct answer, while giving explanations to the answers according to the participant's social difficulties i.e., the right behaviour to adopt according to the situation presented.

# TRAINING WORK-RELATED SOCIAL SKILLS USING A TABLET-BASED INTERVENTION

## Details

The app first displays a list of the five main themes of social skills: Managing and expressing emotions, Respecting the work environment/Carrying out professional tasks, Respecting the rules of politeness, Interacting with others, Adapting to others and dealing with the unexpected. Working by these themes allows for short training sessions and makes it easier to navigate the tablet. In each theme the participant can navigate through the different social skills

## Involved

Seven French disability employment services were involved as partners. Professionals working in these services are disability employment advisors, disability employment coordinators, vocational rehabilitation counsellors, job coaches, educators, psychologists and occupational therapists.

## Resources

Article: <https://www.tandfonline.com/doi/full/10.1080/07370024.2023.2242344>

Website: <https://www.cnrs.fr/fr> / <https://www.lisn.upsaclay.fr/?lang=en>

Twitter: <https://twitter.com/CNRS> / <https://twitter.com/LisnLab>

# CAFÉ JOYEUX

Café Joyeux was created to challenge stereotypes about cognitive disability and to promote inclusion through visible employment. It seeks to offer dignified job opportunities and raise public awareness.



## Implemented

Rennes, Paris, Bordeaux, Lyon, Tours, Montpellier, Nantes (France) and internationally in Brussels (Belgium), Lisbon and Cascais (Portugal)



## Description

Café Joyeux is the first French café-restaurant family that employs and trains people with mental and cognitive disabilities to open hearts to people's differences for a more empathetic and harmonious society.

# CAFÉ JOYEUX

## Details

The Café Joyeux recruits and trains people with mental and cognitive disabilities. After the recruitment phase, team members start out as interns or secondees from the organisations where they work. Once their skills have been assessed, the members are employed on a permanent basis and trained by the vocational school, a team made up of specialists in HR, management, cooking and specialist educators. They are then assigned to functions adapted to their abilities and are supervised by professional and caring managers in the restaurant business. They learn all of the following roles: greeting, cashier, food preparation and waiting.

## Involved

Specialist educators, HR specialists, managers and catering professionals.

## Resources

Website: <https://www.cafejoyeux.com/en/>

Instagram: <https://www.instagram.com/cafejoyeux/>

Twitter: <https://twitter.com/cafejoyeux>

Linkedin: <https://www.linkedin.com/company/cafejoyeux>

Youtube: <https://www.youtube.com/@cafejoyeux>



# MYRTILLO CAFE

Myrtillo Café aims to provide employment and empowerment opportunities to individuals with disabilities, particularly those on the autism spectrum. The goal is to promote inclusion, visibility, and professional integration within the Greek community.



## Implemented

Ambelokipi, Athens, Greece



## Description

Myrtillo Cafe has a special purpose and is leading by example within the Greek community by integrating vulnerable groups into the labour market.

# MYRTILLO CAFE

## Details

Myrtillo Cafe recruits individuals with disabilities such as autism spectrum, deafness, learning difficulties and mild movement difficulties. This special group of employees has the chance to feel worthy, to be heard and to gain work experience, so that they can dream for a better future.

The staff of Myrtillo can be seen working, giving the example to other enterprises to adapt the change and make a difference too.

## Involved

Myrtillo Cafe

## Resources

<https://myrtillocafe.gr/en/home>

<https://startup-project.eu/myrtillo-cafe/>

<https://www.facebook.com/Myrtillo/>

<https://www.instagram.com/myrtillocafe/> <https://twitter.com/myrtillocafe>

# MY LIFE NOTEBOOK

The goal is to improve the well-being and dignity of older people with intellectual disabilities, including autism, through life narrative practices. The notebook facilitates memory recall, communication of preferences, and self-expression.



## Implemented

Spain



## Description

The good practice consists of creating a life notebook of the person with a disability to see what their tastes, desires and preferences are and to have it as a guide for their day to day life.

# MY LIFE NOTEBOOK

## Details

The objective is to provide professionals working with older people with intellectual disabilities with useful and accessible material to record memories and life experiences to improve the psychological well-being and satisfaction of older people at this stage of their lives for a good old age at this stage of their lives for a good old age.

It consists of 4 phases for the notebook elaboration:

1. Recording and evocation of memories phase.
2. Phase of planning the format chosen by the person.
3. Phase of life notebook elaboration.
4. Phase of final party celebration for the life notebook presentation.

## Involved

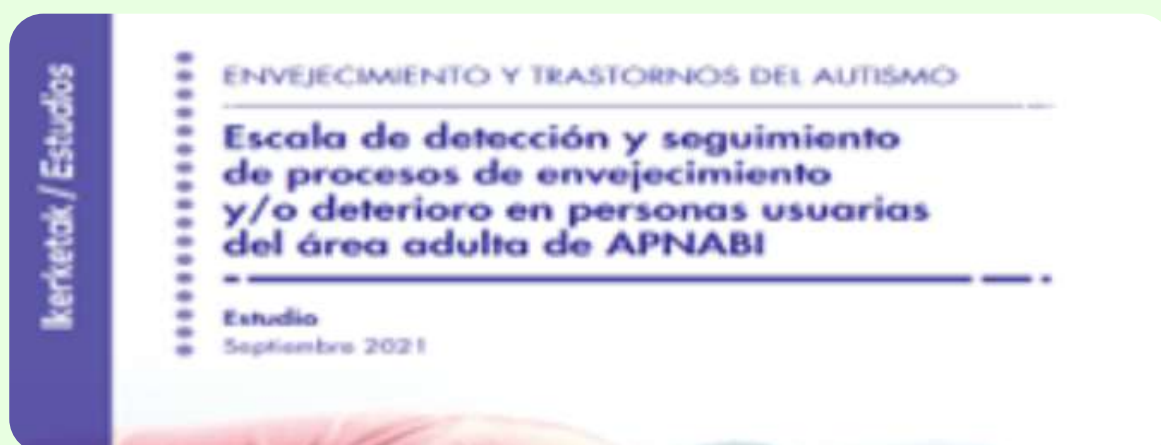
Plena Inclusión  
Generalitat Valenciana

## Resources

<https://plenainclusioncv.org/cuaderno-de-vida/>

## SCALE FOR DETECTING AND MONITORING AGEING PROCESS AND/OR DETERIORATION IN APNABI ADULT USERS

The goal is to improve the well-being and dignity of older people with intellectual disabilities, including autism, through life narrative practices. The notebook facilitates memory recall, communication of preferences, and self-expression.



### Implemented

APNABI - AUTISMO BIZKAIA



### Description

Scale of indicators on autistic people ageing to detect if they are in ageing process

# SCALE FOR DETECTING AND MONITORING AGEING PROCESS AND/OR DETERIORATION IN APNABI ADULT USERS

## Details

### Objectives:

- To recognize premature ageing processes in the adults that the entity supports.
- To adequately support the new needs that are created in relation to the autistic people ageing.
- To respond in a preventive way to these new needs, recognizing and identifying the indicators of this process.
- Plan the necessary support to address the needs related to ageing in the Personal Plan.

### How to use it:

- Annually since the person turns 40.
- When the autistic person is younger than 40 years old but shows possible indicators of ageing/impairment (and these indicators are not related to specific health problems that have nothing to do with ageing), it shall be on an annual basis.
- If the autistic person doesn't show indicators of ageing and deterioration, the scale will be passed every 5 years (the year he/she turns 20, 25... and so on up to the age of 40).

### Evaluation:

The person shall be considered to be in a situation of ageing and deterioration if he/she meets the parameters indicated after the analysis of the validation process of the tool.

## Involved

APNABI, Basque government.

## Resources

[https://www.apnabi.eus/wp-content/uploads/2021/11/apnabi-estudio-envejecimiento-TEA-2021\\_compressed.pdf](https://www.apnabi.eus/wp-content/uploads/2021/11/apnabi-estudio-envejecimiento-TEA-2021_compressed.pdf)

# PIZZAUT

PizzAut combines social inclusion with high-quality dining by creating work environments tailored to the needs of autistic people. It also aims to raise public awareness and advocate for systemic inclusion.



## Implemented

Italy, Lombardia – Nova Milanese (MB)



## Description

PizzAut it is an innovative model of social inclusion, an ever-bustling laboratory that demonstrates how barriers are often only in our heads and not in our hearts. It is an opportunity for many autistic children to gain dignity and autonomy through work, because together we can nurture inclusion.

It is a project that pays great attention to the organizational and sensorial context, in the belief that people with autism need a tailor-made place that helps them develop skills and well-being and does not condemn them to relational and work isolation.

# PIZZAUT

## Details

The project includes:

- analysis of skills
- analysis of preferences
- training

The objective is to create a reference model that becomes a real franchise to export.

## Involved

PizzAut

## Resources

<http://www.pizzaut.it>

<https://www.facebook.com/pizzaut/about>

[https://www.instagram.com/pizzaut\\_official/](https://www.instagram.com/pizzaut_official/)

<https://www.youtube.com/channel/UCtt1ewtv3ohufjANOGh1c7g>



# HUGBIKE®: THE HUG BIKE IN CALABRIA

The aim is to enhance the use of public spaces and promote social inclusion through a specially designed tandem bicycle—HUGBIKE®. It enables people with autism and other disabilities to enjoy safe, inclusive mobility experiences while participating in public life.



## Implemented

Italy, Calabria



## Description

4 HUGBIKEs were placed in 4 different places in Calabria for a better use of urban spaces and times for People with Autism and other Disabilities and their families. For everyone. HUGBIKE® in Calabria is free, for everyone, always available in 4 different places, serving the active participation of People with Autism in social spaces and times.

The HUGBIKE® brand and patent are owned by Fondazione Oltre il Labirinto Onlus and involve People with Autism who, thanks to the support of specialized personnel during the assembly of bicycles, have experienced active inclusion in society through work. The project was born with the collaboration of Banca della Marca, Fondazione Oltre il Labirinto onlus and Cooperativa Il Girasole.

# HUGBIKE®: THE HUG BIKE IN CALABRIA

## Details

The activity promotes:

- Inclusion, some assembly phases of HUGBIKE involve young people with disabilities in a project perspective of social and work inclusion;
- Safety, Riding from the rear seat guarantees greater safety, especially if the passenger is a child or an elderly person, because he is protected by the driver's arms;
- Intimacy, HUGBIKE also offers a particular intimacy in having a relaxing chat with those you care about, pedaling hugged;
- Dignity, the HUGBIKE® project is linked to "Oltre il Labirinto Onlus" which has in its vision the protection, safeguard and dignity for individuals affected by autism.

## Involved

"Oltre il Labirinto Onlus"

## Resources

<https://www.youtube.com/@hugbike6255>

<https://www.facebook.com/Hugbikeitaly>

<https://www.instagram.com/Hugbike/>

<https://twitter.com/Hugbikes>

<https://www.youtube.com/user/oltrelabirinto>

<https://www.facebook.com/OLTRELABIRINTO>

<https://www.instagram.com/oltrelabirinto/>

<https://www.linkedin.com/company/fondazione-oltre-il-labirinto-onlus>

# PEER NETWORKS AND SUPPORT GROUPS

The initiative aims to reduce social isolation among autistic adults by creating structured peer support networks and emotional support groups. It emphasizes empowerment, mutual understanding, and friendship.



## Implemented

Those activities are implemented in the community.



## Description

Establish support groups and networks that connect adults with autism to peers, offering emotional support, practical advice, and opportunities for friendship.

# PEER NETWORKS AND SUPPORT GROUPS

## Details

**Creating Peer Networks:** Establishing peer networks is essential for connecting adults with autism to others who share similar experiences and challenges. These networks provide a structured yet flexible platform where individuals can meet in person or virtually to share their stories, discuss common issues, and offer mutual support, sometimes with a cup of coffee or a drink, with snacks, and a cake. By participating in these peer networks, adults with autism can find a sense of belonging and community that might be difficult to achieve in other settings. These connections can help reduce feelings of isolation and loneliness as participants realize they are not alone in their experiences and hobbies. The shared understanding within these groups fosters a supportive environment. It empowers members to express themselves and seek advice on personal and professional matters, inspiring them to take control of their lives and continue socializing with others.

**Building Support Groups:** Support groups specifically tailored for adults with autism are crucial in offering emotional support and practical advice. These groups are facilitated by trained professionals or experienced peers who can guide discussions and provide resources. Topics covered in support groups can range from coping strategies for daily challenges to navigating relationships and employment. Those groups' opportunity allows them to talk about subjects they are interested in most. By addressing various issues, support groups can equip individuals with practical tools and knowledge to handle multiple aspects of their lives more effectively. Additionally, these groups can serve as a space for members to celebrate their achievements and milestones, no matter how small or big, and share those experiences. The meetings show significant signs of boosting their self-esteem and motivation, validating their efforts, and recognizing their progress.

# PEER NETWORKS AND SUPPORT GROUPS

## Details

**Fostering Friendships and Social Connections:** Beyond providing emotional and practical support, peer networks and support groups offer invaluable opportunities for forming lasting friendships. Social connections developed within these settings can extend beyond the group meetings, leading to social outings, collaborative projects, and a stronger sense of community. Various friendships formed through those groups are often based on mutual respect and understanding, as members share similar life experiences and challenges. These bonds offer a reliable source of support and companionship, particularly important for adults with autism who may struggle with social interactions in other contexts. By fostering such friendships, peer networks and support groups can enhance their members' overall quality of life, providing them with a stable and nurturing social circle that reassures them and makes them feel at ease.

## Involved

APIS team in collaboration with Apostolos Loukas Protipo Kentro

## Resources

[www.apisnonprofit.org](http://www.apisnonprofit.org)

Instagram: @apis\_nonprofitorganization

Facebook: Apostolos Loukas Protipo Kentro

Facebook: Autism Assessment Support Practice center - AASP

# COMMUNITY INTEGRATION PROGRAMS

The programs aim to foster meaningful community engagement for adults with autism through inclusive social activities and skill-building workshops. They also promote awareness and collaboration across community members, family organizations.



## Implemented

Those activities are implemented in the community.



## Description

Develop programs that encourage participation of adults with autism in diverse social events, workshops, and public activities to foster meaningful engagement with the community.

# COMMUNITY INTEGRATION PROGRAMS

## Details

**Development and Implementation of Programs:** Developing programs that encourage the participation of adults with autism in diverse social events, workshops, and public activities is crucial for fostering meaningful community engagement. These programs are tailored to the unique needs and preferences of individuals with autism, ensuring that they feel comfortable and supported in any new social setting. For instance, organizing workshops on social skills could involve role-playing exercises, adults with autism can learn communication strategies taught through interactive games, and adults' anxiety management could be addressed through relaxation techniques. This gives participants the tools to navigate social interactions more confidently. Additionally, these programs include various activities, from arts and crafts to sports and technology-based events in the community, to cater to a wide range of interests and abilities, thereby maximizing participation and enjoyment.

**Community Collaboration and Support:** The success of those programs depends on us and the entire community. Collaborating with local community organizations, businesses, and educational institutions is essential to help the community to be part of this process. Part of those programs is to secure resources, venues, and volunteers to support the activities by forming partnerships. Local businesses are hosting workshops or providing job shadowing opportunities, while schools and universities might offer their facilities and expertise. This collective effort helps to raise awareness and promote inclusivity, creating a more welcoming environment for adults with autism. The role of each community member is integral to this process, making them feel valued and part of the solution.



# COMMUNITY INTEGRATION PROGRAMS

## Details

**Evaluation and Continuous Improvement:** The people working to make those programs successful are committed to regularly reviewing our programs to ensure they meet your needs and achieve their goals of fostering community engagement. Feedback from collaborative companies or volunteers, even the people with autism families, and program facilitators are collected and analyzed to identify areas for improvement. This feedback informs the organizing team to make the proper adjustments to the program structure, the types of activities offered, and the support provided. The success stories and positive outcomes are shared daily to highlight these programs' benefits and encourage further participation and community involvement. Their voice shapes our programs, making everyone feel heard and influential in this journey toward a more inclusive and connected community.

## Involved

Those programs involve adults with autism, the community, volunteers, family members, and employees from the organizations through Apostolos Loukas Protipo Kentro.

## Resources

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Instagram: @apis\_nonprofitorganization

Facebook: Apostolos Loukas Protipo Kentro

Facebook: Autism Assessment Support Practice center - AASP



# GOOD PRACTICES IN HEALTH OF AUTISTIC PEOPLE



# MINDFULNESS-BASED THERAPY FOR AUTISM SPECTRUM (MBT-AS)

The aim is to reduce depression, anxiety, and rumination in high-functioning adults with autism through structured mindfulness training.



## Implemented

Adult Autism Center of Eindhoven (The Netherlands)



## Description

This practice is the first controlled trial to demonstrate that adults with ASD can benefit from MBT-AS. High-functioning 42 adults with ASD were randomised into a 9-week MBT-AS training or a wait-list control group. Results revealed a significant reduction in depression, anxiety and rumination in the intervention group in comparison to the control group.

# MINDFULNESS-BASED THERAPY FOR AUTISM SPECTRUM (MBT-AS)

## Details

**Week 1:** Rationale and program content were presented. Mindful eating exercise and body scan activities were performed. Home practice was explained and planned for the coming week.

**Week 2:** The body scan was practised. Home practice (difficulties) was discussed. A five-minute mindful breathing meditation was performed. Home practice was explained and planned. The session ended with another short meditation focused on breathing.

**Week 3:** Home practice was discussed. Information was given about physical reactions to stress. The participants were taken through a mindful walking exercise. The five-minute breathing exercise was performed, followed by an introduction of mindful movements. The session ended with planning of home practice and a short breathing meditation.

**Week 4:** A sitting meditation was introduced, focusing on breathing and on bodily sensations. A five-minute breathing exercise was practised. After discussing home practice, participants were taught to do a listening meditation. This was followed by an evaluation. The session ended with planning home practice and a mindful movements exercise.

**Week 5:** A sitting meditation was taught, which focused attention on breathing, the body and sounds. Home practice was discussed, followed by a five-minute breathing exercise. The usefulness of meditation techniques in stressful situations was explored and discussed. Home practice was planned and the session ended with a short movement exercise.

# MINDFULNESS-BASED THERAPY FOR AUTISM SPECTRUM (MBT-AS)

## Details

**Week 6:** The session started with a sitting meditation, focusing on breathing and bodily sensations. Psycho-education was given about ruminative thoughts and the relationship with autism. A meditation exercise was practised, focusing on observing thoughts from a detached perspective. Homework was discussed, followed by a five-minute breathing exercise, home practice planning and a short movement exercise.

**Week 7:** A sitting meditation focusing on breathing and bodily sensations was performed. Home practice was discussed, followed by a five-minute breathing exercise, mindful observing thoughts and home practice planning. The session ended with a short breathing meditation and a movement exercise.

**Week 8:** The session started with a sitting meditation, followed by a movement exercise. Home practice was discussed, a body scan was performed and home practice for the following week was planned. Finally, a short movement exercise was practised.

**Week 9:** This session opened with the body scan or a sitting meditation, depending on the preference of the participants, followed by a movement exercise. Home practice was evaluated. The participants were asked about their experiences with mindfulness in the past nine weeks. After a meditation chosen by the participants, each individual wrote down whether and how they wanted to incorporate mindfulness in their lives

## Involved

A psychologist and a clinical psychologist

## Resources

Article: <https://www.sciencedirect.com/science/article/abs/pii/S0891422212002156>

Website: <http://www.autismepunt.nl/>

Instagram: <https://www.instagram.com/autismepunt/>

Twitter: <https://twitter.com/autismepunt>

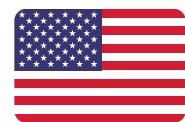
# CLEVELAND CLINIC AKRON GENERAL

The aim is to provide tailored healthcare services for autistic adults, easing the transition from pediatric to adult medical care, and improving overall patient experience.



## Implemented

Cleveland Clinic Akron General



## Description

Akron General is one of the first hospitals for adult patients, who live with autism, so that they can get the care they need, in a way that works for them.

# CLEVELAND CLINIC AKRON GENERAL

## Details

Autism is considered as a paediatric diagnosis, and is often difficult for young adults to transition from seeing a paediatrician to an adult setting.

Akron General hospital eases this transition by having more than 650 employees that are trained to identify a person with autism spectrum disorder, and caregivers that are trained in adapting their approach and using visual supports in order to achieve better medical outcomes.

In addition, Akron General provides supportive accommodations such as tablet devices and picture charts, so that the communication barriers can be reduced and has sensory-friendly materials in care areas.

Supplementary caregivers are informed by hospital's electronic medical records that a patient's autism, so that they can move the patient into exam rooms instantly, away from noisy areas, such as waiting rooms, that can be overwhelming for some people with autism.

## Involved

Employees and caregivers

## Resources

<https://autismakron.org/index.php/people/news/9-uncategorised/596-ccag-autism-friendly>

# AUTISM FRIENDLY INITIATIVE (AFI)

The aim is to improve the healthcare experience for autistic patients by training staff and modifying clinical environments to meet their sensory and communication needs.



## Implemented

Boston Medical centre



## Description

AFI trains healthcare professionals and also provides consultations to partners in Europe, Asia, Australia and North America, in order to improve healthcare experience for patients with autism spectrum disorder (ASD) and their families.

# AUTISM FRIENDLY INITIATIVE (AFI)

## Details

Patients with Autism Spectrum Disorder (ASD) often have distinct sensory and communication needs that can make healthcare visits particularly challenging. The Autism-Friendly Initiative (AFI) is dedicated to transforming healthcare environments into calmer, more comfortable, respectful, and supportive spaces that are thoughtfully tailored to meet the unique needs of autistic patients.

At Boston Medical Center, AFI has implemented a comprehensive set of interventions across four key domains: individualizing patient care, modifying the sensory environment, training clinicians, staff, and students, and providing targeted support to help patients and families prepare for visits. These evidence-based strategies are designed to reduce stress and enhance the quality of care for individuals with ASD.

AFI's innovative work has been published in leading academic journals focused on advancing care for autistic individuals. Notably, AFI developed and published the Autistic Patient Bill of Rights, a document that outlines the fundamental rights of autistic individuals in healthcare settings and serves as a guide for promoting dignity, autonomy, and equitable care.

In addition to its clinical efforts, AFI consults with and trains healthcare professionals around the world, helping them build the skills and confidence needed to provide more inclusive and effective care. AFI also hosts virtual professional development conferences that further promote best practices in autism-friendly healthcare.

## Involved

Clinicians, staff and students

## Resources

<https://autismakron.org/index.php/people/news/9-uncategorised/596-ccag-autism-friendly>



# NHS HIGHLAND DENTAL CARE FOR AUTISTIC PATIENTS

The aim is to provide accessible and comfortable dental care tailored to autistic patients' needs, reducing anxiety and improving appointment success rates.



## Implemented

Highland, Scotland



## Description

NHSW's Autism Strategy Group enables the autistic patients and their carers, through tips and practical advice, so that they can have the best support within a dental setting.

# NHS HIGHLAND DENTAL CARE FOR AUTISTIC PATIENTS

## Details

When NHS guides know that an autistic patient will be attending his first appointment they send them a pre - visit questionnaire in order to find out how they can make his visit easier. Also they offer to send a pre - visit pack so patients can see some of the items that will be used by the dentist. It is really helpful, especially for children.

The time of the appointment can have a significant impact on the success of the visit. Often autistic patients have difficulties in changing their daily routine so they make sure to talk to the patients first. In addition they make sure that the patient won't have to wait in a crowded waiting room, as an alternative they can wait in the car park till the appointment.

They, as well, try to have a low-arousal environment which addresses turning off the lights or the radio.

Other tactics may be used such as social stories, for example they can show a picture of the dental chair so the patient gets familiar with. Autistic people often have a favourite topic to talk about or have their own object for comfort, the NHS guides inform the doctor in order to make the patient feel comfortable during their stay.

## Involved

National Autistic Society, NHS, collaborating hospital and facilities.

## Resources

<https://autismakron.org/index.php/people/news/9-uncategorised/596-ccag-autism-friendly>.

# AUTISTIC PEOPLE CARE GUIDE IN THE EMERGENCY ROOM

The aim is to improve emergency care quality for autistic individuals by providing health professionals with practical guidance and accessibility measures tailored to their specific needs.



## Implemented

Castilla y León



## Description

Guide to help facilitate the work of Emergency Department professionals to improve the quality of care provided to autistic people and their families.

# AUTISTIC PEOPLE CARE GUIDE IN THE EMERGENCY ROOM

## Details

The guide contains information about autism in the health area.  
In the third part, the guide contains difficulties in hospital emergency departments in the treatment of autistic patients.

By other hand, contains different accessibility measures to the emergency departments (Systematic desensitisation programs; healthcare training to professionals on ASD; Information about the autistic person; treatment accessibility and quick tips in the emergency departments)

The fourth block collects the care circuit.

## Involved

Junta de Castilla y León, Autismo Burgos and Fundación ONCE

## Resources

<https://www.saludcastillayleon.es/institucion/es/publicaciones-consejeria/buscador/guia-atencion-personas-tea-trastornos-espectro-autista-urge.ficheros/485541-Guia%20Atenci%C3%B3n%20Urgencias%20Autismo.pdf>

# MOURNING GUIDE FOR PROFESSIONALS SUPPORTING AUTISTIC PEOPLE

The aim is to assist professionals in supporting autistic individuals through grief and bereavement processes, respecting their pace, needs, and coping strategies.



## Implemented

Autismo Burgos



## Description

It is a guide for professionals in the field of autism to accompany autistic people in the loss of loved ones.

# MOURNING GUIDE FOR PROFESSIONALS SUPPORTING AUTISTIC PEOPLE

## Details

The guide starts with a brief explanation about the 3 stakeholders:

- Family: sets the pace of the interventions and who will tell professionals in which process we should support and accompany the autistic person
- Autistic person: needs the professionals accompaniment and respect for their pace, characteristics and abilities throughout the whole process
- Professionals: The role of professionals is to accompany the autistic person throughout the process.
- 

It contains the steps to help them during the mourning:

1. Previous work
2. Family consensus
3. Accompaniment to the person
4. Daily routines

## Involved

Autismo Burgos

## Resources

Duelo AB (1).pdf

# SPORTS CLIMBING FOR CHILDREN AND ADULTS ON THE AUTISM SPECTRUM

The aim is to promote healthy living and motor skills development through sports climbing, improving physical fitness and coordination among autistic individuals.



## Implemented

Italy, Lombardia



## Description

Promote healthy living through sport among young people and adults with autism.

# SPORTS CLIMBING FOR CHILDREN AND ADULTS ON THE AUTISM SPECTRUM

## Details

Learn new general or specific motor tasks; strengthen the muscles of the arms, trunk and all postural muscles; increase coordination between upper and lower limbs; increase joint flexibility.

## Involved

“Autismo è...Associazione Onlus”

## Resources

<https://www.autismo-e.it/progetti-sport-e-tempo-libero/arrampicata-sportiva/>  
<http://facebook.com/AutismoeBergamo/>



# AUTISM AND NUTRITION: FOOD-AUT

The project aims to improve the health and nutritional well-being of individuals with autism through tailored menus and dietary guidelines. It also supports caregivers in managing balanced meals at home for sustained health outcomes.



## Implemented

Italy, Lombardia, Laboratory of Dietetics and Clinical Nutrition of the University of Pavia



## Description

The Pellegrini Group presented today together with the Sacra Famiglia Onlus Foundation the results of the FOOD-AUT scientific research project, conducted by the Laboratory of Dietetics and Clinical Nutrition of the University of Pavia directed by Professor Hellas Cena.

# AUTISM AND NUTRITION: FOOD-AUT

## Details

FOOD-AUT aims to improve the health status of people with autism spectrum syndrome (ASD) through the development of menus for collective catering and nutritional indications aimed at caregivers/parents, with the aim of supporting the latter in managing meals at home.

The Laboratory has developed menus specifically designed for these people, both from a nutritional and sensorial point of view.

## Involved

Pellegrini Group in partnership with the Sacra Famiglia Onlus Foundation.

## Resources

[https://twitter.com/F\\_SacraFamiglia](https://twitter.com/F_SacraFamiglia)

<https://www.facebook.com/FondazioneIstitutoSacraFamiglia/>

[https://www.instagram.com/fondazione\\_sacra\\_famiglia/](https://www.instagram.com/fondazione_sacra_famiglia/)

<https://www.youtube.com/channel/UCpyoukh3ljXLX61bHkD2f0Q>

# BOCCIA

Boccia promotes physical, mental, and social development in adults with autism through inclusive, structured sport. It enhances coordination, boosts self-esteem, and fosters social interaction in a supportive environment.



## Implemented

Boccia is typically played in indoor sports halls or gymnasiums, which provide the necessary space and controlled environment required for the game. Boccia can be played in various settings, including schools, community centres, sports clubs, and specialized facilities for individuals with disabilities.



## Description

Boccia is a precision ball sport designed for athletes with disabilities. It promotes inclusivity and competition at various skill levels. In addition to enhancing physical coordination and concentration, playing Boccia can improve mental well-being and provide a valuable social outlet for participants.

# BOCCIA

## Details

**Introduction to Boccia for Adults with Autism:** Boccia, a precision ball sport initially designed for athletes with severe physical disabilities, has evolved to be inclusive of individuals with a range of disabilities, including adults with autism. The game involves throwing leather balls as close as possible to a white target ball, or jack, on a long, narrow court. Boccia's adaptable nature, with straightforward rules, makes it an accessible and engaging activity for adults with autism. It promotes physical activity and provides a structured environment that can help improve focus and concentration, reassuring caregivers and support professionals about its suitability.

**Health and Physical Benefits:** Playing Boccia offers numerous physical health benefits for adults with autism. The sport requires players to develop fine motor skills and hand-eye coordination as they aim and throw the balls precisely. Regular participation in Boccia can enhance muscle strength and control, contributing to overall physical fitness. Furthermore, the game's emphasis on strategic planning and concentration can help improve cognitive functions, offering a holistic approach to health. For individuals with autism, these physical activities can be particularly beneficial, offering a controlled and predictable environment that can help reduce anxiety and increase confidence in their physical abilities.

**Mental and Social Benefits:** Beyond the physical advantages, Boccia also provides significant mental health and social benefits for adults with autism. The sport encourages social interaction and teamwork, fostering a sense of camaraderie and community. This can be particularly important for individuals with autism, who may find it challenging to form social connections in other settings. Boccia offers a platform for making friends and developing social skills in a supportive environment. Moreover, the sense of achievement from mastering the game and participating in competitions can significantly boost self-esteem and contribute to a positive sense of identity, enhancing overall mental well-being. Through Boccia, adults with autism can enjoy a fulfilling and inclusive sporting experience that supports their physical, mental, and social development, empowering them with a strong sense of confidence.

Nowadays, Boccia is one of the sports in which teams compete in the Paralympic Games and various regional and national championships.

# BOCCIA

## Involved

Boccia involves a variety of participants and stakeholders, each playing a crucial role in the sport's ecosystem, such as athletes, coaches and trainers, referees and officials, volunteers, families and caregivers, organizations and federations, spectators and fans.

## Resources

[www.apisnonprofit.org](http://www.apisnonprofit.org)

Instagram: @apis\_nonprofitorganization

Facebook: Apostolos Loukas Protipo Kentro

Facebook: Autism Assessment Support Practice center - AASP

# NEXT STEPS

The next step was the selection process, involving a structured evaluation by a multidisciplinary Experts Committee including academics, healthcare professionals, and educational practitioners.

## 6. Results of the Experts Committee

A Google Form questionnaire was developed to collect evaluations from experts on the 16 practices. The Experts Committee included healthcare professionals, university researchers, association leaders, trainers and project development managers, who have +16 years of experience (fig.1).

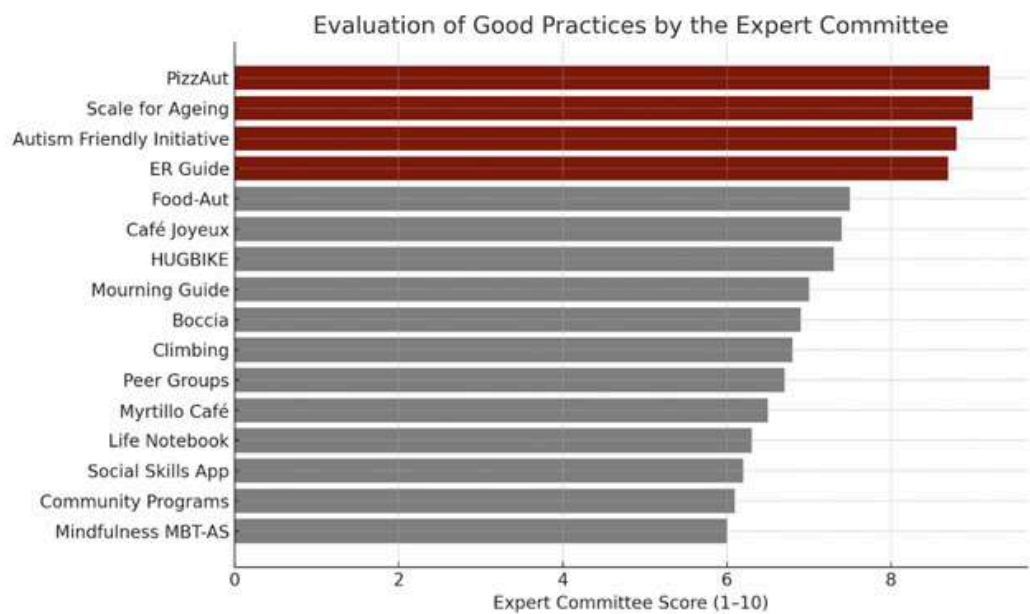
Each practice was assessed using criteria like impact, transferability, innovation, and feasibility. Based on the collected feedback, four practices emerged as particularly outstanding.

The four selected practices are:

1. **Scale for Detecting and Monitoring Ageing in APNABI Adult Users** – A structured tool for identifying signs of ageing in autistic adults, enabling timely and personalised interventions.
2. **PizzAut** – A model of social inclusion through inclusive pizzerias, offering training, work, and community integration to autistic youth and adults in Italy.
3. **Autism Friendly Initiative (AFI)** – Implemented at Boston Medical Center, this programme transforms hospital settings to be more inclusive and accessible for autistic patients through staff training and sensory-friendly environments.
4. **Guide for Caring Autistic People in the Emergency Room** – Developed in Castilla y León, Spain, this guide includes desensitisation programmes, healthcare professional training, and the integration of alerts in electronic medical records.

These good practices will be further explored during the Limassol meeting and will serve as the basis for operational training aimed at their implementation in European contexts. The results are presented below.

# RESULTS



## EXPERTS COMITEE RESULTS

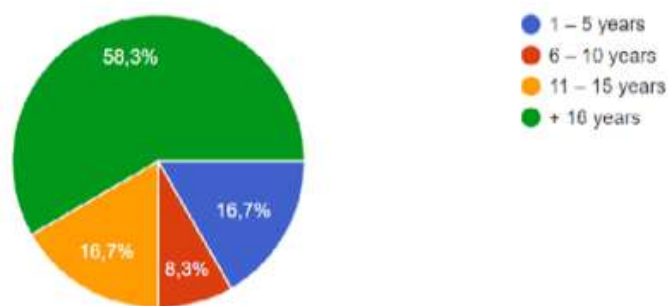


Fig.1: Years of experience reported by participants.



# RESULTS

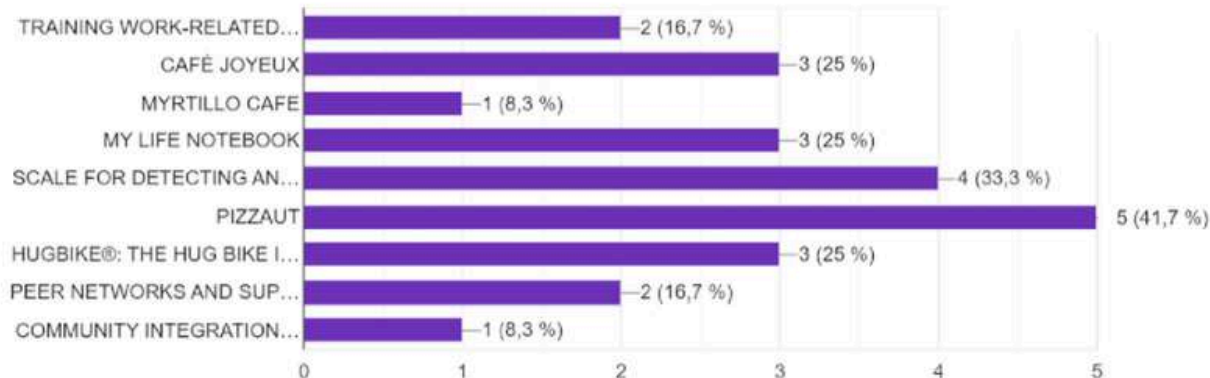


Fig. 2 The best practices in social inclusion selected by participants

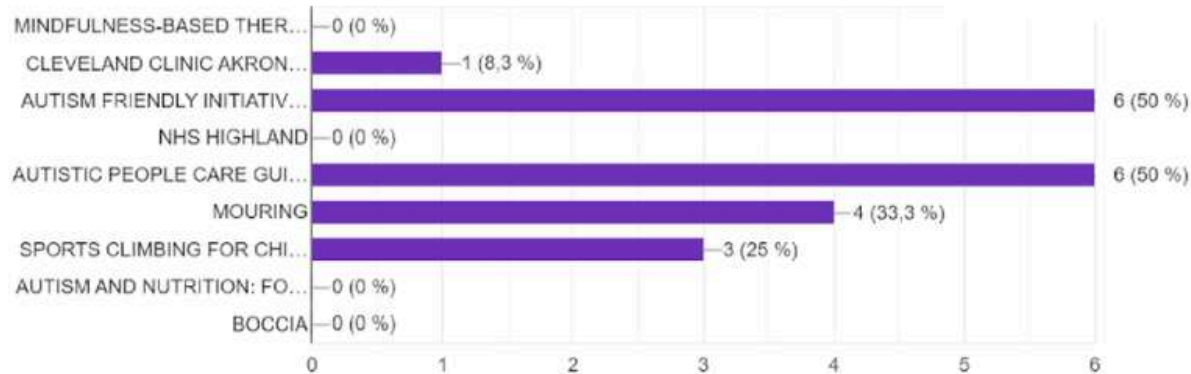


Fig. 3: The best practices in health selected by participants.

# SCALE FOR DETECTING AND MONITORING THE AGEING PROCESS AND/OR DETERIORATION IN APNABI ADULT USERS

The scale for detecting and monitoring the aging process and/or deterioration in APNABI adult users was developed in response to the awareness that aging—although a success of modern society—brings new challenges, particularly for autistic individuals. As people grow older, specific needs arise that require dedicated attention and targeted interventions. Recent studies suggest that autistic people may begin to show signs of early ageing around the age of forty, making it essential to have a system in place that allows professionals and families to detect and respond to these changes promptly.

APNABI Autismo Bizkaia, a key autism organization in the province of Bizkaia (Spain), has developed a scale designed to identify these early signs. The tool supports the recognition and management of new needs associated with aging, enabling preventive and individualized interventions. The scale is based on a set of indicators divided into two main categories: physical (e.g., balance loss, sleep disturbances, gastrointestinal problems) and cognitive-emotional (e.g., increased loneliness, mood changes, anxiety, and attention difficulties).

The tool is used by professionals working in adult autism services—such as day centers, supported housing, or sheltered workplaces—and is administered annually from age 40, or earlier if concerning signs are observed. In the absence of symptoms, the scale is administered every five years starting at age 20.

A key element of this good practice is the collaborative and continuous evaluation approach. The assessment process includes input from all stakeholders—family members and professionals—and ideally should be carried out by the same professionals over time to ensure consistency and reliability. It is also crucial to track the individual's evolution over time by comparing current results with those from previous years to detect even subtle changes.

The evaluation is based on a 1–5 Likert scale, where 1 indicates no deterioration and 5 indicates severe deterioration. If the average score is 2.4 or higher, the individual is considered to be undergoing ageing or deterioration. However, even with a lower average score, the presence of three or more indicators scoring 3 or above is enough to prompt closer attention from the support team.

This scale not only provides a current overview of the person's condition but also helps plan more tailored and effective interventions in the personal support plan, contributing to a healthier and more active ageing process that respects each individual's unique characteristics.

# PIZZAUT

PizzAut is much more than just a pizzeria—it's a dynamic social laboratory and a living example of inclusion, proving every day that the hardest barriers to break are those in the mind, not the heart. The project originated in Lombardy, Italy, from a vision to create a space where autistic individuals can work, grow, and feel part of the community, gaining dignity and autonomy through meaningful employment. In a context where job opportunities for autistic adults are often limited, PizzAut provides a concrete response, turning the challenge of employment inclusion into a powerful opportunity for personal and collective empowerment.

Each person entering the PizzAut world is welcomed with attention and respect for their individual traits. The process begins with a skills and preferences assessment, leading to a personalized training program. Participants learn to manage all aspects of restaurant work—from pizza making and table service to cash handling and organizing the space. But PizzAut is not just about job training; it also offers psychological and educational support within a calm and stimulating environment, adapted to the sensory and relational needs of autistic individuals.

The project launched in 2021 with the opening of the first restaurant in Cassina de' Pecchi (Milan area) and expanded in 2023 with a second location in Monza, inaugurated in the presence of the Italian President, Sergio Mattarella. The dream doesn't stop there: the goal is to transform PizzAut into a replicable model, a national (and potentially international) franchise network that spreads a clear and powerful message of inclusion. With every pizza served, a new awareness is born: when work is designed with care and empathy, it can truly change lives—restoring confidence, independence, and a rightful place in society.

# AUTISM FRIENDLY INITIATIVE (AFI)

The Autism Friendly Initiative (AFI) was born with a clear and meaningful goal: to make healthcare experiences more accessible, respectful, and humane for autistic individuals. Initiated at the Boston Medical Center, the project's influence extends far beyond a single institution. Through tailored training for healthcare professionals, personalized consultation, and targeted interventions, AFI is transforming how healthcare systems engage with autistic patients—supporting their well-being across adulthood and into old age.

For many autistic adults, hospital visits can be deeply distressing due to overwhelming sensory stimuli and communication barriers. AFI addresses these challenges with a model based on four key pillars. The first is personalized care, ensuring that medical services align with each patient's communication, emotional, and sensory needs. The second focuses on environmental adaptations—softer lighting, reduced noise, and calming spaces help minimize anxiety. The third pillar is education: doctors, nurses, students, and hospital staff are trained to understand autism and respond with empathy and awareness. Finally, the initiative supports visit preparation with visual tools, checklists, and sensory kits that help reduce patient stress.

While AFI was developed at Boston Medical Center, the model has been shared and replicated across Europe, Asia, Australia, and North America—proving that autism inclusion in healthcare is a global priority. Though the initial effort includes staff training and development of support materials, the long-term benefits in terms of health outcomes, trust, and inclusion are profound. AFI reminds us that even highly technical environments like hospitals can become spaces of respect, welcome, and authentic care.

# AUTISTIC PEOPLE CARE GUIDE IN THE EMERGENCY ROOM

Health is a universal right, yet for many autistic individuals, equitable access to healthcare—especially in emergency settings—remains a challenge. Barriers go beyond the physical and include communication difficulties, lack of understanding of healthcare procedures, and the rigid nature of emergency environments. In response, a practical and structured solution has been developed: **the Care Guide for Autistic People in Emergency Services, implemented in Castilla y León, Spain.**

This guide is the result of collaboration between Autismo Burgos, the regional government of Castilla y León, and Fundación ONCE, involving healthcare professionals, social workers, and families. It is designed as a practical, accessible tool for use in emergency rooms, where time pressures often hinder individualized care for autistic patients.

The guide is structured into five sections. It begins by outlining the legal and social context, followed by a description of autism characteristics and key barriers to care. Practical strategies to improve emergency care accessibility are then provided, along with a detailed care pathway and useful supporting materials.

A core component of the practice is **building networks** among autism organizations, healthcare providers, and families. The first step is introducing the guide to emergency departments, emphasizing how adapting care not only improves outcomes for autistic individuals but also enhances overall healthcare quality.

One of the most innovative aspects is the **desensitization program**: a slow, continuous process that familiarizes autistic individuals with emergency room settings through videos, guided visits, and simulations involving medical staff in uniform. This gradual exposure, carried out in collaboration with families and caregivers, may span several years.

Another pillar is **staff training**, which goes beyond theoretical knowledge to foster empathy and adaptability. Professionals are trained in alternative communication methods, sensory-based behaviors, and strategies to build effective interaction.

The guide also introduces **electronic health record alerts**, notifying staff in advance when a patient is autistic, enabling pre-emptive adjustments to care.

In emergencies, having a **support person**—a family member or professional—is crucial. They provide essential information on communication preferences, stress triggers, and pain expressions. Medical staff are trained to work alongside support persons, valuing their insight and emotional support.

The guide also includes **practical care adaptations**: offering choices to enhance control, using play and distraction, employing positive reinforcement, starting with simple tasks, incorporating visual aids like pictograms, and managing pain sensitively. Physical restraints, if ever necessary, must be used only with a deep understanding of the individual and in coordination with their support team.

Quick recommendations include: reducing wait times, minimizing sensory overload, respecting personal space and timing, using simple language and visual supports, avoiding unnecessary touch, and maintaining a calm, compassionate attitude.

As the autistic population ages, adapting emergency services to meet their needs is no longer optional—it is essential. This guide offers a tangible example of how healthcare can evolve toward greater inclusion and respect for neurodiversity, contributing to healthier, more active ageing for autistic individuals.

These practices were selected based on their excellence and alignment with the principles of good practices (Why, What, Where, How, Who), their scalability, and their potential to be adapted in diverse local contexts.

# BEST PRACTICES IMPLEMENTATION



**AHA4AUTISM**



# EMERGENCY ROOM

## Why?

Everyone has the right to health protection. However, comprehensive healthcare continues to be a goal yet to be achieved for many people with disabilities who, due to specific circumstances, face challenges in accessing healthcare services. International regulation (Convention to Protect the Rights of Disabled Persons. Art. 25) and Spanish regulation (Spanish Constitution. Art. 43. Law 16/2003, of May 28th, on Cohesion and Quality of the National Health System. Art.23. Royal Legislative Decree 1/2013, of November 29th, which approves the Consolidated Text of the General Law on the Rights of Persons with Disabilities and their Social Inclusion. Art 7.) and Castilla y León (Law 8/2003, of April 8, on the Rights and Duties of Individuals in Relation to Health in Castilla y León. Art. 4.3. and Law 8/2010, of August 30, on the Organization of the Health System of Castilla y León. Art. 54.2) Regulation.

All these regulations establish that accessibility to healthcare centres, services, and provisions for people with disabilities is a quality criterion that must be guaranteed under conditions of equality with other citizens. To make this right to equality effective, the healthcare system must promote “positive action measures,” which include “special and preferential healthcare programs and actions” for people with disabilities. Different studies carried out in Spain highlighted significant difficulties and limitations in accessing healthcare services by autistic people, the lack of training of healthcare professionals regarding the characteristics of autistic people and the need to implement specific protocols aimed at ensuring access to healthcare services. These studies, show that autistic people need a healthcare system that is understanding and flexible.

## Why?

Emergency room (ER) represents a care system characterized by high patient volumes, leading to overcrowding and improper use. On the other hand, healthcare professionals working in these services must respond quickly and effectively to critical situations. The challenge increases when patients with extreme difficulty tolerating waiting times and sensory overstimulation, and who require special treatment, come to these services.

Attending to autistic people in ER represents a socio-health challenge that involves associations, ER professionals, and families. The process begins with associations through systematic desensitization programs. In these programs, with the support of the ER, autistic individuals are prepared to be treated in emergencies in the future, equipping them with the necessary skills to face a situation that poses significant challenges for them. This effort requires collaboration with families and the involvement of the healthcare system, which must promote continuous training for professionals and disseminate action guidelines. Additionally, establishing alerts in the Electronic Health Record (EHR), in collaboration with associations, constitutes good practice.

In Spain, between 26.9% and 55.1% of all emergency cases attended to adults involve people over the age of 65. Additionally, between 13.2% and 28.7% involve individuals over the age of 75 (Navarro et al., 2016).

The older people are, the more they rely on hospital services and therefore the more they go to emergency services, so it is necessary to adapt the Emergency Room Services to autistic people. Nearly half of people over the age of 65 experience prolonged limitations, and the effects of climate change and environmental degradation exacerbate their health.

This will lead to an increased demand for healthcare, assistance, and support services (European Commission, 2021).

## What?

This guide (Esteban et al., 2014) aims to provide recommendations to improve the professional-patient interaction and facilitate access for autistic people to ER. Its contents are structured into four key blocks:

**Block 1:** Contextualizes and justifies the need for the guide.

**Block 2:** Defines and describes the characteristics and difficulties of autistic people.

**Block 3:** Specifies accessibility measures for ER.

**Block 4:** Highlights the care circuit in ER.

**Block 5:** Includes annexes addressing specific aspects discussed in previous blocks.

This guide is the result of observation, analysis, and reflection by a group of healthcare professionals and technicians from autism parent associations in Castilla y León. It is intended to be a simple, useful, manageable, and eminently practical working tool.

## Where?

The guide was implemented in Castilla y León (Spain) and it was made by Autismo Burgos Association, Junta de Castilla y León and Fundación Once.

## How?

If you want to implement the Good Practice, these are the steps that you should follow:

1. Communication with the healthcare system.
2. Presenting the best practice and its benefits: justification, description, etc.
3. Collaboration with other social and healthcare agents. Incorporating the social and healthcare care guide into other disabilities.

## GUIDE

### DESENSITIZATION PROGRAMS

To make emergency systems accessible to autistic individuals, it is essential to implement desensitization programs tailored to autistic people. This process should begin at the association or centre to which the individual with autism belongs.

Desensitization programs involve simulating an emergency room setting, with professionals wearing typical emergency attire, using devices and techniques similar to those employed in such services, and showing videos and photos of the entrance, reception area, triage, and emergency room of the local hospital. Subsequently, the autistic individual approaches the entrance to the emergency room, enters, and waits in front of the reception desk. Finally, with a scheduled appointment with a service professional, a mock medical examination is conducted within the emergency room itself. Coordination between emergency room professionals and autism association technicians is crucial.

Desensitization programs often span many years and, in many cases, continue throughout the person's lifetime. These are slow processes, but by creating positive experiences, greater cooperation from the autistic individual can be achieved during their next visit to a healthcare setting.

## GUIDE

### **TRAINING IN AUTISM TO HEALTHCARE PROFESSIONALS**

It is essential, the previous knowledge from the healthcare professionals in autism.

Professionals in hospital services must become aware of the need for specific training on the characteristics that define autism, the special intervention needs, and the perceptual, communication, and comprehension challenges autistic individuals face regarding environments and complex rules.

Some key aspects of training and raising awareness about autistic individuals among emergency department staff include:

- General characteristics defining autism.
- Main challenges they face in accessing healthcare.
- Proposals to improve the interaction between healthcare professionals and autistic patients.
- Alternative and augmentative communication methods for autistic individuals.
- Behavioral control methods.

### **ALERT SYSTEMS IN ELECTRONIC MEDICAL RECORDS (HER)**

To notify the professional attending to an autistic individual or third parties about significant health issues that, if overlooked, could harm the patient, it is crucial to include appropriate alerts in the patient's medical record. These alerts should clearly indicate the patient's conditions and specific health concerns.

## GUIDE

### INFORMATION ABOUT THE AUTISTIC PERSON

The autistic individual should visit the ER accompanied by a family member or a professional from the association providing their care, whenever possible. This companion should provide as much documentation as possible about the individual's medical history.

On the other hand, it is advisable for healthcare professionals to rely on companions. They are undoubtedly the ones who know the autistic individual best.

For this reason, it is helpful to ask companions specific questions about autistic individuals: How do they respond to new situations? How do they communicate? What do they enjoy? How well do they tolerate waiting? Do they have hypersensitivity to any stimuli? How do they handle pain? What has worked well in the past?

It is also important for healthcare professionals to show understanding toward families when they bring their child or relative to an ER. Families of autistic individuals experience significant daily stress, which is further heightened when they have to visit an ER.

#### *Accessible Care*

Providing care to autistic patients in ER can be challenging for healthcare professionals. The following techniques can be employed when performing certain examinations or medical tests on autistic patients. It is important to tailor these strategies to the specific characteristics and needs of the autistic individual:

- **Choice:** offer different options to allow the patient to choose. For example, "Which ear should we check first, your right or your left?" or "Would you prefer to lie down or stay seated?"
- **Distraction:** if the patient has a special set of interests, engage them by asking about those interests, encouraging them to play with toys or objects they enjoy. If they like singing or counting, encourage them to do so.

## GUIDE

- **Modelling:** use imitation to help the patient understand what will happen, feel calm, and maintain a sense of control. Dolls or other objects can also be used to represent the patient and medical equipment.
- **Rewards:** reinforce attempts to perform the requested behaviour, even if the patient cannot fully complete it, and ignore disruptive or problematic behaviours.
- **Start with Easy Tasks, Then Progress to Difficult Ones:** everyone feels motivated by success. Begin by asking the autistic patient to perform a simple task. Once they complete it successfully, respond with praise like "Very good," and then move on to a more complex request.
- **Visual Cues:** use images to explain procedures, showing what will happen and what is expected of the patient. Use familiar images and pictograms that the autistic individual recognizes. It is helpful to have appropriate pictograms for emergency department use available.
- **Mechanical Restraint:** when necessary, seek help from the family or companion. They know the autistic individual best and can identify the most effective and least invasive methods to achieve this.
- **Pain Management:** for autistic patients who have hypersensitive skin, apply numbing cream for injections. While waiting for the cream to take effect, cover the area to prevent the patient from touching or removing the cream, and try to distract their attention.

## GUIDE

### QUICK TIPS FOR EMERGENCY ROOM (ER)

It is essential to consider the following aspects regarding autistic individuals in ERs:

- Waiting is the most challenging part of the visit. Efforts should be made to avoid or minimize it, if it does not delay care for higher-priority patients based on triage levels.
- Whenever it is possible, place the autistic patient in a quiet space where they can remain with their companions, avoiding excessive sensory stimulation.
- Ask companions about what works best, what should be avoided, and how the patient responds to anxiety. They know the patient best.
- Key Attitudes for Healthcare Professionals:
  - Be prepared to work on the floor, on the companion's lap, or wherever the patient feels most comfortable.
  - Use a soft tone of voice, fewer words, and simple language.
  - Do not expect eye contact.
  - Support explanations with images to enhance understanding.
  - Ignore inappropriate behaviours.
  - Respect the patient's personal space and avoid physical contact whenever possible.
  - Allow the patient to touch equipment and materials, if feasible. Have repair materials available.
  - Always remain calm and avoid abrupt movements.
  - Whenever possible, anticipate and explain what will happen next in a simple and clear way.
- Adapting the Physical Environment:
  - Reduce the lights if the patient is sensitive to light.
  - Lower noises or speaker volumes if the patient is sensitive to sound.
  - Ask the companion about the patient's response to unusual stimuli, such as medical gowns or glasses.
- Important Considerations:
  - All ER staff involved in the care of the autistic patient should be prepared to assist when necessary. Their involvement is crucial for success.



## GUIDE

### RESOURCES:

- Pictograms: you can find pictograms in the guide.
- Guide <https://www.saludcastillayleon.es/institucion/es/publicaciones-consejeria/buscador/guia-atencion-personas-tea-trastornos-espectro-autista-urge.ficheros/485541-Guia%20Atenci%C3%B3n%20Urgencias%20Autismo.pdf> in <https://www.saludcastillayleon.es/institucion/es/publicaciones-consejeria/buscador/guia-atencion-personas-tea-trastornos-espectro-autista-urge.ficheros/485541-Guia%20Atenci%C3%B3n%20Urgencias%20Autismo.pdf> Spanish
- Find other complemented actions in the health area. “ASI”, program in Castilla y León (Spain) whose objective is to be proactive and adapt health care to people with severe disabilities (physical, sensory, intellectual or mental) and/or autism, which entails the need for permanent accompaniment. (Link to the program: <https://drive.google.com/file/d/1Pwl0Zw3qS0pja6l93yG63Syn-3QCQy7t/view?usp=sharing>)

# THE AUTISM FRIENDLY INITIATIVE (AFI)

## Why?

The Autism Friendly Initiative (AFI) is essential for promoting active and healthy aging among individuals with autism spectrum disorder (ASD). Many adults with ASD face unique sensory and communication challenges, particularly in healthcare settings, which often lead to increased anxiety and avoidance of necessary medical care. By improving the healthcare experience through tailored interventions, AFI helps to ensure that individuals with autism receive appropriate medical attention, thereby fostering their overall health and well-being. This proactive approach not only addresses immediate healthcare needs but also contributes to long-term positive health outcomes and quality of life.

## What?

The Autism Friendly Initiative focuses on training healthcare professionals and providing consultations to various partners across Europe, Asia, Australia, and North America. The initiative aims to enhance the healthcare experience for patients with ASD and their families by creating a more accommodating and understanding environment. At Boston Medical Center, AFI implements a series of interventions that address the distinct needs of patients with ASD. These interventions include individualizing patient care, modifying sensory environments to reduce stress, training clinicians, staff, and students on autism awareness, and offering preparatory support for patients before their visits. By concentrating on these key areas, AFI seeks to make healthcare settings more navigable and supportive for individuals with autism.

## Where?

The Autism Friendly Initiative takes place at Boston Medical Center. This institution serves as a model for how healthcare environments can adapt to better serve patients with autism.

## How?

To implement the Autism Friendly Initiative, several steps and resources are necessary:

- Training and Workshops: They begin with training sessions for clinicians, staff, and students on autism awareness, communication strategies, and sensory sensitivities.
- Development of Sensory Toolkits: They create sensory toolkits that include items like fidget tools and calming materials to help patients manage their anxiety during hospital visits.
- Environmental Modifications: They assess and modify the sensory environment of healthcare settings to reduce overwhelming stimuli (e.g., adjusting lighting, reducing noise).
- Preparation Resources: They develop materials to help patients prepare for visits, including visual guides and checklists.
- Feedback Mechanisms: They implement a system to gather feedback from patients and families to continually improve the initiative.
- Timeline: The initial training and toolkit development takes a few months, followed by ongoing evaluations and updates based on patient feedback.

# PIZZAUT

## Why?

PizzAut is a project of significant importance in promoting healthy and active aging, offering individuals with autism the opportunity to achieve real autonomy and live with dignity through meaningful employment. For many adults with autism, finding a job and feeling part of a community represent major challenges, which can lead to feelings of isolation and limited opportunities for personal growth. PizzAut works to break down these barriers by creating a work environment that is tailored to individual needs, thereby supporting the development of both social and professional skills. Through employment, individuals with autism can gain independence, increased self-confidence, and a strong sense of community, contributing positively to their long-term well-being (<https://www.pizzaut.it/>).

## What?

PizzAut is an innovative project that helps people with autism by providing a workplace designed for their specific needs. Each participant is initially assessed based on their abilities and preferences, after which they receive personalized training designed to develop the necessary skills, respecting each individual's pace and capacity, in schools, businesses, and any other contexts aiming to become more inclusive. The goal is not only to secure employment but also to foster a sense of belonging and integration within the community. PizzAut aims to become a replicable model, which can be expanded to other cities through a franchising system, promoting the concept of inclusive workplaces and broader social integration for individuals with autism.

## Where?

The first PizzAut restaurant opened in Cassina de' Pecchi, in the province of Milan, in the Lombardy region of Italy, in 2021. In 2023, the second restaurant was inaugurated in Monza, in the Lombardy region of Italy, even larger and more engaging, with the honor of being opened by the President of the Republic, Sergio Mattarella (<https://www.pizzaut.it/>).

## How?

The best practice of PizzAut refers to an initiative that combines social solidarity and the empowerment of individuals with autism. PizzAut is a social pizzeria created by a group of individuals with autism and supported by a team of educators, family members, and operators, with the goal of providing them with employment and inclusion opportunities.

PizzAut's best practice is manifested in four aspects, including (<https://www.pizzaut.it/>):

**Selection:** each participant is initially assessed based on their abilities and preferences, taking into account individual timeframes and capacities, both in schools and businesses, and in any context seeking to become more inclusive.

**Professional training:** individuals with autism are trained to work in the pizzeria, learning skills such as pizza making, table service, cash register management, and other restaurant-related competencies.

**Psychological and educational support:** in addition to vocational training, psychological and educational support programs are provided to help individuals with autism develop their skills in a stimulating and inclusive environment.

**Community awareness:** PizzAut offers the community an opportunity to better understand autism and its challenges. Furthermore, PizzAut brings the "Best Pizza in the Known Galaxy" to streets and squares, conveying a strong message of inclusion and change.

# SCALE FOR DETECTING AND MONITORING AGEING PROCESS AND/OR DETERIORATION IN APNABI ADULT USERS

## Why?

Ageing is considered a triumph of humanity as a society, showcasing the human capacity to grow older and live increasingly longer lives due to advances in medicine and care over the years, including for autistic individuals. However, it also poses a challenge we must address as a community. The societal shift towards an increasingly older population is one of the major challenges (Cambero & Baigorri, 2019).

The ageing process brings about changes in individuals and societies, requiring our attention to ensure what is known as active and healthy ageing. Adults on the spectrum experience unique and persistent support needs and challenges as they age (Perkins & Berkman, 2012).

There is a scarcity of studies related to interventions for ageing autistic individuals, unlike the numerous studies on the increased prevalence and diagnosis of autism in Europe and globally.

Studies, begin to speak of indicators of early aging in the autistic population, noting that the health problems that the person has presented throughout his or her life intensify when entering ages around 40 years (Vidriales et al., 2016). Thus, this scale is intended to identify those persons who are in the process of aging and/or deterioration, so that the professionals who care for them and their families can attend to them and adapt services to their circumstances.

## What?

This is a scale “Scale for detecting and monitoring ageing process and/or deterioration in APNABI adult users” (APNABI, 2021).

“APNABI Autismo Bizkaia” is the non-profit association, declared of public interest, which brings together families of autistic people in Bizkaia. It is the reference organization in its field of action.

The scale objective is:

- To recognize the early ageing process in autistic adults.
- Support, in the adequate way, the new needs that are created in relation to the aging of autistic people.
- Respond preventively to these new needs, recognizing and identifying the indicators of this process.
- Plan the necessary support to address the needs related to aging in the Personal Plan.

The scale has two indicators divided into different subgroup: physical indicators and cognitive and emotional indicators.

The scale should be used by the professionals who support autistic people in the different services from the adult area.

## Where? When?

The scale, should be used with autistic people users from services such Center Days, Housing, Occupational Employment Center, Special Employment Center, Supported Employment and Unemployment in the following cases:

- Annually, since the person turns 40.
- When the autistic person is younger than 40 years old but shows possible indicators of ageing/impairment (and these indicators are not related to specific health problems that have nothing to do with ageing), it shall be on an annual basis.
- If the autistic person doesn't show indicators of ageing and deterioration, the scale will be passed every 5 years (the year he/she turns 20, 25... and so on up to the age of 40. Starting from 20 years old).

## How?

As we previously mentioned, the scale should be used by the professionals who support the autistic people in the different services from the adult area.

The professional should be following the following recommendations:

- That the vision and information of all the agents that support the person (services, family, among others) be considered.
- As far as possible, the same professionals should always be the ones who pass the scale.
- That, as far as possible, the evolution of the person is considered.
- Remembering the person's situation a few years ago, comparing it with the current one, not only focusing not to put the focus only on “the now”.
- The scale should be passed at times of the year when it is appropriate to make an evaluation of his or her Personal Plan, as a complementary process.
- The scale has, in each indicator, a subjective evaluation section, fill it in whenever you consider it necessary.
- Keep the evaluations of previous years. It is very important to have the vision and evolution in the past years in order to be able to complete the current one. These evaluations will be automatically saved in the results base (excel) of the Google questionnaire tool of each work centre.



# SCALE

As we mentioned before, there are two main indicators, divided into different subgroups in order to evaluate the ageing process of autistic people.

The indicators have a rate from 1 to 5 (being 1 no deterioration and 5 situations of great deterioration). The professionals must rate the indicators from 1 to 5 depending on the autistic person situation. The study uses the Likert scale. Likert scales are great for capturing the level of agreement or their feelings regarding the topic in a more nuanced way (Bhandari, P. & Nikolopoulou, K; 2023)

PHYSICAL INDICATORS	RATE FROM 1 TO 5
<i>LOSS OF MOBILITY/BALANCE/STABILITY:</i> related with visual impairments and how it affects mobility. Fear of slopes, unstable pavements and claiming support for it. Spatial disorientation	
<i>Increased sedentary lifestyle:</i> overweight is a factor that predisposes people to a more sedentary lifestyle. Physical injury or illness is related to a lack of motivation to be active.	
<i>Alterations in sleep conciliation</i>	
<i>Alterations in weight (gain and loss), without causes that can explain it explain it</i>	
<i>GASTROINTESTINAL DISTURBANCES (CONSTIPATION, SPHINCTER CONTROL DISTURBANCES, REFLUX, SOMETIMES THESE PROBLEMS ARE DERIVED FROM ORAL PROBLEMS):</i> constipation is the most common indicator. Also, bedwetting, indicates a decline in the ability to control sphincters	

SCALE

COGNITIVE AND EMOTIONAL INDICATORS	RATE FROM 1 TO 5
<i>INCREASED LONELINESS/SADNESS/LOSS OF MOTIVATION/DEPRESSION/HEARTACHE.</i> The most salient observations are related to a characteristic feature of autistic persons and that is the selective and functional interest in social relationships; usually in cases where there is low participation there are no traits of sadness or depression, but it is valued as an autism trait.	
<i>Increased states of anxiety and/or stress</i>	
<i>DECREASED ATTENTION / SLOWER RESPONSE TO STIMULI:</i> in these cases, it is evident that individuals experience a significant decline in this indicator. They may either require verbal prompts for tasks they previously performed independently or need support to sustain attention during medium to long-duration tasks.	
<i>Memory disturbances (memory loss, difficulties in remembering...).</i>	
<i>EMOTIONAL CHANGES/SUDDEN MOOD SWINGS/IRRITABILITY:</i> several aspects related to this indicator are highlighted, such as the causes of these changes: emotional shifts, irritability, etc. The following stand out: aging of parents and concerns about it, difficulties in understanding daily occurrences (instructions they do not comprehend, unexpected events, or disagreements), spending extended periods without seeing their parents, seasonal factors (summer, heat), and premenstrual periods, primarily.	

## SCALE

To evaluate if a person is at risk of ageing/impairment, the medium of the total indicators (physical and cognitive) is 2,4.

The aging processes as we know, are a series of changes produced in the person as he/she gets older, changes in several areas: biological, physical, cognitive, psychological, etc..., as well as different rhythms according to the circumstances of each person (genetics, nutrition, social environment, physical activity, etc...). In summary, we can affirm that aging is not a linear or uniform process but depends on many factors.

We establish the following criteria to assess that a person is in the process of person is in the process of aging and/or deterioration:

- To have an average in all indicators equal to or higher than 2.4.
- If the average score is lower than 2.4 but the person has scores equal to or higher than 3 in at least 3 indicators, the person is at risk of entering the aging/impairment process, or at least the focus should be placed on this aspect by the entire professional team that supports him/her.

The remaining 12 good practices, while not selected for deep focus, offer valuable strategies across various domains such as education, nutrition, socialisation, community participation, and mental health. Together, these practices reflect the core mission of AHA4AUTISM: to foster dignity, empowerment, and active, healthy ageing for autistic people through cross-border cooperation and innovation.

American Psychiatric Association. (2023). Diagnostic and statistical manual of mental disorders (5th ed., text rev.). American Psychiatric Publishing.

APNABI (2021). Scale for detecting and monitoring ageing process and/or deterioration in APNABI adult users. [https://www.apnabi.eus/wp-content/uploads/2021/11/apnabi-estudio-envejecimiento-TEA-2021\\_compressed.pdf](https://www.apnabi.eus/wp-content/uploads/2021/11/apnabi-estudio-envejecimiento-TEA-2021_compressed.pdf)

Autism Europe (2023). Building An Inclusive Society For Autistic People.

Badia, M., Orgaz, M. B., Verdugo, M. A., & Ullán, A. M. (2013). Patterns and determinants of leisure participation of youth and adults with developmental disabilities. *Journal of intellectual disability research*, 57(4), 319-332.

Bhandari, P. & Nikolopoulou, K. (2023). What Is a Likert Scale? | Guide & Examples. Scribbr. <https://www.scribbr.com/methodology/likert-scale/>

Brown, J., & Murray, D. (2002). Strategies for enhancing play skills for children with autism spectrum disorder. *Education and training in mental retardation and developmental disabilities*, 312-317.

Camero Rivero, S. & Baigorri Agoiz, A. (2019). Active aging and senior citizenship. *Empiria. Revista de metodología de ciencias sociales*, 43, 59–87.

Chowdhury, M., Benson, B. A., & Hillier, A. (2010). Changes in restricted repetitive behaviors with age: A study of high-functioning adults with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 4(2), 210-216

Cottini, L. (2019). Gli interventi efficaci nei disturbi dello spettro autistico: uno sguardo alle principali linee guida. *Giornale Italiano dei disturbi del Neurosviluppo*, 4(1), 33-68.

Cottini, L. (2021). Servizi per l'inclusione sociale e per l'abitare: possono essere inclusivi anche se sono rivolti solo a persone con disabilità? Lo sguardo interessato della didattica speciale. *Italian Journal of special education for inclusion*, 9(1), 074-079.

Cottini, L. (2024). L'autismo in età adulta. Percorsi inclusivi per una vita di qualità. Carocci.

European Commission (2021). The Green Paper on Ageing.

Esteban, N., Merino, M., Muñoz, D., Martín, D., Martín, L., Rodríguez, C., Mongil, B., Carrascal, E., Melero, A., Domínguez, C., & Martín, I. (2014). Guide for caring autistic people in the Emergency Room. Federación Autismo Castilla y León.

Esbensen, A. J., Seltzer, M. M., Lam, K. S., & Bodfish, J. W. (2009). Age-related differences in restricted repetitive behaviors in autism spectrum disorders. *Journal of autism and developmental disorders*, 39(1), 57-66.

Frith, U. (2009). L'autismo. Spiegazione di un enigma. Editore Laterza.

Gillespie-Lynch, K., Sepeta, L., Wang, Y., Marshall, S., Gomez, L., Sigman, M., & Hutman, T. (2012). Early childhood predictors of the social competence of adults with autism. *Journal of autism and developmental disorders*, 42(2), 161-174.

Gotham, K., Marvin, A. R., Taylor, J. L., Warren, Z., Anderson, C. M., Law, P. A., Law, J.K., & Lipkin, P. H. (2015). Characterizing the daily life, needs, and priorities of adults with autism spectrum disorder from Interactive Autism Network data. *Autism*, 19(7), 794-804.

Gottschalk, J. M., Libby, M. E., & Graff, R. B. (2000). The effects of establishing operations on preference assessment outcomes. *Journal of Applied Behavior Analysis*, 33(1), 85-88.

Gray, K., Keating, C., Taffe, J., Brereton, A., Einfeld, S., & Tonge, B. (2012). Trajectory of behavior and emotional problems in autism. *American journal on intellectual and developmental disabilities*, 117(2), 121-133.

Hedley, D., & Uljarević, M. (2018). Systematic review of suicide in autism spectrum disorder: current trends and implications. *Current Developmental Disorders Reports*, 5(1), 65-76.

Howlin, P. (2013). Social disadvantage and exclusion: adults with autism lag far behind in employment prospects. *Journal of the American Academy of Child & Adolescent Psychiatry*, 52(9), 897-899.

Howlin, P., Moss, P., Savage, S., & Rutter, M. (2013). Social outcomes in mid-to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *Journal of the American Academy of Child & Adolescent Psychiatry*, 52(6), 572-581.

Howlin, P., Savage, S., Moss, P., Tempier, A., & Rutter, M. (2014). Cognitive and language skills in adults with autism: A 40-year follow-up. *Journal of Child Psychology and Psychiatry*, 55(1), 49-58.

ISS - Istituto Superiore Di Sanità (2023). Raccomandazioni della Linea Guida sulla diagnosi e sul trattamento di adulti con disturbo dello spettro autistico. ISS, Roma

Jordan R., Powell S. (2003). Incoraggiare la flessibilità negli adulti con autismo. In H. Morgan (a cura di), *Adulti con autismo. Bisogni, interventi e servizi* (pp.59-75). Erickson, Gardolo.

Keller, R., et al. (2023). Essere adulti con autismo. Diagnosi e nuove sfide esistenziali. *Giornale italiano dei disturbi del neurosviluppo*, 8, (1), 45-54.

Lai, C. L. E., Lau, Z., Lui, S. S., Lok, E., Tam, V., Chan, Q., ... & Cheung, E. F. (2016). Meta-analysis of neuropsychological measures of executive functioning in children and adolescents with high-functioning autism spectrum disorder. *Autism Research*, 10(5), 911-939.

Law 8/2003, of April 8<sup>th</sup>, 2003, on the rights and duties of persons in relation to health. *Official Gazette*, 103, April 30<sup>th</sup>, 2003.

Law 16/2003, of May 28<sup>th</sup>, 2003, Cohesion and quality of the National Health System. *Official Gazette*, 128, May 29<sup>th</sup>, 2003.

Law 8/2010, of August 30<sup>th</sup>, 2010, of the health system of Castilla y León. *Official Gazette*, 235, September 28<sup>th</sup>, 2010.



Lever, A. G., & Geurts, H. M. (2016). Age-related differences in cognition across the adult lifespan in autism spectrum disorder. *Autism Research*, 9(6), 666-676.

Lord, C., Bishop, S., & Anderson, D. (2015). Developmental trajectories as autism phenotypes. In *American Journal of Medical Genetics Part C: Seminars in Medical Genetics* (Vol. 169, No. 2, pp. 198-208).

Magiati, I., Tay, X. W., & Howlin, P. (2014). Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: A systematic review of longitudinal follow-up studies in adulthood. *Clinical psychology review*, 34(1), 73-86.

Matson, J. L., & Cervantes, P. E. (2014). Commonly studied comorbid psychopathologies among persons with autism spectrum disorder. *Research in developmental disabilities*, 35(5), 952-962.

Matson, J. L., Wilkins, J., & Ancona, M. (2008). Autism in adults with severe intellectual disability: An empirical study of symptom presentation. *Journal of Intellectual and Developmental Disability*, 33(1), 36-42.

Navarro García, C., Prado, J. and Sarría, A (2016). Use of emergency departments for elderly patients with multiple morbidity in Spain. *Revista Española de Geriátría y Gerontología*, 51(4), 244-245

NICE-National Institute for Health and Care Excellence (2016). Autism spectrum disorder in adults: Diagnosis and management. National Institute for Health and Care Excellence.

Parmenter, T. R. (1988). An analysis of Australian mental health services for people with mental retardation. *Australia and New Zealand Journal of Developmental Disabilities*, 14(1), 9-13.

Royal Legislative Decree 1/2013, of November 29<sup>th</sup>, 2013, approving the Consolidated Text of the General Law on the Rights of Persons with Disabilities and their Social Inclusion. *Official Gazette*, 289, December 12<sup>th</sup>, 2013.

Shattuck, P. T., Seltzer, M. M., Greenberg, J. S., Orsmond, G. I., Bolt, D., Kring, S., Lounds, J., & Lord, C. (2007). Change in autism symptoms and maladaptive behaviors in adolescents and adults with an autism spectrum disorder. *Journal of autism and developmental disorders*, 37(9), 1735-1747.

START AUTISMO. (2014). Manuale e linee guida per l'inserimento di persone con autismo. Autism Europe.

Steinhausen, H. C., Mohr Jensen, C., & Lauritsen, M. (2016). A systematic review and meta-analysis of the long-term overall outcome of autism spectrum disorders in adolescence and adulthood. *Acta Psychiatrica Scandinavica*, 133(6), 445-452.

UN: General Assembly, Convention on the Rights of Persons with Disabilities: Resolution approved by General Assembly, 24th January 2007.

Vidriales, R., Hernández, C. & Plaza, M. (2016). Study "INSETEA: Aging and Autism Spectrum Disorder - An Invisible Stage of Life". Madrid: Confederación Autismo España.

World Health Organization. (2001). International classification of functioning, disability and health: ICF. World Health Organization.





## EXCHANGING GOOD PRACTICES ON ACTIVE AND HEALTHY AGEING FOR ADULTS WITH AUTISM AND THEIR CAREGIVERS

Erasmus+ Adult Education project | Ref: 2023-1-ES01-KA210-VET-000166128

The project "Exchanging good practices on Active and Healthy Ageing for Adults with Autism and their caregivers" is co-funded by the Erasmus+ programme of the European Union. The contents of this document are the sole responsibility of Fundación Miradas, Autism Praxis Infinity Solutions (APIS) Ltd, University of Calabria and Greek Carers Network EPIONI and neither the European Commission nor the Spanish Service for the Internationalisation of Education (SEPIE) are responsible for any use that may be made of the information contained therein".



Co-funded by  
the European Union