



## Intellectual Output 2 Certification System for 'Autism Friendly Spaces' Research by Autism Europe and CRPD Compiled by Prisms

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## 1. Introduction

Autism is a neurodevelopmental disability. It is estimated that 1% of the population is on the autism spectrum. That amounts to around 7.5 million people in Europe.

Autistic people often experience exclusion in social settings where they struggle interacting with other people. Each time people on the autism spectrum are excluded, the effects accumulate, often leaving them isolated within their communities. To include autistic people into the communities, awareness among the general public, support services and public policies have to be improved.

Inclusion for people on the autism spectrum also means having access to education, employment, health care, as well as living in a society where other people make an effort to understand and include them.

The legal right to include people with disabilities such as autistic people in their respective communities is enshrined in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

Autism-Europe (n. d) Social inclusion <u>https://www.autismeurope.org/what-we-do/areas-of-action/social-inclusion/</u>

Autism Europe (2003) Autism and Inclusion<u>https://www.autismeurope.org/wp-</u> content/uploads/2017/08/ae-eypd-inclusion-final-eng.pdf

UNCRPD (2006) <u>Article 19</u> on independent living and inclusion into the communities https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-withdisabilities/article-19-living-independently-and-being-included-in-the-community.html







# 2. Rationale

## 2.1 Accessibility

Accessibility for people with disabilities like those on the autism spectrum is legally enshrined in the UNCRPD. Article 9 requires "ensuring persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communication technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas." Article 9 makes specific reference to ensuring access to "communications, including information and communication technologies and systems" on an equal basis with others. For autistic people making communication accessible goes beyond simply translating information into an easy-to-read format or using pictograms, but would additionally require a transition towards more simplified structures and processes e.g. when developing/adapting goods and services.

This last issue was among the premises of the European Accessibility Act (EAA), a European Union directive from 2019 regulating accessibility requirements for products and services. While the EAA has a rather restricted scope, it is nonetheless a first step into the right direction to foster better accessibility for people with disabilities. It is therefore key that European Economic Area member states take the necessary steps to implement the directive at national level.

## UNCRPD (2006) Article 9 on accessibility

https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-withdisabilities/article-9-accessibility.html

Official Journal of the European Union (2019) Directive (EU) 2019/882 of 17 April 2019 on the accessibility requirements for products and services <u>https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=uriserv%3AOJ.L\_.2019.151.01.0070.01.ENG&toc=OJ%3AL%3A2019%3A151</u>%3ATOC

# 2.2 The legal framework

To enforce and monitor the legal basis laid down by the UNCRPD, the Committee for the Rights of Persons with Disabilities (CRPD) was established. The full participation of civil society, in particular persons with disabilities and their representative organizations, is essential in the monitoring and implementation process. As such, organizations of people with disabilities and self-advocates should be involved in the monitoring process. Autism-Europe for its part contributes to the process by presenting its own Alternative Report to the CRPD, the next report is due in 2022.

On a European Union level, the EU Framework for the UN Convention on the Rights of Persons with Disabilities is a mechanism set up in 2013 by the European Union to promote, protect and monitor the implementation of the UNCRPD. The European Disability Forum (EDF) is a full member together with the European Ombudsman, the European Agency of Fundamental Rights and the European Parliament.

Autism-Europe (n.d) UN CRPD monitoring <u>https://www.autismeurope.org/what-we-do/rights-promotion/un-crpd-monitoring/</u>

Fundamental Rights Agency of the European Union (2013) EU CRPD Framework: <u>https://fra.europa.eu/en/cooperation/eu-partners/eu-crpd-framework</u>













### 2.3 Sensory Processing of people on the Autism Spectrum

Many people on the autism spectrum have difficulty processing everyday sensory information such as sounds, lights and smells. These sensory sensitivities can have a profound effect on an individual's life and autistic people are expected to cope with the sensory challenges.

A survey run by Autism-Europe and its partners within the project Autism Friendly Spaces between October 2020 and January 2021 on how to make public spaces more autism-friendly which gathered 128 complete responses found that the level of noise is the most challenging for autistic people. In spaces outdoors, this would be hard to improve on but the indoor spaces can improve on this issue with adjustments such as better soundproofing of floors, walls, ceilings, etc.

Equally, respondents in the survey found that navigating crowds, finding accessible communication and the light in a given space can pose a large problem for autistic people.

*Further* reading: National Autistic Society (n.d;) <u>"Too much information"</u> <u>https://www.autism.org.uk/what-we-do/campaign/public-understanding/too-much-information</u>

## 3. Criteria for 'Autism Friendly Spaces'

This Certification System enables private sectors and public entities to apply for the 'Autism Friendly' Award. The criteria for being granted the award include:

- A) Commitment to raising awareness and be part of the campaign for this project. This will be done through a provision of a pack with resources which are prepared by Prisms to be used for this aim.
- B) Choosing minimum two employees to do the four online modules. At completion, they will receive a certificate and be awarded 'Autism Ambassador' title. They will be the main reference point to provide guidance to customers/clients regarding autism.
- C) Adjustment of physical spaces to better cater for people with autism. This will be done with guidance by professional people in the area. This will include an on-visit check. The adjustments are listed down below according to the type of service:

#### 1. Supermarkets

A focus group and qualitative interviews were led by Ashley Robertson in her PhD research 'Sensory experiences of individuals with Autism Spectrum Disorder and autistic traits: a mixed method approach' (2013). Stimuli related to sensory domains (vision, touch, taste and smell) were described as being difficult to deal with. The main complaints were in the visual, which involved strong stimuli ('bright lights') and certain types of lighting ('Bright, humming fluorescent lights'). Some participants described certain types of lighting as 'artificial' and 'horrible'. As with auditory stimuli, some people reported ill effects. One person disclosed that they felt unwell when they went to the supermarket ('the lights in the big supermarkets give me a headache and I feel sick'), with another disclosing that some colours had the effect of physically unusual ('I feel really weird like time is disjointed!').

Moreover, the above mentioned survey found that in supermarkets, noise, crowds, accessible communication, and lighting need the most improvement with 34%, 25%, 19%, and 12% respectively. Conversely, it was found that sign-posting, smell, and displays were least in need of improvement with 7%, 6%, and 3%.







A person on the autism spectrum from Belgium commented: "I used to just think about bringing my wallet, now I have to think about a coin for a shopping cart, a ticket for the parking spot, a reusable bag, a member's card, but the fact that you have to be fast at the checkout counter and pack everything very fast is a bigger problem than anything above."

A support person of autistic persons filling in the questionnaire on their behalf from North Macedonia suggested: "Persons with autism should have priority when waiting in queues, no matter where."

A support person of autistic persons filling in the questionnaire on their behalf from Malta demanded: "[...] supermarkets should have a period of time stipulated for them. [...] More awareness to the employees at the shop about autism."

As a result, we recommend to have:

- Soft lights
- No loud noises
- No music
- No sounds from the cash points or machines
- Images that explain what can be found in each aisle

Others might include:

- Grating cheese and other products from before
- Quiet room if supermarket has space available

### 2. Restaurants/Cafeterias

In 2016 the Autism Society of America together with a number of other partners began promoting a nationwide programme which encouraged businesses including restaurants to become autism friendly and provide autism friendly spaces. The initiative highlighted how such efforts are to be addressed through a universal design as a number of issues are not solely for autistic persons but are of benefit to society in general. Furthermore, the National Autistic Society UK (2020) notes that autistic individuals may find it too difficult to dine in a noisy environment and factors such as providing a relaxing setting may provide a less anxious environment.

- Use of light dimmers
- Lowering the music volume as necessary
- Include gluten free menu
- Clear labelling across the premises
- Provision of easy to read menus

Others might include:

- Photos of the meals in the menu
- Quiet area with no music

References:

https://www.autism-society.org/living-with-autism/communityinclusion/autismfriendly/businessprogram/

https://www.autism.org.uk/











### 3. Health services

The 2020 journal article titled 'Healthcare access for autistic adults: A systematic review' presents a study that identified barriers and enablers of healthcare access for autistic individuals. This qualitative and quantitative study which took into consideration the clinician knowledge, the environment, and life events concluded that effective communication is the main barrier and that lack of awareness on autistic needs amongst practitioners plays a central role. Consequently, providing an environment that makes it easier for both autistic people and practitioners to communicate effectively is crucial.

- Soft lights
- Scheduling of appointments to avoid crowded waiting areas
- Explanation of next steps before using any equipment or administering medication
- Clear visual labelling around the clinic / pharmacy / shop

#### References:

Healthcare\_access\_for\_autistic\_adults\_\_A.251.pdf

#### 4. Office

In 2019 the Job Accommodation Network (JAN) presented a document titled 'Accommodation and Compliance Series: Employees with Autism Spectrum'. The report highlights the main areas that must be analysed when employing autistic individuals and thus how the office environment must be adjusted accordingly. According to the said report the questions that must be addressed by the employer include what difficulties may the particular individual experience and thus what specific job tasks are problematic as a result of these limitations. This would then require an assessment of what accommodations are available to reduce or eliminate these potential issues. In addition, the said report makes reference to the importance of having awareness training provided to the rest of the staff as well as following up with the employee in question to evaluate the effectiveness of the accommodations and to determine whether additional accommodations are needed.

- Flexible Schedule
- Provision equipment such as noise cancelling headsets and fidget devices
- Wall calendars and planners
- Quiet Room

CRPD

- Alternative lighting
- Alternative forms of interviews such as working interview
- Task lists (it can be visual)
- No fluorescent lights
- Using headphones when possible to cater for a quiet environment

#### References:

file:///C:/Users/ellos001/Desktop/CRPD/Research%20Unit/Research%20Projects/Autism%20Friendly %20Spaces/Literature%20Collected%20by%20CRPD/Employment/Accommodation\_and\_Complianc e\_Series\_Employees\_with\_Autism\_Spectrum%20(1).pdf





## 5. Travelling - airport and transport

#### Accessibility of public spaces

The above mentioned survey found that for outdoor public spaces, noise, accessible communication, light, sign-posting, and crowds need the most improvement with 25%, 21%, 16%, 16%, and 16% respectively. Conversely, smell, and displays were least in need of improvement with 7% and 5% respectively.

How to make bus stops and train stations as well as bus and train travel accessible?

The European Union Regulation 1371/2007 on passengers' rights and obligation also includes a specific chapter on the rights of passengers with disabilities and particularly features the right to transport and the right to assistance. It shall be provided at no additional cost, notably during the boarding and alighting of the train and assistance in using facilities on board available for all passengers. Currently, the Regulation demands a maximum 48-hours' notice period for assistance. We are aware that this is far from enough. Furthermore, the regulation stipulates that important information should also be provided to all passengers in accessible formats. In case the mobility equipment of a passenger with disabilities is damaged, lost or destroyed, the passenger has the right to full compensation.

A support person of autistic persons from Malta filling in on their behalf the questionnaire for the survey mentioned above wanted "Free online announcements in regard to changes in bus schedules and destinations in Malta."

A support person of autistic persons filling in the above mentioned questionnaire on their behalf from France suggested: "Quiet place to rest. A person to drive you through (in train station, airport) also during the travel Special area in train to avoid peak hour crowd.

What has to be improved to make land travel accessible?

We recommend:

- Making available plans or social stories or videos describing the train station/bus terminals
- Training staff and drivers in autism awareness
- Proper and clear signage
- Use of colours for different lines/terminals
- Live updates if there are any bus schedules changes
- Equipping train and bus stations with dedicated launch areas (multi-sensory/quiet rooms)

What has to be improved to make air travel accessible?

We recommend:

- Making available plans or social stories or videos describing the airport
- Training airport staff in autism awareness
- Employing service staff/dogs to guide autistic people
- Ensuring fast track special assistance
- Allowing autistic people to visit the airport in advance to familiarized themselves (E.g. through dedicated Airport familiarization days)
- Equipping airport with dedicated launces (multi-sensory/quiet rooms)











What has to be done to make parking accessible?

A parent from North Macedonia pointed to the availability of parking spaces for autistic people. "Free parking in municipalities where they live, work and study. At the moment, free parking is available only for people with physical disabilities and blindness. But, it's a serious problem when you're driving with a person with autism and you need to park far away because of payment or no available parking slots. These persons have tantrums, which are often caused by impatience to get somewhere. This assumes free parking in front of the building or house where the person lives (marked – not only for people with physical disabilities).

We recommend:

- EU parking card to be mainstreamed for people with all disabilities including those on the autism spectrum
- Plans, video and social stories describing the (functioning of the) parking spaces
- accessible sensory friendly parking spaces/garages

## European Disability Forum (n.d.) Rail travel <u>https://www.edf-feph.org/rail-travel/</u>

London Gatwick Airport (n.d.) Special assistance for people with hidden disabilities <u>https://www.gatwickairport.com/at-the-airport/passenger-services/special-assistance/hidden-disabilities/</u>

Belfast International Airport (2015) Special assistance: Autism Awareness <u>https://www.belfastairport.com/special-assistance/autism-awareness</u>

Dublin Airport (n.d.) Assistance for passengers with autism <u>https://www.dublinairport.com/at-the-airport/help-and-support/travelling-with-autism</u>

Venezia Airport (n.d.) Informazioni generali, raccomandazioni e consigli di viaggio per gli accompagnatori di bambini e adulti con autismo. <u>https://www.veneziaairport.it/info-e-assistenza/autismo.html</u>

Youtuber Khaled Al Ameri (2019) Airplanes and Autism: <u>https://www.facebook.com/khalidalameri/videos/309329339754941/</u>

European Commission (2020) European Parking Card https://europa.eu/youreurope/citizens/travel/transport-disability/parking-card-disabilitiespeople/index\_en.htm

## 6. Retail shops

Writing about a personal experience Lynne Soraya (2015) illustrates the difficulties associated with shopping in retail outlets for autistic people. The main issues relate to sensory overload and lack of understanding and awareness from non-autistic individuals. This is also sustained by the National Disability Authority (2017) who state that many people with autism have sensory difficulties and thus creating 'low arousal' environments is key when designing autism friendly spaces. Furthermore, when assessing accessibility for persons with disability retail outlets should not only include physical spaces but also an assessment of sensory difficulties.

- Use fragrance free cleaners
- Offer a personalised service (Autism Ambassador)









- Clear signage and labelling
- Dimmed lights not flourescent
- No excessive background music for example screens can be muted

Others may include:

- Providing children with sensory toys
- Having a quiet area
- When possible schedule an appointment

References:

Good-practice-in-supporting-adults-with-autism.pdf

https://www.psychologytoday.com/us/blog/aspergers-diary/201503/shopping-while-autistic

#### 7. Museums

Sass (2016) researched about the basic accommodation that should be provided by museums to be fully accessible by individuals with an intellectual disability. Although the said research is not specifically about autism friendly spaces it does draw upon the fact that having a universal design is beneficial for all members of society. This is also evident in a number of other research papers such as Tuschen (2015) who identifies social stories in museums as a medium of accessibility and understanding. This is also sustained in the 'Museums & Social Issues' journal (2016) titled 'Social participation of families with children with autism spectrum disorder in a science museum' which states that "there is a dynamic relationship between the person and the environment, in which the environment can facilitate or serve as a barrier to social participation" (pg. 124).

- Clear signage
- Dimmed light
- Guided Tours headphones could be provided
- Sensory Maps
- Social Stories with visuals

Others might include:

- Having a quiet room
- Providing colouring books or sensory toys

References:

Designing Social Stories for the Brooklyn Children's Museum.pdf Lussenhopetal2016SocialpartoffamASDmuseumMuseuesmSociallssues.pdf Sass\_Courtney.pdf

## 8. Cinemas

In 2019 the 'UK Cinema Association' together with partners from the autism organisation 'Dimensions' and the 'BFI Film Audience Network' launched training resources for cinemas who wish to offer autism friendly environment and screenings. The data was collected and developed by autistic people











themselves and experts within the industry. A number of elements were addressed that are usually associated with traditional cinema screening, such as excessive noise, lengthy adverts and trailers amongst others. The training resources include a number of tips that could easily be adopted for an autism friendly environment which include amongst others:

- Pre-screening preparation •
- Programming and film title choices
- Publishing listings and taking bookings •
- Adjustments on the day .

## References:

https://www.cinemauk.org.uk/wp-content/uploads/2019/04/AFS-Guide-for-cinemas-2019.pdf







