The war in Ukraine and autistic people: testimonies and support actions across Europe

Autism-Europe N°77 / June 2022

AE's projects: Young Mediators for Inclusion and Autism Friendly Spaces

World Autism Awareness Day: review of #AutismDay2022 campaign

> Register for the Autism-Europe's 2022 Congress



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#### More news at: www.autismeurope.org

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08

SUPPORT FOR AUTISTIC PEOPLE IN UKRAINE





# Edito

#### Dear readers,

This issue is dedicated to autistic people and their families who are currently facing the dire consequences of the war in Ukraine. Our Ukrainian members and partners have alerted us about the alarming situation faced by autistic people and their families, as they are particularly vulnerable during armed conflicts. Autistic people and their families appear to be overlooked in some cases by humanitarian aid agencies, as the nature or extent of the disability is not fully understood, leaving vulnerable individuals and families without access to official channels of support.

Today, more than ever, solidarity is key to support people in Ukraine and as they seek refuge in other countries. Autism-Europe is cooperating with its Ukrainian member organisation and other stakeholders to support autistic people in Ukraine at this critical time. We would also like to highlight the efforts of our network across Europe to support their Ukrainian counterparts and welcome refugees. However, civil society alone cannot address the challenges of the war and it is critical that public authorities are aware of the needs of autistic people and provide them with adequate support. We call on all political leaders and humanitarian actors to take action for Ukrainian autistic people and their families in Ukraine and abroad.

Our upcoming International Congress taking place on 7-9 October 2022 and hosted by the JiM foundation in Poland will also address the repercussions of the war in Ukraine. For the first time, the event will be accessible online with high-quality access to its sessions, presentations, workshops, discussion panels, and more. You can also attend in person, in the historic city of Kracow, Poland. We look forward to seeing you there!

Best regards,

#### Collaborators

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**Director**, Aurélie Baranger





**President,** Harald T. Neerland







# The war in Ukraine and autistic people:

### testimonies and support actions across Europe

Since the beginning of the war in Ukraine, Autism-Europe has cooperated with its Ukrainian member organisations and other stakeholders to support autistic people and their families at this critical time. AE strives to highlight the needs of autistic people and calls for them to receive adequate support. In the following pages, you will find interviews of our members experiencing the consequences of the war. You can also discover some of the resources and support actions for autistic people and their families in Ukraine and those that had to flee their country.

**Interview with Child** With Future on the situation of autistic children in Ukraine

Children and especially children with disabilities are among the groups most affected by the war in Ukraine. We wanted to know what is the current situation of children with autism in the country. To achieve this, we spoke with Iryna Sergiyenko, Director of the Foundation "Child With Future", a Ukrainian non-profit organization helping autistic children. This interview was conducted in cooperation with the European Disability Forum in Spring 2022.

Question: We know the difficulty of communication in general, but in this war situation how is the best way to communicate to autistic children what is happening?

Iryna Sergiyenko (IS): Most parents start with explaining the new rules verbally. Initially, that is all they have and their priority is teaching their child the new safety protocols. Soon after the invasion, visual explanations were created for autistic children, outlining that Russia has attacked Ukraine and the rules to keep themselves safe. Some children have taken a special interest in the war and asked their parents for deeper explanations and updates on what is going on. There aren't visual support stories that explain the situation in detail, so parents can only rely on themselves and their ability to explain. Autistic children with access to phones and internet have

taken to reading the news themselves. For those children, a support story on how to not overwhelm themselves with the news would be helpful. Likewise, a similar guide for parents.

However for many autistic children there was no explanation on their level of understanding. All they know is that there are new rules, and their routine has been destroyed. They cling to what is left of their routines, refusing to interrupt their breakfast even if an air raid siren is going off. They don't understand the danger, and parents are afraid of traumatising them by explaining the war and the dangers that it brings. Those parents would benefit from a guide on how to explain things to their child without creating more trauma. Especially if their child is non-speaking and it is hard to gauge their level of understanding.

#### Question: Are you supporting children and their families to leave? How the journey look like?

IS: Currently we are able to help with information. Families have to rely on volunteer organisations to transport themselves across Ukraine and abroad. We provide them with information on centres they can request help from – both within and outside of Ukraine.

We are also supporting families with online consultations and webinars, giving them the tools to work with their children by themselves at home. And of course we are collecting donations to be able to help them more.

The journey starts in their city. If it is surrounded or occupied, the first hurdle is to get out. Some are evacuated by foot, others may pay for a bus ride, or leave in their own car – it depends on the situation. One thing everyone knows do not trust russian "green corridors". It

only gives them easy targets. Likewise, russians are known to target vehicles marked with red crosses or "children". Some cities had railway services. Those trains were extremely full – people had to sleep on the floor, in the corridors and on top of each other. Barely enough space to sit, much less lay. The lights would be off all the way, no phones or light sources allowed, and the train would go slower than normal in order to avoid detection by russians.

Ukraine, or to the West. If a family is travelling by car, they will have to get through many roadblocks on their way. They will have to show passport and state their destination at each. Often their car will be searched. Travel like that can take days - it took one of my friends five days to get through what is normally a 10-hour drive. There's also the issue of curfew, as many regions will have it starting at 8pm. This means that the family will have to



#### **Question: Besides meeting their basic** needs, what are the main obstacles you are identifying?

**IS:** Parents are used to having specialists as a support system. Without them, they lack the skills to guide their children through the wartime. They don't know how to deal with trauma, PTSD, heightened anxiety and depression that their autistic children are going through. Many of those children are showing new behaviours that are very concerning to parents (e.g., episodes of smearing feaces on the back of the sofa with no memory of doing so).

Some autistic children and teenagers were taking regular medicines - those are hard to find now. As a Foundation,

we do not deal with drugs or medicines. So the best we can do is refer families to volunteer organisations that handle those things. I am not sure what, if anything, can be done to improve this.

Families often have to evacuate with bare essentials. That means that items that the autistic child used to de-stress and soothe themselves are no longer available.

Autistic persons are often forced to be in crowded spaces for long periods of time, without appropriate support items to ease the sensory or social issues.

Parents in Ukraine know little about mental health. Most of them would benefit from seeing a psychologist, but may be unaware that it would help them, or if it is an option they can choose. Or

Usually a family will head for central

find somewhere to stay or drive non-stop. Either way, it is a very hard journey.

At the border, they will have to wait for a long time. Most likely they will have to say goodbye to the father of the family, as Ukrainian men under 60 years old are not allowed to leave the country. Needless to say, it is very traumatic for the whole family. They don't know if they will see their father/husband again. Most of the time, they only have a vague idea of where they are heading to.

Volunteers across the border are doing their best, but with millions of Ukrainians seeking shelter, they are overwhelmed too. Having to stay in shared shelters is hard for anyone, even more so for an autistic child. If their mother is unable to find separate lodgings or a centre for her child to continue therapy, they will often go back to Ukraine after weeks of trying.

their internal bias will prevent them from seeking help.

Service providers for autistic kids have been relocated and in many cases have nothing but their knowledge. We are collecting donations to help them acquire the items they need to once again provide services for families with autistic kids.

All centres are facing large debts on utility bills. Mostly inordinate amounts for heating due to new legislation putting the same tariff on private centres as on big shopping malls. Our preschool that can have 36 children at most and has to pay at least 300.000 UAH (about 10.000 EUR). We and many others are facing the danger of being closed down and our building confiscated.



МЫ ПОМОГАЕМ СЕМЬЯМ С **ДЕТЬМИ-АУТИСТАМИ В УКРАИНЕ** 



We are the first and only preschool for autistic children that prepares them for regular schooling. We have reached out to the government and nothing. Other centres are facing the same issues and have reached out to us for help. We are coordinating the efforts as best we can, but there's a limit to what we can do when dozens of centres have to pay tens of thousands of euros they don't have.

Between being unable to open due to the war, using centres as shelters (including our own) and parents having no money to pay with, Ukraine is facing a humanitarian catastrophe when it comes to supporting families with autistic children.

We are doing our best to coordinate with other centres and see how much all of us need to stay open. The numbers are horrifying. None of us will be able to stay open. The government doesn't care to forgive the debts or amend tariffs to a more sane amount.

#### Question: Do you cooperate with other organisations of disabled people in Ukraine in the context of the conflict?

IS: Yes. We have a network for organisations that work with autistic children. Quite a few of them provide services for more than autism.

#### Question : How can we help children with autism and their families that remain in Ukraine?

**IS:** Donate to support the functioning of our centres. That is honestly the best way to help. I understand the desire to help directly by sending care packages and fidgets, but in the long run it is not helpful. Just as autism cannot be "fixed" with medication, our families cannot be helped with toys. They need proper support structures. And those are being destroyed by the debts that our government refuses to forgive.

So the other way to help? Put international pressure on the Ukrainian government to forgive debts incurred by facilities that provide support for people with disabilities.

#### Question: What are the main needs of the refugees?

IS: Appropriate housing and language barriers are the first issues they face. It is followed by need for guidance on confirming diagnosis, receiving therapy, education and other support for their child.

Question: Do you have information regarding the situation of autistic people who are institutionalised?

Ukraine does not have many centres for institutionalised autistic persons. Many of the patients have evacuated to other countries with their families. So those centres don't function. There is a campaign going on in Ukraine to evacuate people with disabilities first, since they face the biggest risk of death in wartime. Patients who did not have family to take them, have been evacuated to other countries too. For example, Germany and Israel have agreed to take in the children who have been living in orphanages [1] and who need special assistance.

#### **Question:** What would you ask of the institutions (at the national and international level) and all stakeholders involved?

IS: Please donate and please put pressure on your and our governments to help us. Autism is not talked about as widely as other disabilities - I've heard reports that even the Red Cross doesn't know how to help autistic children. As I said before, we need donations to help ourselves and international pressure on our government to ease the monetary pressure on us. Then those tens of thousands of Euros that would be spent on unfair utilities tariffs would be spent directly on the families in need.

#### Autism-Europe and its members support autistic people affected by the war in Ukraine

Members of AE from all over Europe are offering different support actions and services to help autistic people and their families affected by the war situation in Ukraine. AE created a webpage to highlight contact points and support.

Scan the QR code and read about all the support activities and services that AE's members are offering



**Autism-Poland** Association about the situation on the border with Ukraine

Małgorzata Wokacz-Zaborowska is the representative of Autism-Poland Association at Autism-Europe. Members of this association are helping children and adults with autism to integrate into the country after having travelled thousands of kilometres seeking refuge.

Question: We know the difficulty of communication in general, but in this war situation how is the best way to communicate to autistic children (both Ukrainian and Polish) what is happening?

Małgorzata Wokacz-Zaborowska (MWZ): Here in Poland the stories, comments, pictures of war are now unavoidable. Our children meet new collegues at schools, in kindergartens and in other places. They experience a new language, new names, even new music. We need to communicate it in a proper way by adapting to the capabilities of our children so they may understand it. My son, who is an autistic person, is 12 years old. When the crisis started, he seemed interested, a bit worried, but also confused since he did not know how to ask a question. So we discussed the situation using very simple messages, showing a map and explaining what a war is in general, but at the same time caring for his sense of security. We avoid watching TV and discussing the situation with other adults when he is around. Many parents struggle with communicating this war situation to



children with autism, especially when a child is not verbal, so they often turn to a specialist for help. We all need to learn how to communicate it properly.

Question: When you receive autistic people and their families at the border, what is the integration process like? How do you do that first needs assessment? and how do they arrive?

MWZ: First of all, I need to point out that there is no one social support system for the refugees with special needs functioning in Poland. The situation was unexpected and surprised us all, so starting from the very first days there were more and more volunteers and NGOs involved, located close to the Polish border with Ukraine so as to help as soon and as much as possible. At the same time some organizations started to communicate and coordinate the efforts of various organisations involved in helping Ukrainian families with persons with autism. That is what we did in the Autism-Poland Association that unites 30 organizations from all over Poland that are acting for the benefit of autistic children, adults and their families. We have been gathering information from our members referring to what they are doing, how are they helping, what are their capacities in this regard. We have been constantly updating that list. Then we shared information with other organizations in Poland and abroad, first of all with Autism-Europe and its members. We also shared it on the social media including various Facebook groups, so that it may reach volunteers, activists and also directly people searching for help.

we first need to meet basic needs that are accommodation, food and safety. Then we may think of defining and meeting special needs. We have been facing problems with finding proper accommodation, since the collective shelters are not appropriate for people

In each case when we help Ukrainians,

with special needs. People arrive by trains, buses or cars, some of them come on foot to the border after walking for many days. Some of them change to another means of transport at the border. Some are more independent, have relatives or friends here, some try to find right away a place on their own, but many of them need assistance even starting with evacuation. Some people come with no luggage, they just escaped their house with empty hands, no documents, no money, not to mention medical files. There are some organizations and volunteers in Poland that are coordinating the whole way of evacuation of individuals, cooperating with Ukrainian partners. But the needs are enormous, transport conditions are difficult and thus many people with disabilities are still waiting for a chance to leave Ukraine.

One aspect should be emphasized here, there is no efficient social welfare system, fully covering all needs of people with disabilities in Poland. There are many Poles with disabilities waiting for an appropriate support, some waiting for many years. So the situation when there are thousands of people with special needs arriving in Poland, puts us all in a difficult situation. Nevertheless, we all are open to help as much as possible and to share what we have here. Sometimes it is not much but it may mean a lot for others.

> Read her full interview by scanning this QR code



#### Autism Unity Website

The Autism Unity Website was created by an international team with roots in Ukraine to ensure access to therapeutic care for Ukrainian children with autism and other developmental disabilities in countries of relocation.

#### The objectives of this platform are to :

- Address the mental health and wellbeing of parents and families and build the capacity and skills of parents to better meet the needs of their children.
- Coordinate a system that helps families navigate services and connect to autism-specific resources

in a variety of languages and across several countries.

· Improve and enhance the quality of services for families by building the capacity of professionals and organizations through training and pathways to international credentialing and higher qualification.

Through this platform, **families of autistic** children and specialists can connect to make sure they receive the support needed, including speech therapists and other services.

There is also a space to share personal testimonies to raise awareness on the situation Ukrainian autistic families are experiencing.

You can contribute as a volunteer - for example by providing information about the available services in your country.



#### AE and EUCAP call to ensure the protection of Ukrainian autistic people

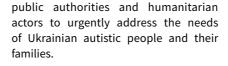
After consulting with AE member Child with Future (Ukraine), AE, together with the European Council of Autistic People (EUCAP), launched a call to actions for policy-makers and all relevant stakeholders to ensure the protection of Ukrainian autistic people.

Autistic people and their families are largely invisible and underserved by humanitarian aid dedicated to supporting the people of Ukraine. Through this joined position paper, AE and EUCAP are calling on all political leaders, public authorities and humanitarian actors to

address the urgent needs of Ukrainian autistic people, including refugees.

Our partners in Ukraine have alerted us about the alarming situation currently faced by autistic people and their families. For instance, Ukrainian autistic adults without intellectual disabilities are generally undiagnosed in Ukraine and many neighbouring countries do not have access to any official support services or social protection.

Through this call to action, we want to bring attention of all political leaders,



If you are interested in raising awareness and advocating across Europe to address the urgent needs of the autistic in Ukraine and abroad, you are welcomed to use this call and share it among your network.



#### Make a donation to support the activities of our Ukrainian member



#### **Details for payments in national currency** (USD)

- Beneficiary : International non-governmental organisation Children with autism support foundation "Child With Future"
- Short name : INGO "CASF "Child With Future"
- Current account № : UA50334851000000002600912120
- Beneficiary code : 37038710
- Beneficiary bank : AT "PUMB", Kyiv city
- Purpose of payment : Voluntary donation

**Autism-Europe's first hybrid General Assembly and Council of** Administration meetings in Krakow (Poland)

In 2022, the combined Annual General Assembly (AGA) and Council of Administration (CA) meeting was a first on many levels. It was the first to take place in the city of Krakow, Poland and to be held in hybrid format. For the first time our network had to address the consequences of an armed conflict for the autistic community of one of its members, Ukraine.

Over 50 member associations and individuals from 24 countries were present during the AGA and CA. Around 20 representatives met on site. The venue was chosen in preparation for the 13th Autism-Europe International Congress 2022 to be hosted in Krakow in September.

AE associated member, Farm of Life, run by the Fundacja Wspólnota Nadziei (Community of Hope Foundation) welcomed a delegation from AE for an exchange and study visit on the Friday prior to the meeting. It is one of the only community-based residential services for autistic adults in Poland.

During the AGA meeting, members received information about and approved the work conducted by Autism-Europe's secretariat in 2021 and the work programme for 2022, funded under the EU's Citizens, Equality, Rights, and Values (CERV) programme. Furthermore, AE members received updates about all projects Autism-Europe is currently involved in.

Elections also took place and half of the CA members were renewed in accordance with AE by-laws. The Annual General Assembly also welcomed a new associated member from Romania: Autism HELP Association.

#### **Exchanging about the situation** of the autistic community in Ukraine

Central to the AGA meeting was an exchange about the situation of autistic people affected by the armed conflict in Ukraine. AE's member from Ukraine, Child with Future, represented by its president Irvna Sergiyenko remotely connected from Kyiv, Ukraine, as well as its director Ina Sergiyenko, remotely connected from the UK, shared updates on how autistic people and their families are dealing with the armed conflict, both in Ukraine and as refugees fleeing their country.

Different actions taken by AE members across Europe to support the autistic community in Ukraine were shared. AE also highlighted the call addressed to EU policy-makers together with the European





Council for Autistic People (EUCAP) to ensure the protection of autistic people in Ukraine. Members from Poland and other countries presented some of their actions to support Ukrainian autistic refugees. The session made particularly clear the need for additional funding and coordination at national and EU levels to address the needs of autistic people from Ukraine.

#### **Preparing AE's upcoming congresses** and AE's 40<sup>th</sup> anniversary

During the CA meeting, Autism-Europe representatives also took part in a brainstorming session about the celebration of AE's 40th anniversary in 2023. Members had fruitful group discussions to reflect on the achievements, progress, past, and future of the autistic community at the European level.

The Jim Foundation updated the CA delegates on the latest developments in the run-up to the 13<sup>th</sup> Autism-Europe International Congress. Finally the CA voted for the 14<sup>th</sup> Autism-Europe International Congress to be held in Dublin, Ireland in 2025. AE's Irish full member Aslam will host it.



# Young Mediators for Inclusion project

# Young Mediators for Inclusion (YMI): Promoting the inclusion of young autistic people in the community

Running from 2019 to 2022, the YMI project – co-funded by the EU programme Erasmus+ – aims at including young autistic people in their community life through social mediation. In spite of the COVID-19 pandemic, YMI successfully trained young mediators through internships in 2021 in Portugal, Spain, and Sardinia, Italy. With the support of the young mediators, several young autistic people were in turn successfully included in community activities.

When parents try to include their autistic children in regular community activities, be it sports, music, arts, or simply spending time with their peers, most of the contexts are not prepared. In the case of those who live in more socio-economically disadvantaged contexts, all these difficulties are combined and families struggle to find solutions to foster the inclusion and development of their children. In Europe, many autistic children only have access to activities in segregated contexts.

Thus, outside the school environment, autistic children and young autistic people, especially those with complex support needs, continue to live parallel and invisible lives paths compared to their peers without disabilities. This is where the YMI project stands out, as it prioritises inclusion as the only possible form of intervention fully respecting human rights principles. "(...) all persons with disabilities (shall have the equal right) to live in the community, with choices equal to others, and (there) shall (be) effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community (...)" - Article 19 of the United Nations Convention on the Rights of People with Disabilities

## YMI developed an innovative methodology through the model of "mediator for inclusion"

The YMI project aims at promoting the full participation of young autistic people in activities of their communities on equal terms with their peers through the concept of social mediation. It developed an innovative methodology and used the figure of the "mediator for inclusion" to break prejudices and stereotypes and to demonstrate that inclusion, even for people with additional support needs, is possible.

Young mediators received training and undertook internships to become agents to support the effective communication between the families of people on the autism spectrum and the community activities (e.g. in clubs, cultural centers, youth camps, extra-curricular activities, etc). However, the mediators were not there to substitute the personal assistant(s) or the (informal/ family) carers of young autistic persons.

To develop the training curriculum, the project coordinator Inovar Autismo and project partners Autismo Burgos and Diversamente ODV held focus groups with autistic people, their relatives, and inclusion experts in their respective countries (Portugal, Spain, Italy). Thus, they identified the critical factors for the successful inclusion of autistic people into their communities. The ISCTE business school in Lisbon (Portugal) then evaluated these factors.

In 2021, trainees took part in the pilot test of the two training courses developed by partners from Portugal, Spain and Italy. The course curriculum had practical and theoretical components. The mediators trained via the pilot training were mainly university students and autism professionals as well as staff members from community services.

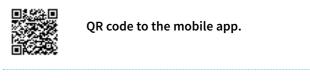
After their internships, mediators, autistic people, and their families who benefited from the programme shared their testimonies and feedback. For example, a mediator Maria accompanied Pedro, a young boy from Spain, to his first communion ceremony and after-party. For Pedro's parents, this experience was wonderful.

Valeria, a 16-year-old autistic Italian girl did an internship at a local library with the support of her mediator. As a result, she did the inventory task independently. Ivana also accompanied Valeria to learn how to use public transport to travel between her home and her school. Guilherme, a 23-year-old non-verbal autistic young adult from Portugal attended surf classes with his mediator Mariana. He said he enjoyed interacting with people and learning to surf. Mediator Mariana, a young psychology student, also learned a great deal about how to communicate with Guilherme.

To foster the replication of the YMI initiative by other stakeholders, Autism-Europe coordinated the development of the European Guide for the social inclusion of autistic people in their communities. VET provider and IT project partner InterMediaKT (Greece) then developed a mobile application (app) featuring the European guide together with testimonies from autistic people, mediators, the disability rights communities, service providers as well as policymakers. ISCTE business school Lisbon (Portugal) finally evaluated the project.

At the end of the project, an international conference on 6 July 2022 was hosted by the European Economic and Social Committee (EESC), 'a European Union body' representing the EU's civil society based in Brussels, Belgium. Portuguese State Secretary for Inclusion, Ana Sofia Antunes, closed the international conference by welcoming the YMI project and commenting on the relevance of the mediation for the inclusion scheme in Portugal while referring to the current national strategy for people with disabilities and their independent living.







QR code to the video recording



QR code to the project website



### **Autism Friendly Spaces:** inclusive public spaces for autistic people

The Autism Friendly Spaces (AFS) project launched in 2019 aimed at promoting a more accessible society and participation in social activities of youngsters on the autism spectrum. It also developed online modules, criteria and guidelines for retailers and services to become accessible to autistic people and apply for an AFS award.

The AFS project's main objectives were to create a positive change in the community by strengthening the competences of educators and youth workers to develop better inclusion strategies for students and young people on the autism spectrum. Overall, it also aimed at promoting better accessibility to encourage public and private spaces, through a Certification System to become an 'Autism Friendly Space'.

#### The main objective of this project is to create a positive change in the community by:

- 1) Strengthening the competences of educators and youth workers in the knowledge, attitudes and better inclusion strategies for students/ young people on the autism spectrum
- 2) Increasing accessibility to public and private spaces, through a Certification System enabling the application for 'Autism Friendly Spaces' and a nationwide awareness campaign
- 3) Supporting young people on the autism spectrum socially through a pilot youth hub, created specifically for them

### AFS Online Modules to learn about accessibility for autism

The four online learning modules of AFS are easily accessible, open access and can be undertaken by any interested stakeholder. These modules are linked to the Certification System that enables private sectors and public entities to make their spaces 'Autism Friendly'.

Indeed, these modules are designed to train youth workers and autism ambassadors in shops and services to address the access needs of autistic people. Trainees who follow the learning modules can in turn implement these measures in their schools and youth centres, with shops and services having the possibility to be certified as 'Autism Friendly'.

The online modules offer a comprehensive overview of what autism entails in various areas of life. Module 1 introduces autism. Modules 2 to 4 highlight the sensory, cognitive and social aspects to be taken into consideration to accommodate the needs of autistic people and make a space "autism friendly".



From left to right : Margaret White from Prisms Malta; the Minister of Inclusion from Malta, Hon. Julia Farrugia Portelli; MEP Alex Agius Saliba from the Socialists and Democrats Party at the European Parliament; Aurélie Baranger, AE's Director





#### The project partners are:

- NGO Prisms from Malta (Coordinator)
- Commission for the Rights of Persons with Disability from Malta
- Agency Żgħażagħ from Malta
- NGO Learning Designers from Spain
- Macedonian Scientific Society for Autism from North Macedonia
- Autism-Europe from Belgium.

### Final conference in the European Parliament

On 13 July 2022, Autism-Europe organised the final hybrid international multiplier event of the AFS project in the European Parliament. The event was hosted by MEP Alex Agius Saliba and welcomed also by the Minister of Inclusion from Malta, Hon. Julia Farrugia Portelli.

#### **Autism Friendly Spaces Awards**

The project created the **Criteria for AFS Quality Label** and called on businesses and services to become a welcoming place for autistic people and their families, notably by training autism ambassadors. A variety of businesses and museums received the Autism Friendly Spaces Award.

Malta International Airport, National Museum of Archeology - Heritage Malta and McDonald's MIA are some of the Autism Friendly places awarded during the project. You can discover the videos that highlight the various way different spaces became autism friendly and how this achieved through the project on the AFS webpage.

In addition, the project has created an app, including map where you can find Autism Friendly Spaces in all partner countries.

> More information : www.autismfriendlyspaces.eu



### **Autism-Europe International Congress 2022:** A Happy Journey through Life

The 13<sup>th</sup> International Autism-Europe Congress is around the corner. Between the 7<sup>th</sup> and the 9<sup>th</sup> of October, our member, the JiM Foundation will host the 2022 Autism-Europe International Congress in the historical city of Kracow, Poland. Throughout these 3 days, more than 1300 participants will celebrate 'A Happy Journey through Life' with experts from around the world to promote a positive vision for autistic people and their families.

After Nice, France in 2019, the Autism-Europe Congress is back this year in Kracow, Poland. This is the first time that our Congress will be held in a hybrid format - participants, in addition to being able to join us at the ICE Kraków Congress Centre, the venue chosen for this edition, can also follow all contents of the Congress online with high quality access to sessions, presentations, workshops, discussion panels and more.

The chosen theme of the 2022 Congress is A Happy Journey through Life to highlight the importance of taking a lifespan perspective on autism research and practice, with the promotion of wellbeing for all being the focal point. The Congress has the ambition to showcase three perspectives on the newest scientific trends in the autistic community targeting researchers, practitioners, and autistic people, their family members and caregivers. Throughout the 3 days of the Congress, we planned a programme that promises to be diverse, inclusive and open to sparking constructive debates.

#### Friday, 7<sup>th</sup> October

After registrations, the first day of the Congress will start with the **Opening** ceremony at the Auditorium Hall of the ICE Kraków Congress Centre with welcoming speeches by representatives of JiM Foundation, Autism-Europe, Scientific Committee members and policy makers. Dr. Connie Kasari will then give a presentation about What is the research evidence for educational

programs delivered in schools?, opening the stage for many more talks featured on this year's programme. The day will unfold with two symposia about communication, healthy living and gender identity and autism; oral sessions about diagnosis, screening and school practices; and another keynote speech, this time given by Dr. Petrus de Vries with Ensuring research with relevance to local communities. The first day will end with a workshop on Autism and happiness: Mission (im)possible given by Peter Vermeulen, Belgium.

#### Saturday, 8<sup>th</sup> October

The second day of the Congress will begin with the Ukraine support session, dedicated to talks about wartime trauma, clinical approaches to autism and post-traumatic stress disorder for war victims, among other practical workshops. During the second day, we will be presented with 3 main speakers: in the morning, Ewa Furgal will give us a lecture on A focus on adults and empowerment, and in the early afternoon, Dr. Catherine Lord will share her knowledge with us about What do interventions in autism do and not do, followed by Dr. Emily Simonoff with a talk on Mental health interventions for children and young people on the autism **spectrum**. The second day's programme will be completed by symposia related to the support of families marginalised by ethnicity, culture, language, and finances; an oral session on mental

health; and a panel discussion entitled What are the foundations of Autistic flourishing? Later, to celebrate 'A Happy Journey through Life', we invite all participants to put on their best smiles on and join us at the Gala Dinner, the social event of this year's Congress.

#### Sunday, 9<sup>th</sup> October

The final day of the Congress will open with two inclusive symposia about Better mental health and wellbeing for autistic people and their families and Building positive peer relationships in schools. Targeting researchers, practitioners, and autistic people, their family members and caregivers, an oral session focusing on Transition into adult life of people on the spectrum will also be given on the Theatre Hall of the ICE Kraków Congress Centre. Later, Stephen Shore will present an interactive workshop on Developing skills in Self-Advocacy and Disclosure for Autistic People. The third day of the Congress also counts with two keynote speakers: Dr. Brian Boyd with a talk on Reconceptualising repetitive behavior in autism and Dr. Isabel Dziobek with a A future look at the potential for technology to improve the lives of autistic people. The Congress will end with the Closing Ceremony where the city that will host the Autism-Europe Congress in 2025 will be announced.

Congress Registration



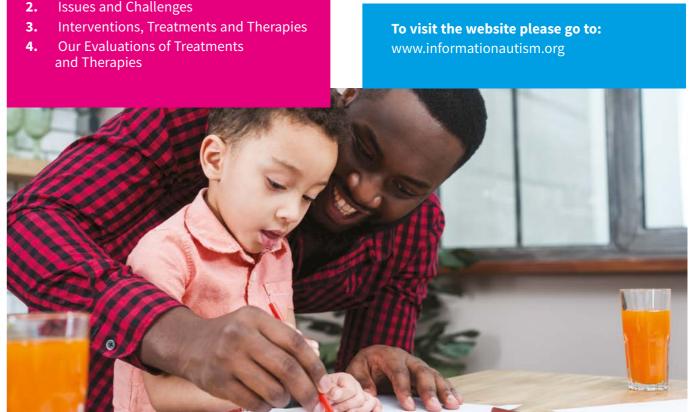
This summer, the John and Lorna Wing Foundation launched the "Information Autism" websitewww.informationautism.org. It provides impartial, scientifically accurate and accessible information on autism and interventions designed to help autistic people. It is aimed at anyone with an interest in autism, including autistic people, families, parents and carers, professionals, researchers, service providers, policy makers and the mainstream media.

Information Autism replaces the former Research Autism website, and aims at providing the public with information about autism and related issues. This website provides up-to-date, scientifically reliable information about autism. It includes information about a wide range of treatments, therapies and services used to help them. It also includes information about some of the issues, problems and challenges that autistic people may face.

The website has been designed to act as a gateway to some of the other resources on autism around the world. Information Autism also includes a Glossary section as well as a Publications and Links section. All information is provided in EasyRead and Text Version making the website accessible.

#### You can find four main information categories in the website :

- **1.** Autism, Definitions, Diagnosis
- **Issues and Challenges**
- and Therapies





### **INFORMATION AUTISM**

#### About the intervention section

Information Autism was set up to provide an objective evaluation of the scientific evidence behind the most commonly used interventions.

Here you can find information about a wide range of interventions, including what they are, what they are supposed to achieve and whether there is any supporting scientific evidence behind them.

The objective is not to prove or disprove a given intervention, but rather to report on the scientific evidence behind each intervention, irrespective of whether that evidence is positive, negative or mixed. The website provides information on educational, medical and other types of interventions.

Please also note that descriptions and evaluations do not constitute a recommendation about whether or not an intervention is suitable for a particular autistic person. That is a decision for the autistic individual (and/or their carers, clinicians and others) to make.

### **Discover our #AutismDay2022 campaign:** 'A Happy Journey through life'

In early 2022, Autism-Europe launched its on-going #AutismDay2022 campaign "A Happy Journey through life", in line with the motto of AE's 13th International Congress. The campaign promotes a holistic approach to ensure that autistic people can live fulfilling lives.

AE collected **testimonies and experiences** from autistic people and their families on what happiness means to them and how they would like society to change to become more inclusive for autistic people. Their messages were widely shared on social media to highlight the needs of the autistic community particularly during April, autism awareness month.

AE has also disseminated key **policy messages** through different channels (including social media) highlighting what needs to change to promote happy and fulfilling lives for autistic people and their families. We underlined the needs of autistic people in relation to various policy priorities, at the EU, national, regional and local levels to engage with and reach out to policy-makers.

AE and its members raised awareness of various issues such as access to education, health, employment, social inclusion, community support services, etc. At the EU-level, ensuring that the implementation of the new Strategy for the Rights of Persons with Disabilities 2021-2030 and the European Pillar of Social Rights Action Plan take continuously into account the needs of autistic people is central to our advocacy work.

To realise their right to education, autistic learners should have access to individualised support based on their evolving capacities

#AutismDay2022

We were impressed by all the submissions received for the art competition! This contest gave autistic people and their supporters the chance to show through art what happiness means to them. We would like to thank all those who participated in the competition and sent their artistic pieces. The winner was David McLaughlin and his beautiful paintings, which actually illustrate the cover of this magazine.

a Autism





### **ContrataTEA: a link between** socially responsible companies and autistic people looking for a job

Employment is a fundamental factor to improve the quality of life and inclusion in society of any person in addition to being an essential element to enjoy adult life with autonomy and independence. However, between 76% and 90% of adults on the autism spectrum are not in employment (Autism-Europe, 2019).

The contrataTEA project emerged in 2017 to try to improve the unfavourable situation faced by autistic people regarding access to the labour market. Three confederations representing autistic people in Spain joined forces: Confederación Autismo España, FESPAU and Confederación Asperger España and began to work together on this common goal. Since then, the project has been developed thanks to funding from Fundación ONCE.

#### Which objectives are pursued by contrataTEA?

Since it began, contrataTEA has positioned itself as an intermediary that facilitates communication between people on the autism spectrum and companies, nurturing relationships that benefit both the collective and the business sector. To achieve this, we work through several lines of action:

- · First, training the professionals of the employment services of the social federations, associations and foundations that work with autistic people.
- Secondly, sensitising and raising awareness within companies to promote labor inclusion and facilitate the incorporation and maintenance of jobs for autistic people.
- And finally, transversally with the two previous objectives, contrataTEA tries to explore and find innovative solutions to address the high rate of unemployment and the lack of job stability for adults on the autism spectrum.

#### Training the professionals:

In relation to this first objective, we launched a training programme in 2023: Job coaching specialised in autism. With this programme. contrataTEA wants to offer practical and functional tools for associations to develop support units for the employment of people on the autism spectrum in the open labour market as well as training professionals in the field of autism designing programmes and methodologies for inclusion in employment.

Also, this methodology offsets a common theoretical framework for labour inclusion in all organisations that provide support to autistic people.

Logo of the project ContrataTEA

For the implementation of this training, we use different techniques, such as the reflexive reading of bibliographical texts, carrying out different practices grounded in reality, watching videos, personal work, forum participation and assessment of learning through evaluation questionnaires. In addition, students have personalised tutoring throughout the training, which is provided by associations and foundations with more experience in the field of supporting employment for people with autism.



#### Sensitising and raising awareness in companies:

Different materials and resources can be found on the project website, such as tips, videos, infographics and other tools. These materials offer information to the public on the different phases of an employment relationship: recruitment, selection processes, as well as starting and staying in employment.

The intention behind providing these resources is to underline that hiring an autistic person is not only a good opportunity for the employee to increase their autonomy and quality of life, but that people on the autism spectrum also have numerous skills and capabilities that make them excellent employees. Alongside their individual abilities, some traits traditionally associated with autism can give them a considerable advantage in the workplace. In addition, diversity in the company improves the work environment, enriching human capital and awakening the pride of belonging among the staff.

- Tips for the recruitment phase: recommendations are made to publish job offers that make it easier for qualified autistic candidates to submit their application. For example, autismfriendly job offers are those that are published in a clear, concise way, omitting information that is not relevant to the position.
- Tips for the selection process: job interviews can be a barrier for autistic people, since several factors directly linked to their condition might interfere there: some autistic people may have trouble understanding body language, eye contact information to provide, abstract thinking or answering hypothetical questions. Also, the waiting times and facing new environment mean a source of added stress. Some useful tips for this process may be to anticipate the conditions of the interview (protocol for accessing the place of the interview, possibility of waiting times...), conducting the interview in a quiet room, away from noise, intense smells, dazzling lights and distractions. In addition, it is recommended to use a clear, explicit, direct and assertive language. Exploring other alternatives to the interview such as an on-the-job test or requesting a sample may be a good idea.
- Tips for hiring a person on the autism spectrum: information is provided in an attractive format so that companies can learn that the first adaptation of the position for the autistic person can be done by the personal job coach, in collaboration with the work centre, depending on the characteristics and skills of each person. These adaptations are always flexible, so they can be changed or even removed altogether, according to the support needs of the autistic employee. Collaborating with the rest of the team at work in this process will be of great help.

#### **Exploring innovative solutions:**

Finally, *contrataTEA* tries to find new solutions and innovative ways of increasing companies' interest in meeting people on the autism spectrum. Specifically, in 2022 we have participated in a Design thinking process, for which we have had diverse profiles: professionals from associations who work with autistic adults, representatives from companies and autistic people who already have a job or are looking for one. Design thinking is a method for generating innovative ideas that focuses its effectiveness on

understanding and providing solutions to people's real needs. The objective of this methodology is, through the participation and collaboration of all relevant stakeholders: to manage to collaboratively generate the "hows" that allow concrete actions that contribute to increasing the employability of autistic people. Having worked together for several months trying to find new ways to answer that question, we hope that we will be able to launch new and original projects very soon.



By encouraging empathy, you can promote the participation of your employee with ASD



For more info, job offers for autistic people and other resources, please check out **our website:** https://www.contrataTEA.es/

# The **Brick-by-Brick**<sup>®</sup> programme

### **Developing skills and building friendships** through collaborative LEGO® play

"When you make friends at Brick Club you know them for the rest of your life" - Thomas, age 10, Brick Club member

> For children such as Thomas, coming to Brick Club is a highlight of their week. Run at school or in clinic settings, Brick Club is a playful, child-led group programme designed to support autistic children to have positive social experiences and develop a range of skills through collaborative LEGO® play.

Play Included C.I.C. is a social provider in the UK that upholds the principle that play has the power to help all young people grow. In partnership with the LEGO Foundation, Play Included have developed the Brick-by-Brick® programme training for professionals who wish to run Brick Clubs with the children and young people they support. With a strong focus on neurodiversity and learning through play, the Brick-by-Brick<sup>®</sup> programme focuses on building on a child's strengths and supporting skill development in a playful and enjoyable way.

#### What is the **Brick-by-Brick**<sup>®</sup> programme?

The Brick-by-Brick<sup>®</sup> programme represents the latest thinking in supporting autistic children through LEGO<sup>®</sup> play. The methodology was developed for autistic children or any child who might need support with social

and emotional wellbeing. In Brick Club, young people work together as a team to build LEGO sets or freestyle creations. Brick Club sessions are delivered by health and education professionals who have received training in the Brick-by-Brick programme methodology where the focus is upon playful facilitation.

The programme is carefully designed to support young people to have enjoyable and meaningful social experiences, using skills such as collaboration, communication and problem solving. The programme can be adapted to support a wide range of strengths and needs but tends to work best for children and young people who use words to communicate, who are able to work with LEGO bricks and are motivated to build with others.

The Brick-by-Brick<sup>®</sup> programme builds on the methodology of what was previously known as LEGO based therapy. Whilst building LEGO<sup>®</sup> sets in different roles together remains a significant part of the programme, the Brick-by-Brick







programme methodology advocates for more than children building a LEGO® set as an Engineer, Supplier or Builder. Contrary to much existing thinking about the format of Brick Clubs, group sizes can vary from just 3 young people to much larger groups with everyone working in sub teams on a particular project. Children are encouraged to make decisions about what to build, and they can help each other by looking at the instructions together and support each other to find the pieces and put them in the correct position. Young people can also choose to create their own models together, without following set instructions, using their creativity and imagination. The goal of Brick Club is to create an environment where children experience learning through play in an inclusive and relaxed setting which supports children's saocial and emotional wellbeing. While Brick Club supports developing cognitive, emotional and social skills, it is equally important that children feel confident, capable, and empowered.

#### What are the benefits of **Brick Club?**

"I've definitely made lots of friends with everyone that goes to Brick Club and it's helped me make friends outside of Brick Club" – Ben, aged 10

In Brick Club, children and young people come together with others who share similar experiences and interests. Young people can be themselves, meet others who share an interest in LEGO<sup>®</sup> building, and start to experience positive social relationships. Over time, this may lead to long-term friendships and a sense of belonging. As young people begin to feel more confident and develop their skills, they start to feel less anxious in a group situation and their sense of agency and self-esteem improves.

One of the best things about Brick Club is that children enjoy attending. It's motivating and fun to build LEGO® models as a team. Being in a relaxed, accepting and low-anxiety space means that children often don't feel stressed at Brick Club. This means it's easier to play together with others: collaborating, sharing ideas, communicating and problem-solving.

Academic research has demonstrated this methodology shows promise to support social development in autistic children (e.g. Linsay, Hounsell & Cassiani, 2017). A recent large scale randomised control trial in the UK has found the approach to be cost-effective (Wang et al, 2022) with high levels of acceptability from parents and teachers (Barr et al., 2022).

"Brick Club is an amazing programme that allows your child to develop skills in a small group and then take those skills with them into their everyday life" - Alison, parent

#### **Brick-by-Brick**<sup>®</sup> programme Training for professionals

"The training was so easy to navigate and informative. I cannot begin to share how excited we are about having this programme at our center!' - Director, Social Minds Center, Florida, USA

The best outcomes for children happen when Brick Clubs are run by well-trained professionals, who have a playful attitude and who feel relaxed and confident with the methodology. It is important that Brick Clubs are child-led and facilitate children building on shared interests and common goals. Skilful facilitators spot opportunities for playful learning without disrupting children's flow. The facilitator learns when to hang back, allowing young people to work together and figure out solutions to challenges by themselves, guiding only where needed. To do this well requires specialist training and support.

With this in mind, Play Included have developed a Brick-by-Brick<sup>®</sup> programme training pathway for health and education professionals. The Level 01-Initiate Course is a self-paced online course, covering all the background and basics in the Brick-by-Brick programme methodology. It also includes a module on neurodiversity, developed by neurodivergent consultants, which introduces the concept of neurodiversity, and provides new facilitators with an opportunity to expand their understanding and expectations of different ways of being. A neurodiversityinformed approach can help enrich professional practice and improve access for people with all kinds of difference. The Level 02- Facilitator Course is a face-toface course focusing on experiential learning of playful facilitation. The training courses build on each other to deepen learning and develop the skills of professionals over time.

The initial pilot and the online and face-to-face facilitator training have been evaluated by AT-Autism, an experienced, independent, specialist organisation, providing a range of autism -related services, including rigorous programme evaluation. Following the pilot programme, children and parents reported increased friendships,

confidence, comfort in groups, agency, calmness, and happiness, and a reduction in distractibility and worries after their child attended Brick Club. On the Facilitator training, evaluation reported a high level of satisfaction from attendees, who rated it as effective, interesting, and accessible. They also reported that their expectations had been fully met, and for 60% of attendees, they had been exceeded. They said that following the training they felt more confident, competent, and motivated, and regarded the training as essential in carrying out the role effectively. All training attendees said they would recommend it to others.

Evaluation is ongoing and will continue to involve the experiences of the children and young people, their families, and the facilitators. Evaluation is an essential, and inbuilt component of the programme going forward, as Play Included are committed to the continuous improvement that this participatory approach offers.

#### **Free Resources for** Home and School

The Brick-by-Brick<sup>®</sup> programme is designed to support friendships and peer relationships outside of the home, but LEGO<sup>®</sup> bricks can be used creatively to support wellbeing, relationships and play in the home too. Play Included have developed free Play at Home LEGO® building activities for families, all of them designed to be relaxing, fun, and playful for everyone. They also have free Building Friendships LEGO activities for schools to support social and emotional development for the whole class.

Dr. Gina Gomez de la Cuesta, Director, Play Included C.I.C. Mx Sonny Hallett, Neurodiversity Consultant Professor Richard Mills, Associate Consultant and Adviser to the Board, AT Autism Dr. Margaret Laurie, Research & Evaluation Lead, Play Included C.I.C. Dr. Jean McPherson, Senior Psychologis and Programme Lead. Play Included C.I.C.

#### Find out more

If you are interested to find out more about the Brick-by-Brick® programme, please visit the Play Included website at :

playincluded.com



### **Help Autism Association** is the largest organisation in Romania dedicated to help children and teenagers on the autism spectrum

The central aim of the Help Autism Association is to improve the quality of life and the transition to adulthood of autistic children and teenagers. Its mission started in 2010 and it now supports over 3000 people in therapy at multiple day centers and at their homes. For this purpose, this association counts with a team of more than 60 specialists, among them psychotherapists, speech therapists, physiotherapists, social workers, fundraisers, ambassadors of the cause, and volunteers. Our new member, Help Autism, is actively engaged with the following activities:

#### 1. Diagnosis and evaluation

 Help Autism seeks to contribute to the "National Program for Early Detection of Autism Spectrum Disorder and related disorders" in Romania. After children and teenagers are referred to a psychiatrist by family physicians, Help Autism invites them to obtain a complete, free diagnostic and evaluation programme. In this phase, Help Autism team applies all necessary tests to assess the levels of impairment.

#### 2. Therapy planning

• Experienced specialists draw up personalised therapeutic programmes and recommend a mix of therapies specific to each child or teenager on the autism spectrum.

• At Help Autism, an autistic child or teenager is then enrolled in individual therapy to learn ABA in stages and to provide the building blocks for other forms of intervention as HELP Logo for speech therapy, HELP Kineto for movement therapy or socialisation activities.

#### 3. Family School

· Family involvement is perhaps the most important criterion in the development of autistic children and teenagers after therapy. The Family School is a mandatory programme at Help Association and includes: the ABA course, active participation in the therapy, and monthly workshops designed for the needs of the parents.

#### 4. Information and support

• Help Association knows how hard the road into the unknown is. For this reason, this association assembled the Help Family Support, a team of parents that provide information and assistance every step of the way to children and teenagers



with autism and their families. Help Association also offers free counseling with a psychologist to help parents support in a healthy way the special needs of autistic children and teenagers.

#### 5. Financial support and social assistance

• Therapy of autistic people can be one of the most expensive socio-medical routes. Help Autism social assistance specialists also support families to get a Disability Classification Certificate and understand the benefits, allowances, and incentives they can get and how to get them.

For the last 10 years, Help Autism has been aiming to improve the quality of life of autistic people from an early age and increase awareness on autism. From a wide range of dissemination campaigns, this association is a co-organiser of the ABA International Conference, a unique yearly event in Southeast Europe and has been involved in projects of the cause financed by national and international bodies. In 2020, Help Autism created the Help Home project - aiming to develop independent life abilities for adolescents and young people with autism.

#### Do you want to know more about **Help Autism Association?:**

www.helpautism.ro Website : Facebook: www.facebook.com/helpautism.ro **Instagram :** @helpautism\_romania Youtube: www.youtube.com/channel/ UC1dsbevofrWB2u2NXsnoh w

#### **Help Autism Association**

is an associated member of Autism-Europe

#### **Member Associations of Autism-Europe**

#### **FULL MEMBERS**

#### National associations of autistic people and parents

#### ANDORRA

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#### **BELGIUM**

#### **Association Pour** l'Epanouissement des Personnes

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#### **Vlaamse Vereniging voor Autisme** (V.V.A.)

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#### ICELAND

Einhverfusamtökin Haaleitisbraut 11-13 IS - 108 Revkiavik Tel: +354 562 1590 E-mail: einhverfa@einhverfa.is Website: www.einhverfa.is

#### IRELAND Irish Society For Autism (I.S.A.)

16/17 Lower. O'Connell Street IRL - 1 Dublin Tel: + 353.1.874.46.84 Fax: + 353.1.874.42.24 F-mail: admin@autism.ie Website: www.autism.ie

#### **Autism Spectrum Information Advice** and Meeting Point (AsIAm)

17-21 Temple Road Blackrock / Co Dublin A94DN40 Email: info@asiam.ie Website: https://asiam.ie/

#### ITALY ANGSA APS Onlus

Via Casal Bruciato 13 00159 Roma E-mail: segreteria@angsa.it Website: angsa.it

#### LITHUANIA

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#### MALTA

Autism Parents Association (APA) P.O.BOX 30 Marsa MTP 1001 Website: http://www.autismparentsassociation.com/ Email: autismparentsassociation@ gmail.com

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Website: www.sposa.sk

#### SPAIN

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#### **Autismo Burgos**

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