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IPA+

Autism- training for inclusion

Module 1: Introduction



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1. Introduction to the IPA+ Project

What

- The project “**IPA+, Inclusion of people with autism in Europe. Towards a specialized training model for professionals**” aims to empower diverse types of professionals at different moments of their professional career, promoting new skills and competences to address real gaps in the current labour market.

Why

- The main objective is to develop a basic training of reference for all professionals working with people with autism – regardless their area of knowledge – which responds to those training gaps within the target countries, as well as the demands of society in general and of this group of population and their families.

How

- The training to be developed and tested under IPA+ will have a lifelong perspective, following an evidence-centred approach, and the contents will be based on scientific advances and outputs.

Who

- The project brings together academics, multidisciplinary professionals, parents and self-advocates from various autism organisations across Europe. Those involved come from various backgrounds – both national and cultural – and have a wide set of skills.

When

- Running from September 2016 to August 2018, the project is funded by the European Commission’s Erasmus + Programme.

2. Participants

- **University of Valencia** (UV, Spain) – Project Coordinator
- **Federação Portuguesa de Autismo** (FPDA, Portugal)
- **Autizam Srbija**- Savez udruzenja Srbije za pomoc osobama sa autizmom (SSA, Serbia)
- **Autism-Europe** (AE, Belgium)
- **Autismo Burgos** – *Asociación de padres de personas con autismo* (AB, Spain)

University of Valencia - Polibienestar

Who

- Polibienestar is a Public Research Institute belonging to the University of Valencia. It is specialized in research, innovation and social technology, technical advice and training in the field of public policies.
- Polibienestar is composed by an interdisciplinary team with 34 senior and 24 junior researchers with national and European experience. These researchers come from 9 national universities and 2 International ones.

Vision, mission and values

- Its vision is the improvement of welfare, sustainability and quality of life of society.
- Its final mission is to work for a higher efficacy and efficiency of public policies through innovative, comprehensive and interinstitutional proposals with an interdisciplinary approach.
- Values: Equity, transparency, equality, quality, independence rigor and ethics.

Expertise

- Polibienestar develops interdisciplinary research applied in social sciences.
- Polibienestar has a large experience in European funds with more than 30 projects under different programmes of the European Commission, such as, such as VI and VII Framework; Ambient Assisted Living (AAL); II and II Health from the DG Sanco; or Erasmus+.
- Polibienestar is members of Fundación Miradas within the framework of the Chair “Miradas por el Autismo” (Sights for Autism) aimed to promote the rights of people with ASD and their families and to reinforce skills and competences of professionals working with them.

Federação Portuguesa de Autismo



FPDA - Federação Portuguesa de Autismo

WHO

- FPDA - Portuguese Federation of Autism is a non-profit NGO, founded in 2003/2004. It replaced APPDA founded in 1971.
- FPDA represents 12 associations member at national level and the Portuguese islands Azores and Madeira.

Vision, mission and values

- The mission of FPDA is the unconditional defense of the rights of persons with ASD and their families.
FPDA also represents its federated associations at national and international level.
- The values of FPDA are: Non discrimination; solidarity; Inclusion; Representativeness.
- The vision of FPDA is to be recognized as the Portuguese representative association of people with ASD.

Expertise

- FPDA is a member of the General Assembly of Autism-Europe.
- FPDA is a member of CMIPD (City council for disabled people).
- FPDA is a member of the council (Ministry of Education) for the evaluation and counselling of the Resources Centres for inclusion.
- FPDA is a member of the Social council in the Department of Psychology and Sciences of Education at Lusíada University.

Autizam Srbija



Who

- Serbian Society of Autism was established in 1977.
- 16 local associations operate within the Society, and this network is constantly expanding.
- Society is a parental, non-profit organization and all active members, parents and professionals are volunteers.
- <http://www.autizam.org.rs>
- Society is a member of National organization of persons with disabilities of Serbia and is a full member of Autism Europe.

Mission and objectives

- The mission of the Society is working on solutions for the rights of people with autism to:**
 - Adequate diagnostics
 - Education
 - Right to work
 - Quality medical care
 - Social care
 - Help their families
- Some of Society's objectives:**
 - 1.Respecting and practicing all adopted laws protecting the rights of people with autism.
 - 2.Greater education of health workers to treat illnesses that are not a consequence of autism.
 - 3.The inclusion of individuals and groups directly affected by autism (parents and associations) in the process of adopting laws, policies and decisions.

Principles

- SSA actions are based and legitimized by the next principles:
 - Autism is NOT:**
 - Autism is NOT a mental illness and should not be treated that way
 - Children with autism are not bad-mannered children with behavioral problems
 - Autism is not caused by emotional deprivation, e.g.. "cold parents syndrome"
 - It is true:**
 - People with autism are emotional
 - People with autism want to communicate
 - People with autism can be educated
 - People with autism can work

Values

- In the rehabilitation of people with autism, various evidence based treatments and therapies may be used. Rehabilitation consists of three requests:
- complexity (conducts the medical, social, vocational rehabilitation)
 - continuity (there must be an intensive period of rehabilitation implementation)
 - teamwork (cooperation of various profiles of experts in the rehabilitation).
- With different therapies, special education professional work, environment acceptance, and a lot of love, patience and care from an early age, it is possible to achieve a lot.

Services

- Representing the rights of people with autism and their families
- Providing advocacy services for people with autism and their families
- Empowering families of people with autism
- Educating parents and professionals
- Creating and implementing of support services
- Initiating opening of daily centers in the country (since 1989.)
 - Family assistant
- Advisory and therapeutic support and help line services for parents
- Help line
- Booklet for the exercise of the rights and procedures of people with autism and their families

Autisme Europe



WHO

Autism-Europe (AE) is an international association. We aim to **advance the rights of people with autism and their families** and to help them **improve their quality of life**.

Autism-Europe brings together over **80 associations of parents** of people with autism in **38 countries**, as well as **governments** and **European and international** institutions.

Vision, mission and values

AE's mission is to improve the quality of life of all persons with autism and their families in Europe.

AE's main objectives are, among others, to ensure full implementation and respect of the rights and the effective participation of people with disabilities.

Expertise

AE activities include:

- Influencing the European decision-makers to combat discrimination and foster inclusion
- Running initiatives to improve the quality of life of people with autism and their families
- Promoting scientific research on autism and evidence-based information on autism
- Exchanging best practices
- Raising public awareness

Autismo Burgos



Autismo Burgos
Federación Autismo Castilla y León

Who

- Autismo Burgos is a parental Nonprofit Association of social initiative founded in 1984, members of Autism Europe, Autismo España, Federación de Autismo Castilla y León
- Currently we have 223 clients and 99 professionals (Feb 2017)
- <http://www.autismoburgos.es/>

Mission and objectives

- Our **mission** is to improve the quality of life of people with autism and their families by creating, developing and optimizing the required services to meet their specific needs through the following **objectives**:
- Promote the integral development of people with Autism and maximize their abilities
- Encourage their social integration.
- Provide them with comprehensive, continuous, flexible and applied care in the least restrictive environment
- Defend the rights of people with autism and their families.
- Give support and advise to the families.

Principles

- Autismo Burgos actions are based and legitimized by the next principles:
- People with autism are full citizens to exercise all their rights.
- They must participate in their community.
- Their quality of life can be improved with suitable support.
- They need comprehensive and specialized care in every stage of development and every sphere of their lives.
- The Autism Spectrum Disorders have their own identity.

Values

- Coherence
- Asociativism
- Participation and team work between families, professionals and people with autism
- Compromise
- A fighting spirit
- Focused on people and their individual skills, interests and needs respecting their context
- Development of skills
- Professionalization
- Continuous improvement throughout assessment systems
- Innovative attitude
- Adaptation to change with openness and flexibility
- Transparency: accessible, accurate and reliable intervention in all processes.

Services

- Diagnostic Assessment and Guidance
- Family Support
- Special Education School for children with ASD “ El Alba”
- Day Centre for adults
- Housing Services “El Cerezo” and “El Olivo”
- Leisure Time Service
- High Functioning Services
 - Social Skills Program
 - Personal Assistant Service
 - Academic Support
- Capacity: Supported Employment
- Other activities: First Lego League, Tecnoarte
- Regional branches: Aranda de Duero, Medina de Pomar, Miranda de Ebro

3. Brief introduction to autism

What is autism?

- Autism is a lifelong disability that affects the way people perceive the world and interact with others.
- Symptoms are usually apparent from early childhood.

What does “Spectrum disorder” mean?

- Autism is a ‘spectrum’ condition, which means the symptoms affect individuals differently and to varying degrees, ranging from mild to severe.
- This spectrum includes a wide range of people who go from having significant intellectual disabilities and requiring a high level of support in their daily lives, to being of average to high intelligence and requiring a lower level of support.

What are the common symptoms?

- Difficulties with social communication and social interaction and restricted and repetitive patterns of behaviours, activities or interests.
- Sensory difficulties such as increased or reduced sensitivity to light, sound, colour, smell, taste or touch are frequent
- Sometimes, other disabilities and medical conditions can coexist

Is there a cure?

- There is no cure but there are treatments to help the person to cope with the individual challenges they face
- Research has demonstrated that the best treatments for people with autism are early and specialised behaviour-based therapies

What causes autism?

- Autism has a strong inherited basis and it may result from multigene interactions or from spontaneous mutations in genes with major effects.
- The interaction between genetic and environmental factors is also being studied
- it is not due to vaccines reaction, emotional deprivation or the way a person has been brought up

4. Prevalence

Over the past 30 years, the number of reported cases of autism has increased rapidly in all countries where prevalence studies have been conducted. This increase is partly a result of:

- increased awareness of autism among health care professionals, parents and the broader population;
- changes to the diagnostic criteria for autism;
- children being diagnosed at a younger age;
- demographic and geographical variables.

An estimated 1 in 100 people has autism across the European Union

Greater proportion
of males
4:1

5. Situation of Autism in the European Union

- The European Union and all but one EU Member State have ratified the United Nations Convention (UNCRPD) on the rights of persons with disabilities.
- It enshrines the rights of persons with disabilities in all areas of life.
- The EU ratified the UNCRPD in 2010, the first international human-rights convention ever ratified by the European Union
- Ratification lead the EU to develop its Disability Strategy 2010-2020 (EDS)
- It has led to a number of pieces of legislation relevant to autistic people, such as the European Accessibility Act (Regulating accessibility of products and services)
- The EU has also recently launched a Pillar of Social Rights to foster better respect of social rights and improve access to employment in the EU
- However, national approaches to autism remain mainly national competences and there is so far no general harmonization
- Access to diagnosis, education, support services, and independent living allowances vary greatly from one country to another.

6. Necessity of this course

- Taking into account the diversity of the profiles of people on the autism spectrum as well as the current approaches and intervention models which are restructuring support services and the role of professionals, a new educational strategy is needed to qualify professionals to support people with autism in the different contexts and spheres of life and throughout their lifetime.
- This course intends to address the training gaps that have emerged from this new framework improving the required competences and qualification of professionals working in the field of autism. Some of the identified gaps are:
 - Heterogeneous and dispersed educational offer with difficult geographic access.
 - Training characterized by being done separately from practice.
 - Low commitment of public and private organizations.
 - Training not fully satisfying expectations, especially in the case of people looking for a specialized training.
 - New learning formats, such as online courses, are perceived as an opportunity.

Biography

Autism and the United Nations Convention on the Rights of Persons with Disabilities (2011): Available at: <http://www.autismeurope.org/files/files/un-leaflet-2012-final-en.pdf>

Article: Legal Capacity of People with Autism: Available at: <http://www.autismeurope.org/files/files/Publications-2012/legal-capacity-for-people-with-autism.pdf>

Position paper on care for people with autism : Available at: <http://www.autismeurope.org/files/files/docpos08-uk.pdf>

“Todo sobre el autismo” capítulo 12 (2016): Available at: <http://www.bibvirtual.ucb.edu.bo/opac/Record/100024856/Details>

The autism "epidemic": Ethical, legal, and social issues in a developmental spectrum disorder.

[Graf WD](#)¹, [Miller G](#)², [Epstein LG](#)², [Rapin I](#)² (2°17): Available at: <https://www.ncbi.nlm.nih.gov/pubmed/28275086>

Other Links

Autism Burgos Ethic Code Guide. Available at: <http://www.autismoburgos.es/wp-content/uploads/2014/01/Resumen-Codigo-etico.pdf>

Self regulation strategies. Available at: <http://learninginaction.com/PDF/SRS.pdf>

About autism. An explanation by Autism-Europe: Available at: <http://www.autismeurope.org/about-autism/>

What is autism?: Video by the National Autistic Society: <https://www.youtube.com/watch?v=d4G0HTIUBII>

The IPA + Partnership



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