

AUTISM SPECTRUM: BARRIERS IN SOCIETY



CORSO INTERDISCIPLINARE DELLA SCUOLA SUPERIORE DI STUDI AVANZATI

BARRIERE FISICHE, VIRTUALI E
CONCETTUALI: RAGIONAMENTI SUI LORO
SIGNIFICATI DI IMPEDIMENTO, DIFESA,
LIMITE, IDENTITÀ

web.uniroma1.it/sssas

Rome, 19 January 2017
Aula Pasquini, Istituto di Zoologia, Sapienza



Pietro Cirrincione
self-advocate
Vice-president

Autism-Europe
Brussels, Belgium
AutismEurope.org

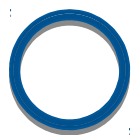


@autismeurope

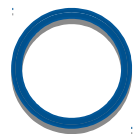


/autismeurope.AE

What is Autism-Europe?



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



Autism-Europe brings together over **80 autism associations** and hundreds individual members in more than 30 European countries, as well as **governments and European and international** institutions.

What is Autism-Europe?



European Economic and Social Committee
a bridge between Europe and organised civil society

Autism-Europe has established a structured **dialogue** with the **European Institutions** and is also active towards the **World Health Organisation (WHO)**.

Autism-Europe enjoys **NGO participative status** with the **Council of Europe** and, in July 2002, lodged a **collective complaint** with the **European Committee of Social Rights**, becoming the first disability NGO to undertake such action.

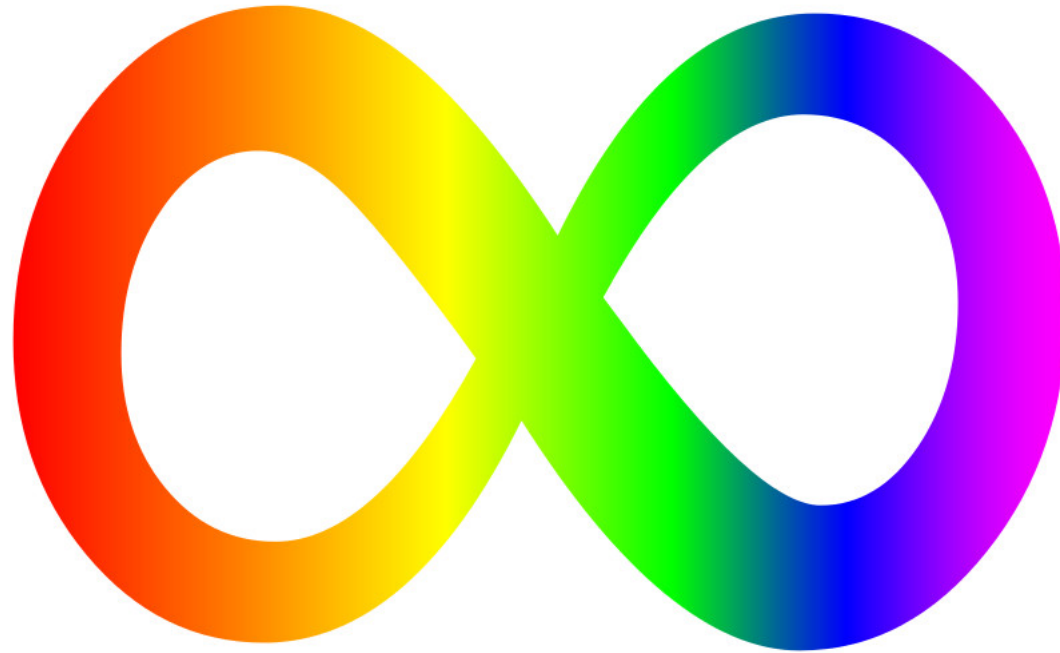
To maximise its impact on European Union policies, Autism-Europe also works in strategic alliances with other relevant organisations. Autism-Europe is a founding member of several international umbrella NGOs active in disability and social protection such as

- the **European Disability Forum (EDF)** of which it holds the Vice-Presidency,
- the **World Autism Organization (WAO)**,
- the **European Coalition for Community Living (ECCL)** and
- the **Platform of European Social NGOs**.



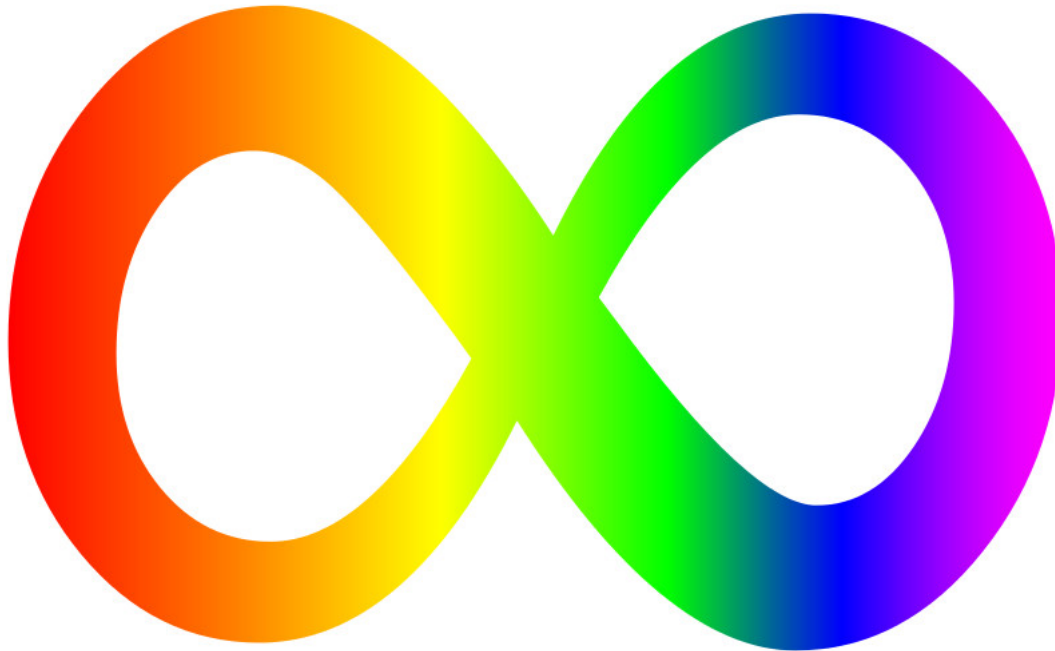
In order to implement its objectives and maximise its impact on EU policies, Autism-Europe has built strategic alliances with **European social partners**.

Autism spectrum is very broad



The rainbow-colored infinity symbol represents the diversity of the autism spectrum as well as the greater neurodiversity movement. An alternative to puzzle piece autism symbols, which are strongly disliked by many adults on the spectrum

Autism spectrum is very broad



Autism spectrum conditions can manifest as difference, disability or skills, from person to person and within the same person, depending on which social context this person is living too.

When you see one person on the autism spectrum, you have seen only one person on the autism spectrum.

Zoology and autism spectrum 1/2



This lesson is taking place in a classroom
dedicated to Pasquini in Zoology Institute

and coincidentally...

Pasquale Pasquini (1901-1977)
Prof. of Zoology at Sapienza University
Founder of Zoology Institute

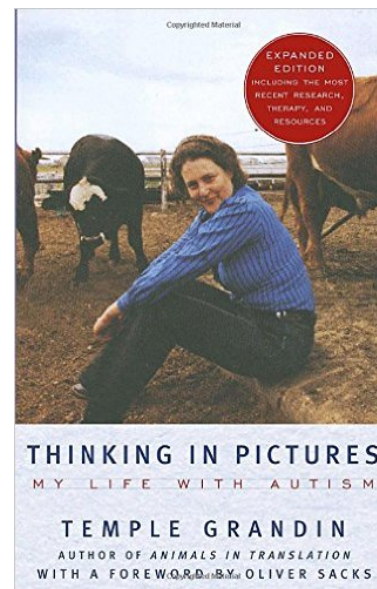
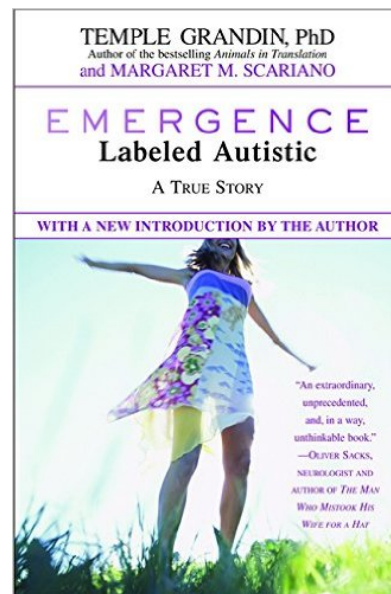
Zoology and autism spectrum 2/2



Temple Grandin (1947-), the most famous living woman on the autism spectrum

Prof. of Animal Science at Colorado State University

In North America, almost half of the cattle are handled in a centre designed by Temple Grandin



Skip to content Skip to navigation

Convention on the Rights of Persons with Disabilities (CRPD)

Convention

- Ratifications/Accessions: 172
- Signatories*: 160

Optional Protocol

- Ratifications/Accessions: 92
- Signatories*: 92

(* Signatories include countries or regional integration organizations that have signed the Convention and its Optional Protocol)



- **10th Anniversary of the adoption of CRPD: 2006 to 2016**
- **Infographic on the CRPD and the COSP** (prepared October 2016: ([Word](#), [PDF](#)))
- **Status of Ratifications to the CRPD** (prepared May 2016) ([JPG](#), [PDF](#)) (also available at the [UN Enable Facebook page](#))
- **Support Universal ratification of the CRPD**
- **The Convention in Brief**
 - [Guiding Principles of the Convention](#)
 - [Entry into Force](#)
 - [Monitoring of Implementation](#)

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The CRPD

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UN CRPD 2006-2016

Celebrating 10 Years of the Convention on the Rights of Persons with Disabilities

The Convention's aim is to “protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.”

The UN Committee on the Rights of Persons with Disabilities **monitors how countries** that have ratified the Convention **are doing** by reviewing them regularly and issuing concrete **recommendations** on how **violations** can be tackled and **rights** upheld.

<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPD10.aspx>



CRPD10YEARS

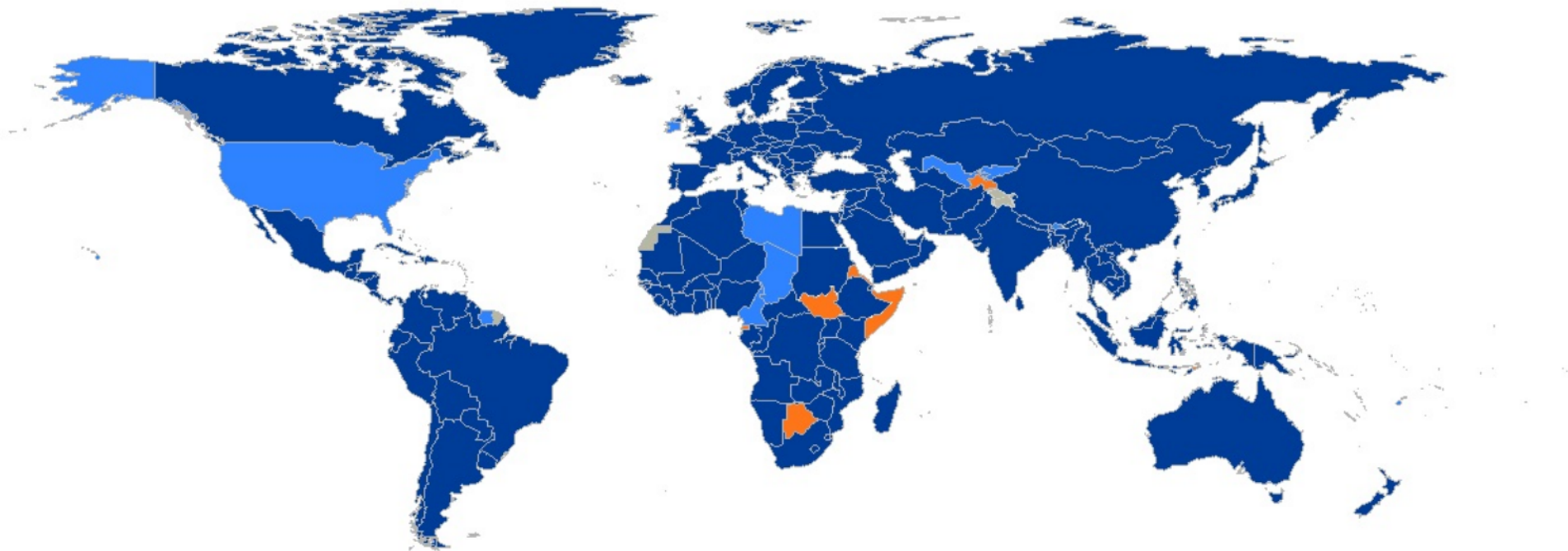
disability rights are human rights



CRPD 10
Convention on
the Rights of
Persons with
Disabilities
2006 - 2016

Convention on the Rights of Persons with Disabilities

Last Updated: 17 Jan 2017



Country Status

State Party (172) Signatory (15) No Action (11)

Definition and meta-data: <http://www.ohchr.org/Documents/Issues/HRIndicators/MetadataRatificationStatus.pdf>

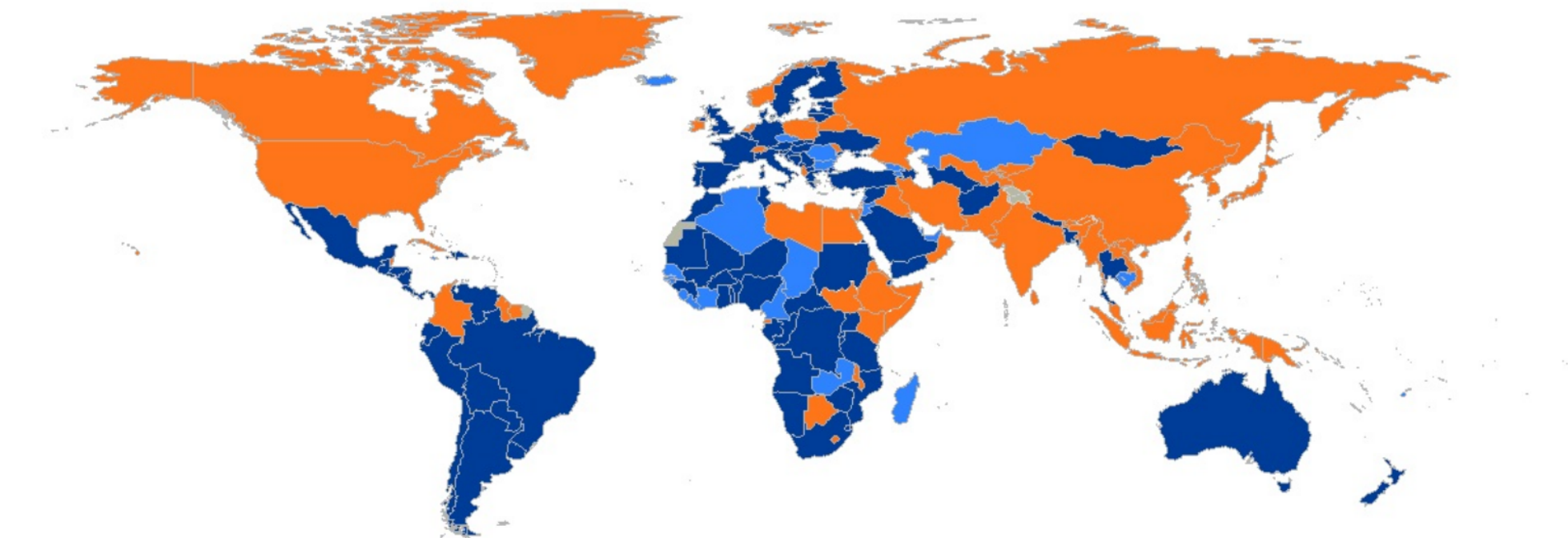
Source: Database of the United Nations Office of Legal Affairs (OLA) <https://treaties.un.org>

For application of treaties to overseas, non-self-governing and other territories, shown here in grey, see <https://treaties.un.org>

Note: The boundaries and the names shown and the designations used on these maps do not imply official endorsement or acceptance by the United Nations. Final boundary between the Republic of Sudan and the Republic of South Sudan has not yet been determined Dotted line represents approximately the Line of Control in Jammu and Kashmir agreed upon by India and Pakistan. The final status of Jammu and Kashmir has not yet been agreed upon by the parties.

Optional Protocol to the Convention on the Rights of Persons with Disabilities

Last Updated: 17 Jan 2017



Country Status

State Party (91) Signatory (28) No Action (79)

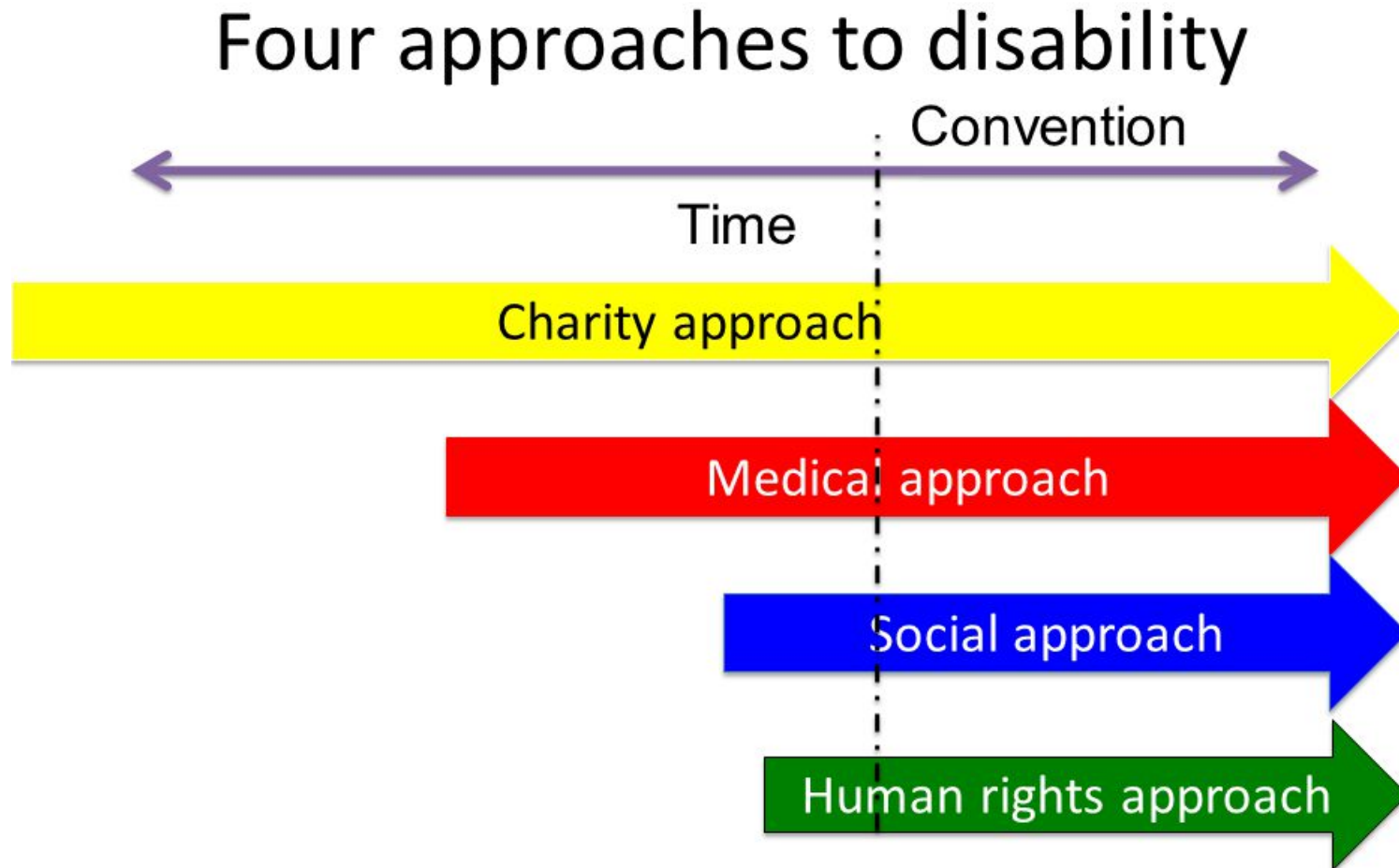
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Models for disability definition



UN CRPD: definition of disability

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various **barriers** may hinder their full and effective participation in society on an equal basis with others.

Article 1 - Purpose



CRPD10YEARS

disability rights are human rights



CRPD 10
Convention on
the Rights of
**Persons with
Disabilities**
2006 - 2016

European Union and UN CRPD

UN Convention on the Rights of Persons with Disabilities was **ratified by the European Union in 2010**, it is the **first** legally binding core international human rights instrument to which the EU is a party. Also ratified by all EU Member States, but Ireland.

It is the **first treaty** that allows for **continuous national oversight** of the human rights situation, differently from earlier UN human rights instruments.

In order to implement it, the EU adopted the **Disability Strategy** with **8 areas of priority**:

- Accessibility
- Participation
- Equality
- Employment
- education and training
- social protection
- Health
- External action



On 5 June 2014, the **European Union** published its **first report on the implementation of the UN CRPD**.

The report outlines **adopted measures**, but does not include an **assessment** of their actual **implementation** and of the **budget** available to do so. In this sense, it also lacks self-criticism.

The report presents a **too strict view of the competences of the EU** and of the actions in which the EU as a whole or the European Commission have been involved and have had impact on the rights of persons with disabilities.

The report **does not address the diversity** of persons with disabilities.

EU report on implementation

http://ec.europa.eu/justice/discrimination/files/swd_2014_182_en.pdf

EDF Alternative report on implementation

http://www.edf-feqh.org/Page_Generale.asp?DocID=13855&thebloc=34273

Autism-Europe Alternative Report

AE Alternative Report on the CRPD Implementation by the EU

Persons on the autism spectrum are **still discriminated** against in many areas of life, **even among persons with other disabilities**.

The **austerity measures** that have been adopted by EU Member States (Mss) to deal with the financial and economic crisis, including the shortage of appropriate and adequate services, support and reasonable accommodations to the particular needs of persons on the autism spectrum **have enhanced their discrimination, dependency** from others, **poverty** and **social exclusion**.

<http://www.autismeurope.org/files/files/autisme-europe-alternative-report.pdf>

European Accessibility Act

Published by the Commission on 02/12/2015.

Autism-Europe's position paper highlights the need for the Act to present **clear** and **precise accessibility criteria** for persons with disabilities, including autism spectrum.

Detailed requirements are necessary for the legislation to be properly transposed by the member states and to ensure efficient harmonisation of accessibility of goods and services throughout the EU.

It followed on from **recommendations** given to the EU by the United Nations Committee on the Rights of Persons with Disabilities **to swiftly adopt** the **European Accessibility Act** with the **participation** of **people with disabilities**.

<http://www.autismeurope.org/publications/newsletter-subscribe/newsletter-63-2016/autism-europe-welcomes-the-proposed-european-accessibility-act-and-issues-its-recommendations-3.html>



Communication barrier

People on the autism spectrum and intellectual disability have poor or **no verbal language**, they need **pictures and symbols**.

Augmentative and alternative communication (AAC) is an umbrella term that encompasses the communication methods used to supplement or replace speech or writing for those with impairments in the production or comprehension of spoken or written language.

In web accessibility you should avoid “**cognitive overload**” because often online services make cascading demands on cognitive resources, creating an overload that makes extrinsic and intrinsic cognitive processing unnecessarily difficult.



W3C and WCAG



The **World Wide Web Consortium (W3C)** is the main international standards organization for the World Wide Web.

Founded and currently led by **Tim Berners-Lee**, an English computer scientist, best known as the inventor of the World Wide Web.

The **Web Content Accessibility Guidelines (WCAG)** are published by the Web Accessibility Initiative (WAI) of the W3C.

They are a set of guidelines that specify how to make **content accessible, primarily for people with disabilities** — but also for all user agents, including highly limited devices, such as mobile phones.

The current version, WCAG 2.0, was published in December 2008 and became an ISO standard, ISO/IEC 40500:2012 in October 2012.

WCAG 2.1 will be published in 2018 and they will include also web accessibility for people with **cognitive and learning disabilities**



Barrier in school: Bullying



For Asperger syndrome the frequency of bullying in inclusive schools is of 75%, four times greater than neurotypical victims (Little, 2002).

For the entire spectrum in special schools the frequency varies 6-46%, on the contrary the frequency of aggressive attitudes of young in the spectrum is similar to that of neurotypicals (Van Roekel et al., 2010; Sterzing et al., 2012).

Bullismo e spettro dell'autismo

DOSSIER

Bullismo e spettro dell'Autismo

Pietro Cirrincione
Consigliere di Amministrazione di Autism-Europe come self-advocate
Vicepresidente del Gruppo Asperger onlus

10 **R**iporto il mio punto di vista sul problema del bullismo e lo spettro dell'autismo, situazioni che conosco bene in quanto ho la sindrome di Asperger e sono stato vittima di bullismo ed emarginazione sia nell'infanzia sia nell'adolescenza. La mia diagnosi è arrivata molto tardi, solo nel 2006, quando ormai avevo 35 anni, da quel momento mi sono attivato molto nel volontariato in questo campo insieme alle associazioni di famiglie e persone nello spettro, che rappresento a livello nazionale ed europeo.

Integro quindi il mio punto di vista con le esperienze di questi ultimi anni, confermate anche dalle ricerche della comunità scientifica.

Cos'è il bullismo

Il bullismo è un comportamento o atteggiamento violento, ripetuto nel tempo, contro studenti o giovani coetanei più deboli, non più considerati dai bulli come esseri umani, ma come oggetti da usare a proprio piacimento contro la volontà delle vittime.

Gli alunni e studenti che rientrano nello spettro dell'autismo sono terribilmente esposti al bullismo, costituendo delle vittime predilette dai bulli; per la sindrome di Asperger la frequenza di bullismo nelle scuole inclusive è del 75%, quattro volte maggiore rispetto alle vittime neurotipiche. (Little, 2002); per lo spettro intero nelle scuole speciali la frequenza varia dal 6 al 46%, al contrario la frequenza di atteggiamenti aggressivi di giovani nello spettro è simile a quella dei neurotipici (van Roekel et al.,

2010; Sterzing et al., 2012).

Il bullismo si manifesta sotto diverse forme:

- gli insulti e la derisione; costituiscono una violenza verbale o scritta (se su Internet);
- le aggressioni fisiche; sono spesso dolorose anche a seguito di poca forza esercitata a causa di un'eventuale particolare sensibilità tattile, frequente fra le persone nello spettro dell'autismo;
- l'aggressione verbale; spesso è dolorosa anche a causa di un'eventuale particolare sensibilità uditiva, situazione anch'essa frequente;
- le minacce, la manipolazione o l'emarginazione; costituiscono una violenza psicologica e sociale;
- l'imitazione e lo scimmiettamento; anch'esse una violenza psicologica.

Perché e quali fattori aumentano il rischio di essere vittima di bullismo

Una persona nello spettro dell'autismo può facilmente risultare agli occhi degli altri come strana o diversa, generando a volte uno stigma riconducibile alla disabilità o alla diversità in generale, producendo in alcuni casi discriminazione e intolleranza, soprattutto da parte di giovani arroganti e prepotenti.

Fra le tante conseguenze negative c'è il bullismo nelle scuole, che nell'età adulta ha come corrispondenti il mobbing e lo sfruttamento sul lavoro e l'emarginazione della società in generale. Le difficoltà delle persone nella parte alta dello spettro dell'autismo, a volte, non sono evidenti come quelle di chi ha anche disabilità intellettiva; per chi gli sta attorno è, quindi, difficile capire che sono in difficoltà e sono le ultime a ricevere aiuto o solidarietà. Di contro, tale inferiore evidenza, motiva di più il bullo a continuare perché si ritrova davanti una vittima che all'apparenza non dovrebbe esserlo e in più è meno pro-

Bullismo e spettro dell'Autismo Autismo Oggi N. 23 - novembre 2012, 10-13



AUTISMO OGGI

N. 23

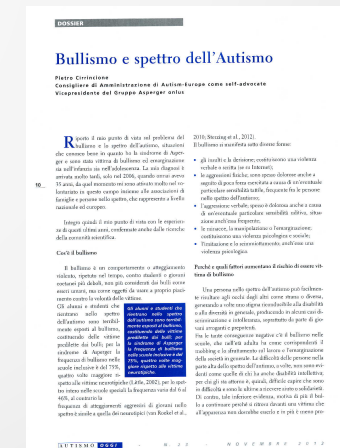
NOVEMBRE 2012

www.asperger.it/?q=bullismo

Bullismo e spettro dell'autismo

Le vittime: le loro vulnerabilità

- strane e diverse
- ingenuie e manipolabili
- con difficoltà non evidenti
- indifese e incapaci di chiedere aiuto
- non interpretano le situazioni
- non intuiscano il pericolo
- confusione gioco/violenza
- confusione pubblico/privato (molestie)
- incomprensione delle regole sociali
- mancanza di confronto con i coetanei
- senza amici



Autismo Oggi N. 23 - novembre 2012
www.asperger.it/?q=bullismo



Bullismo e spettro dell'autismo

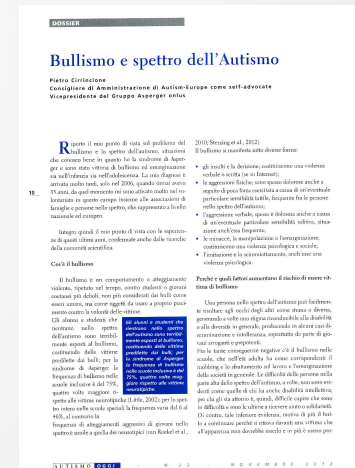
Situazioni a rischio

Situazioni non strutturate:

- poca sorveglianza del personale scolastico
- maggiore stress per gli studenti nello spettro
- le stranezze e diversità spiccano di più



Illustrazione di Marc Boutavant

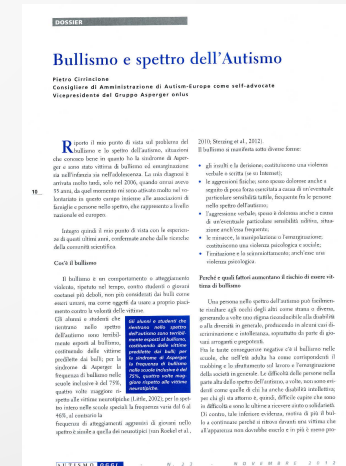


Autismo Oggi N. 23 - novembre 2012

Bullismo e spettro dell'autismo

Prevenzione: nei confronti dei bulli

- rimuovere disagio interiore
- guardare i compagni come essere umani e non oggetti
- rispetto dei sentimenti e dignità altrui
- trattare gli altri come vorresti essere trattato
- non punirli ma educarli (vero strumento di cambiamento)



Autismo Oggi N. 23 - novembre 2012

www.asperger.it/?q=bullismo



Bullismo e spettro dell'autismo

Prevenzione: nei confronti delle vittime

- diritto a non essere vittima
- spiegare le diverse forme di violenza
- ci sono persone che possono aiutare
- differenze pubblico/privato, intimo/non intimo, appropriato/non appropriato
- situazioni a rischio
- migliorare abilità sociali
- diagnosi corrette e supporto professionisti
- autoconsapevolezza (verso i 9 anni di età)



Bullismo e spettro dell'autismo

Prevenzione: nei confronti del contesto

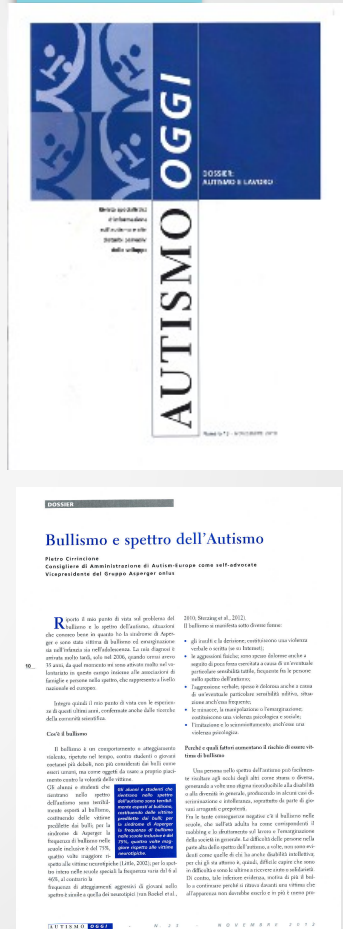
- sorveglianza da parte degli adulti
- soprattutto in situazioni non strutturate
- compagni: non isolare le vittime
- sensibilizzare i genitori
- sensibilizzare sullo spettro dell'autismo
- promuovere la cultura della diversità
- promuovere l'inclusione



Bullismo e spettro dell'autismo

Prevenzione: nei confronti degli insegnanti

- sorvegliare le vittime incapaci di segnalare
- sensibilizzazione sullo spettro dell'autismo
- promuovere la solidarietà fra i compagni
- stimolare i compagni a isolare i bulli
- educare i bulli





BEN X

IL FILM DEBUTTO
DI NIC BALTHAZAR

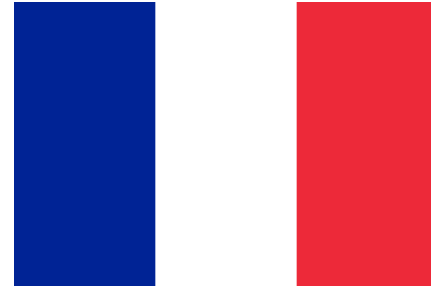
IL CORAGGIO È TUTTO

Ben X (2007), film drammatico diretto da Nic Balthazar
coprodotto in Belgio e Paesi Bassi www.benx.be

Autism-Europe vs France, complaint No. 13/2002



vs



Complaint presented to **European Committee of Social Rights** of Council of Europe for not satisfactorily implementing Art. 15§1 and 17§1 of Part II and Article E of Part V (**right to education**) of the **Revised European Social Charter** (1996)



European
Social
Charter

Charte
sociale
européenne



France did not provide sufficient education opportunities, facilities and services of an adequate standard or **quality** to children and adults with autism for both **mainstream education** as well as **special education**.

Autism-Europe claimed that the failure to take the necessary steps to ensure the **right to education** of children and adults with autism resulted in **violations** of:

- the **right** of persons with disabilities to **independence, social integration and participation in the life of the community**,
- the **right** of children and young persons to **social, legal and economic protection**
- the **prohibition on discrimination** because children and adults with autism did not enjoy the same level of education as other people

Assessment of the follow-up - Autism-Europe vs France

The **French Government states in 2014** that **three autism plans have been implemented** since the Committee's decision: 2005-2007; 2008-2010; 2013-2017.

As to **access to education**, the information gives several sets of **figures** relating to pupils with autism being educated in schools.

In order to assess whether the discrimination has come to an end, Committee asks for the information on the follow-up given to decisions that will be submitted in October **2017**, to state **what proportion of children with autism are educated** in general or specialist schools as compared to the proportion for other children, whether or not disabled.

The Committee finds that the situation has not been brought into conformity with the Charter.

<http://hudoc.esc.coe.int/eng/?i=cc-13-2002-Assessment-en>

UN CRPD art. 24 - Education

The lack of education can be challenged by the UN CRPD, since States Parties recognize the right of persons with disabilities to education and to effective individualized support.

Comments by AE on issues about art. 24 EU CRPD report:

Issues: to provide quality education and social development simultaneously

Solutions: inclusive mainstream education by qualified personnel and peer support

www.autismeurope.org/files/files/int-crpdcss-eur-21346-e.pdf#6



CRPD10YEARS
disability rights are human rights

UN CRPD art. 24 – AE Alternative report

- promotion of the use of ESF to fund the **training** of **school staff** on teaching and communication strategies for persons with autism;
- **monitor** the access to education of pupils with autism;
- collect comparable, disaggregated by disability, **data and statistic** across EU countries on access to mainstream school, to primary and secondary education, to vocational training and to employment of children and adults with autism;
- establish common **standards on the qualification** of support teachers and assistants for pupils and students with autism.

www.autismeurope.org/files/files/autisme-europe-alternative-report.pdf#21



CRPD10YEARS
disability rights are human rights

General Comments No. 4

General comment No. 4 (2016) on Article 24: Right to inclusive education

“[...] persons with disabilities are now recognised under international law as right-holders, with a claim to the **right to education without discrimination and on the basis of equal opportunities**. [...]

2 [...] Sustainable Development Goal (SDG) 4 also affirms **inclusive quality and equitable education**. [...] **only inclusive education can provide both quality education and social development** for persons with disabilities, and a guarantee of universality and non-discrimination in the right to education.

3 [...] **Many millions of persons with disabilities continue to be denied a right to education**, and for many more, education is available only in settings where they are isolated from their peers and receive an inferior quality of provision.”

<http://www.ohchr.org/Documents/HRBodies/CRPD/GC/RighttoEducation/CRPD-C-GC-4.doc>

Education in ITALY: milestones 1/2



1977 – Public **mainstream schools for all** students: no more special classes/schools

1992 – Law 104/1992 "**Framework Law** for the assistance, social integration and the rights of disabled persons": a very strong jurisprudence about **disabilities**, in some aspects strongest than UN CRPD

2005 – **Scientific Guidelines** about autism by Sinpia (Italian **Society** of Child and Adolescent Neuropsychiatry)

2007 – Autism **table** sponsored by the **Ministry of Health**

2008 – Founding of Fantasia (National **Federation** of autism spectrum **associations**)

2009 – Ratification of **UN CRPD** and Optional protocol

Education in ITALY: milestones 2/2



2011 – **Scientific Guidelines** about autism spectrum interventions in children and adolescents by ISS (**National Institute of Health**) and **stakeholders**

2012 – **Guidelines** on autism: Agreement between the Government, Regions and local authorities in the **Unified Conference of State and Regions**

2015 – **National Law** 134/15 on the autism spectrum: it places treatment for autism among the **essential services** provided by the Italian **healthcare system**. It also updates **guidelines for prevention, diagnosis and care** and promotes **research** in the field

2015 – Law 208/15 (Stability Law 2016) sets "**Fund** for the care of individuals with autism spectrum disorder" with an annual budget of 5 million Euros

2016 – Decree for the update of the **Essential Levels of Assistance** (LEA 2016): the **NHS** will ensure people on the autism spectrum: early diagnosis, care and individualized treatment, through the use of methods and tools based on the best scientific evidence; updating the guidelines every three years

Education in ITALY: situation



Inclusive mainstream school for all
but often there is **lack of qualified personnel**.

Problems:

- implementation
- public funds
- quality of training of support teachers

Limits hard to assure:

special teachers/students with disabilities = 1/2, 1/1 in some cases

special teachers hours/week = 9 to 25

students/students with disabilities needing intensive support = 20/1

Peer support

Some students in classroom become support for student with disabilities together teachers.

DISCRIMINATION

UN Special Rapporteurs call for an end to discrimination of people on the autism spectrum

Speaking ahead of World Autism Awareness Day in April 2015, United Nations human rights experts highlighted the **need to end discrimination** against people on the autism spectrum, and **celebrate diversity**.

In many countries people on the autism spectrum **lack access to services** which would support, on an equal basis with others, their right to health, **education**, employment, and living in the community.

When available, services are too often far from human rights friendly or evidence-based. Therefore, they asked for more accessible and inclusive services to be made available to people on the autism spectrum with urgency and on a global scale.

<http://www.autismeurope.org/publications/newsletter-subscribe/newsletter-60/un-special-rapporteurs-call-for-an-end-to-discrimination-of-people-with-autism.html>

Autism Spectrum Disorders in Europe is a new, trans-European programme involving university, charities and expert institutions to increase understanding of autism spectrum.

In ASDEU, Autism-Europe is responsible for:

- **assessing** health, education and existing social policies in Member States to support people on the autism spectrum from all ages, communities and affected families.
- developing a **public health plan** addressing autism.

Common challenges across many countries of the European Union were reflected in the literature review that was conducted, consultation and responses to the survey:

- Late or inadequate diagnosis
- Poor access to interventions
- Lack of proper lifelong education and vocational training opportunities
- Lack of social habilitation
- Lack of access to employment
- Social exclusion
- Lack of awareness

<http://asdeu.eu/>

Currently some Member States have **national autism plan or strategies** and some have **autism-specific legislations**:

- France
- UK
- Hungary
- Denmark
- Italy
- Ireland

Two countries are **developing strategy or legislation**:

- Spain
- Malta

In other countries, autism-recommendations are implemented via more mainstreamed instruments.

Hungary, Belgium



Hungary

After autism national strategic plan 2008-2013 they now have **professional figures** specifically trained about autism spectrum.

But it is still lacking quality of education and there are **still special schools**.

Belgium

Francophone Belgium in 2016 adopts an Autism Plan, a common, proactive **policy to improve the care and living** conditions of all individuals concerned (children, adults, families etc.).

The main objective is to enable **individualised and life-long support** and ensure **inclusion in society** through four common lines of action:

1. An inventory of the lack of solutions for people on the autism spectrum or dependency needs
2. The screening and the diagnosis of disability
3. Information and awareness
4. Training



<http://www.autismeurope.org/publications/newsletter-subscribe/newsletter-64-2016/francophone-belgium-adopts-an-autism-plan.html>



Autism Act 2009 is the first autism-specific legislation to be adopted in Europe

New mental health strategy for England announced for 2016-17

Development of a **“care pathway”** for autism which should help autistic people get a **timely autism diagnosis** and **accessible mental health support**.

Although autism is not a mental illness, many autistic people struggle with mental health problems, such as anxiety or depression, and rely on mental health services for support.

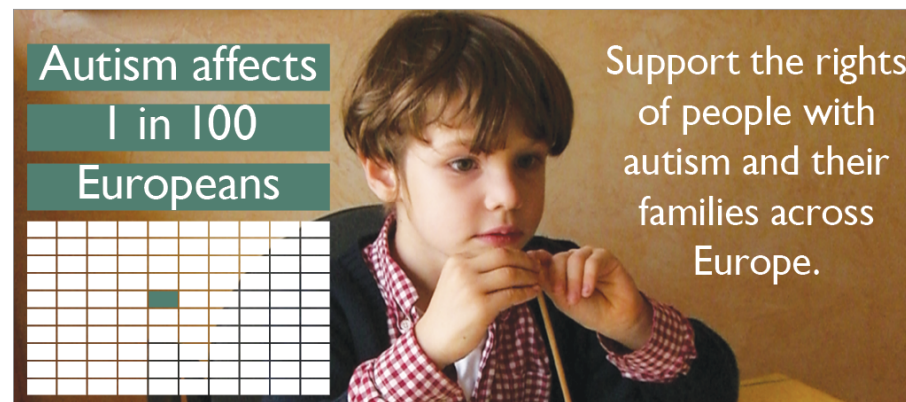
This is in large part in response to the National Autistic Society's diagnosis campaign.

<http://www.autismeurope.org/publications/newsletter-subscribe/newsletter-64-2016/new-mental-health-strategy-for-england-announced.html>

EP Written Declaration on Autism

In September **2015**, the European Parliament officially adopted the Written Declaration on Autism, co-signed by **418** Members of the European Parliament (**MEPs**).

The document calls on the European Union and its Member States to adopt a **European strategy for Autism**.



Sign the **WRITTEN DECLARATION ON AUTISM 0018/2015** for a European Strategy on Autism that will:

- Support accurate detection and diagnosis across Europe
- Promote evidence-based treatment and support for all ages
- Foster research and prevalence studies
- Encourage the exchange of best practices

Nicola Caputo (S&D), Enrico Gasbarra (S&D), Miriam Dalli (S&D), Marian-Jean Marinescu (PPE), Ivan Jakovčić (ALDE), Renata Briano (S&D), Peter Niedermüller (S&D), Maite Pagazaurtundua Ruiz (ALDE), Daniel Buda (PPE), Barbara Kappel (NI), Lampros Fountoulis (NI), Milan Zver (PPE), Ivo Vajgl (ALDE), Tibor Szanyi (S&D), Kostas Chrysogonos (GUE/NGL), Rosa Estarás Ferragut (PPE), Biljana Borzan (S&D), Marek Plura (PPE), Jose Blanco Lopez (S&D), Ivan Štefanec (PPE), Dubravka Šuica (PPE), Eleftherios Synadinos (NI), Demetris Papadakis (S&D), Igor Šoltes (Verts/ALE), Eduard Kukan (PPE), Eva Kaili (S&D), Momchil Nekov (S&D), Marlene Mizzi (S&D), Laurentiu Rebega (S&D), Mara Bizzotto (NI), Georgios Epitideios (NI).

The Written Declaration can be signed in Brussels in the office PHS 07C085/87 or in Strasbourg in the office LOW T02024. You can also sign, scan and send the attached form to WritDeclSign@europarl.europa.eu

<http://www.autismeurope.org/activities/world-autism-awareness-day/world-autism-awareness-day-2015-2/the-european-parliament-written-declaration-on-autism-2015/>

Barriers in sport

There is inclusion in sport for people on the autism spectrum, there are **Paralympic Games**, Special Olympics, but athletes on the autism spectrum are not easily categorized for competition, for ex. association football is especially for blind people and with cerebral palsy.

THE 2016 PARALYMPIC GAMES



AUTISTIC FOOTBALL CLUB



Inclusive football sport club of people on and out of the autism spectrum



AUTISTIC FOOTBALL CLUB



youtu.be/2o8XDM5eCD4

www.AutisticFootball.club

AFC wins Solidarity Football Festival tournament in Rome together Simone Perrotta, world champion in 2006 FIFA World Cup, 26 May 2016

THE SCIENTIFIC MONITORING

It is based on a Social Engagement Scale (SES), which unlike the Social Responsiveness Scale does not measure social skills, but the level of integration and inclusion in the social group (in this case the team) regardless of the social skills of the people involved. The SES has been developed by psychologist Orazio Russo of Farm Cooperative G. Garibaldi and Associate Professor Fiorenzo Laghi^[2] of the Department of Development and Socialization Processes of the Faculty of Medicine and Psychology of Sapienza University in Rome.

This observational test, still undergoing standardization, is the result of a study that has lasted five years in Farm Cooperative Garibaldi, to meet the needs of social and work inclusion of people on the autism spectrum needing very intensive support and then it was extended to all members of the social group including carers and professionals.

There is no literature about it even though there are some studies in social psychology that deal with engagement, but without measuring tools and more oriented to the observation of the contexts rather than the inclusion of individuals with characteristics that make them different from the social group^[3], in particular the aspect that concerns the sharing of objectives that is at the heart of the model has never been considered previously in the literature as a condition favouring inclusion.

Other studies using the same concepts relate largely the study of economics and marketing in reference to business strategy.

[2] <http://dip38.psi.uniroma1.it/en/node/6049>

[3] https://en.wikipedia.org/wiki/Social_engagement

SHARING SPACES	SHARING ACTIVITIES	SHARING OBJECTIVES	SOCIAL SHARING	EMOTIONAL SHARING
✓/he/she tolerates other known people to be in the same space ✓/he/she tolerates people in a distance of one meter ✓/he/she tolerates physical contact ✓/he/she tolerates the presence of strangers ✓/he/she tolerates to enter in unknown public places ✓/he/she tolerates to enter in places for together people that create specific difficulties	✓/he/she is able to follow a routine of playing and/or present activities ✓/he/she is able to follow a functional routine ✓/he/she is able to perform small activities within a consolidated routine ✓/he/she tolerates changes to consolidated routines ✓/he/she performs tasks upon instructions	✓/he/she follows the rules ✓/he/she completes a targeted activity in individual autonomy ✓/he/she performs targeted activities in coordination with peers ✓/he/she shows satisfaction in completing goal activities ✓/he/she proposes others ✓/he/she creates new strategies for making the group pursue the objectives	✓/he/she makes requests for help to complete a task ✓/he/she asks for attention to the reference person ✓/he/she asks for attention in group ✓/he/she shows his/her interests ✓/he/she shows interest in other conversations ✓/he/she starts conversations of mutual interest	✓/he/she shows response to situations that trigger emotional content ✓/he/she shows appropriate responses to situations that trigger emotional content ✓/he/she expresses obligations, his/her emotional certainty and personal experiences ✓/he/she tends to involve others in group situations ✓/he/she has gathered emotional experiences registered by peers ✓/he/she establishes reciprocal emotional interactions
0 never	1 sometimes	2 half the time	3 often	4 always

[oral poster V6A]

AUTISTIC FOOTBALL CLUB^[1]: INCLUSIVE FOOTBALL SPORT CLUB OF PEOPLE ON AND OUT OF THE AUTISM SPECTRUM

[1] AFC asd is for Autistic Football Club associazione sportiva dilettantistica (community amateur sports club).

BACKGROUND

The idea of setting up a community amateur sport club with the support of Gruppo Asperger Lazio onlus (a volunteer organization of families and people on the autism spectrum), Giuliaparla onlus (a cooperative of services) and Cooperativa Garibaldi (a cooperative of workers on the autism spectrum) is born from the football tournament organized in World Autism Awareness Day 2015 in Rome when one mixed team of people on the autism spectrum, voluntary carers and parents played.

MAIN POINTS

Team and community amateur sport club are composed of men and women, on and out of the autism spectrum, carers, family members and also people who don't deal with autism spectrum. Weekly trainings from October till June at SS Romulea, an accredited football centre. Monthly friendly matches, competitive tournaments, recreational activities, members meetings. The project also involves: professional football players and coaches; a team of people on and out of the autism spectrum that manages events communication; associations and cooperatives in the autism spectrum field.

CONCLUSIONS

The project applies UN CRPD article 30 for participation in recreation, leisure and sport and aims to future participation in competitive leagues and to include other persons on and out of the autism spectrum forming an adults team and a kids team.

RATIONALE

Most people of each age is involved because football is very popular, meeting point between carers and people on the autism spectrum. Being a team sport it naturally promotes social skills. Competitive sport fosters competition. A sport club gives a sense of responsibility, makes its members active, facilitating inclusion, self-determination, self-advocacy, autonomy. Inclusion is further enhanced joining FIFA regulations and not disability special ones. Sport promotes psychophysical well-being. Motor skills assessment administered by qualified personnel for explosive strength (standing long jump), elastic explosive strength (triple jump) and speed test (10, 20, 30 meters).



**XI Autism-Europe
INTERNATIONAL
CONGRESS 2016**
16 - 18 September 2016 EICC, Edinburgh, UK



AUTISTIC FOOTBALL CLUB



WWW.AUTISTICFOOTBALL.CLUB

info: 0039 349-715-3785



WATCH
OUR
VIDEO

ETHICS AND PERMISSIONS STATEMENT AND/OR DISCLOSURE OF POTENTIAL CONFLICT OF INTEREST. Author and co-authors pay for participating in the project, they are active in a voluntary manner, the support of associations and cooperatives covers sports materials and some of the costs of sports training.

AUTHORS

PIETRO CIRRICIONE, president and captain of AFC, he is on the autism spectrum; Vice-President of Autism-Europe asbl as self-advocate; Board member of Gruppo Asperger onlus and Gruppo Asperger Lazio onlus; he participates also to a project for including people on the autism spectrum in athletics

MATTEO GIAMMARUGHI, vice-president and player of AFC, Personal Care Assistant in Giuliaparla onlus

TOMMASO ARROTTA, board member and coach of AFC, manager of a social trattoria including workers on the autism spectrum; professional football coach and ex professional football player in the second national division of the Italian football league

GIUSEPPE LEVANTO, board member and player of AFC, Personal Care Assistant in Giuliaparla onlus

CONTACTS

WWW.AUTISTICFOOTBALL.CLUB / asd@autisticfootball.club
President Pietro Cirricione +39 349 715 3785
Vice-president Matteo Giammarughi +39 328 981 8530
Coach Tommaso Arrotta +39 348 920 7184

Operational Headquarters: via Farsalo 21 00183 Roma - Italy
Registered Office: via Alfredo Grandier 27 00134 Roma - Italy / Tax Number 9783020583

AUTISTIC FOOTBALL CLUB

Background

A mixed team of people on the autism spectrum, voluntary educators, parents and people who don't deal with autism is born in WAAD 2015 tournament with the support of:

- **Gruppo Asperger Lazio onlus** (a volunteer organization of families and people on the autism spectrum)
- **Giuliaparla onlus** (a cooperative of services)
- **Cooperativa Garibaldi**
(a cooperative of workers on the autism spectrum)

www.AutisticFootball.club



AUTISTIC FOOTBALL CLUB



Rationale

Football is popular, promotes social skills, psychophysical well-being, responsibility, inclusion, self-determination, self-advocacy, autonomy.



Inclusion enhanced by joining FIFA regulations and not disability special ones.

Motor skills assessment by qualified personnel.



AUTISTIC FOOTBALL CLUB



Scientific monitoring

It is based on **Social Engagement Scale** (SES), which unlike the SRS does not measure social skills, but the level of inclusion in the social group (in this case the team) regardless of the social skills of the people involved, with sharing of objectives as a condition favouring inclusion.

- The SES has been developed by psychologist Orazio Russo of Farm Cooperative G. Garibaldi and Associate Professor Fiorenzo Laghi of the Department of Development and Socialization Processes of the Faculty of Medicine and Psychology of Sapienza University in Rome.

Scientific monitoring

SHARING SPACES	SHARING ACTIVITIES	SHARING OBJECTIVES	SOCIAL SHARING	EMOTIONAL SHARING
a) he/she tolerates other known people to be in the same space	a) he/she is able to follow a routine of reinforcing and/or pleasant activities	a) he/she follows the rules	a) he/she makes requests for help to complete a task	a) he/she shows any reaction to situations that trigger emotional content
b) he/she tolerates people in a distance of one meter	b) he/she is able to follow a functional routine	b) he/she completes a targeted activity in absolute autonomy	b) he/she asks for attention to the reference persons	b) he/she shows appropriate reactions to situations that trigger emotional content
c) he/she tolerates physical contact	c) he/she is able to perform small activities within a consolidated routine	c) he/she performs targeted activities in coordination with peers	c) he/she asks for attention in group	c) he/she expresses adequately his/her emotional contents and personal experiences
d) he/she tolerates the presence of strangers	d) Transition among different activities	d) he/she shows satisfaction in concluding useful activities	d) he/she shares his/her interests	d) he/she tends to involve others in group situations
e) he/she tolerates to stay in unknown public places	e) he/she tolerates changes to consolidated routines	e) he/she praises others	e) he/she shows interest in others' conversations	e) he/she has welcomed emotional experiences expressed by peers
f) he/she tolerates to stay in places (or together people) that create specific difficulties	f) he/she performs tasks upon instructions	f) he/she creates new strategies for making the group pursue the objectives	f) he/she starts conversations of mutual interest	f) he/she establishes reciprocal emotional interactions



0 never	1 sometimes	2 half the time	3 often	4 always
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Main points



AUTISTIC FOOTBALL CLUB

Weekly trainings at SS Romulea, an accredited football centre. Monthly friendly matches, competitive tournaments, recreational activities, members meetings.

The project also involves:

- professional football players and coaches;
- a team of people on and out of the autism spectrum that manages events communication;
- associations and cooperatives in the autism spectrum field



AUTISTIC FOOTBALL CLUB



Conclusions

The project applies UN CRPD article 30 for participation in recreation, leisure and sport.

AUTISTIC FOOTBALL CLUB



We are participating in competitive leagues and aim to include other persons on and out of the autism spectrum forming an adults team and a kids team.

Self-advocacy



Self-advocacy

Self-advocacy is the **defence of their rights in first person** and refers to the civil rights movement of persons with disabilities, born from the larger civil rights movement of the '60s and '70s.

People with disabilities have the right to take control of their lives, talking for themselves, they can always ask for the support of others.

Self-advocacy and UN CRPD

“In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall **closely consult with and actively involve persons with disabilities**, including children with disabilities, through their representative organizations.”

Article 4, paragraph 3 of the Convention on the Rights of Persons with Disabilities

Report of the Special Rapporteur

Report of the Special Rapporteur on the rights of persons with disabilities

"37. The Convention on the Rights of Persons with Disabilities has accelerated the process of establishing **organizations of self-advocates** with intellectual disabilities, **of autistic persons** and of other individuals who may need extensive support to express their positions.

Organizations of parents and relatives of persons requiring support have often played a role in providing such support and one can find organizations that include parents as well as self-advocates. **The role of parents** in such organizations **should increasingly move towards the provision of support, with self-advocates in full control.**

States need to ensure that the will and preferences of persons with disabilities themselves are given **priority**.[...]"

http://ap.ohchr.org/documents/dpage_e.aspx?si=A/HRC/31/62

<http://www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/SRDisabilitiesIndex.aspx>

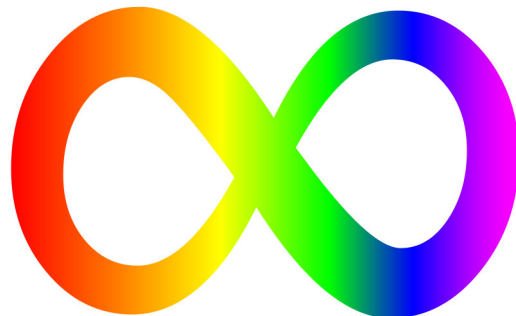
Neurodiversity

The definition of neurodiversity was formulated by the Australian Judy Singer, published on New York Magazine in 1998.

It is the idea that **we are all neurologically different**, that people on the autism spectrum do not have a disease but rather a **developmental profile** with a different cognitive development and a delayed social/emotional development, a unique set of characteristics, which can manifest as difference, disability, or gifts/skills, from person to person and within the same person.

Each person has the **right to develop in their own way and at their own pace**, not on the basis of what the outside world considers necessary developmental steps attached to specific physical ages.

Person centred is one of the keys to helping people believe in themselves.



Different point of view



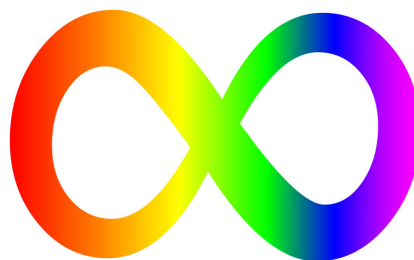
Acceptable language 1/4

On the principle of respect for diversity, it is important to use language that people are comfortable with. However, there are some terms that are likely to cause offense and that it is advisable to avoid using.

In 2016 the National Autistic Society (NAS), the Royal College of GPs and the UCL Institute of Education conducted a survey within the UK of people connected to autism, to enquire about preferences regarding the use of language.

Amongst British autistic adults, the term '**autistic person/people**' was the most commonly preferred term. The most preferred term amongst autistic adults, families and professionals was '**people on the autism spectrum**'.

<http://www.autismeurope.org/about-autism/acceptable-language/>

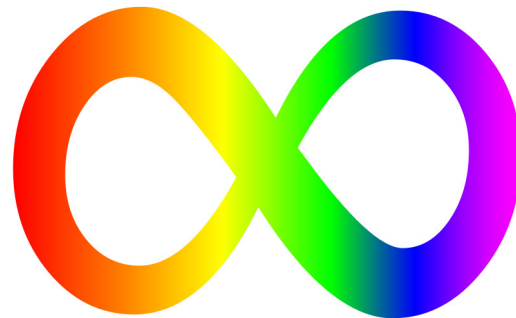


Acceptable language 2/4

Within Autism-Europe itself, to reflect this feedback from the UK, cater for a preference among native speakers of other European languages towards the term '**person with autism**' and in order to keep in line with the United Nations Convention on the Rights of Persons with Disabilities that utilises person-first language throughout, all three of the above terms are used interchangeably within our communications.

Some people refer to themselves and one another as an **autist** / **autie** / **aspie**. Whilst we accept that people may wish to refer to themselves and each other in this way, it is often less acceptable when used by a '**neurotypical**' person.

<http://www.autismeurope.org/about-autism/acceptable-language/>



Acceptable language 3/4

Terms/expressions that are likely to cause offense

1. Suffers from OR is a victim of autism: consider using the following terms instead:

- is autistic

- is on the autism spectrum

- has autism / an autism spectrum disorder (ASD) / an autism spectrum condition (ASC) (Note: The term ASD is widely used by many professionals, you may prefer to use the term 'autism spectrum condition' or 'on the autism spectrum' because it avoids the negative connotations of 'disorder'.)

2. Kanner's autism

3. "Asperger's syndrome is a rare / mild form of autism"

4. "Autism is a disease / illness": consider using the following instead:

- autism is a disability

- autism is a condition

<http://www.autismeurope.org/about-autism/acceptable-language/>

Acceptable language 4/4

5. retarded / mentally handicapped / backward: these terms are considered to be derogatory and offensive.

Consider using the following terms instead (where it is appropriate to do so):

- people with a learning disability
- people with a developmental disability
- people with an intellectual disability

6. normally developing children / adults: consider using the following terms instead:

- neurotypical (Note: This term is only used within the autism community so may not be applicable in, for example, the popular press.)
- typically developing children / adults

<http://www.autismeurope.org/about-autism/acceptable-language/>

European Strategy for Self-Advocacy

Autism-Europe is open to comprise members from the whole autism spectrum, including **organizations led by self-advocates**.

Informal meetings among AE members and local self-advocates groups are conducted regularly.

In 2015 during an AE board meeting, self-advocates held a workshop "Involving self-advocates" on how to ensure that autism organizations are representative of the whole spectrum

<http://www.autismeurope.org/files/files/conference-bcn-2015/involving-self-advocates-barcelona-03-05-2015.pdf>

In 2016 one self-advocate was elected as the vice-president of AE and one AE full member has chosen to have a self-advocate represent them for all AE meetings and activities.

In some European countries organizations led exclusively by self-advocates already exist for many years but none of them are yet AE members.

Publications, activities, meetings and governing bodies of autism organizations have to be **as accessible as possible by people from whole autism spectrum**, implementing UN CRPD, fulfilling in practice disability movement historical right:



World Autism Awareness Day

2 April

[UN Home](#)[Main Page](#)[Background](#)[2016 Observance](#)[Secretary-General's Message](#)[Call to Action](#)[Videos](#)[Resources](#)[Past Observances](#)[UN Observances](#)

"On this World Autism Awareness Day, I call for advancing the rights of individuals with autism and ensuring their full participation and inclusion as valued members of our diverse human family who can contribute to a future of dignity and opportunity for all."

Secretary-General Ban Ki-moon

2016 Theme: "Autism and the 2030 Agenda: Inclusion and Neurodiversity"

Autism and other forms of disability are part of the human experience that contributes to human diversity. As such, the United Nations has emphasized the need to mainstream disability in the Organization's development agenda. Mainstreaming disability requires an integral approach in the design, implementation, monitoring and evaluation of policies and programmes in all political, economic and societal spheres, so that inequality is not perpetuated.

In September 2015, the UN General Assembly adopted the ambitious new 2030 Agenda for Sustainable Development, which includes [17 Sustainable Development Goals \(SDGs\)](#) and 169 targets that promise to leave no one behind.

While all SDGs are universally applicable, disability and persons with disabilities are explicitly referenced in the following goals: 4) [Quality Education](#); 8) [Decent Work and Economic Growth](#); 10) [Reduced Inequalities](#); 11) [Sustainable Cities and Communities](#); and 17) [Partnerships for the Goals](#).

This year's observance will look ahead to 2030 and reflect on the new SDGs and their implications for improving the lives of people with autism.

World Autism Awareness Day (WAAD)



On December 18, 2007, the **United Nations General Assembly** adopted **Resolution 62/139**, tabled by the State of Qatar, which declares **April 2** as **World Autism Awareness Day (WAAD)** in perpetuity.

This United Nations resolution is one of only three official disease-specific United Nations Days and will bring the world's attention to autism spectrum, a condition present in tens of millions. The World Autism Awareness Day resolution **encourages** all **Member States** to take measures **to raise awareness** about autism spectrum throughout society and to encourage **early diagnosis** and **early intervention**. It further expresses deep concern at the **high prevalence** rate of autism spectrum **among children** in all regions of the world and the consequent developmental challenges.

European campaigns

Each year, Autism-Europe works together with our member organisations to conduct campaigns to raise awareness of autism spectrum and the rights of people on the autism spectrum across Europe.

Activities and events in Europe

Autism-Europe members organise a wide range of events and activities across Europe to mark World Autism Awareness Day each year.

<http://www.autismeurope.org/activities/world-autism-awareness-day/>

Respect, Acceptance, Inclusion

Take it, share it,
and spread awareness
of autism for more
acceptance and inclusion!



World Autism Awareness Day | 2 April

www.autismeurope.org #AutismDay2016

15

« Respect, Acceptance, Inclusion » Campaign Toolkit

Thank you!

Thank you for your support in previous years, it's your participation that makes the difference!

Let's make it happen together!



World Autism Awareness Day 2017



**World Autism
Awareness Day
2 APRILE**

The European theme for WAAD 2017, like for this interdisciplinary course, coincidentally is:

**Break barriers together for autism,
let's build an accessible society**