

Involving self-advocates



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“Nothing about us, without us!”

How to ensure that autism organizations are representative of the whole spectrum

Barcelona, 3 May 2015

Involving self-advocates

Making sure that people with autism **come** at the center of the decision-making process in autism organisations **together** their representatives.

Discussion and recommendations drawn following the discussion.

Self-advocacy

Self-advocacy is the **defense 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.



Self-advocacy

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

People with disabilities have the right to make decisions about their lives without the influence or excessive control of others.

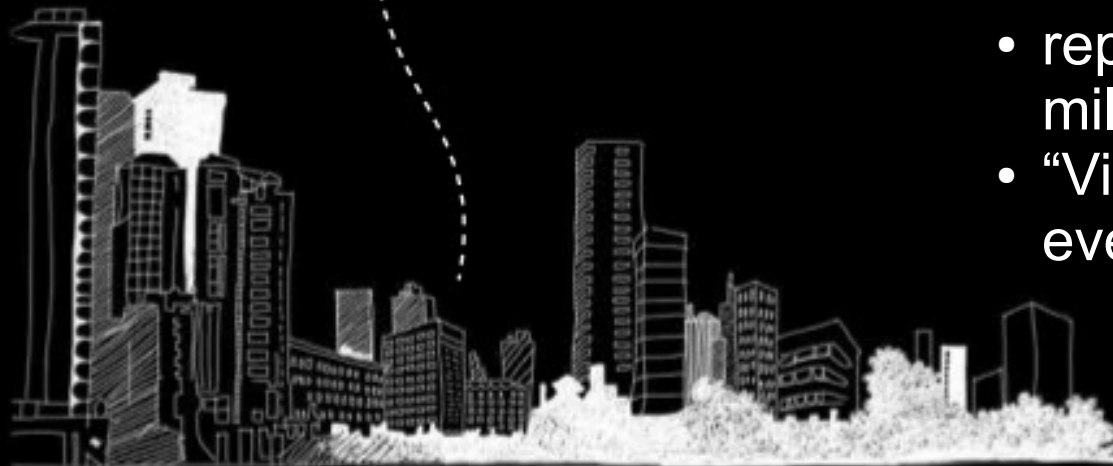


NOTHING ABOUT US WITHOUT US!

- 55 Full members
 - 30 National Councils
 - 25 European NGOs
- 14 Ordinary Member NGOs
- 5 Observer members
- 47 Associate members



- independent organization
- self-advocates
- democratic organization
- fight for the inclusion
- united disability movement
- strong and extensive network
- representing 80 million Europeans
- “Visibility of disability everywhere”



Self-advocacy and autism



“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***



Self-advocacy and autism

A bit of history.

Self-advocacy in autism spectrum is born more recently.

Temple Grandin published her first book in **1986**.



Self-advocacy and autism

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



The word **aspie** was invented by American Liane Holliday Willey in **1999**.



Self-advocacy and autism

At the end of '90s there were born many virtual communities and groups of persons in autism spectrum in the USA.



Self-advocacy in Italy



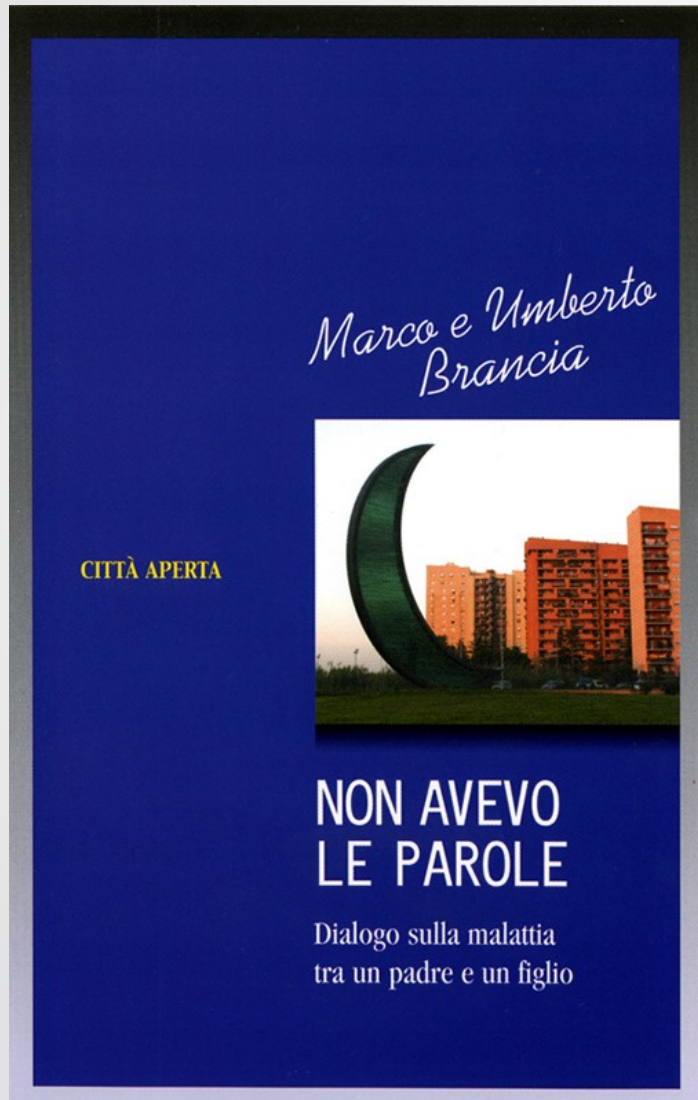
ASPERGER PRIDE

A favore della neurovarietà

The first association made only by people in autism spectrum in Italy, Asperger Pride, was born in **2011**.



Self-advocacy in Italy

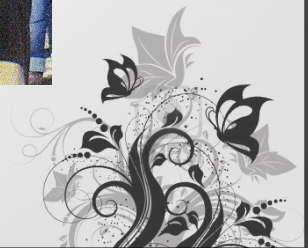


In **Italy** personal accounts of people in autism spectrum to the public began in **2006**.



Self-advocacy in Europe

First self-advocates actively involved in Autism-Europe arrived in **2010**.



My European activities



- Since 2010 I joined the Board of Directors of Autism-Europe as self-advocate
- Since 2010 I represent Autism-Europe at the European Conference on Disability of the European Commission and the European Disability Forum

www.autismeurope.org

My European activities (2010)



My European activities (2011)



My European activities (2012)



European Parliament of People with Disabilities (2012)



with a disability are a resource, not a

My European activities (2013)



My European activities (2014)



Antecedents

4 May 2013 – AGA Istanbul

Document 5-AGA-CA-Report external evaluation 2012

CABINET LEFEBVRE - nARÉ

I . s . é . e

External evaluation report
of Autism-Europe activities
under PROGRESS in 2012

Antecedents

CABINET LAFEBVRE-NARÉ
I . s . é . e

During this discussion, it was especially obvious that AE and its members organizations, are organizations “of parents” of persons with ASD. For example, we could see during the meeting that some of the representatives of parents did rephrase or reinterpret testimonies that did not require such rephrasing. All considered, there is **a thick list of reasons for persons with ASD not to be in the best situation to express their own ideas and expectations:**

- Some parents in general may (and/or have to) keep a “parental”, therefore “unequal” behaviour towards the generation of their children, even when the latter are adults in life.
- Such “unequal” behaviour may be especially widespread, and sometimes needed, when the children grown adults are persons with disabilities, deeply dependent on their parents and/or with strong needs of support.
- ASD are, among other consequences, a disability in the field of interpersonal communication. Therefore:
 - People with ASD, even at a “high functioning level”, may meet difficulties in expressing their own views, sharing experiences, take part effectively in debates, build common ground between them and lasting associative organisations.
 - Parents of persons with ASD may feel a specific need to assist them and possibly substitute them in expressing their experience and needs before wider audiences.

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Antecedents

- There is a solid common ground of parental experience between AE representatives of members, including the management of facilities for children and so on. The self-expression of (younger) adults with ASD is probably, so far, not a common ground of experience between parents' organizations.
- Last but not least, the most sensitive issues for parents regard the most disabled persons, with the deepest dependencies or highest needs of support; while the most strongest issues for representation in the community, may be expressed by "highly functioning" persons with Asperger, and with lower (even if not negligible) support needs. That gives objective reasons for parents' organizations to fear that more self-expression of persons with Asperger, might undermine the social and political support to families of deeply disabled children and adults.

All these objective reasons clearly **undermine the ability of parents' associations to empower (younger) adults with autism**. As one of the participants in the Lyon encounter put it:

On the Night of Autism on April 14th⁹, we were not powerless but... merely the associations were there.

(Translated from:) La nuit de l'autisme, on n'était pas impuissants mais... c'étaient surtout les associations.

The solutions are not easy to find. The encounters AE sets up are a first step.

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Antecedents

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They are only one of several steps AE and its member organizations already took in order to foster self-representation of persons with ASD. For example:

- AE may send self-advocates as its representatives to events: one of them (Pietro) took part to the jury of the “Vodafone Foundation Smart Accessibility Awards”, attended the European Day for People with Disabilities on 3 December 2012...
- AE supports a training (that will take place in 2013) intended for parents, self-advocates and so on. The UK National Autistic Society (NAS) and and APLA (Czech Republic) will come by five self-advocates at this training day.
- Several national organisations, members of AE, do represent persons with Asperger and have some sitting at their own Board.

We suggest AE might

- Go on fostering self-representation and supporting self-advocates as participants in AE work and representatives of AE externally;
- Discuss (possibly once again) the issue of “how to” facilitate self-organization and collective expression of persons with ASD, when able to represent themselves.

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Some questions

- Which is the role of self-advocates?
- How to represent people with autism?
- How to represent children and people who cannot represent themselves?
- How to organize people who cannot organize themselves?
- How can self-advocates and parents cooperate for a common objective?