YMI

Young Mediators for Inclusion

European Guide for the inclusion of persons on the autism spectrum

Co-funded by the
Erasmus+ Programme
of the European Union

CONTENT

Disclaimer: Throughout this manual, we will use the terminology "autistic" and "person on the autism spectrum" to refer to autistic people. The use of Identity-First language and Person-First language meets the preference of most of the autistic community. We acknowledge that native speakers of other European languages also use the term “person with autism” in line with the Person-First language of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)[1]*. We also acknowledge that professionals, researchers and parts of the autistic communities still prefers the term “Asperger’s (Syndrome)”* [2] *.*

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[1] Cf. Autism-Europe’s acceptable language guidelines accessed here: https://www.autismeurope.org/about-autism/acceptable-language/

[2] Cf. National Autistic Society - Asperger syndrome and other terms accessed here: https://www.autism.org.uk/advice-and-guidance/what-is-autism/asperger-syndrome

YMI PROJECT

Project framework

Nationally and internationally the vast majority of autistic persons continue to live on the margins of society. When parents try to include their autistic children in regular community activities, be it sports, music, arts or simply being together 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 with the family itself as barrier to find minimal solutions enhancing the development of their children. In Europe, most entities working in this area develop specific activities for people with disabilities, in controlled and 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 life paths compared to their peers without disabilities. This is where the Young Mediators for Inclusion project stands out, as it prioritizes inclusion as the only possible form of intervention in light of human rights paradigms.

This project aims, through an innovative methodology and using the figure of the "mediator for inclusion", to break prejudices and stereotypes and to demonstrate that inclusion, even in cases with additional support needs, is possible.

Consortium

Inovar Autismo (coordinator and implementing partner)

Autismo Burgos (Implementing partner)

Autism-Europe (Dissemination and monitoring body)

Diversamente ODV (Implementing partner)

ISCTE (Monitoring body)

InterMediaKT (Technical body)

Objectives

- Design and test an innovative pilot methodology in order to include children/youngsters on the autism spectrum in regular community structures on an equal basis with other children/youngsters;
- Empower and train young university students as “Young Mediators for Inclusion” (facilitating agents that promote the inclusion in articulation with families and contexts);
- Empower and train technicians and other staff from community structures in order to ensure the effective participation of children/youngsters on the autism spectrum;
- Design a European Guide for the inclusion of children/youngsters on the autism spectrum.

Expected Results

- IO1 - Creation of an innovative curriculum for two training courses (young university students and professionals or staff from the community structures);
- IO2 - Implementation of the courses - pilot tests (theoretical and practical components);
- IO3 - Design of a “European Guide for the inclusion of people on the autism spectrum”, based on the acquired/developed learning and knowledge.

Project Length

October 2019 - August 2022

Source: Freepik.com

AUTISM & INCLUSION

History of discrimination of autistic persons

Several authors and researchers have studied autism in the last century. Despite great progress in the diagnostic history of the autism spectrum, much of the research has also contributed to the existence of prejudices and stereotypes associated with autistic people.

The concept of "autism" was created in 1908 by the Swiss psychiatrist Eugen Bleuler (1857-1939) to describe the escape from reality into an inner world, observed mostly in patients with schizophrenia. Childhood schizophrenia and the concept of "early autistic syndrome" influenced the diagnoses of autistic children and these were considered as critical cases in clinical psychiatry. Thus, and according to the history of psychiatry, many people used terms such as "idiot" or the concept of "mental retardation" to refer to autistic people.

According to several authors, the first investigative studies date back to 1943, when Austrian-American psychiatrist Leo Kanner (1894-1981) published the article "Autistic Disturbances of Affective Contact". This article described 11 cases of children with "extreme isolation from early life and an obsessive desire" for their routines. In addition, it also contained a record of the clinical picture of a boy identified as Donald T., who was considered the first autistic patient.

Also, Bruno Bettelheim (1903-1990), an Austrian-American psychology professor in several American universities, contributed to the first studies on autism. Bettelheim claimed that the cause of autism was "refrigerator mothers": “cold” mothers, who did not show feelings or emotions, which led their children to isolate themselves. His theories were accepted internationally for more than two decades, which negatively impacted the psychological well-being of several families, because they felt guilty and frowned upon by society.

In 1944, Austrian pediatrician Hans Asperger (1906-1990) wrote the article "Autistic psychopathy in childhood", highlighting the occurrence of some conditions linked to autism, mostly in male children. It has recently been rediscovered that Asperger was heavily involved with the Nazi eugenics program (Aktion T4) and sent hundreds of disabled children (including autistic ones) to be "euthanized" as they were "not fit for life". The majority of the autistic communities today rejects the term "Asperger's Syndrome" which has meanwhile also ceased to be part of DSM-V and ICD- 11.

Disclaimer:

Researchers, professionals and parts of the autistic communities still use the term “Asperger’s (Syndrome)”. According to the National Autistic Society (NAS) “Each person is different, and it is up to each individual how they choose to identify. Some people with a diagnosis of Asperger syndrome may choose to keeping using the term, while others may prefer to refer to themselves as autistic or on the autistic spectrum.”[1]

Image; Freepik,com

In 1952, the American Psychiatric Association published the first edition of the Diagnostic and Statistical Manual of Mental Disorders DSM-I. It was a worldwide reference for researchers and clinicians, providing standard nomenclatures and criteria for the diagnosis of established mental health issues. In this first edition, the various manifestations of autism were classified as a subgroup of childhood schizophrenia, and were not considered as a specific, independent condition.

It is important to note that in this historical period the families of babies and children labeled "abnormal" were encouraged to "get rid" of them. These children were considered “freaks”, and represented a shame or punishment for the family. Thus, not only the children were segregated, but also the family, as socially they were not well regarded or accepted. It was common for these children to be separated from the family, and later committed to “mental asylums”, hospitals, or other institutions.

References

Baron-Cohen, S., Klin, A., Silberman, S. & Buxbaum, J. (2018). Did Hans Asperger actively assist the Nazi euthanasia program? Molecular Autism, Article number: 28 (2018).

BRITO, Maria Cláudia; MISQUIATTI, Andréa Regina Nunes. Transtornos do Espectro do Autismo e Fonoaudiologia: atualização profissional em saúde e educação. In: Autismo: a questão do diagnóstico. 1ª ed. – Curitiba, PR: CRV, 2013 cap. 01. p. 11 a 22.

De Moura Evêncio, K. M., & Fernandes, G. P. (2019). História do Autismo: Compreensões Iniciais/ The History of Autism: Initial Understandings. ID on line. Revista de psicologia, 13(47), 133-138.

Autismo e Realidade (2020). Marcos históricos do Autismo. Consultado em: https://autismoerealidade.org.br/o-que-e-o-autismo/marcos-historicos/

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[1] National Autistic Society - Asperger syndrome and other terms accessed here: https://www.autism.org.uk/advice-and-guidance/what-is-autism/asperger-syndrome

Autism: Definition and concepts

Autism is a lifelong developmental disability which affects how people communicate, experience and interact with the world. Autism is a spectrum and affects people in different ways. Like all people, autistic people have their own strengths and weaknesses, preferences, dreams and interests. Research has shown that there is a genetic factor at the origin of the development of autism. However, there are also other factors, which, combined with genetics, may be at the origin of autism:

- Advanced age of the parents at the time of conception;[1]
- Environmental factors such as prenatal exposure to infections and toxic exposure[2]
- Extreme prematurity or very low birth weight;[3]
- Any birth difficulties leading to periods of oxygen deprivation in the baby's brain and lack of prenatal vitamins.[4]

As mentioned before, autism is present throughout the person's life. There may be changes in the expression of the person's characteristics and needs, depending on their development, the context/ environment in which they live and the experiences they acquire throughout their life.

In order for autistic people to be included, to have their rights guaranteed and to actively participate in the community they need support appropriate to their needs (which may undergo constant changes and adaptations).

These contexts include:
- School (primary, secondary and higher education)
- Training
- Employment
- Housing context
- Social relations and support networks
- Formal support (from the state, social security, etc.)

Autism as a spectrum

Autism expresses itself in different ways in different people. The most important thing is that **each person is recognized as a person.**

Like a visible spectrum of light that includes an infinity of colours, the autism spectrum includes an infinity of characteristics, differences, profiles, interests, capacities.

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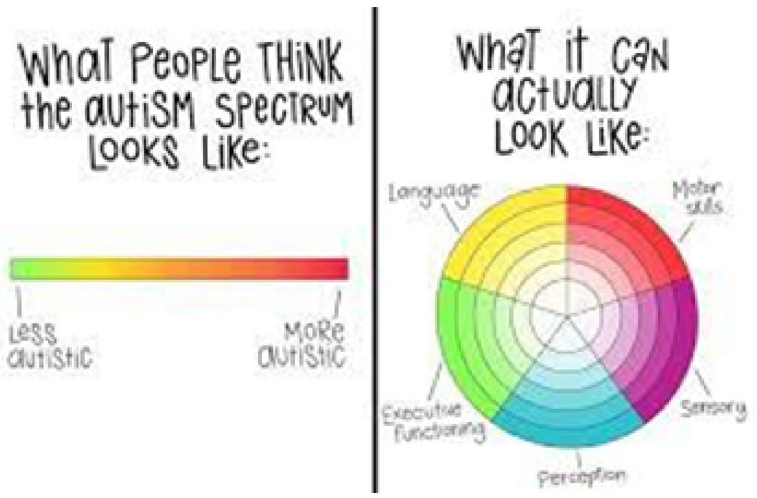
[1] Autism Spectrum News (2020) The link between parental age and autism, explained. Accessed here: https://www.spectrumnews.org/news/link-parental-age-autism-explained/

[2] Modabbernia, et al. (2017) Environmental risk factors for autism: an evidence-based review of systematic reviews and meta-analyses. Accessed here: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5356236/

[3] Lampi et al. (2012) Risk of Autism Spectrum Disorders in Low Birth Weight and Small for Gestational Age Infants. Accessed here: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3449022/

[4] Gardener et al. (2011) Perinatal and Neonatal Risk Factors for Autism: A Comprehensive Meta-analysis. Accessed here: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3387855/



Each autistic person is different. The person may like to talk a lot or be completely non-verbal. (S)he may (not) like physical contact like touch.

What is common for most autistic people is the difficulty in establishing and/or maintaining relationships and adjusting correctly to contexts.

EXTERNAL LINKS
Watch the video “Young people explain Autism”
Watch the video “Young people explain Autism - Communication”

Autism in girls and women

Autistic women face widespread discrimination in all fields of life. Access to education and employment, implementation of reproductive rights, freedom of choice, and th lack of participation in policy making are some of the main issues autistic girls and women are facing. This is happening mainly because:

- Autistic girls and women remain heavily underdiagnosed
- Diagnosis is generally later than in boys and men. Diagnostic guidelines are designed with the male perspective and its characteristics in mind, so autistic girls and women do not always fit the stereotype of autism and diagnosis is less easy;
- Diagnostic assessments are needed that take into account the differences between the manifestations that occur in gender differences.

Some differences:

- Greater interest in social norms;
- Greater preference for symbolic or fictional games, to the detriment of males;
- Greater tendency to imitation, also social;
- Less persistence (or more hiding) in relation to echolalia and stereotypes

EXTERNAL LINKS
European project “autism in Pink” on the needs of autistic women
Autistic Women & Nonbinary Network (AWN)
National Autistic Society
What Women with Autism Want You to Know

What is Masking?

Many people on the autism spectrum feel compelled or forced to pretend they are not autistic.

Many of them invest considerable effort every day in monitoring and modifying their behaviour by observing other people and imitating behaviours, ways of dressing, speaking, interacting, etc.

What is Stimming?

Although there is little concrete research available to answer the question whether stimming has a function, in recent years several autistic people have described a wide variety of functions of their repetitive behaviours.

"Stimming can be a way to calm and reduce anxiety, maintain awareness of their bodies, focus concentration or deal with overwhelming sensations or emotions. The same behaviour can serve different purposes in different people, or even the same person at different times, depending on the situation or mood." (Spectrum News)

- They are not exclusive to autism;
- They may appear throughout developmental process;
- They may have different origins: expression of well-being or pleasure; sensory self-stimulation; expression of discomfort, boredom; a way to calm anxiety; promotion of concentration; control of overload;
- The same behaviour may have different functions in different people, or even in the same person, in different situations.

EXTERNAL LINKS
Watch the video “Young people explain stimming”

Strengths of autistic people

- Attention to detail: Meticulousness, Rigour, Accuracy;
- In-depth focus: Concentration, Free from distractions;
- Observation skills: "listen, see, learn" approach; Fact-finding;
- Absorption and retention of facts: Excellent long-term memory;
- Visual skills: Visual learning and memory; Focus on detail;
- Methodical approach: Analytical; Specific patterns, repetition;
- Innovative approaches: Mental processes/ original thinking; Innovative solutions;
- Creativity: Discriminative imagination; Expression of ideas;
- Tenacity/ Perseverance and Resilience: Determination; Challenging opinions;
- Acceptance of difference: Less inclination to judge others; May question norms/rules;
- Integrity: Honesty, Loyalty, Commitment.

Autism and the concept of Neurodiversity

- In 1998, the Australian psychologist, Judy Singer, introduced the term neurodiversity as opposed to the idea of impairment;

- Atypical (or neurodivergent) "neurological wiring" is not, as we have seen, a disorder to be treated and cured. Rather, it is a human difference that must be respected like other differences (sexual, ethnic, among others);

- The concept means that there are different types of neurodevelopment, which generate different ways of dealing with information... All the different ways of processing information should be recognized and respected, and there should be no modification or elimination of them;

- Accepting neurodiversity as part of what is considered normality implies providing each person with the necessary support to be able to participate fully as a member of the community.

- According to autistic standards, the typical human brain is easily distracted, is obsessively social, and suffers from a deficit in attention to detail. In addition, a large number of studies have shown that so-called neurotypical people, process information from the general to the specific;

- In contrast, the brains of autistic people go from the specific to the general, paying more attention to details, "disconnecting" from the social world to further develop their particular interests;

- It is part of the diversity of society;

- Opposite perspective to research on a cure for autism;

- Positives are valued more than difficulties.

- Protects and enhances the rights of autistic people;

- Values the need to work on self-esteem and confidence;

- Leaves an important warning regarding the extent to which autistic people want to change and stop being who they are.

IMPORTANT:

It is important to provide support to the person to ease the development of their potentialities and their inclusion in all spheres and areas of the community;

DON’T expose (without support) the person to potentially anxiety-producing situations in which we know the person cannot manage: public, unstructured situations, improvisation, group games, conflict resolution;

HIGHLIGHT the person’s skills and knowledge, making these known to others where appropriate: musical and artistic interests, values, character, skills, etc.

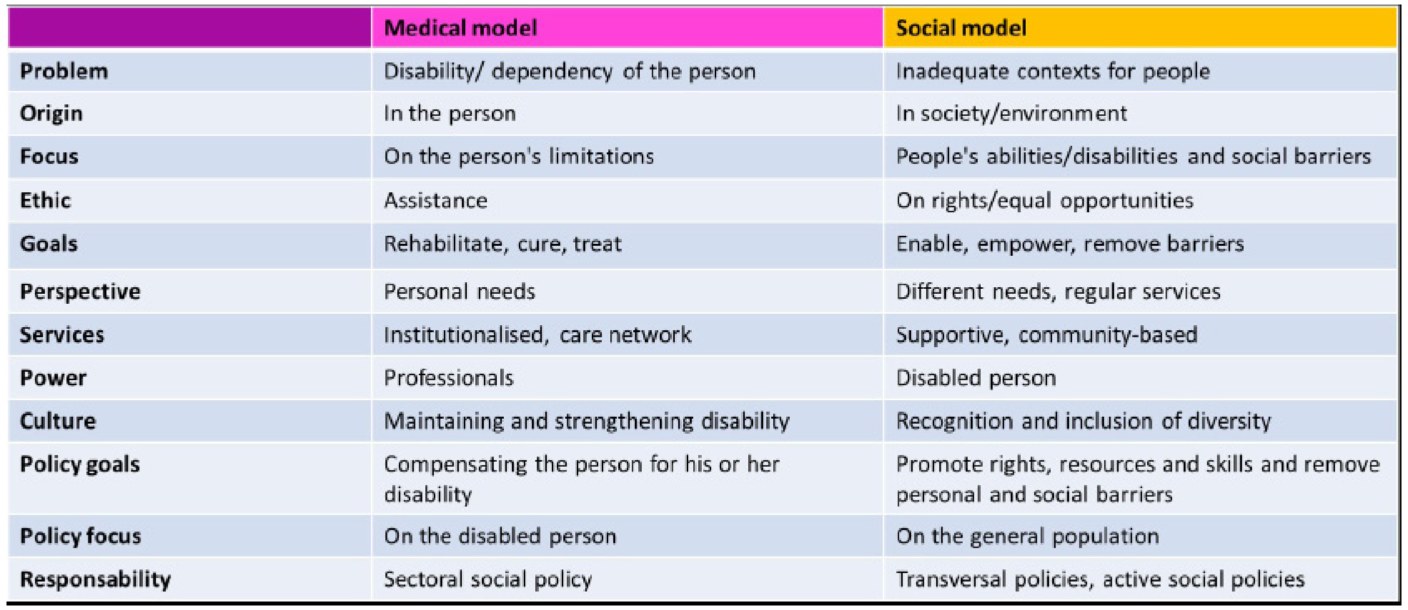
THE DISABILITY MODELS From Stigmatization to Inclusion

It is important to look at the main theoretical approaches that have been developed around disability.

- The medical model states that the barriers and limitations faced by people with disabilities derive directly from their actual or imputed functional impairments. This view emphasizes the "deficit" perspective, conceptualizing disability as an "abnormality," a failure, a loss or dysfunction of the body. (Pinto, 2015).
- The social model emerged in the 1970s in opposition to the medical model. The basic premise of the social model is that disability should not be understood as an individual problem, but as an eminently social issue, shifting the responsibility for the disadvantages of people with disabilities to society's inability to anticipate and adjust to diversity (Oliver, 1990).

According to the social model:

- The inclusion of people with disabilities is a challenge to society;
- Society must change its patterns and organization to integrate all people.



	Medical model	Social model
Problem	Disability/ dependency of the person	Inadequate contexts for people
Origin	In the person	In society/environment
Focus	On the person's limitations	People's abilities/disabilities and social barriers
Ethic	Assistance	On rights/equal opportunities
Goals	Rehabilitate, cure, treat	Enable, empower, remove barriers
Perspective	Personal needs	Different needs, regular services
Services	Institutionalised, care network	Supportive, community-based
Power	Professionals	Disabled person
Culture	Maintaining and strengthening disability	Recognition and inclusion of diversity
Policy goals	Compensating the person for his or her disability	Promote rights, resources and skills and remove personal and social barriers
Policy focus	On the disabled person	On the general population
Responsability	Sectoral social policy	Transversal policies, active social policies

Convention on the Rights of Persons with Disabilities

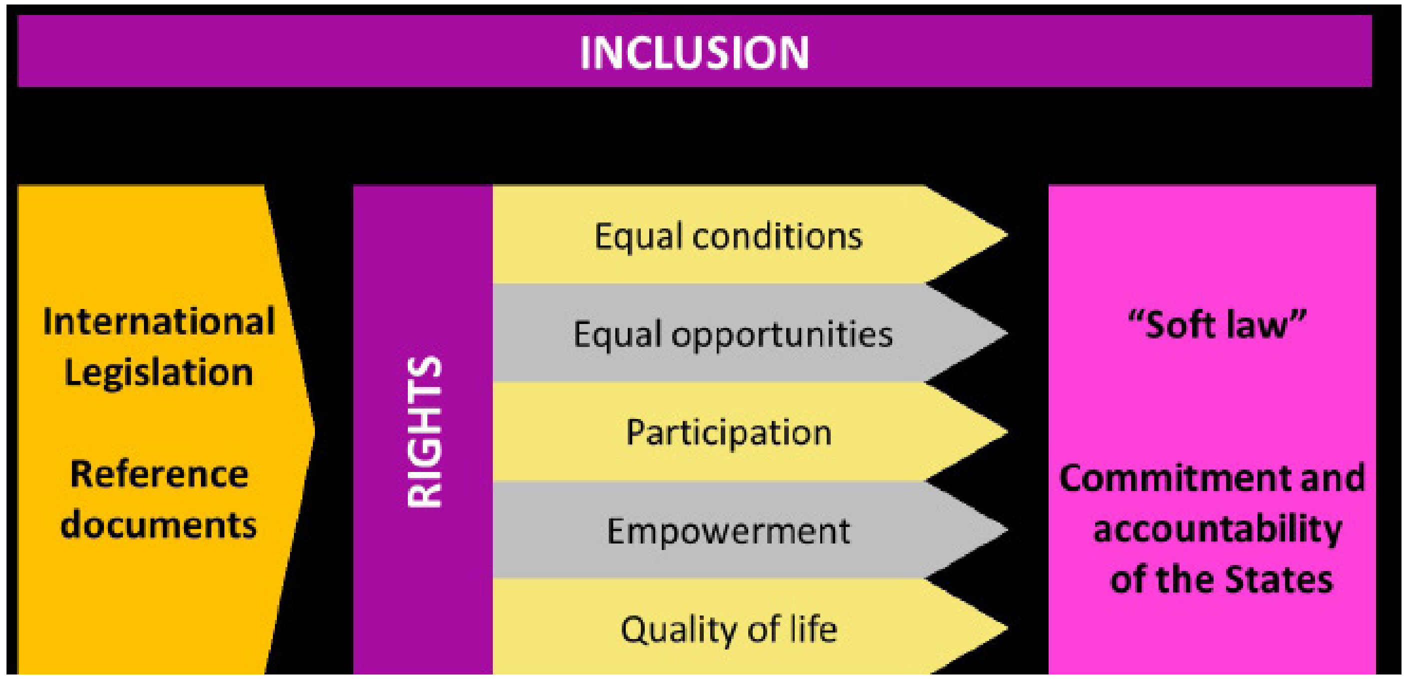
The United Nations Convention on the Rights of Persons with Disabilities was adopted in 2006.

This convention aims "(...) to promote, 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." (Article 1)

The European Union's agenda has also been influencing the international framework as far as public policies for disability are concerned, mainly since the 1990s.

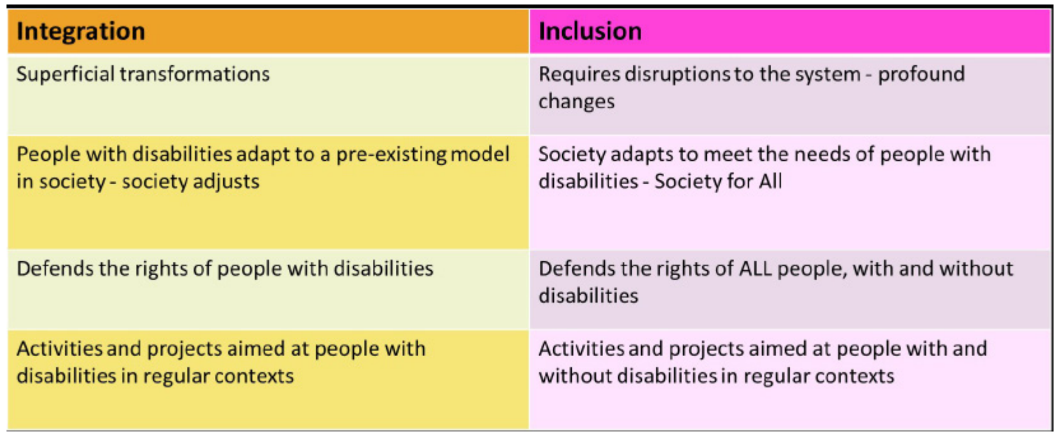
One of the aspects to keep in mind regarding the development of a European disability policy is the empowerment of civil society, embodied in the European organizations of people with disabilities and/or their families that, by joining forces, have created Autism-Europe and the European Disability Forum (EDF).

Concept of inclusion

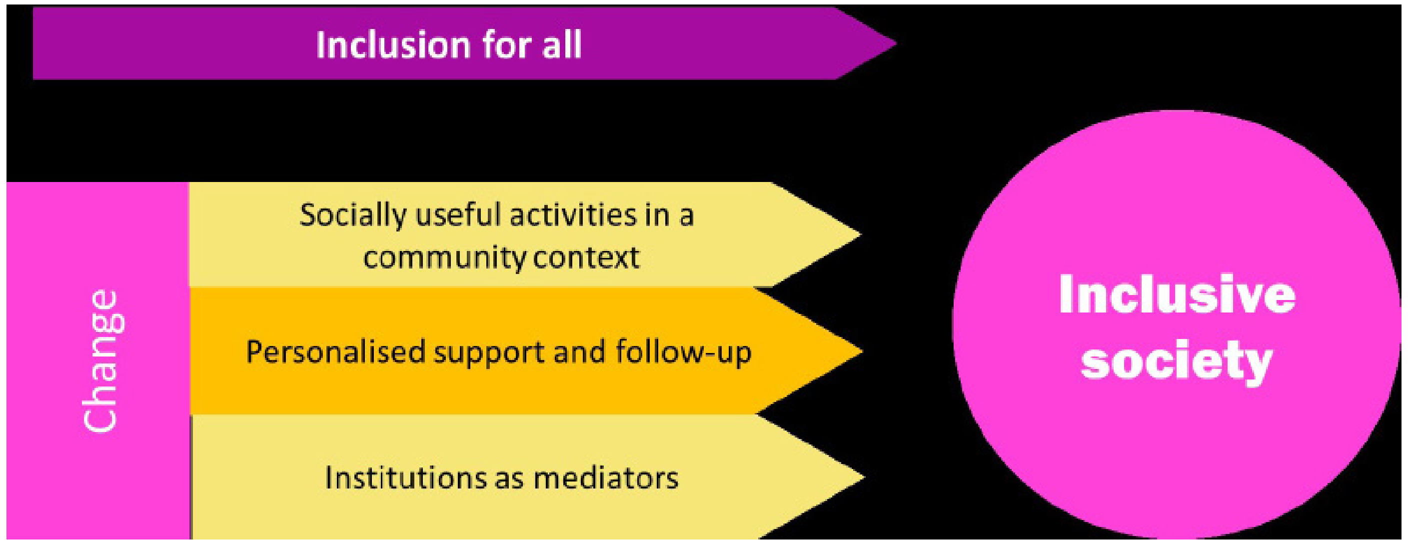


Inclusion is:

- Being able to participate in all the regular contexts of the community;
- "Be part of" ... "Having a voice" ... to make free choices about all areas of life or at the limit, to have decision support;
- Plan activities, services, equipment, for ALL - people WITH and WITHOUT disabilities;
- Not divide, not segregate, not separate, not create walls between "us" and "the others";
- To respect and believe in the potentialities of the other, not to infantilize him/her, not to diminish him/her, not to decide for him/her under the pretext of protecting him/her.



Integration	Inclusion
Superficial transformations	Requires disruptions to the system - profound changes
People with disabilities adapt to a pre-existing model in society - society adjusts	Society adapts to meet the needs of people with disabilities - Society for All
Defends the rights of people with disabilities	Defends the rights of ALL people, with and without disabilities
Activities and projects aimed at people with disabilities in regular contexts	Activities and projects aimed at people with and without disabilities in regular contexts



Inclusion for all

Change

Socially useful activities in a community context

Personalised support and follow-up

Institutions as mediators

Inclusive society

There are "good practices"

Change

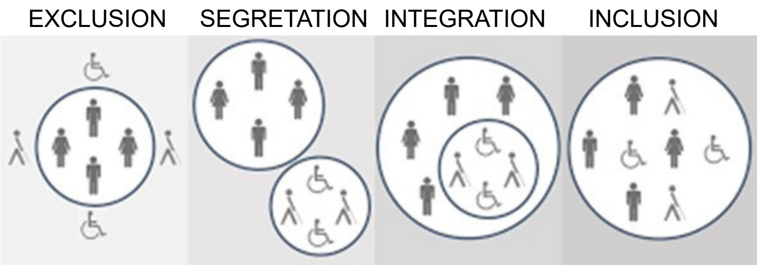
Massify inclusive practices

Learn from these experiences

Raising awareness among institutional actors

Predisposition of families and organisations to change

Inclusive society



Inclusion also is:

- Universal Design
- Reasonable accommodation
- A society for All
- Enabling contexts for diversity

Not inclusive:

- Special schools;
- Social services like occupational centers and residential homes (Asylums);
- Activities only for people with disabilities;
- Vocational training answers only for people with disabilities;
- NGOs in the disability field that do not employ people with disabilities / do not have people with disabilities on the board, and do not give them a voice;
- Separate sporting and cultural events.

↓ Non-inclusive practices result in:

Reinforcement of stigma, isolation, division and segregation leading to parallel lives.

MAIN BARRIERS TO INCLUSION TO BE OVERCOME

The family as a barrier

The family is the central nucleus of primary networks. The family has a key role to play in initiating its member with disability towards autonomy and promoting the best possible inclusion.

The child's development, the acquisition of all the possible abilities, the achievement of maximum autonomy at every stage of growth and his or her social inclusion depend to a large extent on the family.

A closed, fearful, and excessively protective attitude on the part of the family hinders the child's growth in that transition which should lead him or her to become an adult with a project for an independent life (albeit assisted, to varying degrees and in proportion to his/her needs) that can be fully achieved within the community in which he or she lives.

There is no doubt that the possibility of accessing an adult identity also depends on the attitudes and behaviours that the family adopts towards the growing child: "permission to grow up" often depends on the family's consent and when this consent is lacking, the possibility of being included in the community is reduced and the risk of marginalisation increases.

On the other hand, it is not difficult to understand that a fa–mily may struggle to see its child with a disability as an adult since the very same difficulty is also widespread in families with non-disabled children.

However, in the first case, there are some specific or more recurring elements, such as the tendency to think that one is indispensable forever as a parent, the preoccupation with the future and an excess of attention that usually lead to the same educational styles, prolonged well beyond what is necessary.

Distancing oneself from the idea of the 'eternal child', guiding one's child through the process of growth and providing him or her with the tools to cope with the journey towards autonomy and inclusion in society becomes a challenge for the very adulthood of his or her parents.

Some families develop this ability on their own, others find it more difficult and look for support either in disability-oriented NGOs, which are becoming more and more widespread due to the lack of dedicated services, or more rarely in generic parenting support services, which are not very present in the culture and practice of services.

Associations facilitate network interventions and mutual self-help (they often offer it internally), allow the comparison of common and shared experiences between people who find themselves in situations with similar problems, facilitate the establishment of relationships of trust with other people perceived as similar, accelerate the identification and modelling with those who have already faced a problem, and perhaps with good results.

This confrontation not only allows the emergence of parental skills, if latent, but also reinforces them, supporting and enhancing resilience, understood both as the ability to cope with a critical event, and as the ability to respond and react appropriately to it, setting in motion new resources and potential.

...and when it comes to autism?

When it comes to a complex disability such as autism, the lack of guidance and support services for the family can have even worse consequences: the interventions implemented in childhood gradually thin out and even stop as adolescence and adulthood progress (therapy, school, educational service, etc.).

The family finds it difficult to look for functional solutions focused on growth and inclusion; these are often reduced to activities that create a constant and continuous commitment for the child/young adult, useful only to fill an aimless time. In essence, the very network of services that should provide greater support in this critical phase, in which the family system also reveals its weaknesses, widens, in fact, its links and even totally dissolves them.

The image that the services have of the family and the image that the family (parents first) has of the services represent a ground that needs constant mediation.

Provided that the services manage to envisage not only the person with a disability but also the family, as the recipient (even indirectly) of the interventions, the family may be able to play a positive role in fostering real experiences of inclusion, bringing an authentic point of view for the self-determination of the child, and contributing effectively to his/her emancipation and social inclusion.

WHAT CAN MEDIATORS DO?

Involve the family in the decision-making process.

Encourage the family to “break the automatism”, e.g., all those tasks that the family does for the autistic person that they should do themselves. This is usually done to make life easier for everybody and to make the day flow smoothly, but it leads to unhealthy habits in the long run.

Help the family recognize the person with autism’s abilities and skills so that they can learn to allow the person to stand on their own two feet.

Barriers of the existing public policies

Legislation VS Reality

At a regulatory level, legislation has sought to identify the tools needed to implement independent living projects that can guarantee a full and dignified life for all, even when the support of the family network is lacking.

The UN Convention on the Rights of Persons with Disabilities (2006) states in Article 3 that people with disabilities should enjoy "the full and effective participation and inclusion in society".

The municipality is the body, which, at the request of the person concerned, can develop an individual project.: A comprehensive project can be generated which can be carried out in agreement with the health authority, which "includes" the services and measures provided by these two institutions.

This is the way to achieve social and health inclusion, which has not yet been fully accomplished, precisely because 'including' several interventions in the same project is not enough to make it a life project.

For the sum of the interventions to become a project, it is necessary to " incorporate" them, with each other, with the individual for whom the intervention is made and, of course, with the environment in which the project is carried out.

The long road to formal recognition of the rights of persons with disabilities is embodied in the UN Convention on the Rights of Persons with Disabilities, adopted by the UN General Assembly in 2006. "The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by persons with disabilities, and to promote respect for their inherent dignity" (Article 1.1).

What happens in reality?

Work placement projects are almost always short-term and end in themselves. They are not structured in such a way as to provide continuity and contract renewal and are usually low paid. What happens, therefore, is that the person with autism loses, during employment, all the economic benefits to support their needs; then they find themselves at the end of the work experience, having to start all over again with the process to obtain the benefits to which they are entitled. Faced with such a prospect, many autistic people and their families do not even attempt to get into employment.

Another very common situation derives from society's lack of awareness of autism. Situations of marginalisation are generated, even unintentionally, aimed at "protecting" the person on the autism spectrum, thinking that it is good to make them do different activities (at school, in the gym, etc.) and separate from those of other people. The law on inclusion exists, but people are not prepared to apply it and end up continuing to divide and marginalise.

Once more in relation to the lack of awareness about autism, it happens that people are afraid of the autistic individual, who is seen in the collective imagination as potentially aggressive, dangerous, unpredictable, and therefore difficult to include. People prefer to keep them at a distance and do not seek contact with them. Again, legislation exists, but it is not implemented in community level as it should be as local authorities are not provided with the tools to enforce it. There is a lack of awareness programmes in schools, starting as early as primary school and continuing through to university. There is a lack of awareness programmes in workplaces and leisure centres.

A few examples about physical disabilities:

People who use a wheelchair, are blind or deaf can only be full members, able to perform jobs at a sufficiently high level, if society changes its basic conditions to include them. Their relative lack of productivity is not inherent to a disability, it is the product of discriminatory social measures.

- people in wheelchairs can get around well and do their jobs as long as buildings have ramps, buses have platforms and so on.

- blind people can work more or less anywhere in this age of audio technology and tactile signage if workplaces include these technologies.

- deaf people benefit from the use of email and other visual technologies in workplaces if they are structured to include them.

What about intellectual disabilities, autism, neurodiversity?

- One might think that while this reasoning may apply to people with sensory-motor disabilities, it is not for those with severe intellectual and mental disabilities.

- These are citizens who are mostly considered incapable of understanding, irresponsible for their actions, even dangerous to themselves and others, too complex cases for which it is less demanding to provide purely custodial interventions and various forms of institutionalisation.

- Productivity is necessary and beneficial to society, but society is also founded on important bonds of solidarity that hold it together.

- So, it is not essential to be productive to gain the respect of others and the recognition of one’s human dignity. Perhaps the focus should be shifted from disabilities to the abilities that each person has, the existing skills that people can deploy to achieve self-determination.

Making its members fully-fledged citizens is the duty of every society through its institutions.

Each disability indeed has distinctive features that characterise it and requires specialised interventions and responses, but the fact that a person has specific characteristics does not mean that he or she does not also have the same needs as other human beings: **the need to be respected, recognised, to have emotional security and to belong.**

In short, the idea of a life project means to always start from the entirety of the person: this does not mean ignoring the specificities of the individual's development, rather it means not identifying it with one single aspect.

The tendency to identify people with disabilities primarily by their most socially perceptible characteristic and to focus on (negative) difference gives them the indelible mark of distinctiveness and reinforces the classificatory tendency of policies that propose particular structures for each category.

Autistic persons as a barrier for themselves

Autistic people frequently face issues related to mental health, such as depression, high levels of stress or anxiety. Many of these aspects are linked to the fact that they try to fit in and belong to a community (Nuske, et al.2019). However, the lack of understanding and training of the community leads to frequent episodes of frustration and perception of failure. The lack of information of the community about autism and its characteristics, make social and attitudinal barriers persist. The prejudice, stigma, and ignorance, may severely influence self-esteem, confidence, and the ability to self-representation of the people on the spectrum.

Low self-esteem and self-confidence lead anyone to doubt their own abilities, having a direct influence on the performance of their activities, both at a professional and personal level. This is no different for autistic people, it increases possible difficulties at the level of expressive communication which could further worsen the situation. This can be particularly apparent in the interactions with other people.

Some examples:

- When interacting with another person autistic people may get too close, not considering the other person's space, or they may start a conversation about a topic that is not appropriate
- People on the autism spectrum may seem insensitive because they cannot understand so well what the other person is feeling.
- Autistic persons may also prefer to spend their time doing activities that do not involve interaction than participating in social events in the workplace.

On the other hand, there are also autistic people with great verbal communication skills, but then their way of interacting may not be the most adequate for the context where they are. They may, for instance, talk about their interests for a long time without considering what the other person is thinking.

For autistic people it can be extremely difficult to interpret the feelings, thoughts, and actions of others, as well as it can be difficult to predict what will happen next, not understanding, sometimes, the concept of danger. In this aspect, we must also consider their specificities regarding change and new situations. Social and sensory barriers can become a real difficulty if adequate preparation and involvement of the community are not promoted in order to find strategies to overcome these barriers.

In our work, we often meet people on the autism spectrum who have stopped believing in themselves, because they repeatedly deal with this feeling of failure. This feeling can become such that it turns into an invisible barrier - the person stops believing it is possible because "it never works".

It also happens that, because a certain activity did not work at the first attempt, the idea is that it is impossible to carry it out. On the other hand, the perception of one's own difficulties and not knowing how to manage/deal with them can lead to avoidance situations.

For example: "I know I don't like a certain situation therefore I won't try it".
However, many times these "failures" are caused by external barriers, namely, as we mentioned earlier, the lack of knowledge and preparedness to deal with diversity in the community.

MEDIATION FOR INCLUSION

Concept of mediation

Mediation is the assistance to two or more interacting parties by third parties who (usually) have no authority to impose an outcome.

Mediation has lengthy historic roots dating as far back as 977 when Viking women would intercede in fights between men to calm the spirits.

The interacting parties' **relationship could be improved by the mediator's intervention** therefore they seek the assistance of a third party who selects from several available approaches and is **influenced by various factors** such as:

ENVIRONMENT
INDIVIDUAL CHARACTERISTICS
TYPE OF CONFLICT
TRAINING

Once applied, these approaches can yield **outcomes for the disputants, the mediator and the third parties** (e.g., satisfaction, perception of fair treatment). Regardless of the outcome, the process itself is important!

For mediation to occur, the interacting/disputing parties must request or permit a third party to mediate. In the case of autism that would be:

- the community and the autistic person
- the family and the person on the autism spectrum.
- Two more factors are worth mentioning: norms and expected benefits.

1) **Norms are** frequently embedded in the culture, and they are a powerful source that can motivate disputants to seek assistance from a third party. Yet if these norms are not part of the culture itself, they will rarely be powerful enough to go past the existing legislation.

Ex: Asian countries frequently seek assistance from a third party to resolve conflicts. It is a regular procedure in their societies and citizens are used to having their disagreements handled by third parties. In contrast, since disputants in the United States are unfamiliar with mediation, they hardly ever rely on that process.

2) **Expected benefits** is another reason that might lead disputants to seek further assistance. The disputants might realize that the mediator possesses some expertise on the problem, might have a method for overcoming the issue and could help build a positive relationship between the parties. Plus, they could enable the parties to keep **control of their conflict.**

In conclusion, there are 3 Defining Elements of Mediation:

1. Assistance or some form of interaction by
2. a third party who
3. does not have the authority to impose an outcome.

What goals and approaches should mediation have?

BE IMPARTIAL?	Some scholars agree that mediators should be impartial so that the outcomes of the mediation will be based on the merits of each side's case.
BE PARTIAL?	Some argue that the mediator should be partial toward the weaker party to protect it.
OPERATE IN TANDEM?	Some advocate that mediation be used in tandem with other third-party approaches such as psychotherapy and nongovernmental organizations (NGOs) that provide benefits to the disputants.
OPERATE INDEPENDENTLY?	Other scholars and practitioners believe that each profession should operate independently, rather than blurring responsibility and overloading the dispute with third parties.

What positive approaches and techniques can the mediator employ?

Mediators can:

- provide each or both disputants with information
- determine which points are negotiable for each party
- advise/educate the disputants,
- encourage concessions
- rely on reflexive techniques such as reframing the opponent in a more positive light
- help the parties to develop new norms and assist them in implementing their agreement
- build trust between the disputants and call for consideration and apologies
- help the parties to jointly perceive new collaborative goals
- at times the mediator might use other third parties, asking them to advise the disputants

ROLE AND PROFILE OF THE YOUNG MEDIATOR FOR INCLUSION

Role

- The Young Mediator for Inclusion will help improve the quality of life for autistic individuals by enhancing social inclusion in a variety of daily contexts.

- The Young Mediators for Inclusion will mediate the communication between the family, the school/ the job context, the specialists, and the various caretakers in different life contexts.

- The mediator is a facilitator, someone who can "bridge the gap" between the person on the autism spectrum and the community (family, school, job, peers).

Ex: he/she can help the autistic person introduce themselves and engage in a conversation when they join a party or a meeting at the pub.

- The mediator is a translator – often people on the autism spectrum do not realize that they are experiencing discrimination – someone who can "decode" these situations can help enhance their self-determination.

Ex: he/she can help the autistic person stand for themselves whenever they are being left out, not taken into appropriate consideration, or even treated condescendingly in social contexts.

- The mediator is an empowering tool for the community. They promote true inclusion, therefore the contexts in which they work can potentially change their focus from a narrow-minded and segregating approach to a bigger, inclusive one that focuses on people's rights and active participation in life in the community. It is clear now that contexts need to be reinvented and "updated" to present times.

- Mediators raise awareness on autism. They help decode some of the behaviours people on the autism spectrum might show, explain certain situations in a double-perspective approach: person-context and context-person.

Ex: He/she could help a particular context understand that autistic people may be quite sensitive to noise and loud sounds; as a result, they may show clear signs of distress and become agitated.

The same way he/she could help the person on the autism autism get accustomed to the fact that certain contexts will always have reasonably loud music (e.g., the gym, a pub) and look for healthy ways to deal with it together.

Profile

The Young Mediator for Inclusion (YMI) will mediate the inclusion of the autistic person in age-appropriate contexts.

Ex: parties with peers, peer meetings in social contexts such as pubs, squares, beach trips, gym etc.

The Young Mediators for Inclusion could also be and/or provide age-appropriate role models of adaptive and social behaviours. Ex: clothing, hairstyle, texting peers and so on.

The most appropriate personal profile for a mediator. He/she should:
- Be enthusiastic and energetic
- Be patient
- Keep a calm attitude
- Keep a relaxed tone of voice
- Not be loud or impulsive
- Be empathic
- Have a non-judgmental approach

The mediator has some specialised training in AUTISM:
- he/she knows the main aspects of behavioural intervention:
    reinforce adaptive behaviour
    shaping
    modelling
    assessing the problem
    behaviour functioning
- he/she knows the augmentative and alternative communication (AAC)

Source: Freepik.com

What is augmentative and alternative communication (AAC)?

- Symbols and Pictures
- Sign Language
- Facial Expressions
- Communication Devices
- Texting
- Gestures

The mediator has reasonable knowledge in:

- Autism
- Human rights
- Inclusion
- Functional interaction
- Communication and emotion management
- Functioning of the institutions
- Local legislation and/or policy initiatives

To plan successful evidence-based interventions the mediator needs to:

- consistently gather data from the intervention, which will help him/her make educated decisions and promote effective changes throughout the programme.
- know how to define clear and measurable goals (can this specific person reach this specific goal?).
- know how to define how much time is needed to reach specific goals (taking the specific individual into account).
- know how to assess the efficiency of the intervention (were the set goals achieved?).
- understand the gathered data to define what changes must be made (how can I further improve my intervention?).
- working as a team with the autistic person, the family and the technicians of the community

In conclusion
- Despite their training, mediators should mainly mediate between peers, promoting active participation in citizenship, self-determination, and self-advocacy.
- The mediator motivates and encourages.
- He/she mediates with reason and sensitivity, empathy, and an open mind.

The **benefits from mediation for inclusion** can positively affect not only persons on the autism spectrum (who can even become mediators themselves) but also their families (increasing their confidence and understanding of their and their children's rights), the institutions (increasing the number of trained staff; providing a higher quality of life to its users; promoting a gradual transformation) and the community as a whole.

STRATEGIES FOR A MORE POSITIVE MEDIATION

The mediator will use a variety of strategies that are indicated in the scientific literature as the golden standard of the intervention for autistic people.
Some of these strategies are:

- Visual supports.
- Positive Behaviour Support.
- Social stories.

Visual supports

visual supports include using a visual diary that structures the autistic person's daily macro activities or a specific activity. Visual diaries give predictability and help clarify what specific tasks need to be completed and in what order. They can be helpful in any context from the school to the workplace, to the gym, etc.

Ex: writing a work email: the visual diary will show all the things and actions that are needed to complete that task.

PBS: Positive Behaviour Support

Values Led: PBS supports human rights and promotes respect, dignity, inclusion, and a life without unnecessary restriction. PBS means treating people equally and working in partnership with the person and their family to make things better for everyone.

Promoting Quality of Life: the overall aim of PBS is to improve the quality of a person's life and that of the people around them. This includes children, young people, and adults, as well as older people. PBS provides the right support at the right time for a person so they can lead a meaningful and interesting life participating in activities and learning new skills.

Understanding Behaviour and Meeting Needs: PBS uses different methods to gather information to work out what people's behaviour means. It improves support and empowers people to use better and less harmful ways to get their needs met. This often involved using a range of different approaches that enhance a person's life.

Making Systems Work for the Person: Giving the right support at the right time so people can thrive and fulfil their potential. This may mean changing the way the person is supported. Carers and staff may need training, and service structures and cultures may need to change. Continuous review is important to make sure support carries on working well for the person and those around them.

Social stories:

social stories can be defined as "situations" that the autistic person is going to experience soon. They are told through a sequence of pictures, as one would see in a comic book, that shows exactly what is going to happen so that they can be prepared without worrying or getting upset (e.g., going to the dentist).

Communication: A complex and continuous system through which the different members of society are interconnected.

To communicate means:

- "To put in common."
- "To enter into relation with";
- "Exchange."
- Promote the recipient's satisfaction.

What?

- Ideas and Concepts;
- Feelings and Experiences;
- Values and Beliefs;
- Opinions;
- Needs and desires.

For there to be communication there has to be:

- A good transmission;
- A good reception.

Communication Features:

- Bilateral and circular phenomenon
- Universal
- Inevitable
- Structuring of interpersonal relationships

Functions of Communication: Informing, Sharing, Educating, Socializing, Distracting, Asking, Persuading.

Dimensions of Communication:

1. Verbal Language

- Oral
- Written

2. Non-Verbal language

- Kinesthetic Language
- Paralinguistic Language
- Proxemic Language
- Physical Appearance
- Physical Contact

Importance of non-verbal communication: Non-verbal communication expresses our feelings and emotions. It includes information about the content of the verbal message.

It is important because:

- It tends to be more authentic than verbal, given its diversity and richness;
- It is more difficult to control;
- Through it, emotions and feelings can transpire more easily.

Kinesthetic Language: Refers to all body movement

- Our face is permanently mobile and full of expression.
- The smile, the look, the eyebrows, etc., communicate our feelings, reactions, and emotions; however, these movements are not always conscious.
- Our gaze can be an immense source of messages.
- Gestures are also a reinforcement of our verbal message. Gestures should reinforce the content of verbal communication. When we are angry, gestures often become large, fast and aggressive. In addition, gestures are also a form of communication.

Mediator's Posture:

- Open face, practicing active listening.
- Physical posture that shows "openness".
- Gestures consistent with what is said, in smooth movements.

For a better communication…

- The **voice** should be projected so that the interlocutor can hear it.
- **Tone** should not be too high or too low. It should reveal confidence and helpfulness.
- **Articulation**. One should not slur or eat words. Words should be well articulated when they may give rise to ambiguity.
- **Pronunciation.** Don't worry about your accent, but pronounce all the words.
- **Modulation**. Modulation is an excellent way to keep people interested and involved (as opposed to monochordia). The accentuation of words is important. The meaning of the message varies, depending on which words are accented.

Importance of Feedback:

- Allows the interlocutor to become aware of their evolution in relation to the proposed objectives;
- Motivational factor in that it establishes goals and guidelines for growth;
- Stimulates people to give their best;
- When goals are objective and feedback is specific, subjects have more opportunities to correct aspects that need improvement and consequently perform better.

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What about Autism?

Social Communication

- Autistic people often communicate in a very specific way;
- They may have some difficulty understanding and interpreting instructions and expectations that are not explicit;
- There are autistic people with great language abilities, but their way of interacting may not be the most appropriate for the context (e.g., they may talk about their interests for a long time without taking into account what the other person is thinking).
- Very literal understanding of language, requiring extra effort to understand metaphors, idioms, irony or sarcasm (e.g., the expression "if you need help I can give you a hand" may be understood by the person in a literal way).

Social Interaction

- Most of the time, learning social skills requires additional training or study. (e.g., through some reports of autistic people, it is possible to see that sometimes they can hear better and learn if they do not make eye contact).
- Difficulty interpreting/reading emotions through other people's facial/body expressions, as well as respecting appropriate social distance.

Thinking

Literal thinking - it can be difficult for autistic people to understand the true meaning of some expressions used in everyday life:

- Figures of speech (ex: Waking up with the chickens; having butterflies in your stomach; It's raining cats and dogs);
- Sarcasm
- Metaphors
- Jokes

Source: Freepik.com

Strategy Management

The use of such strategies needs to be tailored to each autistic individual, as they are all different, depending on their abilities, level of understanding, preferred communication method, etc.

The mediator will work in strict collaboration with the family and with all the caretakers involved in the educational and life project of the person on the autism spectrum.

The mediator will foster the development of self-advocate abilities, problem-solving, academic, and soft skills by organizing motivating and stimulating learning opportunities for autistic people.

The mediators´ to do list

The adopted strategies highly depend on the specific individual, and they will be discussed in advance with the psychotherapists, but before starting to work with a peer on the autism spectrum, the mediator should follow specific steps that will allow a potentially successful mediation:

- **Get to know the story of that autistic person** (who is he/she? How old are they? What do they do in life? What do they like? What are their aspirations?).
- **Talk to the family** (get to know the life context in which the person on the autism spectrum lives their everyday life – learn the story of that family – what do the parents have to say about their child? In what areas are they struggling?).
- **Get to know the context** in which the autistic person will interact (who works there? What kind of people are they? What do they know about autism? are they open-minded?).
- **Get to know the person on the autism spectrum** (how do they interact with you? What idea do they have about their family, the community? What are they struggling with? What expectations do they have about the mediator?

COMMUNITY SERVICES

Key actions to make community services more inclusive

- **Community services can be made more inclusive through the training and qualification of the contexts and its technicians.**
- **It is important to monitor, observe and learn from experience.**
- **Equally important is the transformation of contexts. The path must be laid WITH people.**

Community services can be made more inclusive through the training and qualification of the contexts and their technicians.

Oftentimes the community service is reluctant when it comes to autistic people. There's a tendency to take for granted the person's lack of independence, or better, their ability to achieve independence.

Mediators need to let the community service see that the person on the autism spectrum can express their needs, complete the tasks they've been assigned and be independent.

KEY ACTIONS - It's fundamental for mediators to:
Let the autistic person speak for themselves whenever possible and in front of the community service.

Insist that the community service address the person on the autism spectrum directly
Include the autistic person in any conversation with the community service, making them an active part of the discourse.

Provide community services with a range of tools, methodologies and procedures to adapt the context and make it more autism-friendly.

COMMUNITY SERVICES
What if the institution does not know about autism, has prejudice about autism or regards the person with autism as too much responsibility?

The young mediator for inclusion will help the institution overcome the possible prejudice toward the person with autism by explaining how they can positively contribute to that context. He/she will inform the community services about the practical and social needs of individuals with Autism.

The mediator will also reassure the institution of their presence and supporting role for the person with autism.

The young mediator for inclusion will provide practical and social support to help the Community Services implement their activities, therefore exerting a positive effect on the inclusion of the autistic individuals.

He/she will promote new events in the Community Services to promote the inclusion of individuals on the autism spectrum.

as humans, we are scared
of what we do not know
BUT knowledge is power
knowledge sets us free

REFERENCES
- Kressel, K., and Pruitt, G.D. (1989). Mediation Research. San Francisco: Jossey-Bass.
- Johnson, D.W.R.T., Johnson, B., Dudley, M. W., Magnuson, D. (1995). The impact of peer mediation training on the management of school and home conflicts. American Educational Research Journal, 32, 829-844.
- Maley, Y. (1995). From adjudication to mediation: third-party discourse in conflict resolution. Journal of Pragmatics, 23, 93-110.
- Schrerer, T. M. (1997). Alternative dispute resolution in the federal tax arena: the internal revenue service opens the doors to mediation. Journal of Dispute Resolution, 215-227.
- Umbreit, M.S., Coates, R.B. (1993). Cross-site analysis of victim-offender mediation in four states. Crime and Delinquency, 39, 565-585.

Vanayan, M., White, N., Yuen, P., Teper, M. (1997). Would you like to be a peer mediator? Willingness to be a peer mediator among elementary students: effects of gender and gender. Alberta Journal of Educational Research, 43, 57-60.

- Silver, C. (1996). Models of quality for third parties in alternative dispute resolution. Ohio State Journal on Dispute Resolution, 12, 37-93.
- Wall, J.A., Stark, J.B., Standifer, R.L. (2001). Mediation – a current review and theory development, Journal of conflict resolution, 45(3), 370-391.
- AA.VV., Canevaro A. e Ianes D. (a cura di), Orizzonte inclusione, Erickson, 2015
- AA.VV., ICF e Convenzione ONU sui diritti delle persone con disabilità, Trento, Erickson, 2009
- Bonomo V., Persona con disabilità: operatività del servizio sociale professionale, in “La professione sociale” n. 28, CLUEB, dicembre 2004
- Bortoli B., Case managment, in “Dizionario di servizio sociale”, Dal Pra P. (a cura di), Carocci, 2005
- Caffarena C., Servizi, famiglia, territorio: un intreccio ricco di prospettive per le persone disabili, in “L’integrazione scolastica e sociale”, vol.7, n. 4, Erickson, settembre 2008
- Caldin R., Famiglia e sviluppo delle autonomie, in “Orizzonte inclusione”, Canevaro A. e Ianes D. (a cura di), Erickson, 2015
- Canevaro A., La lunga strada dell’integrazione nella società per una vita autonoma e indipendente, in “L’integrazione scolastica e sociale”, vol.8, n. 5, Erickson, novembre 2009
- Cesaroni M., Lussu A., Rovai B., Professione assistente sociale, Edizioni del Cerro, 2000
- Dal Pra Ponticelli M. (a cura di), Dizionario di servizio sociale, Carocci, 2005
- Dal Pra Ponticelli M. (a cura di), I modelli teorici del servizio sociale, Astrolabio, 1985
- Dal Pra Ponticelli M., Lineamenti di servizio sociale, Astrolabio, 1987
- Folgheraiter F., Interventi di rete e comunità locali, Erickson, 1996
- Folgheraiter F., L’utente che non c’è. Lavoro di rete e empowerment nei servizi alla persona, Erickson, 2002
- Fornasa W, Medeghini R., Nuzzo A., Vadalà G., Inclusione sociale e disabilità, Erickson, 2013
- Goussot A. (a cura di), Il disabile adulto,Maggioli, 2009
- Lepri C., Viaggiatori inattesi. Appunti sull’integrazione sociale delle persone disabili, Franco Angeli, 2011
- Lepri C. (a cura di), La persona al centro. Autodeterminazione, autonomia, adultità per le persone disabili, Franco Angeli, 2016
- Lerma M., Metodo e tecniche del processo di aiuto, Astrolabio, 1992
- Maguire L., Il lavoro sociale di rete. L’operatore sociale come mobilizzatore e coordinatore delle risorse informali della comunità, Erickson 1994
- Martini E. R., Sequi R., Il lavoro nella comunità, NIS, 1988
- Massaro A.S., Samory E., La presa in carico, in “La professione sociale”, n. 44, CLUEB, dicembre 2012
- Medeghini R., La personalizzazione del progetto di vita, in “Animazione sociale”, Edizioni Gruppo Abele, giugno-luglio 2006
- Monti M., Il progetto di vita, in “L’integrazione scolastica e sociale”, vol.7, n. 1, Erickson, febbraio 2008
- Moretti G., Riabilitazione e integrazione del disabile. Dai principi ai metodi, Roma, Armando, 2006
- Motta C., L’aiuto personalizzato, in “La professione sociale”, n. 33, CLUEB, giugno 2007
- Nussbaum M., Le nuove frontiere della giustizia, Il Mulino, 2007
- O.M.S., ICF-CY. Classificazione Internazionale del Funzionamento, della Disabilità e della Salute. Versione per bambini e adolescenti, Erickson, 2007
- Pavone M., Il progetto di vita per lo studente disabile, in “L’integrazione scolastica e sociale”, vol.7, n. 2, Erickson, aprile 2008
- Pavone M., Famiglia e progetto di vita. Crescere un figlio disabile dalla nascita alla vita adulta, Erickson, 2009
- Sanicola L. (a cura di), L’intervento di rete, Liguori, 1994

SERVICES IN THE COMUNITY

Other chapters of this guide
- explain the Young Mediators for Inclusion (YMI) project itself
- what inclusion means for autistic people
- as well as what the rationale and function of the mediators shall be

This chapter will tackle the services in the communities in which the mediators will be “employed”. Moreover, in line with the social model of disabilities, strategies will be presented to facilitate the inclusion of autistic youngsters, those with additional disabilities (e.g. intellectual), co-occurring conditions (e.g. ADHD) or (mental) health issues. Services in the communities for people with disabilities are rooted in concept of independent living.

Article 19 on living independently of the **United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)** states that people with disabilities

- shall “have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others”
- shall “have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community”

When defining independent living, the European Network on Independent Living (ENIL) points out that this **basic human rights concept** is older than the UNCRPD and influenced its creation. Independent living:

- based on the self-determination of people with disabilities
- does NOT mean being independent from other people, but having freedom of choice and control over one’s own life(style)
- requires that services must be available, accessible to all and provided on the basis of equal opportunity, free and informed consent, and allowing people with disabilities flexibility in their daily life
- requires that built environment, transport and information are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services

ENIL defines **personal assistance** as a tool that allows for independent living which;

- purchased through earmarked cash allocations for people with disabilities in order to pay for any assistance needed
- should be provided on the basis of an individual needs assessment and depending on the life situation of each individual

In the context of the Young Mediators for Inclusion (YMI) project, it is vital to reiterate that mediators

- shall **NOT be personal assistants** per se
- shall fulfil a role that is at best **additional to personal assistants/carers** for autistic youngsters to include them into non-formal/extracurricular activities/services in the communities

According to ENIL, the development of community-based services for people with disabilities requires
- a political approach
- a social approach
- policy measures making public services, (e.g. housing, education, transportation, health care and other services and support) available and accessible to people with disabilities in mainstream settings.

People with disabilities must be able to **access mainstream services and opportunities** and live as equal citizens.

Self-determination is vital for independent living. Studies suggest an increased n**eed to promote and enhance self-determination f**or youngsters with disabilities.

- One study discusses the increased need for the acquisition of social skills by high school students with learning disabilities as well as those with emotional and behavioral issues

Nonetheless, compared with other youngsters with disabilities, those on the autism spectrum have to make the most advances to be self-determined.

- Another study examined differences in self-determination among students on the autism spectrum, those with intellectual disabilities, and those with learning disabilities
- Self-determination in that study was defined by several categories including:
- autonomy, self-regulation, psychological empowerment, and self-realization
- Results indicate that a**utistic students have significantly lower levels of autonomy** compared to students in the other two groups
- Students on the autism spectrum as well as those with intellectual disabilities have **significantly lower levels of psychological empowerment and self-realization** than students with learning disabilities

One way to increase the self-determination of students with disabilities is through **experience in recreational activities** NOT just through teaching explicit skills.

- Another study explored this link for students with intellectual disabilities
- Found tha**t youngsters had higher levels of self-determination** when spending an increased amount of time actively involved in recreation
- **This means that recreation may be a useful strategy for enhancing self-determination skills**
- For another study, **inclusive extracurricular activities lead to increased self-determination** among students with disabilities.

This in turn underpins the **need for autistic youngsters to join non-formal/extracurricular activities/services in the communities t**o advance their social skills, autonomy, empowerment and self-realisation with the help of young mediators for inclusion

> Mediation is the main strategy that leads to inclusion and independent living of autistic youngsters.

How this was done in practice during the Young mediators for Inclusion pilot project will be the subject of the testimonies from the project in one of the follow chapters.

Sources:

European Network of Independent Living (ENIL) (2022) Independent Living https://enil.eu/independent-living/
ENIL (2022) Personal assistance https://enil.eu/personal-assistance/
ENIL (2022) Deinstitutionalisation https://enil.eu/deinstitutionalisation/
UNCRPD (2006) Article 19 – Living independently and being included in the community https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html
Pierson, M. R. et al. (2008) Factors Influencing the Self-Determination of Transition-Age Youth With High-Incidence Disabilities. Career Development for Exceptional Individuals Vol. 31 No. 2 p 115-125.
McGuire, J. & McDonnell, J. (2008) Relationships Between Recreation and Levels of Self-Determination for Adolescents and Young Adults With Disabilities. Career Development for Exceptional Individuals. Vol. 31 No. 3 p. 154-163.
Chou, Y. et al (2017) Comparisons of Self-Determination among Students with Autism, Intellectual Disability, and Learning Disabilities: A Multivariate Analysis. Focus on Autism and Other Developmental Disabilities, 32(2), 124–132.
Vinoski, E., et al (2016). Building Self-Determination Through Inclusive Extracurricular Programs. TEACHING Exceptional Children, 48(5), 258-265.

Further reading:

Agran, et. al. (2017) Participation of Students with Intellectual and Developmental Disabilities in Extracurricular Activities: Does Inclusion End at 3:00? Education and Training in Autism and Developmental Disabilities, 2017, 52(1), 3–12
Kaljača, S. et al. (2019) Participation of children and youth with neurodevelopmental disorders in after-school activities. Disability and Rehabilitation. Vol. 41 Issue 17
Vicente, E. et al. (2019) Personal characteristics and school contextual variables associated with student self-determination in Spanish context. Journal of Intellectual & Developmental Disability. Vol. 44, Issue 1
Harada, C. M. et al. (2011) Promoting social inclusion for people with intellectual disabilities through sport: Special Olympics International, global sport initiatives and strategies. Sport in Society. Cultures, Commerce, Media, Politics Vol 14 Issue 9: Disability in the global sport arena: a sporting chance.
Delgado, G. R. E.,et al. (2018). Demands of People with Disabilities and Empowerment of Resilient Strategies. International Research Journal of Management, IT and Social Sciences, 5(1), 45-54. https://sloap.org/journals/index.php/irjmis/article/view/29/1084
Bigby C. & Wiesel, I. (2011) Encounter as a dimension of social inclusion for people with intellectual disability: Beyond and between community presence and participation. Journal of Intellectual & Developmental Disability Vol. 36, Issue 4

TESTIMONIES


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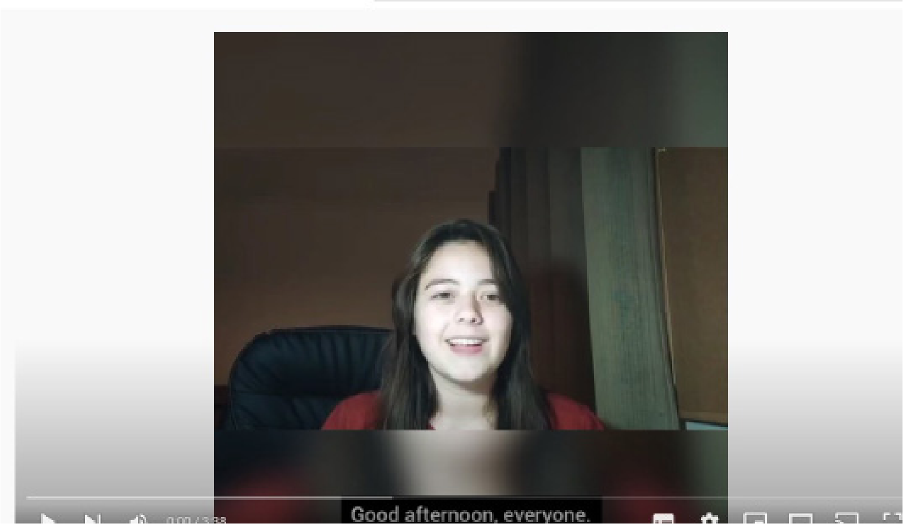
MESA REDONDA DE EXPERTOS:
Gabriel Pérez

YMI
Young Mediators for Inclusion

Gabriel Pérez, autistic person, Spain

“All along my life I’ve had to face many challenges. I wouldn’t have been able to do it without professional support from Asociación Autismo Burgos. For example, I had a little problem with my English teacher and thanks to Marco, my professional support, I could communicate with the head of studies and solve it. It is important to have that support in that kind of situation because it can be difficult to solve these problems”

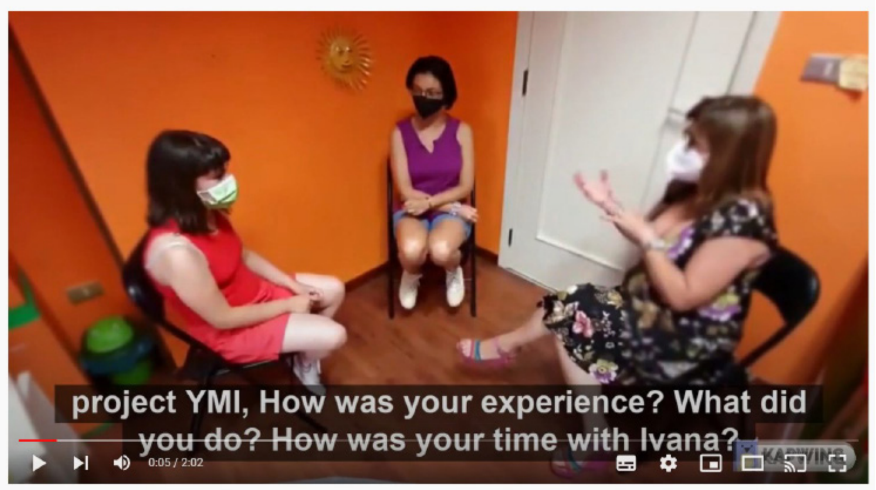
Watch the full testimony here


Good afternoon, everyone.

Catarina Atabao, mediator, Portugal

My job as Bruno’s mediator, consisted on accompanying him on public transports, from his home to the music school and also to be with him on the classes... It was a very positive experience, because not only I learned a lot on the theoretical training, but mainly, I learned a lot on the practical part and I learned a lot with Bruno and his mother. (…) I consider this project of huge relevance in the scope of inclusion of autistic persons.”

Watch the full testimony here

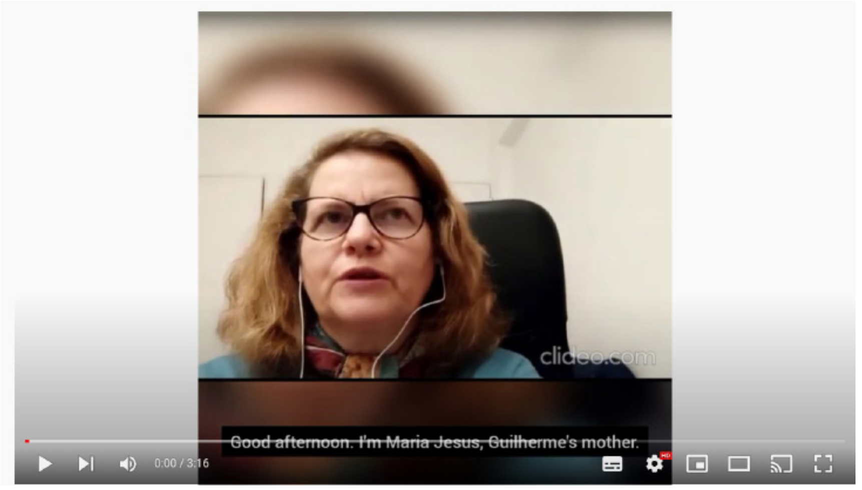

project YMI, How was your experience? What did you do? How was your time with Ivana?

Diversamente - Video from Valeria

Valeria, autistic person, Italy

“I did an internship in a library, I did the book inventory...I had a very good time, I have met other librarians, I have learnt a lot of things about books. At the beginning Ivana helped me, then, little by little, I learnt to do it by myself”

Watch the full testimony here


Good afternoon. I'm Maria Jesus, Guilherme's mother.

Maria Jesus, mother of autistic person, Portugal

“It was with great enthusiasm that we joined the project. And it was thanks to the project that Guilherme could have surf classes close to home. The mediator’s support fundamental to give trust to the school and reducing their fear of leading with a young autistic person. They quickly confessed that it wasn’t as complicated as they thought it would be.”

Watch the full testimony here

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