



YOUNG MEDIATORS FOR INCLUSION

YMI 2019-1-PT01-KA202-061190

**Report of Critical Factors' identification for
the Success of Inclusion of
Young People on the Autism Spectrum in
Community's Activities**

TASKS CARRIED OUT FOR THE PRODUCTION OF THE IO1

1. Literature Review
2. Round Table of Experts
3. Focus Group with persons with autism
4. Focus Group with family members of persons with autism



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MAIN RESULTS

1. Literature Review

Regarding the literature review carried out by the various partners of the Young Mediators for Inclusion project, and looking with a global perspective on the various results in order to elaborate this summary, the main conclusion is that there still is a lot of work to do regarding the identification of good practices for inclusion of people with autism in the community. Many issues are still often addressed according to the individualistic model, looking at disability and autism in particular as an individual problem and not as a social problem.

The research shows that, in general, there are improvements in the area of education. In Spain, Italy and Portugal there are several examples of professionalized and individualized support programmes, providing social, environment and academic curriculum adaptations, an education centred in the child with the promotion of individual interests, potentials and talents, involving the teachers, staff, volunteers, children/young people with autism and their families. In spite of the right of universal education being figured at the Convention on the Rights of the Child, in 1990, it was recommended again in 1994 at the Salamanca Declaration, and figures in the Article 24 of the Convention on the Rights of Persons with Disabilities, since 2006.

The existence and application of those declarations should already be fully installed and be considered a standard and not something exceptional. Nevertheless, several articles reveal that there is a constant growing perception and acceptance of diversity and the need to adapt curriculums and teaching strategies in order to ensure equity, participation and school success of all children (with and without disabilities).

Regarding the inclusion of people with autism in the community, the results found are much scarcer. In 2015 there were two studies, one from the Queen University Belfast entitled "Creating an Inclusive Society... How Close are We in Relation to Autism Spectrum Disorder? A General Population Survey", and one from three Universities from Berlin, called "Psychosocial functioning and life satisfaction in adults with autism spectrum disorder without intellectual impairment". The first study showed that it seems that inclusion is extending, however, it is important to continue to improve the areas of education and support for people with autism.

The second one showed that Individuals with autism reported significant functional impairments and less life satisfaction compared with neurotypical individuals in many areas of life.

"Although impairments were prominent in domains involving interaction with other people such as understanding and communication, getting along with others, and participation in society, daily living skills, were not different from nonclinical participants. Participating in society was identified as the only factor predicting life satisfaction in individuals with ASD". (Schmidt, L., et al., 2015). In 2019, a study carried out in Spain shows that social inclusion and self-determination have still the lowest scores, comparing to material wellbeing and personal development (Moran Suarez, et al., 2019).

We concluded that there are many activities and projects ongoing in society. However, many of them are still designed according to the medical model and do not allow full and effective inclusion of persons with disabilities in the community. We also had the perception that many projects are aimed at people with physical disabilities, but that the number of projects targeted (also) at people on the autism spectrum is quite small. Most of the projects found during our research are developed by NGOs in the area of disability, financed mainly by the State but also by companies and families.

However, both private and public funding is usually annual or biannual, which calls into question the continuity and subsequent quality of the projects. On the other hand, there is a lack of inclusion projects promoted by public entities (except in the area of education and employment) and a lack of funding and support by the state of truly inclusive projects (with the exception of the Independent Living project).

This lack of state investment in inclusive responses with continuity, leaves a vast number of persons with disabilities and their families desperate and helpless.

The research of the various consortium partners shows that, in general, the projects are mainly in the areas of sport, leisure and access to culture, arts (music, visual arts and theater) and holiday camps. In Portugal, Inovar Autismo found some projects related to support networks, community training and independent living. In Italy, the research results reveal that there is a greater concern with pedagogical differentiation and cooperative learning (at the classrooms).

There are few projects that mention the training of technicians and contexts, revealing that there is a gap in this area and possibly a lack of awareness of the importance of training the regular contexts of the community and persons involved in them, so that inclusion can actually happen to its fullest extent.

In terms of technology, Intermediakt, who conducted a survey on apps related to good inclusion practices for people with autism, found several apps of diverse nature such as: games, support groups, communication, social skills and functional life skills. These apps provide help for persons with autism in training joint attention and concentration, recognition, cooperation, identifying and understand emotions, language development, alternative communication, through the use of social stories, games, pictures, visual time structures, etc.

In accordance with the provisions of the YMI project, each partner of the consortium was asked to carry out a brief literature review to reveal good practices of innovative and inclusive projects in the area of autism. However, the ISCTE partner considered that, since the project relies on the figure of the mediator as a tool to promote inclusion and human rights, it is also necessary to clarify the meaning of the key concept: mediation.

Mediation is a key concept of the YMI project. In recent years, mediation has gained increasing importance in different angles, such as education, politics, labor, judicial, community and sociocultural and intercultural (Romero, 2010; Mateus, 2017). The concept of contemporary mediation emerges in the 1970s in the United States of America. In a first sense, mediation arises mainly in the context of alternative conflict resolution, but its field of intervention extends, as mentioned, to the areas of social, family and citizenship cohesion (idem).

The multiplicity of mediation practices tries to address the problems of an increasingly cross-cultural, trans-ethnic and heterogeneous society from the social point of view, which incorporates difference as a daily reality.

Mediation is thus a concept used to refer to the activity of putting into relation different (and sometimes conflicting and/or separated) parts of a social system.

Almeida (2001) sees mediation as a “method of social and cultural transformation”. Thus, social mediation, as a stricter concept, is related to the promotion of inclusion and social participation (Gimenez, 2003).

For the author, in the act of social mediation, the relationship between the parties, influenced by the pre-established cultural difference, tends to get closer due to the mediator's experience and intercultural work.

The most current meaning of “mediator” is linked to the idea of the intermediary, the facilitator, who allows a certain action to happen and / or a certain objective to be achieved (Vieira, 2011).

This personifies the link, embodying the facilitating agent that makes dialogue possible, promotes conflict resolution, as well as access and participation of the most excluded party.

Mediation aims to include, creating bridges, so that communication between the parts of a social system is possible, enhancing the social and institutional relationship between individuals. Vieira (2011) argues that community mediation aims to promote the participation and empowerment of the target population for support.

Regarding the figure and profile of the mediator, in Portugal, Law No. 105/2001 establishes the legal status of the socio-cultural mediator, incorporating guidelines for the definition of the mediator's functions.

Although legislation has been produced to regulate mediation on the integration of immigrants and ethnic minorities, many of the tasks can be transposed to mediation within the scope of inclusion.

In this legislation, the mediator is responsible for:

- i) collaborating in the prevention and resolution of conflicts and in the definition of the social intervention strategy;
- ii) articulate with all those involved in the social and educational intervention processes;
- iii) facilitate communication with and between professionals and the recipient of support;
- iv) advise the recipients in their relationship with professionals from public and private organizations;
- v) promote the inclusion of citizens from different social and cultural backgrounds on equal terms;
- vi) respect the confidential nature of the information related to recipients and their families.

AIThe ISCTE team analyzed the complete list of projects promoted by NGOs and approved for funding in 2019 by the Portuguese National Institute for Rehabilitation (NIR). A first observation that can be made is about the enormous prevalence of projects aimed only at people with autism, that is, non-inclusive. Holiday camps for children and young people with autism, artistic workshops intended only for these people, skills promotion and rehabilitation activities appear in large numbers, instead of inclusive projects.

For all that has been expressed here in the context of this synthetic review of the literature, the practice of mediation tends to constitute an added value for the promotion of the participation and inclusion of several excluded groups, among which the group of people with disability in general and with autism in particular, whose social participation still faces major barriers.

These results are a clear indicator that the work being done is not enough and that there needs to be an improvement and an innovative look at the inclusion and effective participation of people with autism in the community in order to improve their life quality, self-determination and selfrepresentation.

2. Round Table of Experts

During the Round Table of Experts carried out in Portugal, Spain and Italy, it was identified, in all of the three countries, that there are innovative policies, but they are not always accompanied by financial and human resources.

In recent years there have been great advances in the field of regulations and laws that protect the rights of people with disability. However, this progress has not been reflected in the practical application of laws, nor has it impacted as one would expect in people's lives.

In other words, there is a lack of concrete programs and measures that innovate and modify the dynamics created in existing services. Although the regulations exist, on multiple occasions they are not conveniently developed due to the lack of training and knowledge of the professionals involved in the work with people with autism, and the lack of knowledge of how these regulations can be applied in a flexible and adapted way to address their needs.

However, it was also concluded that things are changing and that there is an increased priority for disability issues on the public policy agenda. There has been a considerable steering towards inclusion but many sectors still need deeper awareness.

In the three countries it was identified that the advances in legislation and the development of services are mainly in the area of basic education, leaving other areas such as health, employment, family, leisure activities, etc., without adequate services to the specific characteristics and needs of people with autism

In the scope of education, teachers and other professionals still show difficulties when it comes to person-centered planning and self-representation of people with disability. Even in Italy, where the educational system is becoming increasingly inclusive, teachers often feel scared because they do not know how to deal with the class as a whole

However, when they're given the right tools, they work quite peacefully and cooperate effectively with the specialists' team.

The biggest difficulties are found in high school where there have always been huge obstacles.

Helping young people interact is difficult because of the "rush to the programmes", the urge of carrying on with the class programme for the year, ending up neglecting these young students with autism. Many teachers still lack the minimum basics of special didactics and developmental psychology. Diversamente ODV identified that, at university there is scarce involvement of peers.

There could be more events dedicated to the topic of autism so that university students could know more about it.

Regarding the role of the NGOs, the experts from the three countries considered that the paradigm shift is being slow. Even though many professionals have changed their vision regarding what the objectives of the intervention and support should pursue, there are still many of them struggling, when asked to develop more inclusive, less segregated activities, revealing that the skills and knowledge are not as robust at this level.

Those who work for inclusion quite often miss or neglect the main objective of this mission, which should be first that of listening. It is taken for granted, but people do not listen to the needs, preferences and aspirations of people with disability, and in this particular case, of people with autism.

In general, it was considered that the medical model is still very present. Although the experts feel that we are at a turning point. Ratifying the Convention on the Rights of Persons with Disabilities (CRPD) was very important in this sense, and helped to increase the protagonism of persons with disability.

As also revealed in the literature review, examples of good practices are found mainly in temporary projects. Often, funds get spread over a multitude of small projects, instead of having a single, comprehensive scope.

These projects dissipate the economic resources which could on the contrary be put to good use by carrying out a specific idea of inclusion. In Portugal, experts considered that one of the main barriers that institutions face, in the development of new social services, is the lack of financial resources, together with a lack of specialized training of professionals.

Synergies between small associations are essential in the development of projects and social services aimed at the inclusion of people with autism

Regarding the self-representation and self-determination of persons with autism in institutions, it was considered almost non-existent. The Italian experts reported that not all persons with autism are capable of self-representing and self-determining themselves in complete autonomy without the support of a mediator or another person who could facilitate these fundamental aspects.

In order to change that and to increase the intervention of these persons in the life of the institution, there is a need to raise awareness.

It is also important to find a way not only to include people in the community where they live, but also to help them understand their rights and duties. Not recognizing the needs and rights, implies not asking for adequate support. Families and institutions often show overprotection of the persons with disability, not promoting their autonomy, independency and empowerment.

Sometimes the family requests a model of services that is protectionist, where safety and care of basic needs are the priority, leaving behind the issues of self-determination and empowerment (including disclosure).

Finally, it is important to promote positive experiences, which generate trust and security for people with autism and their families, and which enable an environment that enhances the self-determination and self-representation.

Regarding the mediation for inclusion and the role and profile of the mediator, the experts that participated at the Round Tables in the three countries, identified a number of fundamental aspects that should define the concept of mediation for inclusion and the profile of the mediator:

- The mediator can act as a translator, facilitator, someone who can “bridge the gap”. Often, people do not realize that they are experiencing situations of discrimination and oppression and it is necessary to “translate” in order to enhance their self-determination;
 - Someone who facilitates the communication between the family, the specialists and the various contexts of life;
 - Mediators can be fundamental tool, not only to increase the empowerment of persons with autism, but also to be part of empowering contexts that, in turn, become more inclusive and adopt a bigger rights-centered perspective;
 - The mediator should be an agent of transformation of contexts. Be a facilitator in the coconstruction process. The contexts need to be reinvented;
 - Mediators can raise awareness to this specific theme (autism, inclusion, human rights, etc.).
- Help to decode some conducts and explain situations, in a double perspective (person-context and context-person);

Regarding the training that young mediators should receive, the experts highlighted the following aspects:

- Strong training in the area of human rights (including legislation), inclusion, health and wellbeing issues, quality of life indicators, etc.;
- Attend a basic course on communication and emotion management, in order to better relate with families and the several life contexts of the persons with autism;
- Attend a basic course on autism, the principles of the behavioural intervention (reinforce adaptive behaviour, shaping, modelling, etc., the analysis of the problem, behaviour functioning) and on the augmentative and alternative communication (AAC);
- Complete a basic training on the assessment of efficiency of the intervention, so that they can plan an evidence-based intervention. Gathering data helps to make educated decisions on the project and to make effective changes. This young mediator for inclusion must know how to define clear and measurable goals. He or she must know how to define how much time is needed to reach these goals, how they will be assessed, if they've been reached or not and what changes have to be made;
- Know the functioning of institutions so that they can effectively mediate between family and institutions;

-Finally, it is important to note that the expectations towards this young professional cannot be compared to the expectations one would have towards a specialist. The training courses will give a basic preparation, which will increase with experience, but which will not be, in themselves, a guarantee of efficacy. In order to ensure greater success and effectiveness of the intervention of the mediator for inclusion, it is important to involve the family (who will also have a supervisory role) and carry out continuous monitoring and evaluation by the technical support team, as of all the elements involved.

-Despite their training, the mediators should mainly mediate between peers, helping with the participation to citizenship, helping self-determination and self-advocacy. The mediator is someone who assists the person with autism, encourages and motivates him or her.

They need to be able to mediate with reason and sensitivity, empathy and open-mind.

The benefits from mediation for inclusion can affect positively not only persons with autism (enhance participation and intervention; increase the knowledge about their rights; they themselves can also become mediators), but also their families (increase security and understanding of their rights / rights of their children with autism), the institutions (increase of staff with specific training; possibility to provide a higher quality of life to its clients; possibility of a gradual transformation) and the community in general.

Strategy to involve institutions/ service providers:

All participants affirmed that especially people with disability, and also their families, should lead and be involved in all phases of the debate on this topic, representing the motto “nothing about us, without us”. However, families are not always prepared and / or trained to lead this debate. In this sense, it is also necessary to sensitize families through good practices and personal testimonies of other families or persons with autism.

Besides that, it is important that more organizations include persons with disabilities in the board of their organization (what currently doesn't happen). It must be worked with the people and not about them.

When asked about how to integrate the work of mediators in standardized institutions to work in a different way, the experts considered that it must be through the training and qualification of the contexts and its professional staff. It is important to monitor, observe and learn from experience. Equally important is the transformation of contexts. Although, it is necessary to proceed carefully, monitoring and “walking the path with people”, not making them invisible (as institutions and academia often do).

Some strategies were suggested:

- Information has to be accessible to everybody in order to promote participation;
- Prove it is possible: show evidence of the results and the positive impact of the experiences;
- Make people with autism visible in each and every context;
- Open the doors of the institutions, so the community knows the services, needs and abilities of people with autism;
- Modify the curriculums of university degrees, including in all professional profiles subjects or credits directly linked to disability and specifically with autism, in order to expand this knowledge to all areas and disciplines, not focusing exclusively on the typical education and social services;

- Evaluate the impact of the inclusive experiences that are being developed, not only with people with autism but with the rest of the population;
- Create a postgraduate course focused on mediation;
- Link the benefits of inclusion to health aspects, by showing how a positive inclusion reduces the associated mental disorders and psychiatric complications, which reduces health care costs.
- Increase social communication strategies;
- Increase dissemination of good practices;
- Raising awareness about what inclusion means;
- Involvement of society and business in innovative projects;
- Report on social networks.

Finally, in order to sensitize and raise awareness of people with autism and their families to improve / increase their performance in the defense of their human rights, it is absolutely fundamental to involve them in all parts and phases of the projects, debates and design of innovative public policies.

As mentioned before, it is very important to help people with disability to understand their rights and duties and to support their empowerment, selfdetermination and self-representation.

3. Focus Group with persons with autism

In the focus groups held in the three countries with persons with autism, participants were heard about the main barriers and facilitating aspects they encountered throughout their school career, which can be found in the grid below:

Barriers to inclusion	Main positive aspects (during school and in the transition to adulthood):
<ul style="list-style-type: none">• Bullying, being considered as "the weird", left apart what lead to intense feelings of frustration	<ul style="list-style-type: none">• Learn new things
<ul style="list-style-type: none">• Target of verbal violence ("you are boring", "you are ugly") which triggered frustration and decompensation	<ul style="list-style-type: none">• Having several teachers and several experiences;
<ul style="list-style-type: none">• Be treated with condescension (as if he were a child), what led to isolation	<ul style="list-style-type: none">• Friendships that have established themselves in secondary school and that have remained
<ul style="list-style-type: none">• Making and keeping friendships/ social contact	<ul style="list-style-type: none">• Have successfully completed secondary school
<ul style="list-style-type: none">• Making and keeping friendships/ social contact	<ul style="list-style-type: none">• Good relations with colleagues, teachers and assistants
<ul style="list-style-type: none">• Many social barriers: going to a place and don't know what to do (couldn't find the exit in the swimming pool locker rooms, how to ask for an ice-cream, etc.)	<ul style="list-style-type: none">• Improvement of the quality of life after having been made aware of their diagnosis

<ul style="list-style-type: none"> • School, which is not inclusive, non-comprehensive teachers and/or peers 	<ul style="list-style-type: none"> • Getting in touch with associations where they learnt how to interact better and how to stop hiding from people
<ul style="list-style-type: none"> • Distance from a big city (mentioned especially in Italy) 	<ul style="list-style-type: none"> • The support of family, educators and support teachers at school
<ul style="list-style-type: none"> • Support teachers, who have too few working hours 	<ul style="list-style-type: none"> • Adaptations for the whole class group, not only for the student with autism
<ul style="list-style-type: none"> • Non-inclusive extra-curricular activities (basket team, swimming, scouts) 	<ul style="list-style-type: none"> • Functional diversity support at university
<ul style="list-style-type: none"> • Maintain focus and concentration in class (sometimes due to medication) 	<ul style="list-style-type: none"> • Good experience in athletics groups
<ul style="list-style-type: none"> • Communication 	<ul style="list-style-type: none"> • Support of private teachers and schoolmates
<ul style="list-style-type: none"> • Self-built barriers of the people with autism, created as a protection from people's judgment and the possibility to be considered different 	<ul style="list-style-type: none"> • To change from one school to another more inclusive one
<ul style="list-style-type: none"> • Difficulty finding work; 	<ul style="list-style-type: none"> • General improvement after having learnt to control certain reactions, having learnt how to listen, etc.

Regarding the barriers, there was a particular difference between Portugal and Italy, with regard to the level of inclusion in basic school and higher education. While in Portugal, participants experienced more difficulties and barriers to inclusion in primary and basic education, reporting improvements in secondary and higher education (in the vast majority of the cases), in Italy the participants reported precisely the opposite, having experienced more difficulty in secondary schools and universities.

Mediation for inclusion in the eyes of people with autism:

In the view of the young participants with autism, the concept of Mediation for Inclusion is defined by an understanding, empathic, patient and trustworthy person who listens, guides during life, helps to clarify doubts and overcomes barriers in areas that the person with autism does not master well.

The Mediator helps to acquire practical knowledge and objectives so that inclusion is successful.

The participants of the three focus groups held in the three countries defined some fundamental skills and traces of the profile a mediator for inclusion should have.

The young mediator should be someone who:

- Creates a bridge and is a “translator”;
- Observes the difficulties and, especially, the potentialities of the person with autism;
- Supports activities that the person with autism cannot do by himself;
- Acts as an ambassador for the person with autism and prevents from bullying;
- Helps to develop independency (e.g. looking for an apartment);
- Is neutral and conciliatory;
- Has experience in working with persons with autism, or some specific training in the areas of psychology, occupational therapy, pedagogy, social education;
- Has very good communication and management skills;
- Helps with integration into society's activities;
- Cooperates with the person;
- Is open to this type of challenges;
- Isn't prejudiced;
- Has the characteristics of a friend;
- Is able to teach and help

According to the participants, the areas where mediation could be most useful are:

- Daily life: support for independency in the kitchen; assist in managing and organizing responsibilities (such as paying bills, etc.);
- When changing schools;
- In the practice of physical exercise;
- Participate in community activities ("going out more often");
- Do activities that both (person with autism and mediator) like to do;
- Take trips;
- Guide the person, in general, in her/his life;
- In the interaction with other people;
- At the university/internship (organizing school life, carrying out working in groups, helping to establish new relationships, develop social skills, etc.);
- Job search help and housing;
- Opening new horizons/ find new hobbies/ acquisition of new knowledge;
- The mediator could be helpful even after school, as young adults

Finally, the participants mentioned that the mediator for inclusion must respect the privacy of the person they support and not interfere with her/his groups of friends. They also mentioned that more important than having a very long and good curriculum, is to have the right attitudes and profile. In both Portugal and Italy, participants mentioned that the mediator for inclusion could also be someone with autism, as they know some of the peculiarities of a life with this syndrome.

4. Focus Group with members of families of persons with autism

In the focus groups with members of families of people with autism, carried out in the three countries, issues related to the participants' perception about the inclusion of their family members with autism and the concept of mediation for inclusion and the profile of the mediator for inclusion were addressed.

The best strategies for introducing the debate into the community and involving institutions and service providers were also discussed.

Family view on the inclusion process of their family member with autism:

a) Barriers to inclusion identified by the family:

The majority of the participants in this focus group reported that there were / are difficulties in terms of inclusion, especially in the school context. These are mainly due to: a lack of human resources, non-inclusive activities, lack of training, knowledge and understanding in the field of autism, difficulties in dialogue with the school (especially with the multidisciplinary special education team), very rigid academic model, frequent exchange of support teachers, focus on the same basic activities, not taking into account the real possibilities of the child; difficulty to remove previous judgements ("it's a behavioral issue"), maximizing the chances of the student with autism to learn; sensory aspects; few options for the transition to adulthood/ "life after school".

The participants also said that there are big barriers in society in general, such as the lack of knowledge about autism and its characteristics, especially when there are severe, non-verbal cases. The barrier to inclusion is in people's mind - physical disability is almost accepted nowadays, mental one is not because it's not immediately visible.

The participants in Italy also identified some barriers at the institutional level, namely the lack of more projects like the centers of independent living, which promote independency, self-determination and participation.

The "after us" projects are still at an embryonic stage and quite far from even seeing an experimental phase.

The participants ended by saying that young persons with autism start social activities but they refuse them when they don't get support or when they live negative experiences like feeling judged or rejected.

These, and other kind of troubles and difficulties, normally grow up with aging.

b) Despite the negative aspects, the participants were also able to identify positive aspects such

as:

- Better preparation of the school in the secondary education;
- Good monitoring and communication at school;
- Generalization of supports all along the class group, and adaptation of the context to promote understanding;
- A humane component of teaching and non-teaching staff that tries to understand persons with autism;
- Sharing time with neurotypical colleagues;
- Willingness on the part of the school to do something;
- When they (persons with autism) are encouraged to express and participate they show good abilities and strong vocations.

When asked about the main support networks they have had over the years, parents listed:

friends who support in urgent situations, hospital team where autism was diagnosed, school, family members (in-laws, parents and siblings), Associations, Personal Assistants.

The importance of establishing a support network from an early age was also discussed. It is very important to ensure that parents are able to keep their jobs and ensure the quality of life of the family. One mother added that while their kids are children, it is always easier to have support, and that over time, the support networks become weaker.

Mediation for inclusion

In the view of the participants, the concept of Mediation for Inclusion is defined by someone who has several social skills and can help with social, behavioral and communicational problems.

The mediator should have a transversal activity (in different areas of life) and support meaningful activities for the person being supported. The figure of the mediator should also be someone that represents a sort of a specialist in bridging the gap between families and the school / health system / legal aspects / community services and assets.

The Mediator could be important not only for young persons with autism but also for neurotypical young persons, enriching their experience, giving rise to new feelings and new attitudes towards diversity.

In the perspective of the participants, the Mediators for Inclusion have to be selected very carefully, and include the following **aspects**:

- Has to have a set of personal attributes, a highly developed humane profile and be an open person;
- Not be too intrusive;
- Hard skills (knowledge in the field of autism, psychology, pedagogy and other fundamental fields; technical, legal, basic issues - points where parents sometimes have difficulties)
- Soft skills (planning ability, ability to negotiate with different institutions / entities);
- Having a good balance between knowledge and emotion;
- Being a transforming agent in institutions in order to break down barriers and intervene as a "translator";
- He/she would mediate between the student and the teachers;
- Some parents think that he/she should be with the child all the time, even though this might be counterproductive if the child develops an affection for this person and then this person leaves;
- Some parents think that the mediator should be different for each environment: one for school, one for sport, etc. and not a specific mediator for each child with autism. A mediator for each sector;

- A mediator who stays with the family until retirement, is highly unlikely;
 - The mediator could also be included in the health care system - neuropsychiatry and the mental health centre could be the appropriate place for this mediator, and in job centers;
 - The mediator must be aware and know the child's project of adult living;
 - If people were able to afford it, there would be a mediator for each person with autism
- (Depending on the size of the town there would be more than one mediator for each field);
- The mediator could be part of an institution. One mediator for every municipality would be utopian, but maybe in every PLUS, that would be doable;
 - Some parents think that the mediator doesn't have to be the same person who stays with the child until they're grown up - it should be a role in which people can follow one another, somebody who keeps a dossier with all the details and the story of the child;
 - The mediator should not be hired by the family - nobody can guarantee such a role for such a long time, and it would be impossible from a financial point of view

For the mediation of inclusion to work it is necessary to involve not only the persons with autism and their families, but also politicians, entrepreneurs, schools and the community in general.

The participants considered that it is very important to involve children, who are more absorbent and help to raise awareness among parents.

The mediator should be motivated and collaborative, and help to bridge the gap with the various stakeholders. It is also essential that the parties involved are aware that this is an ongoing and not an immediate process.

- In the participants opinion, the benefits from mediation for inclusion can affect positively not only persons with autism (access to activities in the community - for example, go to a soccer game without mum or dad; increased independence, increased activities of interest to persons with disabilities (rather than purely occupational activities), but also the life of the family (to have more support, access to more information and help in areas in which the parents have difficulties (for example in the legal area), support in communication with school, health system, etc.), the institutions (to have a specific and trained support; possibility of offering a better, more inclusive service) and the community in general (to become more aware and open minded about human diversity, disability and inclusion; a resource for universities, schools, employment centers, families, etc.).

The debate on the idea of social utility and relevance of mediation for inclusion, should involve the families, the persons with autism, the whole community, health care services, councils, chambers, schools, various professional areas, etc. When asked about how to do it, and what strategies to use, the participants suggested:

- Thematic roadshow involving the councils, schools, etc.;
- Social networks, media;
- Publicity video explaining the state of the art and presenting the mediator as one of the possible solutions to mitigate the problem of exclusion.

FINAL CONCLUSIONS

Through carrying out IO1 activities, and based on a holistic and heterogeneous sample, we concluded that there are still many barriers to the inclusion and participation of children and young people with autism in the community. In general, we also realized that, although there is often a willingness to help from teachers and other professionals, there is an evident lack of specific training in the area of autism, human rights, diversity and inclusion.

The lack of knowledge and adequacy of activities to the specific characteristics and needs of people with autism was a recurring element that translates into a significant barrier to inclusion.

There is not agreement about the creation of a new professional role: some families defend the mediator as a new professional role, others suggest to attribute their functions to previous professionals from the organizations; anyway, all the families say it must be an accessible figure for all the people in every place and moment, when troubles and special difficulties appear.

According to the literature review, and confirmed by both experts and parents of young people with autism, there are innovative policies and projects.

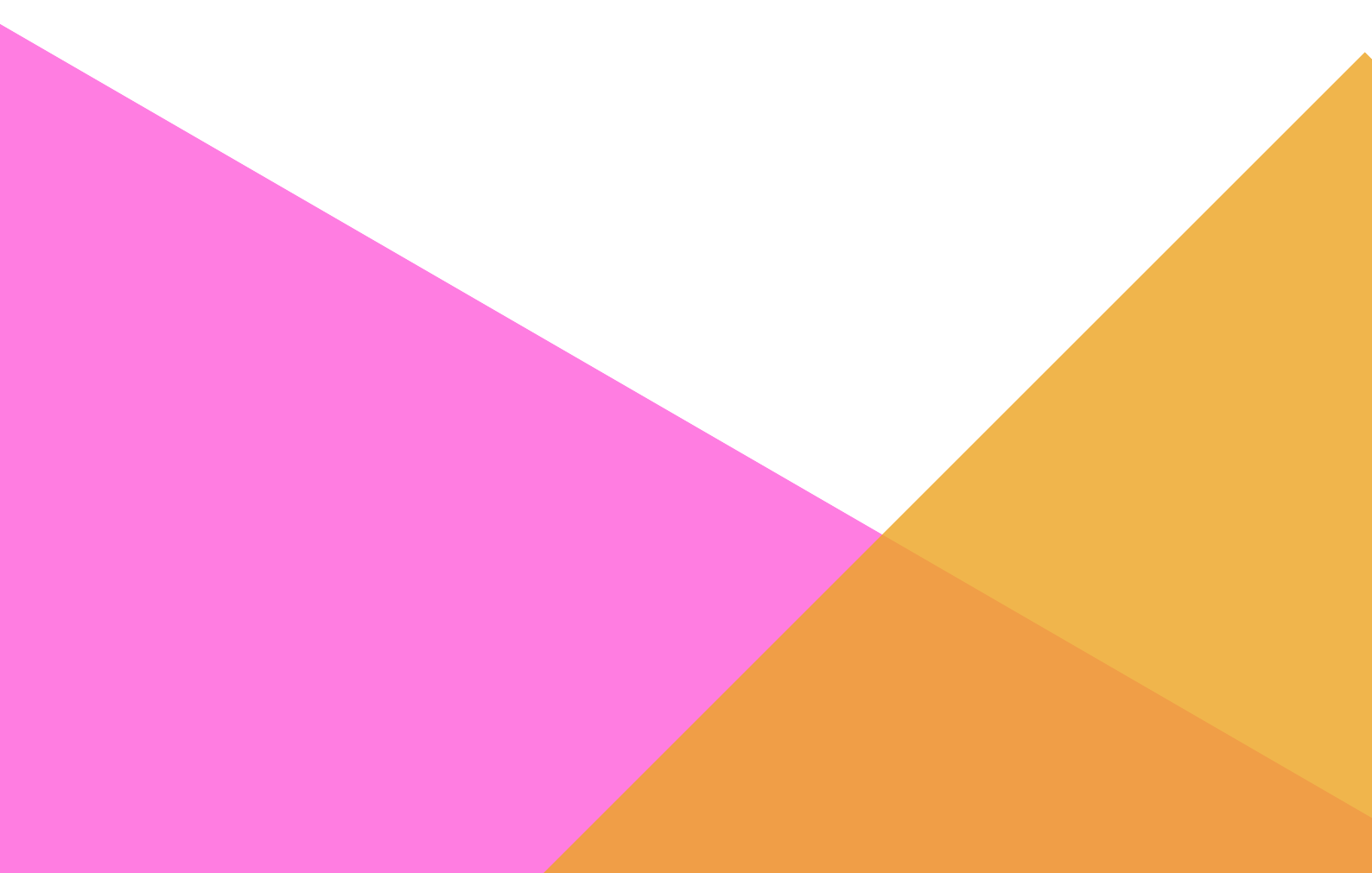
However, there is a great lack of human and financial resources, as well as lasting and consistent practices.

Equally consistent was the awareness that there is an urgent need for people with disabilities to be involved in projects, to be more heard and for projects to be with them and not about them.

Only then, self-determination, self-representation and true inclusion of people with autism / disability will occur.

The biggest barrier to inclusion seems to be the lack of awareness of people and society in general. Being less visible compared to physical disability, autism is not yet accepted.

Considering the profile, competences and skills that the mediator for the inclusion should have, the responses obtained in the various activities carried out in Portugal, Italy and Spain were very similar, constituting important indicators, both for the identification and selection of young mediators, as well as for the design of the course curriculum.



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