

WHY YOUTH WORK NEED TO BE ACCESSIBLE FOR
YOUNG PEOPLE LIVING WITH DISABILITIES?

FOCUS GROUP ANALYSIS – PORTUGAL

ON THE RESEARCH CONDUCTED IN THE 'MOONWALK'
PROJECT



WHY YOUTH WORK NEED TO BE ACCESSIBLE FOR
YOUNG PEOPLE LIVING WITH DISABILITIES?

FOCUS GROUP ANALYSIS – PORTUGAL

ON THE RESEARCH CONDUCTED IN THE 'MOONWALK'
PROJECT



This document was created within the frameworks of the 'MOONWALK' project implemented by Együttható Egyesület, Association Uniamoci Onlus and APCC Coimbra. The project was supported by the Erasmus+ programme of the European Union. Project number: 2018-1-HU01-KA205-047650. This document does not necessarily reflect the official views of the European Commission, the European Union or the organisations co-operating with them. Author: Nagy Melinda, Együttható Egyesület.

find out more: moonwalk.hu

MOONWALK: Focus Groups Analysis

The Portuguese team developed 3 different focus groups. 2 groups of participants with disabilities and one group of professionals working with disabled people. The groups were developed online, using zoom, because of the Covid-19 pandemic. Focus Group 1 and 2 participants were selected from Independent Living Centre and Occupational Activities of APCC.

Group one participants are aged between 21 and 30 years, physically disabled with different motor conditions, two of them totally dependent, one semi-dependent needing help to carry out some activities of daily living, and the rest autonomous. Five participants remain integrated in the family of origin, and two in independent contexts. Four are in a work context, two are students and one is a PhD scholarship holder. With regard to the academic degree of the participants, two are graduates, two are university students, one is a doctoral student and two have secondary education. Two of the elements are activists in the defense of the rights of people with disabilities and one is an adapted cycling practitioner and representative of Portugal at an international level.

Participants of the second group are aged between 25 and 35 years, with a diagnosis of cerebral palsy (three with intellectual disabilities). Three remain integrated in the family of origin, one in an independent context, and two constitute a couple, having recently been parents. Four are inserted in the work context and two are integrated in the APCC Occupational Activities Center. With regard to academic degree, two of the participants are graduates, two with secondary education and two with the 5th year of schooling.

For the professionals group, participants were selected by the moonwalk team which tried to get people from diverse areas and services to ensure variation in professional backgrounds and views. This approach was aimed at ensuring both homogeneity and heterogeneity in the group construction. The focus group was ruled out by disability work as the factor of homogeneity to ensure the degree of commonality among participants, but with sufficient variation to allow for contrasting opinions. Two are coordinators, one of vocational training and the other one of employment mediation - practical training in the workplace; two teachers, one of sports and the other of drama. The other four professionals are: occupational therapist, social worker, psychologist and physiotherapist. Such different groups brought up different and richer and more complex results.

Question 1 - **What does the word disability mean to you?**

When asked what the word disability means, some participants of the group of professionals, surprisingly said they never actually reflected deeply about that. "I also had never stopped to think. (...) It is a condition that any of us can have, which limits us in a certain area (...) We ended up normalizing the concept. » (*Sandra Barbosa - Social Worker*). Or they really tend to normalize it or have a very positive perspective about it: "I don't see it as a limit, but as a condition, to which we have to adapt and accept. » (*Adriana Campos - Theater Teacher*). This may mean that as they try to work a lot acceptance with their clients, maybe there is some kind of positive narrative that they also tell themselves. In some way these are romanticized versions of what disability means.

Thus one of the participants said that: "I am going to refer to the definition, so disability is the absence of a structure or function or dysfunction of a certain competence." (Samuel - Psychologist).

Group 1 talked mostly about difference, condition, stigma, vulnerability, discrimination, pattern of normality, having a hard time to fit in the pattern. «I think that in the word, the concept, we need to evaluate two dimensions. The disability, the biological dimension. It is in fact a disability, that we can't ignore. And also the dimension from where society stands and looks towards deficiency. We have a subjective and an objective dimension. Subjective dimension regards attitudes, barriers, and stereotypes. And all of these build the identity of a person. Society components are what most interfere in life, that have major influence, in the person with disability. (Catarina) «I would go for the medical definition.

All the other definitions that were presented here were imposed to me. You talked about discrimination, that's not our definition. Throughout the years, the definition changed. Instead of being a disabled person, now I am a person with a disability. This is to say that first of all I am a person. (André)

*Group 2 focused a lot on overcoming the possible negative idea that surrounds "disability" as they mostly described it as "**overcoming**... any difficulties that may exist... it means fighting to do what I want, without putting obstacles on myself." (Rita), "**independence**" (Susana Lindim), "**strength**. I don't feel like a disabled person, I feel like a person who has limitations, but who does everything in my reach." (Luís Carlos). Maybe we can say that there was a little resistance to go deeper, some kind of denial. Maybe we can say that Group 1 is more aware or more available to reflect upon their conditions.*

Question 2 - Do any of you consider yourself deficient?

In the professionals group, they all assumed that we all have a type of disability, in which at a certain point in life, it will prevent us from carrying out any activity.

As for the young people, participants in group 2 do not consider themselves disabled.

In group 1 the discussion was different, as at the beginning Rita claimed she did not consider herself as disabled, and Catarina promptly said "I am". Rita went deeper and explained: "I don't consider myself a disabled person, but my condition is obvious. I try that my condition doesn't stop me»

«Yes! The word has a negative connotation, but I am. If not, I wouldn't be here in this group. Using the word disabled has to do with the negative meaning in which it is said» (João)

« The way others include me does not depend on my mood. It has to do with stereotypes and prejudices that they have regarding disability» (Catarina)

«The problem is that we sometimes deny our disability and that will make others think that we can outgrow our disability. » (João)

"We have a hard time using or defining the word disability, because we are using the concept that others have imposed on us. » (André)

Question 3 - In your opinion, what does society think about people living with disabilities?

All focus groups reached the same conclusions: as unable, not part of society, always lay aside, have no rights, no will, no capacity. Also they all mentioned prejudice and an attitude of paternalism towards disabled.

Question 4 - In your opinion, people with disabilities should have an active role in building a more tolerant society?

All groups agreed that people with disabilities should take an active role in building up a more tolerant society. Knowledge, debate, reflection is necessary, they are essential in order they have an interventionist role as well as to realize that this is a possibility.

Question 5 - In your opinion, what is the responsibility of people who do not live with disabilities, to build a more inclusive society?

Create opportunities for people with disabilities to change their perspective about themselves. Show respect to people with disabilities. Society needs more training, more knowledge. *Thus it* has to be collaborative work.

Question 6 - What does the word "interests" means in your opinion?

The concept was a little bit lost in translation, as interests in Portuguese means normally individual will. what I value, what matters to me. What moves me in some way to be in my daily life, like hobbies, something that we identify with, pleasure moments.

Question 7 - Do you think you need to defend your interests in general?

All participants in all groups said yes. A participant in group 1 reinforced that for the disabled people, more than need to defend them, it's a duty.

Question 8 - Who are the people or groups for which people with disabilities need to defend their interests?

Family was mentioned as the first contact to obstacle. The need to start defending interests and rights with the people who are closest to them every day. Disabled need to defend their interests and "show that we do not agree, in our day-to-day lives, because if we do not express our opinion on a matter that we believe is not right with the people who deal with us every day, we will hardly be able to pass on that message to someone who has more power". Institutions were also mentioned (if people are in a residential support) as well as decision-making parties, for example the government.

Question 9 - Are the interests of people living with disabilities and people who do not live with disabilities the same?

Most participants agree that interests are almost the same for everyone, regardless of whether we have disabilities or not. Nevertheless, some claimed interests are individual and each has its own. Of course, everyone has different interests.

Some stated that even though interests are almost the same, maybe for people with disability there are some that have more importance.

«The fact that they are the same is what makes it a problem. It makes our path, for people with disabilities, more complicated. Making the path easier is one of the major goals. Our nature is different. Even though all interests are the same, in my case I need several adaptations »

Question 10 - In your opinion, in general, are people living with disabilities effective in asserting their interests?

In the professionals group, many said that generally they are not, but we should bare in mind the context of the work of the institution and consequently the users that these workers know and work with. These professionals are facilitators in the processes of responding to the interests of people with disabilities.

One aspect that was also mentioned and that may have importance is that: “it depends if it is a congenital or acquired deficiency. A person with training, experience, with diverse resources and a standard path and who acquires a disability or limitation, will probably act in society differently.”

In the groups of participants with disability, opinions vary. Some say that it’s not easy for them, it may take a little longer, they have to work twice as hard so that their opinion can be valued in the same way.

Some state that they don’t think they are effective. They aren’t educated to fight for that kind of rights. The system is built for segregation. They don’t even feel worthy of those rights.

Question 11 - How effective are asserting your interests?

Most participants assumed persistency as a good advocacy skill. But this was not an easy question, even for the professionals. So maybe in a transversal way, this subject reveals some vulnerability.

People tend to give up standing for their rights throughout the time. Even the professionals didn’t considered all to be very effective.

Maybe the fact that this was addressed in a time where we were all feeling lonelier, more vulnerable, more scared, more afraid, more anxious, due to covid-19, makes this self-reflection more difficult and also more unbearable (more negative).

Question 12 - In your opinion, what skills should a young person with a disability have to defend his interests.

In the professionals group, first of all they started to say that the skills would be the same as anyone else, because it is not because of a disability that you have to have specific skills. You should have to have the same ones as anyone to defend his rights.

But also they listed: **courage, persistence, to be and stay well informed, greater ability to be more patient, greater capacity for frustration, degree of tolerance to frustration, resilience, knowing who right to call, knowing the legislation.**

Once again the reality of the institution surfaced as they also said that people who are in institutions like ours, almost always have people, namely social workers, who do social advocacy, which consists of defending their own rights and interests.

As for the groups of disabled people, they all agreed on the referred skills, reinforcing the **ability to argue, to know our rights and fight for them, be very persistent, having knowledge/information.** “In order to argue about something, we need to know what we are going to talk about”, **empathy, determination, ability to self-analysis.**

They also mentioned that this is a human issue, it is not specific to people with disability, although they have more difficulties because society did not educate us for it, they are used that others take the initiative for them.

Question 13 - Concerning the competencies referred, how and when are they developed?

The professionals mentioned that these competences should be developed at school, in the family, the institutions. Sometimes families do not put them in a position of being the ones to decide and often when they come to the institution are the professionals that start to encourage self-determination. The decision making should be from the own individual and not of the family. And that is somehow related to the trajectory of them.

It has a lot to do with their normal development. The acquisition of these skills are acquired throughout life, so the later they acquire certain skills, the later they will have them well defined and be able to apply them the daily life. The question of How? - Education starts at home.

If we think in the context of the school, perhaps the school is also not an enabling context, it has begun to evolve however the perspective of people with disabilities is the "unable", although things have evolved, particularly with the opportunities given. It relates to the experiences that are provided to the person, this will all make them able to be persistent... have decision-making power, to choose, and option”.

There is still a great lack of training, especially in schools, namely in the training of teachers, for them it is all a new world, when it should not be a new world, because children with disabilities have been integrated into schools for a long time, they end up accommodating themselves so much to what they were formatted for – so when something different comes up, it’s like something they couldn’t work with, they don’t have training.

As technicians of this kind of work they also mentioned that it is their role to collaborate in this development of competences: develop competences in the whole school context (teachers, assistants, students); promote the context as a whole, help to develop the skills previously mentioned in children with disabilities and we provide the normal development of skills throughout life and it will diminish this difference between the defense of rights skills between people with congenital and acquired disabilities. As for the participants on the disabled groups, they said that this is a daily work, and it's a learning process throughout life, get to learn to deal with all kinds of situations

They said most competences are developed during childhood, others throughout life and in society, with peers, with people who go through the same barriers. Sharing is fundamental. The feeling of belonging and being understood was mentioned a lot in group 1: sharing similar experiences but also "important within groups to have diversity, there are those who defend one idea and others who defend an opposite idea, and perhaps the consensus is somewhere in between. That is why it is also important to have people without disabilities in our work /conversation groups so as not to radicalize our narrative»

Question 14 - What are the actions / behaviors that maintains the effectiveness of these skills?

Professionals value the support of institutions: the support of Social Work, for example, can facilitate the process of defending rights through information and monitoring; the option of giving them the choice of what they want in terms of customers/ clients, makes them themselves to make the decision; the essential thing is really to listen to them and to know their opinion; listening to them is very necessary; to know what they want, what they intend.

As far as disabled participants are concerned they mentioned the need to be up to date with the current situation in the country to make use of the abilities that were acquired throughout their lives. Also the need to show some work done. "When we do not have a well-defined identity, it is as if we do not know ourselves, and if we do not know ourselves, how can we defend our interests and fight in the best way, if we do not know clearly what we want and what we need. Therefore, the construction of this identity is important and is still in process. And there is still so much to do. (...) It means having the humbleness to try to understand other opinions, other experiences. And having a group identity is a big step towards creating weapons so that we can fight for our interests. I think that what keeps these skills is creating discussion about it, because when we are talking, we are also learning from each other, empowering ourselves. And that is also very important for us, being able to defend our interests"

Question 15 - In your opinion, is it possible to reinforce these skills in young people?

Everyone said yes! Without a doubt.

“If you allow me, I would make a comparison with women's rights, because this issue is very similar, because girls, nowadays, are increasingly aware that they must claim their rights and I think it is the same. It is about education and I believe that the next generations, between people with and without disabilities, all of them will increasingly be able to have better ideas about disability and more respect, and more capacity to be able to claim rights. I think like this because the same thing has happened in all minorities. In the feminist movement, in the LGBT movements, in the racial movements... I think there has been a great evolution, and this is very good.”

Question 16 - What should be done to strengthen these skills?

Professionals once again mentioned the power and the role of institutions. *Participants said:* Show our abilities; Give information. Inform the population and other people about the rights and everything that involves those competencies; need of visibility: “Change is not just doing workshops on disability, it is people walking on the street and seeing the person with a disability, naturally. It does not mean that workshops are not important, of course they are, training is very important, but the natural part, having normal contact is essential”; Giving visibility plus education to change perspectives about disability.

Question 17 - Who should be responsible for promoting these actions / behaviors?

Everyone agreed that we are all responsible. In an individual level and in a more collective level. Professionals say they should find strategies that are more or less within their reach to work on autonomy, capacity for intervention and capacity for reflection.

Professionals also mentioned the burden of daily activities as sometimes they are not always able to be assertive: “Sometimes people fall into disinterest and discouragement from the day-to-day demands of what are needs to be done immediately, and often you forget what your role it is. Knowing how to say no is very important. Those responsible... well start a lot with us and with the attitude that each one of us has in asserting these interests. I think everything is very relative.

Professionals also mentioned the family, the local authorities, other kinds of institutions. " The family has to play a very important role and I think this is an important scale. At the base, if Institutionalized is the institution, but if you're at home, is the family, family with the institution, community, local authority which could have a very important role pair to give answer”. In the other two groups they weren't specif. Just agreed on “Disabled people and people without disability. Everyone should make their point.”

Question 18 - How can organizations - those with no specific focus on disability – can support young people with disabilities in strengthening their rights?

Professionals mentioned the role of municipal councils, parish councils, municipal services, health centers and hospitals, all institutions in the community, cultural centers and libraries, the fundamental role of schools, employment centers and the local resource centers, private companies, in terms of employability.

In the groups of disabled participants, they pointed: to becoming inclusive, not creating stigma, normalizing and promoting the interaction with people with disabilities, for example in schools, having more information, promote accessibilities. “In the same way that a young person without disability is supported. Empowering and not segregating. It’s just a matter of not excluding.

Question 19 - Is there anything else you might like to share on these topics but which have not yet been addressed.

Nothing special was addressed.

One professional said that they also have should go back to study to understand more and better how disability has been viewed over time, so that better strategies can be built.

One disabled participant mentioned that accessibility is one of the important issues giving the example of the lack of parking spaces.