Focus Group Report – Professionals 2022-2023

Name of the project:	From legal incapacity to legal capacity in equiality
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LABOR
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GROUP DESCRIPTION

- Number of participants, age and gender.

The number of participnats of the Focus Group Professionals has been 9, with ages between 23 and 33 years old, being 7 women and 2 men.

- Day(s) of celebration:

The session took place the 7th of October 2022, at 9:00 hours, in the Autismo Burgos Training room.

FOCUS GROUP DEVELOPED (description)

Before starting the session, the objectives pursued in the session were explained to the assistants, as well as the basic rules to be applied: maximum respect to the opinions of the other people, that what is expressed remains in the session and that, therefore, they give their opinion freely and according to the experience and own experiences they have as professionals supporting teenagers and adults with autism.

At all times, the generated atmosphere is very positive, standing out a high participation and interest of all the intervening persons. The session had a total duration of 60 minutes, as it had been agreed at the beginning of it.

INFORMATION

Please answer the following questions according to an overview of the focus group development.

BLOCK 1. WE IDENTIFIED WHAT PARTICIPANTS THINK IT MEANS FOR PEOPLE WITH DISABILITIES TO REACH ADULTHOOD AND WHAT THEY THINK ARE THE MAIN AREAS IN WHICH THEY MAY NEED SUPPORT.

1. **What do you think comes to mind for young people with ASD when we talk about "being an adult" or "growing up"?**
The most common idea is that young autistic people see themselves as entering a period of increased responsibility, obligations, freedom and autonomy. They associate this moment with the fact that their parents are no longer going to be on top of them and that they are going to make a greater number of decisions, more linked to their tastes and preferences.

2. **What do you think are the things that they think an older person should do or does, or what is considered today to be an adult?**
The main answers revolve around living more independently, studying and then working. Also the need to do a lot more paperwork and all those things that their parents do today. In some cases they also link it to intensifying the number of social relationships, partnerships and perhaps starting a family.

3.   What do you think is the best thing about being an adult?

They say that perhaps the feeling of not having to depend on other people for everything, especially their parents, although they also point out that it is difficult to generalise, as the people they support are very diverse and not all of them are thinking of becoming independent and living independently. But they do conclude that not having to depend on the decision of others, although they do depend on their support and help.

4.   And now, what do you think are the things that they think are the worst or least pleasant about growing up?

Generally speaking, the professionals say that they consider that all the complexity associated with many of the formalities that they do not have to do today are done for them by other people, as well as the fact of having to fulfil certain responsibilities and obligations. Similarly, they verbalise the feeling of vulnerability that is often conveyed to them (not knowing, not understanding, etc.).

Likewise, the need of having to intensify their relationships with new people, work colleagues, new places of residence, having to change city, different expectations, etc. are issues that young people with autism consider less pleasant. In many occasions, they point out that they believe that they would link personal difficulties with issues they see that their relatives have had to do and that are related to a greater difficulty of abstraction and planning (going to study or work to another city, buying a house, contracting a telephone, etc.).

In the same way, they comment that due to the overprotection that they appreciate from their relatives, they believe that in many occasions young people with autism are not aware of everything that growing up entails, nor have they faced situations similar to those they can associate with living in the adulthood stage. Hence, it is perhaps a stage that they may have somewhat idealised. Perhaps because of this, and because they have not faced difficult situations, we are also dealing with people who are afraid of making mistakes and of not knowing how to resolve these situations, which is why they will require support from family members and other professionals.

5.   What do you think are the things that frighten or worry them most about growing up, about adulthood in general? Instructions for the moderator: try to get them to come up spontaneously. In any case, areas can be proposed, covering issues such as: studies; employment; independence; independent living and decision-making.

The issues most frequently repeated by the professionals participating in the focus group are those related to work and future employment, as well as to studies. Similarly, they comment on all those related to social relationships and affective-sexual relationships.

To a lesser extent, as they are verbalised by less professionals, although the rest of them confirm that they also consider that these young people have as a concern everything related to housing and living in an autonomous way, the relationship with their parents, the development of day-to-day management and the management of money.
Health and self-care is another concern for young people with autism.

6. **Why do you think they are afraid of that in particular? Instructions for the moderator: go on investigating the reasons.**

Generally speaking, professionals associate that the greatest fears appear because of facing situations that are not known and not experienced until now, or if they have lived them with negative experiences or results; especially in what is related to social relationships with peers, either in the educational or labour field.

Similarly, they consider that they may also be influenced by the message they have heard in their environment, professionals or the media, as well as by the difficulties that other people close to them (family, friends, etc.) may have experienced. In this respect, some professionals comment that the messages they have been given that "you can't" generate great insecurity, in this aspect and in other unrelated aspects. However, there is also another group of professionals who consider that in other cases there are young people who are not fully aware of the limitations they may have due to their own condition.

In the case of social relationships, relationships with other people, many of the fears arise from the difficulty of initiating these relationships, how to manage their emotions properly or how to control the anxiety that social relationships provoke in them.

7. **Can you share any experience you have had in your professional practice that helps us to understand how people with ASD experience these fears?**

Some situations are discussed in which people have to train certain social skills to face new situations or situations in which they show great insecurity, such as going to a place for the first time or meeting a person they don't know. They also discuss how to work on anticipation and planning to counteract these fears and apprehensions.

The professionals also commented on the difficulties that these young people experience and feel in therapy, often related to the management of emotions or the relationship with their families or peers, whether personal or virtual, the latter space also being a place of "difficulty and conflict".

They conclude that a large part of the interventions they develop in the sessions, sometimes in the form of training-learning, and sometimes as support, they consider that they will be the main references for these young people when it comes to identifying their main fears.

BLOCK 2. WE IDENTIFY WHO ARE THE SUPPORTS THEY HAVE AND THE COMPETENCES THEY THINK THESE SUPPORTS SHOULD HAVE.

8. **In whom do you think young people with ASD identify their main supports when faced with those situations that make them fearful or uneasy?**

All professionals conclude that in their families, as well as in professionals from Autismo Burgos who are already supporting them or others. In this respect, they consider that the younger the age, the higher the weight of family support, and as they grow older, family and professionals become more balanced.

However, once again, there are young people who do not directly request support either because they believe that they do not need it or because they consider that having such support places them in a position of "inferiority". Overprotection is also pointed out, which would mean that as they do not face more complex situations, they do not ask for support to deal with them.

It is commented that in some cases, young people with ASD feel great fear of what will happen when their parents grow older or die, which generates great uncertainty.

9. In what aspects do you think they ask for more support?

The main support they ask for has to do with their studies, whether they are at secondary school, high school or university, as well as finding and keeping a job. All of this, depending on the age of the person being supported.

Also in everything related to social, affective and family relationships, as well as the stress that all this causes them. In other words, they demand support for their emotional wellbeing and to organise everything that has to do with social behaviour.

Likewise, as before, the need for support in the area of independent living appears, whether in everything related to housing or in the carrying out of formalities or the handling of money.

Likewise, it is noted that although they do not express it directly, an area in which they do need support is in the areas of self-care (health, medication, food, personal image, etc.), and in basic activities such as clothing.

10. How do you think they assess this support: sufficient, insufficient, permanent, overwhelming, essential...?

They comment that it will depend on the case, as in some people are reluctant to ask for support because they consider that they are "less" than their peers. That is why they do not dare to ask for it. In other cases, the other extreme may be the case. Therefore, it is possible that, depending on the position they are in, they will consider that they are few or many.

In any case, in general terms, it is possible that between the support they receive at home and from the organisation, as well as some outside it, it is possible that they may consider it to be sufficient. Although it is also true that they would certainly like to receive more or others.

11. There are times when things are one way, but we would like them to be another. Today we are trying to find out what the person who supports young people with ASD in issues related to adult life decisions should be like. So I ask you: How do you think they would like the supports they receive or have received in their lives to have been?

The main answers revolve around the fact that these supports are provided with closeness and trust. In other words, support works mainly when there is a connection between people.

In the same way, support that confers autonomy, i.e. that trains you for something and you acquire the necessary competence and confidence, is often very motivating. It is true, though, that many supports, or at least with some young people, need to be of a permanent nature, because when you withdraw them, you are back to square one.

In line with the latter and with the form of support and the support giver, the debate on the generation of dependency relationships arises.

12. **What do you think they would like this support to be like in the future? (Instructions for the moderator: to orientate on whether they would like it to be face-to-face, virtual, by telephone, etc.).**

They also point out that, perhaps because of the age of the people we are asking about and the times in which we live, it is said that they are increasingly demanding more support using ICT technologies (distance learning, modelling videos, infographics, tutorials, etc.), since, among other things, they are easier to access and can always be there.

However, they consider that these cannot and should not be their only supports, as sometimes what they will do is exactly the opposite of what they want to achieve, for example, the improvement of social competences. And of course, for the sake of convenience, there is greater isolation.

13. **Finally, what do you think a person who would support young people with ASD in decision-making and other issues in adulthood should know (in terms of knowledge)?**

We agree that in addition to specific training on people with ASD, as well as an academic socio-educational training to deal with social skills and emotional management, issues related to rights, mediation, various management and how to support decision making could be of interest.

14. **And how do you think it should be on the more personal side? (Instructions for the moderator: try to get them to describe aspects such as age, gender, personality traits; attitudes such as kindness, hobbies, etc.).**

Generally speaking, it is said that you should be a person who connects with the person you support, who is kind but knows how to set limits, reliable, with integrity and enthusiasm for your work. But it is also important to empathise and understand the other person professionally.

It is also said that the person must be responsible and have values.

CLOSE BLOCK

15. **Is there anything you would like to comment on that we have not addressed?**

In this section it is pointed out that for them, as professionals, it is important to be part of a team, as this allows them to support each other or to consult, either with professionals with the same role or with their managers, and in this way, to approach with greater confidence or knowledge the demands or needs of the person with ASD, to get other points of view or to receive guidance on various issues.

At this point, they also talk about decision-making and about how they want to make more decisions that affect or will affect their lives, but that on many occasions these are taken by others or the burden of guidance is very great. They say that they feel that they lack training in how to support decision-making, as this is not something they have been trained in at any point.

Similarly, it is commented that many of the vulnerabilities and support needs do not only appear in the physical world, but also in the virtual world and social networks, as they are also hyper-connected and have difficulties in differentiating the intentions of the other, what may not be real, etc.

CONCLUSIONS

Conclusions linked to the objective of the sessions.

The following conclusions can be drawn from the session with professionals:

- The period of adulthood would be marked by a greater freedom and autonomy of the person with ASD and without intellectual disabilities, and the need to reduce support and make a greater number of decisions. As well as the need to fulfil a greater number of obligations and responsibilities.

- The main support needs identified by professionals revolve around studies and/or work (current or future), as well as social relationships, relationships with their parents and affective-sexual relationships. On a second level are those related to independent living, where all those needs related to housing, living alone in the company of people other than their family, procedures and formalities, money management, etc. are included.
- A third block identified would be related to self-care (health, food, personal image).

- The period of adulthood, with full legal capacity, awakens in many of the young people fears and apprehensions, due to the uncertainty of the unknown, the feeling of being more vulnerable and how to manage support.

- The main support will come from family and professionals. In some cases they express fear about when their parents are no longer there.

- Professionals must have knowledge about autism and a training base of socio-educational nature. But they should also have, without being real specialists, knowledge about rights, legal capacity and various procedures, as well as about adequate support for decision making.

- Support does not always have to be face-to-face, but the opportunities provided by ICTs should also be used, but this should not be a substitute for face-to-face support.

- Vulnerabilities in the physical world are also replicated in the virtual world.

- With regard to the person providing support, she said that they must be able to connect with the other person, have strong values, work in a team, empathy and professionalism.