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## Focus Group Report – Autistic people 2022-2023

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## GROUP DESCRIPTION

- Number of participants, age and gender

8 participants in total, being:

- o 2 girls, de 33 y 24 years old respectively.
- o 6 boys, de 19, 21, 26, 28, 30 y 31 years old resepctively.

- Day(s) of celebration:

9th and 16th of september.

## FOCUS GROUP DEVELOPED (description)

A total of 2 sessions were held. In 2 consecutive weeks, each session lasted one hour. The sessions took place on Friday 9th and 16<sup>th</sup> of September. The sessions were held between 17:00 and 18:00. They took place in the facilities of the “Apitea” Service of the Burgos Autism Association, in a room prepared for this purpose and in a familiar and safe environment for the participants.

The group was guided by a researcher who raised the questions, directed the interventions and guided the practice. This researcher had no relationship or prior knowledge of the participants. The group also had an observer who recorded the results of the interaction and non-verbal communication. The observer also had no previous relationship with the participants.

All participants had previously received information about the purpose of the research and the commitment expected from their participation in the group, making it clear that in no case would they have to prepare anything beforehand, and that they are only asked to participate and take an active part, according to their own personal experiences.

Once both sessions were over, the participants were asked to fill in an anonymous evaluation questionnaire, which allowed us to find out their degree of satisfaction or disagreement with the sessions and the topics dealt with, how they felt personally among the group and with the researcher, and how useful they thought it would be for their future. Once their responses have been analysed, it is clear that the sessions were highly valued by the participants.

## INFORMATION

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

### BLOCK 1. WE IDENTIFY WHAT ADULTHOOD MEANS FOR PARTICIPANTS AND WHAT THEY THINK ARE THE MAIN AREAS IN WHICH PEOPLE WITH ASD MAY NEED SUPPORT.

1. If I mention "being an adult", "growing up", what comes to your mind?
2. What do you think are the things that an older person or what is considered today as an adult person should do or does?

Take on new responsibilities: work or look for work, live alone, become independent, study.

As you get older you become interested in other things that were not important before. Priorities change and you have new topics of conversation. They are also interested in maintaining the tastes they have now, they claim those tastes.

Being an adult also implies analysing things more, why they happen and especially the consequences of your actions.

It means that from now on they are the ones who have to resolve their own issues, although they often feel the support of others. They know where to turn.

They believe that being an adult implies challenges, that it involves changes.

3. What do you think is the best thing about being an adult?
4. And now, what do you think are the worst or least pleasant things about growing up?
5. What things do you think you do in your day-to-day life that you do because you are an adult?
6. Of all the things that we have talked about being an adult, what are the things that scare you the most, that worry you the most? Instructions for the moderator: try to get them to come out spontaneously. In any case, areas can be proposed, covering issues such as: studies; employment; independence; independent living and decision making.
7. Why do you think you are afraid of that particular thing? Instructions to facilitator: Probe for reasons.
8. Can you share any experiences that help us understand these fears?

What worries them most about growing up is the issue of studies.

Work, finding a job, keeping it and having good working and personal relationships and being able to deal with unforeseen events.

They are worried about decision making, about independent living: housing, finding a house and being able to access it, and, above all, they all agree on the fear of "bureaucratic processes": bills, payments, invoices, handling money.

Some of them also agree on the difficulty of planning when they become adults, to be able to manage their time well and organise themselves, to have good social skills... some are worried and concerned about loneliness, about feeling alone.

Going back to decision-making, this is what worries them most about being an adult: they are very anxious, they feel insecure and they worry about the consequences of those decisions. They feel that sometimes they will not be able to measure what will happen once they make that decision.

All of them have made decisions in their lives and have felt "pressure to decide": what to study, where to work, to become independent....

When they make decisions, they generally rely on others, or at least check the decisions they make with other people. They feel good with this help, it makes things easier for them and gives them security.

They say that in the future "it would be exciting" to decide alone.

They do not mind continuing to have help to make the right decisions: advice and counselling.

## **BLOCK 2. WE IDENTIFY WHO THE SUPPORTERS ARE AND THE COMPETENCES THAT THEY BELIEVE THESE SUPPORTERS SHOULD HAVE.**

1. Throughout your life, and when faced with the situations you have just described or others that you remember, who have been your main supporters?
2. In what specific aspects have you felt most supported? Can you describe a specific situation that will help us to understand it?
3. How has this support been: sufficient, insufficient, permanent, overwhelming, essential...?
4. 4. 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 us in matters related to adult life decisions should be like. That's why I ask you: How would you like your support to have been? You can relate specific situations in your life in which you would have liked to receive a different kind of support.
5. 5. Finally, what do you think a person who would support you in decision-making and other issues in adulthood should know (we are talking about knowledge)?
6. 6. And how would you like it to be on a more personal level?

All of them agree that their greatest support comes from their parents and from the professionals of the Association Autismo Burgos.

They have felt supported in all the moments of their lives, but above all in their studies, they have also received a lot of psychological and emotional support, supported in employment and also when they have had to take decisions or when they have already taken the decision.

They also consider "personal assistants" to be important in their daily life and in this support.

In general, they do not have the feeling of a lack of support, perhaps in the school stage, at school they do miss support from the professionals of the centres, they say that, if they had been diagnosed earlier, things would have changed, if they had received more support from the professionals of the school...

## **CLOSING BLOCK.**

1. Is there anything you would like to comment on that we haven't addressed?

Not specifically, and if there was, it came up naturally in the sessions.

## CONCLUSIONS

The development of the focus group has allowed us to get to know the aspects of being an adult in which young people with Asperger's feel more vulnerable. We have analysed their opinions, experiences and personal experiences from the reflections shared by young people of a wide age range, between 19 and 33 years old.

They are clear about who their main supports are, among whom the family stands out, which will continue to have a constant presence in their lives and in the future, complemented by the role of professionals and specialists. The Association (Autismo Burgos) has a relevant role, but different depending on the age of the participants.

In general, they are aware of the changes that their life will have with the arrival of adulthood; it is an issue that worries them and for which, in general, they do not feel prepared.

Among the issues they are most concerned about are studies, future employment and how to live independently. They are worried about not being able to manage their emotions and believe that they will have to develop more social skills, and they do not know how to do this.

They identify being an adult with the obligation to assume greater responsibilities, which in turn implies making decisions, an aspect for which they do not feel prepared.

In general, they feel older and believe that they are effectively assuming more and more of an adult role. However, they openly state that they still have a long way to go to become adults.

The group agrees that they feel vulnerable to possible cheating and bullying, possibly due to the impact of the bullying they suffered in the school environment. They tend to think that in the work environment this will not happen again, although maybe it is more a wish projected in an environment they still do not know in detail, and in which, in most of the work experiences, they feel protected by the support of specialised labour intermediation professionals (in Autismo Burgos or in other entities). They are worried about not being able to manage unforeseen events that prevent them from accessing the job, or having to make decisions that go beyond what was planned. They feel more vulnerable than other people of their age who are not diagnosed with aspergers.

This vulnerability, interestingly, has not been appreciated when dealing with social networks. They all use them, but say that they have received sufficient training to be able to identify where the risks are. Curiously also, when dealing with the subject of partners, they link relationships to the use of networks, which leads us to think that the risks are there, and that there is a false security to which special attention should be paid.

Within the group, the youngest, show a lack of confidence in their abilities, which increases their fear of failure. The stigma of having a diagnosis of disability is detected; they complain about the lack of specialists, especially in the educational system. They demand more information about what Asperger's is: in schools, but especially in what affects them now: the work environment, so that employers are aware of it, and so is society, and so that situations of harassment or isolation that they have suffered are not repeated in the future.

They feel vulnerable, in social relations, and in general, they have not felt supported by their peers, except for the colleagues linked to the Autism Burgos Association, where they have clearly found their circle of relations. That is why they claim that future supports should be linked precisely to this Organisation they trust, or others of similar character.

They are particularly afraid of relationships with their partners. Although their ideal or theoretical future project includes a partner, and even having children (only in a couple of isolated cases), on going deeper into this, it is observed that they do not see themselves as prepared, they do not believe that it is indispensable in their lives and even the stigma of disability reappears, arguing that no one will like them because they are strange, or have strange tastes or simply have a disability. Here too, they call for professional support to help them manage their emotions and learn how to live as a couple. Here too, they feel more vulnerable than the rest of the population and are sure that if others have these problems, they will certainly have them themselves.

Independent living generates a lot of anxiety. They feel pressure from their environment to live alone in the future, but they feel particularly vulnerable in the face of all that is involved in running a household. On the one hand, they need help with domestic matters (cleaning, washing machines, shopping), which is due to their difficulty in planning, organisation and time management. In this respect, they feel that it would be good to receive some kind of support from personal assistants. But they especially feel very vulnerable when it comes to what they call "bureaucratic management": paying and managing bills, taking out insurance, dealing with the administration, dealing with the bank, or taking out the social security voucher, for example. There is a fear of being cheated, and again they feel weaker than the general population or other young people their age, claiming that no one has taught them and assuming that other young people do not need to be taught. They also reproduce family fears about money management.

They recognise that they do not have the tools to solve them themselves. But they are able to provide solutions to solve it: training courses; tutorials on YouTube; mobile phone applications; and specialised services at their disposal and at the disposal of other young people in their environment, linked to the Autism association and open to other people. Again, support appears as an element of salvation and support. They are also worried about the loneliness they could feel in a future of independent life.

Supports are key for young people's life and they have never felt lack of support, except in bullying episodes, when they would have liked to be supported not only by teachers, but also by peers. They clearly identify that their main support has been from their family and from the professionals of the Association. In the former, they have not only received support at school or at work, but also in their social relationships; they have helped them to decide and then supported them in the decisions taken and also in more personal matters. The dependence of the families is greater the younger the age of the young person, and the need for support is great, so that they accept it, even generating a certain dependence.

Professionals form a decisive part of their lives, more so as the young person's age increases, and they show the security they feel in this space.

Regarding the future, they believe that support changes with age, both in terms of who would provide it and in what aspects of their lives, but they do not question the need for it. They demand more support to live independently. For the future, the family is less important, and professionals and specialists are becoming more relevant: in labour issues, psychologists, account advisors... Personal assistants are still needed to help them organise their affairs.

This project for the future is not very different from what might be understood for other young people of their age, although the youngest recognise that they are not yet ready for it, although they are taking steps to achieve their wishes, which include a family, a house to live in and a job.

In short, they are afraid of issues that they identify with being an adult because they see it in their immediate environment. They feel their vulnerabilities, which are mainly associated with independent living and everything that managing a home, bureaucracy, money management and expenses would

entail. They also feel vulnerable to long-term social relationships, although they are comfortable with the peer group that is part of the Association. Los padres son su principal apoyo, pero sienten que los apoyos del futuro deben ser más profesionales. Parents are their main support, but they feel that future support should be more professional. They feel that in the future they will have to continue to have support in those issues that they link to adult life. And they trust that the Association can offer them adult services to accompany them on that path.

Several of the young people say that they are afraid of the routine and monotony of adulthood, both at work and in life in general. They imagine a life as an adult always doing the same activities, and this causes them a certain rejection.

Generally speaking, and taking into account the opinions expressed by the young people who participated in the research, we could conclude that:

- Identification of support: the family is a fundamental element for everyone, and as they get older, the professionals of the Association play a more leading role, stating that it has a relevant role in their lives. It is therefore important for professionals to assume this, to be aware of it and to take care of the interventions, the arrivals and departures of professionals in the lives of young people.
- Fears are: pressure from the environment; the history of bullying; the possible deceptions experienced; the fear of failure; the pressure that they impose on themselves; the vulnerability of feeling different; or the discourses about these vulnerabilities that they hear from their families. Therefore, it would be advisable to modify certain attitudes of the support groups and provide support that would allow them to overcome certain fears, thus contributing to an improvement in the position they are in when they reach youth.
- All the participants agree that the school environment is particularly harsh. Since this is a fact that has been amply demonstrated in the case of students with ASD, we would like to highlight it, given the importance it can have for the quality of life of young people with Asperger's. It is absolutely necessary to continue to be present in the school environment. It is absolutely necessary to continue to be present in educational environments, as specialists in this subject, in order to claim the specificity of this disability and specially to prevent the bullying that most of them say they have suffered.
- Work environments offer them a higher level of security against harassment or discrimination, possibly because all the experiences reported are linked to an accompaniment service, most of the times provided by the Asociación Autismo Burgos, with special care to the environments. This shows the importance of support.
- As we said, it is important to emphasise the importance of supports throughout the young people's life. They are aware that these supports will change, but they will always be necessary. It is necessary to identify a new role for families and the possibility of reducing their presence in order to achieve higher levels of trust, assessing the possibility of parenting schools that help to understand the new role and the intervention of Fundación Miradas, for example, in decision-making.



- Decision-making is undoubtedly one of the most worrying aspects. It is necessary to assess the possibility of generating specific accompaniment programmes, especially in adulthood and in decision-making, intensifying the specialised figure as these become more relevant: banking issues, payments, document management. To value the inclusion in the Fundación Miradas Portfolio of Services.
- Finally, in many of the aspects linked to adulthood, such as payments or independent living, they feel that they have and will have greater difficulties than other young people their age, they start with a feeling of greater vulnerability and less self-esteem. Hence the call for workshops and psychological or self-esteem building support.