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Focus Group Report – Families 2022-2023

Name of the project:	From legal incapacity to legal capacity in equality
Date:	23 – 09 – 2022
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"The project "From legal incapacity to legal capacity in equality" is co-funded by the Erasmus+ programme of the European Union. The contents of this document are the sole responsibility of Fundación Miradas and Labor Societá Cooperativa Sociale and neither the European Commission nor the Spanish Service for the Internationalisation of Education (SEPIE) are responsible for any use that may be made of the information contained therein".

GROUP DESCRIPTION

- Number of participants, age and gender.

The number of participants in the Focus Group of Professionals has been 13, with ages between 46 and 60 years old, being 10 women and 3 men.

- Day(s) of celebration:

The session took place on 7 October 2022, at 17:00 hours, in the room provided in the facilities of Autismo Burgos

FOCUS GROUP DEVELOPED (description)

Before starting the session, the objectives pursued in the session were explained to the attendants, 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 relatives of 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 90 minutes, occupying the maximum time established at the beginning of it.

INFORMATION

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

BLOCK 1. WE IDENTIFY WHAT PARTICIPANTS THINK IT MEANS FOR PEOPLE WITH ASD 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"?

In response to this question, two very different response groups emerge. On the one hand, there are families who say that their children do not think about it, nor do they want to think about it; they just "live for the moment". On the other hand, there are families who say that they have talked about it and discussed it in depth with their children, and in which they have expressed fears and worries about what this stage will be like or is like (although they are not yet aware of it).

In all of this they agree that this is very similar to their brothers or sisters, although the main difference would be in the capacity they have to face or resolve situations.

2. What do you think are the things that they think an older person or what is considered today as an adult should do or does?

In this respect, they comment that from what they have talked to them, being an adult would be to make decisions, to be independent and without the coverage, or a lesser coverage, of their parents. In this section, the issue of work comes up. That is to say, their children consider that being an adult would be marked by finishing their studies, if they have not already done so, and having a job. Likewise, in some cases, they link it to living independently, outside the family environment, but in others they do not.

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

In this question, everything is very much conditioned by the sphere in which they have positioned themselves in the first question. That is to say, in the case of those who feel a great deal of concern, they do not find anything positive, but rather anguish and anxiety. In some cases, because of the possibility that their parents are no longer there or cannot help them. In the case of those who saw it in a positive way, everything related to being able to make decisions and do so more freely.

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

In this question there are also two areas of response, although in this case they are fully complementary. On the one hand, a more emotional one, which would have to do with loneliness, as well as the need to operate in a complex world, in which they feel weak and vulnerable, and with the need to interact with more people. At this point, everything related to the risk of being cheated and the feeling of vulnerability they have, especially in everything related to money or signing contracts that they have not been able to understand (they also agree that perhaps all this is closely related to the alerts that they themselves, as parents, send them on a daily basis).

And on the other hand, the anguish caused by changes in relation to the family, where the passage of time brings changes, such as the death of family members or the abandonment of the home by others, such as siblings.

5. What do you think are the things that scare or worry them most about growing up, about adulthood in general? 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.

Before going deeper into the areas, there is a consensus among the families that all of this will be very much influenced by the vital moment of each person, such as, for example, those who are studying being able to finish their studies, or those who are looking for work to find it.

The employment issue is seen differently by those who have experienced it and those who have not, but it is a concern because in some cases they have encountered difficulties in finding it and then in keeping it.

There is also a certain consensus that one of the things that worries them most is feeling lonely. That is, at that moment when their parents are no longer there or are in the background, and then they will have to make decisions on issues for which they do not feel sufficiently prepared, which they find complex or are not able to measure the consequences. Linked to all this is the issue of overprotection, where parents are aware that they often overprotect their children, thus preventing them from "growing up".

In specific areas, the issue of day-to-day life comes up, both in terms of independent living, such as housing, shopping, food, paying bills and having enough money, etc., as well as everything related to dealing with organisations and companies.

6. Why do you think this in particular makes them afraid? Instructions to the moderator: go and find out the reasons.

In response to the issue of loneliness, it is commented that, although in general terms, your children tend to be people who enjoy their hobbies alone, they like to know that there is someone who can support them, who is attentive or "at their disposal".

Similarly, they link many of their fears to the overprotection they develop with their children, which prevents them from facing different situations, as well as to the fact that they are aware that they are more vulnerable and easy to deceive.

7. Can you share any experiences you have had as a family that help us to understand how people with ASD experience these fears?

In the case of fears about the future, families confirm that when they have tried to talk to them about the future and a future in which they are no longer there, their children do not want to talk about it and are very uncomfortable. This fact appears both in children who are more communicative and those who are not.

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 situations that cause them fear or anxiety?

The parents as a whole confirm that at present, they and the professionals of the Association, as well as other professionals, if they are still in the educational stage or make use of other resources. As their children get older, professional support gains more weight, especially in the field of training and pre-employment, as well as in everything that has to do with emotional support and, if they have needed it, in the field of housing. There is talk of the figure of the personal assistant.

With a view to the future, when they are no longer there, they trust that the professionals will be able to continue providing this support, either in a unique way and with the intensity that their children need or complementary to the role that their siblings can assume. However, this will depend on each family situation or circumstance.

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

Mainly in those related to their day-to-day life. That is to say, parents see that they need support in very different areas, although not in all cases in the same way, it depends on each person. But they do distinguish ongoing support for organising their day-to-day life or what to wear depending on factors such as the occasion or the weather ("for him I would always wear the same thing, whether it's a wedding, whether it's hot or cold"). Similarly, for household chores, they need support, although they say that they may not see it that way.

They also talk about support to study, to look for and maintain employment, to carry out formalities, to take care of their health in cases where they need it, etc. In this respect, the subject of when they are no longer there or when they are older comes up again, and the need for them to have references

and support, not on a continuous basis, but that they can be there for day-to-day life as well as for other things (paperwork, money, etc.) and what has to do with emotional support.

10. Can you share any experiences you have had as a family that help us to understand how people with ASD experience these fears?

In the case of fears about the future, families confirm that when they have tried to talk to them about the future and a future in which they are no longer there, their children do not want to talk about it and are very uncomfortable. This is true both for children who are more communicative and those who are not.

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

11. In whom do you think young people with ASD identify their main supports when faced with situations that cause them fear or concern?

The parents as a whole confirm that at present they and the professionals of the Association, as well as other professionals, if they are still in the educational stage or make use of other resources. As their children get older, professional support gains more weight, especially in the field of training and pre-employment, as well as in everything that has to do with emotional support and, if they have needed it, in the field of housing. There is talk of the figure of the personal assistant.

With a view to the future, when they are no longer there, they trust that the professionals will be able to continue providing this support, either in a unique way and with the intensity that their children need or complementary to the role that their siblings can assume. However, this will depend on each family situation or circumstance.

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They also talk about support to study, to look for and maintain employment, to carry out formalities, to take care of their health when necessary, etc. In this respect, the subject of when they are no longer there or when they are older comes up again, and the need for them to be able to count on references and support, not continuously, but that they can be there both for day-to-day life and for other things (paperwork, money, etc.) and what has to do with emotional support.

It was commented that it is important that there is always someone there, as they all agree that their children are "capable of the best but also of the worst", as they have difficulties in foreseeing, in seeing beyond the now and because they are vulnerable to deception.

With regard to social or couple relationships, they think it is important that they are supported in how to manage them, as in many cases they have major difficulties, and if it were up to them, they would avoid them, although later on loneliness weighs heavily on them.

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

In general terms, the families value the support that their children receive as sufficient, although the issue of overprotection on their part comes up again; in other words, that perhaps they support them too much. In the same way, they value the professional support they receive at present and again show their interest in receiving more support in the future in order to lead a more autonomous life, without "burdening" other family members.

Likewise, in some cases, they comment that the professional support they receive, which they value as very positive, perhaps generates a false sense of security in their children and does not make them realise all that adulthood entails. They give as an example the figure of the personal assistant.

14. 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?

In general terms, they say that they consider that the support they have received has been sufficient, and that the difficulties that their children have had are not so much related to the lack of support, except in the school period when they have felt that the support has been insufficient in the educational sphere and even more so when situations of bullying have arisen that were not dealt with.

They feel that these people were not sufficiently involved and were not aware of the suffering that their sons and daughters have undergone.

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

They value very positively the fact that they are provided directly, although with the intensity and frequency that each person may need. In some cases they will be almost supervisory and consultative, but in others they consider that they will be more continuous.

They also commented that they were interested in the possibility of remote assistance and assistance via ICTs, including the availability of digital tools that could guide them in certain processes.

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

When it comes to decision-making, they should be professionals who help them to make decisions, but who do not make decisions for them. They understand that, although they do not know very well how, there must be methodologies that allow people to make decisions with all the information they need. As mentioned above, they should know about autism, but also about "how the world works", "translating" information and "where to look for help". Also about how to sort out paperwork and help with money management.

In specific cases where the person needs support for self-care issues, it seems important to them that they can have a minimum knowledge about health and how to support in that area.

17. 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.).

On this aspect, it is commented that they have to be trained people, who know about autism and the characteristics of these people, as the supports they need are very specific: organising themselves, structuring themselves, etc.

Likewise, they would like that they could always be the same reference figures; that is to say, that there would be continuity in time, without changes. However, they understand that this is not always easy, as it is normal for professionals to change jobs and try to develop a professional career.

Regarding age and so on, they think it is a good thing that there is not a big difference with the age of their children, as they consider that this way they understand them better. They also consider them to be, as they are, "good people" and "motivated" in their work. And with regard to knowledge, they also value that they have a certain level of specialisation and that they can cover the more emotional aspects through support and interventions.

They should also be approachable but professional and generate trust, but keep their distance.

CLOSE BLOK

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

At this point, the issue of happiness comes up, the longing parents have for their children to be happy, but they are aware that in many cases they are not. Likewise, they comment that their children have the same dreams as the young people of their generation, but they are not aware that in some cases it will be very difficult, or even impossible, for them to achieve them due to their special characteristics.

Similarly, there is a certain consensus that, if their children have fears, the fears they have about their children's future are no less important. It is a shared concern.

Similarly, it is commented that they consider that there should be organisations such as Autismo Burgos and Fundación Miradas, focused on supporting legal capacity, as they understand that this is where their children find support today and, they hope, in the future as well. They demand support and implication from the administrations so that all this is possible.

CONCLUSIONS

Conclusions related to the objective of the sessions.

- The families value very positively the professional support that their children have received and consider that, in the future, and even more so when they are no longer there or are not in a position to do so, they will need professional figures to provide support in those areas that they currently cover.
- They consider that, because of the way their children are, they will always need support, to a greater or lesser extent. And both in day-to-day matters (independent living -housing, self-care, personal image-, organising, structuring, etc.), as well as at more specific times or to cover more complex needs (money, bureaucracy, employment, etc.).
- They are concerned about their children's social relationships, both with their peers and with other people or with their partners, as they consider that, on the one hand, they need support in managing them, as well as in everything related to receiving emotional support to minimise what this entails for them.
- Unwanted loneliness causes pain in their children with ASD, both in the present, but also in the future, where their references will change (parents, siblings, etc.).
- In relation to what the professional who supports them should be like, it is commented that they should be trained people, with a wide range of skills, motivated and who know how to "understand" them; but also who can set limits. It is important that they have digital skills, as this is something that their children value highly.
- They see support for decision-making as a very important area.
- Families are concerned about their children's future and that they can receive the support they need.