

## AUTISM IN PINK: Qualitative Research Report

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### Appendix 1

PWI Results – (from the start and end of project)

# Qualitative Research Report

## Aims of Autism in Pink Project

- To learn more about the lives of women with autism in the European partner countries
- To contribute to improving lives of women with autism – both the project participants and women with autism in general
- To increase the public's awareness of women with autism.
- To improve knowledge of the people supporting and working with women with autism.
- To produce deliverables geared towards achieving the aims above. Deliverables are:
  - a learning approach for women with autism, by women with autism.
  - an online book about experiences of women with autism
  - a documentary film about quality of life and experiences of women with autism
  - a meeting with Members of the European Parliament in Brussels
  - an international conference
  - a training for family members, teachers or professionals associated with participants

## Objectives of Qualitative Research

All of the partner countries of Autism in Pink carried out qualitative research.

### Objective 1: Learning about the lives of the women

One of the main objectives of the qualitative research was to learn more about the lives of the women participants with autism who had volunteered to take part in the project. The resulting information could then be used in different ways to create and contribute to the various deliverables of the project, thereby working to achieve overall project aims of increasing awareness and knowledge, and improving lives.

### Objective 2: The impact of taking part in Autism in Pink

To assess the project aim of trying to improve the lives of the participants, qualitative research was needed to find out the impact of taking part in the project on the women.

## Methods used to meet objectives

### Objective 1

The project set out to learn about various aspects of the lives of the participants: their experiences; the difficulties they have faced, including social and economic problems and those related to gender and health; possible causes of these difficulties; strategies they have used to overcome them, and achievements and success stories.

To find out the things above, all partner countries used the following methods:

- Personal wellbeing Index (PWI) Questionnaire – a measure of participants' satisfaction with their quality of life
- Quality of Life (ComQoL) Questionnaire – back up of information gained from the PWI
- Individual interviews
- Group workshops
- Filming of individuals and groups

The PWI questionnaire was chosen as the framework for collecting information about the women's lives. All participants answered the questionnaire, then the 8 domains that underlie the questions forming the questionnaire were looked at in greater detail during interviews, workshops and filming. The ComQoL gained information that backed up what was learnt from the PWI.

The PWI was chosen because it covers all of the aspects of life that we wanted to learn about. It is succinct and standardised, and all partner countries were able to work more deeply on the 8 domains because their content is not prescriptive; it was possible to adapt the specific nature and content of each domain to the different needs of the different countries. In this way the topics that were most important to the women of each country were able to come out when looking into the domains in greater detail.

The PWI was also chosen because it is congruent with the EU quality of life values, as well as having high validity, reliability and sensitivity.

One of the 8 domains of the PWI was addressed in each workshop. There were also additional workshops, depending on the participants and their needs.

Exact methodologies used to look into each PWI domain in more detail were not identical in each country because of the varied nature of the participants. Overall, the women with good language skills were able to speak about their experiences and difficulties, strategies and successes. Meanwhile, activities were set up in interviews and workshops to observe these areas for the participants who were unable or less able to talk about them.

### Objective 2

In order to learn about the impact of the project on participants taking part, the PWI questionnaire was completed by participants at the start of the project and again towards the end.

In addition, partner countries used their own methods, suitable to the individual participants involved. These methods included a questionnaire about the workshops that was filled in at

the end of each workshop, as well as an evaluation completed by participants at the end of the series of workshops. There was also a questionnaire asking what participants felt were the reasons for any changes in their satisfaction with the different domains of PWI questionnaire, between the start and end of the project. Another questionnaire asked participants whether they would ideally like to continue with workshops or groups of a similar sort, once the official Autism in Pink workshops were over.

Individual interviews and conversations were held in person, by phone and by email with participants both at the start and end of the project, as well as throughout. The women talked about how the project had affected them. Comments and changes were noted and anecdotal evidence was collected.

One participant spoke about Autism in Pink at a conference in London, where she outlined many of the ways in which the project has affected her. Other participants will be speaking about their experiences to the media, so there will be further opportunity to look at the impact of the project in the future.

## Results

### Objective 1

Much information was gathered about the lives of the women. All of this helped to build and shape the deliverables, where many of the results of the qualitative research can be seen.

The different women in the different partner countries showed a range of experiences. But overall, there were some particular points that stood out:

- Autism still tends to be associated with men. This has many consequences in the lives of women with autism, ranging from difficulties in getting a diagnosis, to difficulties in their basic human rights being upheld.

The image shows four presentation slides titled "Sofia's story".

- Slide 1:**
  - Sofia is a woman with Asperger syndrome
  - Sofia is a bit of a loner at school, but she gets by OK academically
  - Her hobby is drawing
- Slide 2:**
  - Her doctor is treating her for depression
  - Her Mum reads something online about Asperger syndrome and tells her
  - After 2 years of trying, Sofia is diagnosed
- Slide 3:**
  - Education and health system fail to consider autism for a long time
    - Diagnosed with depression
  - No diagnosis = no support in education
    - coping with academic and sensory challenges at same time
    - restricted by need to live with parents
  - Difficult to fulfil potential
    - affects her future job role and pay
    - passed over when it came to promotion
  - After diagnosis, Sofia and employer don't know how to change things

Associated articles:

  - UNCRPD Article 25, Health: States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive
  - UNCRPD Article 24, Education: Persons with disabilities receive the support required, within the general education system, to facilitate their effective education and effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion
  - UNCRPD Article 27, Work and Employment: States Parties recognize the right of persons with disabilities to work, on an equal basis with others. This includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities.
- Slide 4:**
  - Limited ability to develop social skills
    - affecting inclusion
    - isolated at school and out of school
  - Unable to leave abusive boyfriend
    - No one to tell / talk to
    - Doesn't want to be alone

Associated articles:

  - UNCRPD Article 3, principle of full and effective participation and inclusion in society
  - UNCRPD Article 30, participation in cultural life, recreation, leisure and sport
  - UNCRPD Article 16, Freedom from exploitation, violence and abuse: States Parties shall take all appropriate [ ] measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects

Slides from the Study Trip to Brussels telling "Sofia"'s story

- There is a need for society to be more understanding, accepting and supportive, and to be more aware of autism. But at the same time we need to treat people with autism as individuals, each with their own value to contribute. Society tends to hold certain stereotypes – these stereotypes are not helpful for anyone with autism, but can be particularly problematic for women.
  - Women with autism who have good language skills might be disbelieved because they don't fit the stereotype of being autistic, but at the same time they might be ostracised because they don't fit the stereotype of being a woman either.
  - Women with lesser language skills might be thought of as being less able overall, or of just having a particular strange talent, somewhat like the Rainman stereotype. But despite lesser language skills, they might be very capable in many areas.
- The reality is that people with autism tend to have a 'spikey' profile of strengths and areas of need, so being stronger or weaker in one area does not necessarily indicate corresponding strength or weakness in others.
- It is essential that the public becomes more aware of 'Masking', which appears to take place more in women with autism than men. The qualitative research showed that many of the participants go to great lengths to compensate for and cover up some of their autistic characteristics by suppressing them, mimicking other people, and using logic rather than instinct to work out social situations. This means that people are not aware of the difficulties that they might be experiencing, or of the reality of the need for appropriate support. It also means that women with autism are constantly putting a lot of extra energy into their interactions, which is exhausting.

## Objective 2

### **Impacts noted from the use of the PWI**

The results for the PWI questionnaires completed at the start and end of the project are presented in bar charts for each country (see Appendix 1).

However, based on our knowledge of the participants, and input gained from them in conversation and other questionnaires, we feel that there is little value in these bar charts alone and that they tell us little or nothing about the impact of taking part in the project.

This is because of changes in the women's lives over the period of the project, which had nothing to do with the project – changes such as in health, employment, housing situation, marital status and education. These changes have had a major impact on the women, and on how satisfied they feel in the eight domains addressed in the PWI questionnaire.

It is also because working on the PWI domains in more detail in the workshops gave the participants greater insight into what each domain meant to them and how they felt about it. So at the end of the project, their answers to the PWI questionnaire regarding their satisfaction in a particular domain could have been based on very different ideas of that same domain, compared with the ideas that they had at the beginning of the project.

More of a sense of understanding of the impact of taking part in the project was gained from observing participants and listening to what they said about PWI domains, rather than looking at the results of the specific PWI questionnaire.

Here are two examples of things that the women said:

One woman was more satisfied with her achievements than she had been – she said that this was because the workshops had helped her to recognise her achievements and think about them on her own terms rather than comparing herself with others.

Another woman was less satisfied with her safety because she had become more aware of dangers and of the fact that misunderstanding can put her at risk.

### **Other insights about impacts of taking part in the project**

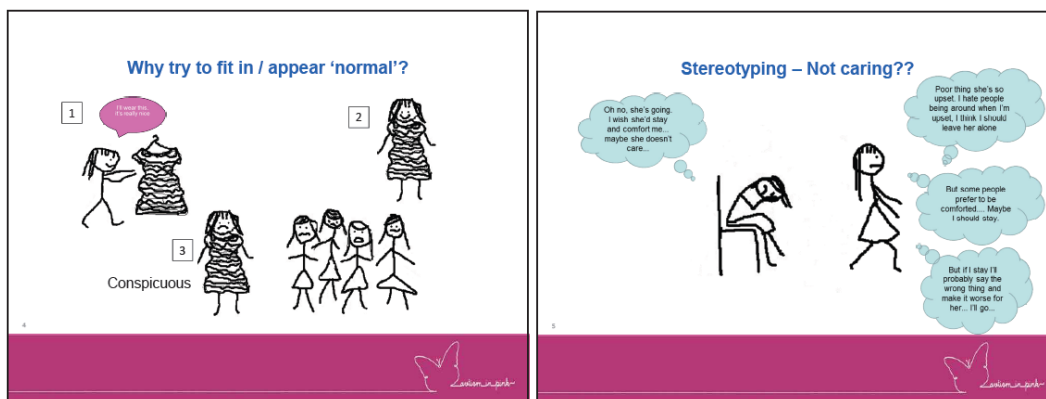
As mentioned, there were many other ways, aside of the PWI, in which insights were gained about the impact on the women of taking part in the project. Some of the things that we learnt from the women about this are described below:

All women who completed the relevant questionnaire answered that they would like to continue the workshops once the project was complete. Women continued to attend workshops for a period of over a year. Attendance was excellent, and no participants chose to leave the project once the workshops had started.

Overwhelming general feedback was that participants felt that workshops had been beneficial, that they had found them supportive and had learnt a lot from sharing experiences and strategies. Most felt that they had learnt more about autism and more about themselves as individuals, and that they had gained confidence and assertiveness from attending the workshops. They enjoyed meeting other women on the autism spectrum, and felt less isolated, less alone, more a part of something bigger than themselves. It encouraged them to know that other people had had similar experiences and faced similar struggles. Some of the women have initiated their own contact with each other, and have met up separately outside of the context of the project. Many of the women are still talking together on the private face book group.

Some women felt frustrated that discussions during workshops went off-track at times. One said that she would have liked more individual involvement. But overall participants indicated that they felt the atmosphere of workshops was safe and comfortable and that the planning, organisation and structure of the workshops worked well to facilitate contributing personally. Many contributed to the planning of the workshops themselves; they felt valued because their opinions were sought and their ideas and feedback were implemented where possible.

The women felt pleased to be able to contribute to the project, and felt that their contributions would go some way towards raising awareness and helping others. Most felt passionate about what we were working on, and they have been very committed across a period of almost 2 years – from their recruitment to the end of the project. Many more women than was possible wanted to represent their country when speaking with MEPs in Brussels and making presentations in Lisbon. A number of participants contributed towards the creation of presentations for both Brussels and Lisbon. As with most deliverables, their suggestions and ideas were taken into account, and they look forward to seeing the outputs that they have helped to create.



*Slides from the International Conference*

Some women were quite disappointed and frustrated by the fact that only five MEPs attended our meeting in Brussels. But we were assured that this was a good turnout, and on the whole the women were happy that two European Parliamentary questions have been raised as a result of the trip to Brussels and that lobbying groups and Members of the European Parliament (MEPs) have contributed towards raising the profile of Autism in Pink, for example in a newsletter and on websites and social media sites such as Twitter. One woman followed up communication on Twitter personally with a Portuguese MEP, who will now be attending the Autism in Pink conference in Lisbon.

Another woman took part in a conference about women and autism, and spoke of her experiences as part of the project. One of the things that she said was that she felt that the project had contributed to her own personal growth and that she now felt more able to identify her strengths. She also said that felt positive about being a part of a European group, part of something which involved cultural diversity.

The women who went to Brussels made a particular effort when meeting the women from the other countries, and even though it was difficult for some of them to deal with the group situation, most seemed to glad to meet a diversity of women, and are looking forward to their trip to Lisbon.

Other women have talked positively about their personal growth as well: one has said that she is looking into aspects of her life that she wants to change, and that she feels empowered to do this largely due to the project – her perceptions and outlook have changed, enabling her to restore her lost faith in herself.

A huge concrete achievement for another of the women is that she has now come forward and told people about her Asperger syndrome, which she had kept very private since her diagnosis due to worries about people's reactions, possible negative repercussions in her job as a teacher, and the stigma and misconceptions attached to autism. She says that the project played a big part in her decision to do this; it helped her realise that she doesn't need to keep her autism a secret and that she should be proud of who she is.



## Summary

Different sources indicate that the impact of the project on the women taking part has on the whole been positive, and the women say or show that they have benefitted.

The main contributing factor to this success has been that the project was not about a non-autistic person telling the participants what they should do to improve things, teaching them social skills, or training them to behave a certain way. Instead it was about the women sharing their experiences, learning from each other, giving each other a space to talk and to be who they are.

Workshops were especially structured -using input and suggestions from the participants themselves- to try to facilitate this. Women were open and honest, tackling difficult and really personal subjects and giving each other lots of encouragement and advice. As the women benefitted from each other and the project, so did the project benefit from the women.

The information that was gained from the qualitative research with the women was important and varied. It is now crucial that we get their messages out to the public.