



## AUTISM IN PINK: Focus Groups

Authors	Richard Mills Sylvia Kenyon
Date	24 December 2013



This project has been funded with the support of the Lifelong Learning Programme of the European Union. This publication reflects the views only of the author, and the Commission cannot be held responsible for any use which may be made of the information contained herein



## Contents

Aim of the focus groups.....	3
Who attended the focus groups? .....	3
Agenda of the focus groups.....	3
Feedback and how feedback was used.....	5

### Appendix 1:

Comprehensive Quality of Life Scale – Adult (ComQuol)

Personal Wellbeing Index – Adult (PWI-A)

Disability Assessment Schedule (DAS)

Basic Personal Data Form

### Appendix 2:

UK PWI Comparisons

## Focus Groups

### Aim of the focus groups

The focus groups were important in gathering feedback from a broader group on the aims, deliverables and methodology of Autism in Pink and its relevance to the project participants: women with autism.

They were helpful in ensuring that the methodologies that we were using and were planning to use were appropriate to work towards the deliverables of the projects and achieve its aims.

### Who attended the focus groups?

Focus groups were attended by women with autism, parents, carers and professionals.

Some partners varied the terms of engagement of these groups to suit local conditions and circumstances, especially taking into account the needs of the project participants who were taking part in the focus groups.

In the UK, a single inclusive focus group was held. All project participants who wanted to be part of a focus group had the ability to take part and voice their opinions independently in a group discussion which includes non-autistic professionals and parents, so it was felt that it would have been inappropriate to hold two separate focus groups.

In Spain, they held separate focus groups for parents, professionals and women with autism. In addition they further separated the groups in relation to autism with and without intellectual disabilities, because this reflected the nature of their project participants; they felt that to have successful discussion in their focus groups they had to recognise that the needs of women with and without intellectual disabilities are very different.

In Portugal and Lithuania, professionals were needed to accompany all of the participants. This was because the majority of their group were women with autism and intellectual disabilities, so support was needed to facilitate and represent women with lower language abilities.

### Agenda of the focus groups

The groups were facilitated by the professional staff of the partner countries in each case, and attended by other staff from the project. A discussion of the background to the project, its funding, expected outcomes and challenges took place, particularly in light of the difficulties represented by the withdrawal of the Slovenian partner and the delay in decision from the EU regarding the Slovenian's formal removal and replacement.

In all countries, the focus groups were informed of the aims of the project:

- To learn more about the lives of women with autism in the European partner countries
- To increase the public's awareness of women with autism.
- To contribute to improving lives of women with autism – both the project participants and women with autism in general

- Improve knowledge of the people supporting and working with women with autism.

Focus groups were also informed of the main deliverable of the project:

- To create a learning approach for women with autism, by women with autism.

Other project deliverables as they are now were not discussed in detail due to the fact that at the time there was no formal leadership or amended work plan, so the future of some of the deliverables as they were then was extremely uncertain.

Each country also explained what it had done so far regarding working towards the aims and deliverables, and what it planned to do in the future.

All countries had collected data using the same forms and questionnaires; all blank forms were shown to the focus groups attendees:

- Data forms – participants' general details and circumstances
- Disability Assessment Schedule (DAS) – a profile of participants' skills and difficulties
- Personal Wellbeing Index (PWI) – a measure of participants' satisfaction with their quality of life, using eight domains designed to cover all aspects of life
- Comprehensive Quality of Life Scale (ComQoL) – information to back up the information gained from the data forms, DAS and PWI

Appendix 1 shows the forms that were used.

The reason for choosing the PWI and ComQoL was explained to the groups: the PWI would allow for subjective data collection on quality of life and the ComQoL objective data. Both enjoy harmony with EU values, and in the case of the PWI, its flexibility and relative brevity, lack of rigid cultural norms and the policy of personalisation of care and support are a bonus.

It was explained in the focus groups that due to the nature of the PWI as mentioned above, it would form the starting point for the framework of the learning approach to be created. In this way all partner countries were starting with same eight domains.

Individual interviews and workshops were being conducted with the project participants in all partner countries to collect more information about the eight PWI domains, specifically the issues and difficulties that participants face in each domain, and the strategies and solutions that they use to overcome them.

Exact methodologies were not identical in each country because of the nature of the participants; their abilities, where they lived, and whether they were part of a specific institution or not. Overall, the participants with good language skills were able to speak in the workshops about their areas of issues and difficulties, strategies and solutions, while activities were set up in the workshops to observe these areas for the participants who were unable to talk about them.

Each country explained their methodologies to the attendees of their focus groups.

Feedback was then sought from the attendees as to the suitability of the aims and deliverables, the appropriateness of the methodologies in achieving the aims, and the appropriateness of the methodologies to the particular project participants of each country.

## Feedback and how feedback was used

The PWI content was thought to create a good framework for the learning material.

It was suggested that comparison with same age women without autism might be useful. This had in fact already been done in the UK, and a bar chart was shown comparing PWI scores for the participant women with autism and a similar random sample of women without autism. See appendix 2a.

The UK focus group suggested that the information on the bar chart in appendix 2a should be divided for reporting purposes into 3: positive, neutral and negative, rather than dividing into 2 and grouping negative and neutral together, as had been done. This was taken on board. See appendix 2b.

The focus groups in general also noted the danger of bias when completing the questionnaires, especially the risk that volunteers might give answers to please researchers.

This was taken into account when analysing PWI results, and emphasis was placed on the narrative of the PWI domains, rather than the numbers (see report on Assessment of Competencies and Identification of Needs).

The impact on sense of self through disclosure was also noted. Focus group participants acknowledged that, for many, the process was potentially traumatic and that care should be taken when eliciting answers. This was one of the reasons for selecting the PWI as it provided a structure but one that was not overly prescriptive and could be adapted to each of the partner country's circumstances. Care was duly taken, participants were involved as much as possible in the planning of the workshops, so that they could be comfortable with the ways in which the workshops were carried out.

Specific points about the PWI that were raised and dealt with in the focus groups included the breadth of each topic, e.g. would sexuality be covered as part of a broader domain on personal relationships? – in this case, it was confirmed that it would. This was taken on board, but in actual fact it was discovered that this was such an extensive topic that it could not be done justice within the context of the project. It will be suggested as an area for further study in the future.

Also raised were the possible limitations imposed by the nature of autistic cognition - whether people would be able to 'imagine' the future and implications of future security. It was noted that the response would vary according to the individual but that it was an important factor. In fact it has transpired that future security is an immensely valuable item and one that generates a great deal of concern amongst some of the participants.

Participants who took part in the focus groups also indicated the importance of staying positive, even though part of the aim of the research was to unearth issues and difficulties to feed into the learning approach. They felt that problems should be addressed but in a positive way – that dwelling on problems should not be encouraged and that focussing on the positive is very important to them: talking about / sharing strategies, transforming bad situations into good situations.

This was very much taken on board in all partner countries; activities were chosen that individuals enjoyed, and strengths and achievements were returned to as much as possible throughout discussion, trying to ensure that negatives were looked at from positive angles if possible.

Other areas covered by the focus groups included 'autistic thinking' and how participants think and process in a different way to more traditional styles of thinking and processing. They also discussed further possible interventions and programs for women with autism that could come out of the project.

Professionals who were part of the focus groups made useful comments and contributions to help guide thinking, especially with regards to trying to ensure that methodologies used in gaining information for the project were appropriate for participants, for example for those who did not want to be part of a group. This led to these participants having more individual input regarding the PWI domains, rather than taking part in group workshops.

The focus groups were also keen to emphasise the role of the project in addressing the misunderstandings of some professionals. Self harm, eating disorders, paranoia, hypochondria, drug use due to peer pressure, and trying to be accepted are all pressing issues – groups felt that often low self-worth can be the cause of these things and are keen that the materials address these issues. Other broader issues discussed by the focus groups included the societal attitudes, for example how men tend to be excused for certain behaviours.

The conference at the end of the project was explored, including the practicalities of attending. It would be the case that partners would present the situation from each country's perspective.

Focus groups also discussed the development of the learning approach and the importance of adapting it to the different audiences: this point will be noted by the partners. Groups were keen to emphasise the importance of this unique project to the women and to urge that the EU adopt a line that was flexible in the changeable circumstances and would allow the development of a unique set of materials – by women with autism, for women with autism.

The principle of 'for women - with women - by women' was endorsed by focus groups as an important aspect of the project.