



AUTISM IN PINK LEARNING APPROACH

RATIONALE

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Table of Contents

1. What is Autism in Pink?	3
1.1. Rationale and background	3
1.2. Autism.....	3
1.3. Women with Autism	4
2. The Learning Approach	5
2.2. Methodology for obtaining structure and content of Learning Approach	6
2.3. The Learning Module Framework.....	8
2.4. The Learning Manuals	9
3. Further Reading.....	9
Bibliography	Error! Bookmark not defined.

1. What is Autism in Pink?

1.1. Rationale and background

Autism in Pink (PM1231/518585-LLP-1-SI-Grundtvig-GMP) is a Grundtvig Multilateral Project, a Lifelong Learning project devoted to a specific target group - women with autism. (Use of the word 'autism' refers to all women on the spectrum including Asperger's syndrome).

The project was developed by a partnership composed of 4 partners (Autismo Burgos, Spain; FPDA Federação Portuguesa de Autismo; Edukaciniai Projektai, Lithuania and National Autistic Society, United Kingdom, who took on the role of coordination). All the partners have experience in different areas in the field of Autism.

There have been few studies devoted to women with autism. In the field of EU projects this population is specifically considered one of the more neglected target groups. The EU disability strategy for 2010-2020 aims to improve the economic and social situation of people with disabilities empowering their full and equal participation in education, employment, use of services and facilities, and in life in general. Women with autism are at risk of being excluded more than men. Recent research indicates that women with autism are also far more at risk of being diagnosed late, being misdiagnosed, or not being diagnosed at all.

The main aim of Autism in Pink is to study women project participants with autism, their needs and competences and to give them the opportunity to share experiences and strategies in order to establish their own ways of overcoming the problems they encounter.

1.2 Autism

There are 5 million people with autism in Europe.

People with autism experience communication difficulties and problems with interpersonal relationships. Many people with autism have cognitive deficits.

“Autism is a life-long neuro developmental condition interfering with the person's ability to communicate and relate to others” (Fombonne, 2003a, 2005; Fombonne, Quirke & Hagen, 2011).

Persons with autism are considered by the European Disability Forum as part of a population with “High complex dependency needs”. The Council of Europe states that they are “in need of a high level of support”. They are recognised as a target group in many other Lifelong Learning Projects of European Union.

The diversity of the situation of people with autism has been recognised in the literature. Individuals range from those who very competent to those who are always in need of support.

Autism is often associated with comorbidities (disturbances and medical conditions) like epilepsy (high incidence), fragile X syndrome, phenylketonuria, tuberous sclerosis, neurofibromatosis and many other genetic diseases. Autism is associated with learning difficulties in about 70% of the cases.

The Charter of Rights of Persons with Autism was recognised as a written declaration by the European Parliament in 1996. The Charter describes the rights of people with autism and states the specificity of autism.

Every document produced by Autism in Pink has to consider the specificity of autism and the diversity of the situation of each woman involved in the project.

1.3. Women with Autism

The discrimination of women is still a reality in many cultures that live in the European space. There have been no previous EU projects that have specifically dealt with the needs of women with autism or systematically addressed the challenges they face.

Sex differences in the prevalence of individuals with autism have been documented in multiple epidemiological and clinical studies, with estimates for male/female ratios ranging from 2.5-1 to 4-1 (Fombonne, 1999, Honda et al.2005, Lingham et al, 2003, Yeargin-Allsopp et al.,2003).

In the Autism in Pink Prevalence Report there is a review of studies in the partners' countries that indicates M/F ratios of: 3.3-1 (UK), 2-1 (Spain), 5-1 (Portugal, 2013), 1,9-1 (Lithuania).

According to findings by Gould and Ashton Smith (2011) many girls are never referred for diagnosis and are missed from the statistics. In their study they identified ways in which girls and women behave differently from men. They present some examples:

- Girls and women are more able to follow social actions by delayed imitation because they observe other children and copy them, perhaps masking the symptoms of Asperger Syndrome (Atwood, 2007)
- “This sort of mimicking and repressing their autistic behaviour is exhausting, perhaps resulting in the high statistics of women with mental health problems” (Dale Yaull Smith, 2008)
- Girls and women are more socially inclined, and are more aware of a need to interact socially. “Many obsessively watch soap operas and have an intense interest in celebrities” (Gould and Ashton Smith, 2011).

Many have a rich and elaborate fantasy world with imaginary friends. Some girls escape into fiction and some live in another world or develop an interest in society people.

This imitation, masking of autistic behaviour and social inclination was very clearly seen in the women who participated in Autism in Pink; we quote from an interview with (A) a Portuguese participant:

- “My favourite hobby is to watch soap operas on TV and to read ‘rose’ magazines; if I was rich I would buy books about the history of Portugal, about princesses and kings and queens.”

And quoting from a UK participant, who was exhausted from dealing with a particularly difficult social situation:

- “I am trying to keep email contact and everything else that takes up energy to a minimum to regain my stability.”

It is important to detect the needs of females, often masked by the correct social behaviour. It is also important to prepare girls for a life of quality as adult women.

Staff and teachers in schools must be trained to recognise and address the needs of students on the autism spectrum especially “the more subtle presentation in girls” (opus cit.) This recognition needs to continue into adulthood; understanding of women with autism needs to improve so that appropriate supported can be given.

2. The Learning Approach

2.1 Introduction

We mentioned the main aim of the project in section 1.1 – to learn more about women participants of the project, and to provide them with the opportunity to share experiences, difficulties and strategies.

This opportunity was provided via workshops where participants met regularly throughout the project. There were ten to twelve participants from each partner country involved; each one was also interviewed individually. Information gained from interviews and workshops was gathered and recorded.

One of the objectives of the project is to develop a learning approach specifically for women with ASD addressing topics such as gender identity, mental health and partner relationships. This learning approach has come out of the information learnt from the interviews and workshops with the participants.

The learning approach consists of an online learning module and two learning manuals – one for women with autism and one for teachers, carers and families. The learning module contains extracts from the Autism in Pink documentary, also available separately as a single 30 minute film; and an online book of personal stories *Breaking the silence - a collection of personal writings and drawings by women with autism*. These elements are intended to help to create deeper understanding by giving real examples and experiences.

2.2. Methodology for obtaining structure and content of Learning Approach

- To define the target group and collect initial data
- To research the competencies and the needs of the women participants, using the Personal Wellbeing Index – Adult (PWI, Cummins 2005) as a basis
- Interviews and workshops

2.2.1. Defining the Target Group and collecting initial data

The project defined the main target group as a group of 10-12 women with ASD aged 16-40 years from each participant country. The total group consisted of 46 participant women, whose average age was 26 years old.

Research began by learning more about the young women involved in the project. In every country the workshop leader completed Individual Data Files that contained information about age, diagnosis, comorbidity, education, current day activities, current living circumstances and social and language outcome measures.

The women involved in the project showed differing levels of functioning and different competencies, for example 10 didn't have receptive language and 7 didn't have expressive language while 20 could understand and 16 could speak about personal experiences or events. Seven didn't establish relations while 14 could maintain social contact with people they know and 11 could maintain contact with other people.

Because of the diversity and uniqueness of women with autism, the instruments used to evaluate their competences had to be appropriate to every girl in the project.

The partners concluded that this brought richness for the research and it would provide a broad range of learning situations and many possible individual challenges.

2.2.2 Producing materials for the Learning Approach using PWI A

PWI-A is the standardised instrument that was used by the project as a basis for assessing the competencies and needs of the women with autism, and collecting subjective data on their quality of life.

The ComQoL A5 (Comprehensive Quality of Life Scale –Adult 5th Edition) was also used to collect objective data on quality of life.

The reason for choosing these instruments:

- Both enjoy harmony with EU values
- PWI had the flexibility to adapt to the diversity of the target group

The PWI is a questionnaire that asks people to score 8 areas of life according to their satisfaction in each area (referred to as a domain). The PWI also asks as an optional question about overall satisfaction with life. The domains are:

1. Standard of living
2. Personal Health
3. Achieving in Life
4. Personal relationship
5. Personal Safety
6. Community Connectedness
7. Future Security
8. Spirituality and Religion

Every woman participant completed the questionnaire in her native language. Interviews and workshops also covering the PWI domains provided information additional background to the scores obtained through the questionnaire.

In this way, a benefit of the flexibility of the PWI is that it allowed results from each country to be systematised in a consistent framework, which could then be used for the Learning Approach.

Among the objectives of the project (original document) we find:

To contribute to the social inclusion of vulnerable group of young women with Autism Spectrum Disorders (ASD) and to provide them with key knowledge and skills in the fields of gender identity, independent life, inclusion and social interaction in order to improve their quality of life.

We would therefore expect the learning approach to be able to fulfill the objective above.

Another benefit of the PWI is that it encompasses all areas of life, thereby ensuring that areas such as gender identity, independence and social interaction were covered.

2.2.3 Workshops

Workshops took place in every country with the main objectives:

- To promote social contexts to women with autism
- To create learning material by women with autism to women with autism
- To share information and understand different cultural contexts
- To improve knowledge of people living and working with women with Autism

However they assumed different strategies. They were adjusted to the audience they had in each country but all involved the women participants.

2.3. The Learning Module Framework

The Online Learning Module forms the primary part of the Learning Approach.

It is divided in 8 sections according to the 8 domains of the PWI instrument. These sections form separate modules accessible online to women with autism, their families and carers or teachers.

Each section begins with the issues/obstacles highlighted by the women participants (individually or in group) in each PWI domain. Although there have been varying definitions of self-regulated learning, it is generally understood to involve learners in *learning goals and strategies* appropriate to the task at hand. Therefore learning goals and strategies follow the issues and obstacles described for each domain and are appropriate in trying to overcome the difficulties described.

For each domain there are also stories from the participants to illustrate.

The Framework of the Learning Module is shown below

PWI Domain

Issues / Obstacles

Learning Goals

Learning Strategies

Stories to Illustrate

Some strategies that the participants discussed could be applied to many different difficulties and learning goals. Therefore there is a final general section of strategies that are not specific to particular PWI domains.

The Online Module is a unique document written by girls with autism for girls with autism.

2.4. The Learning Manuals

The manuals are available online to accompany the Learning Module. They have been tailored for two target audiences:

- Women with autism
- Families, carers and teachers of women with autism

The manuals are available in downloadable pdf form and have been written to specifically address the needs of the target groups, for use with or without the learning module.

3. Further Reading

For more information about Autism in Pink, please see the other outputs from the project:

- Research report: Prevalence Study of Women with ASD in participating countries
- Research report: Assessment of competencies and identification of needs of women with ASD
- Research report: Focus Groups
- Research report: Qualitative Research
- Online book: Breaking the silence - a collection of personal writings and drawings by women with autism
- Documentary: Autism in Pink



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