AUTISM IN PINK:
Assessment of Competencies
and Identification of Needs

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Assessment of Competencies and Identification of Needs

Approach

The approach to the assessment of competencies and identification of needs was developed using standardised instruments for assessing competence and quality of life that would include skills and abilities. These included both qualitative and quantitative methods.

All partner countries used the same instruments, making comparisons possible. All of the instruments used were valid for use in the countries involved in the project. The values were compatible with the values and statutes of the EU and of participating member countries.

Initially, we obtained basic personal data and data on the level of disability using the Disability Assessment Schedule (DAS). This is also a good measure of some of the basic competencies of the women participants with autism, such as language and social abilities.

A literature search identified a number of tools that would have further assessed competencies and quality of life. There were relatively few, however, that did so as succinctly and with as much relevance to the project as the Personal Wellbeing Index (PWI) 2006 and Comprehensive Quality of Life Scale (ComQoL) 1997, developed at Deakin University, Australia by Cummins et al (see appendix 1). Many of the QoL tools in use had not undergone such robust validation checks as the PWI.

In addition, the partner countries used their own individual methods to explore competencies and needs. These methods depended on the women with autism that formed the participant group for each country.

Results and implications for Learning Approach

Disability Assessment Schedule (DAS)

Appendix 2 shows a summary of DAS results from the partner countries. This summary also includes average age at the start of the project, and average age at diagnosis.

Overall, these figures show that there is huge variation between the participant women with autism. Some have communication and social competencies that appear to be only slightly impaired, whilst some are much more impaired in these areas, including some who are non-verbal or lack expressive language, and some who lack receptive language. There is also variation in ability within individual women; for example, it is not necessarily the case that those who have good abilities in language also have good social abilities. Nor that those who lack expressive language also lack receptive language, or vice versa.

All of this is to be expected in that autism is a spectrum condition, in which individuals often present with an uneven or 'spiky' profile of abilities.

It is important that the variation in abilities between and within the participants be reflected in the learning approach to be created as part of this project. There will therefore be a wide range of learning goals (fed by needs) and strategies (fed by competencies and strengths) within the learning approach. For example, some learning goals may better suit the needs and competencies of women with autism who are able to speak, others may better suit the needs and competencies of women with autism that do not speak; some may be useful for women who do not seek social interaction, others may be useful for women who seek social interaction but find it difficult and/or uncomfortable. Some goals and strategies may be

detailed and precise; others may be broader and more general. Some may match some women with autism quite neatly; some may need to be adapted to suit the individual. The inconsistency of appearance of learning goals and strategies will reflect the broad spectrum of needs and competencies of the project participants, and indeed of women with autism in general.

Personal Wellbeing Index (PWI)

The PWI is a questionnaire which asks people to rate eight areas of life according to their satisfaction in each area. Each of these eight areas will be referred to as a PWI domain. The PWI also asks (optionally) about overall satisfaction with life.

Participants were asked to complete the PWI questionnaire where appropriate. Where this was not possible due to level of participants' understanding and/or ability to answer, parents, carers and professionals assisted in completing the questionnaire in whatever way was suitable to the individual participants.

Appendices 3a and 3b show the eight PWI questions and domains, and a summary of PWI results from the partner countries.

These show that general satisfaction of the project participants regarding the eight PWI domains varies quite substantially between the partner countries, and between the domains.

According to the numerical results of the PWI, there is very little by way of dissatisfaction in all of the countries except the UK. Overall, looking at figures from all partner countries, the participants appear to be least satisfied about the domains of 'Future Security' and what they are 'Achieving in Life'.

However, as warned in the focus groups by both participants with autism and professionals, the results of the PWI questionnaires in terms of the numbers must be viewed as only part of the story; when filling in questionnaires, people tend towards putting the answers that they think are desired from them. Other issues may have arisen, such as varied interpretation of the questions, differing perceptions of satisfaction, and parents', carers' and professionals' perceptions not necessarily reflecting the reality of the participants when assisting in completing the questionnaire.

The PWI domains are quite comprehensive, potentially covering competencies and needs of the women with autism in all areas of life including caring for/about themselves, social networking and independence (specifically mentioned by the project work plan). It is therefore very important that the PWI domains were further explored.

Individual Methods

As mentioned above, the PWI domains were further explored in each country. Each domain was examined in greater depth in workshops and interviews, both in groups and individually, depending on what was appropriate to the women. Some participants were able to discuss their needs and competencies in each domain, other participants took part in activities in which their needs and competencies could be observed and explored.

Although from the bar charts in appendix 3b, the majority of participants appeared to have a positive outlook regarding the majority of the PWI domains, in actual fact on further exploration, many more obstacles and areas of dissatisfaction, as well as possibilities for overcoming the obstacles and improving the dissatisfaction, came to light in all domains.

Obstacles and areas of dissatisfaction reflect the needs of the participants, which feed the issues and difficulties, and 'learning goals' part of the learning approach.

However because all project participants are individuals with varying skills and needs, obstacles and areas of dissatisfaction are in no way consistent across the board. Where some had particular difficulties in particular areas, others were able to explain or display ways in which these difficulties could be addressed. The participants who did not have difficulties or had lesser difficulties in these particular areas, could therefore provide ideas/tools to feed the 'strategies' part of the learning approach. Equally, participants who had lesser difficulties in some areas may have had greater difficulties in other areas, for which other participants might have been able to provide ideas/tools.

Strengths of the participants were also explored, with a view to feeding the 'strategies' part of the learning approach.

Appendix 4 shows a summary of the strengths some of the women displayed or gave us examples of during interviews and workshops.

Summary

Needs and competencies form the basis of the learning approach. See appendix 5 for the general framework proposed for the learning approach.

1. Needs, areas of difficulty, areas of lesser satisfaction, obstacles and things that people wanted to achieve were picked up in studying the DAS and PWI domains as outlined. These could feed the 'issues and difficulties' and 'learning goals' part of the learning approach.

2. Areas of ability and strength were also picked up, along with solutions, strategies and suggestions for addressing needs. These could feed the 'learning strategies' part of the learning approach.

3. 'Stories to illustrate' could be fed by the individual experiences of the participants.

4. Concentrating on the specific obstacles and solutions that the participants discussed, or difficulties and strategies that were observed means that the learning approach will be a unique gathering of goals and strategies shaped by the project participants themselves.

Appendix 1

Personal Wellbeing Index Adult (PWI-A) (English) - 4th Edition The International Wellbeing Group MANUAL(2006) Cummins R. Deakin University

Comprehensive Quality of Life scale - intellectual/cognitive disability - 5th Edition (ComQol-I5) MANUAL (1997) Cummins R. Deakin University