

## Workpackage progress update for ASDEU website – July 2017

### WP 3: Adults Treatment and Care

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Relatively little is known in the European Union (EU) and globally about existing services and care for adults on the autism spectrum and the readiness of communities to provide for them.

To achieve a better understanding of services for autistic adults in the EU, a survey on knowledge and experiences with services and care practices for adults was announced in February 2017. The survey was developed in 3 versions for different types of respondents: adults on the autism spectrum, caregivers of autistic adults, and professionals providing services for autistic adults. The survey asks questions about the respondent's background; general knowledge of autism services; awareness of autism in the workplace; diagnosis and medical services; non-medical services (residential, employment, educational, financial, social); services during major life transition such as the transition from adolescent to adult services; and services for elders with autism. The survey was originally launched in three languages: English, Danish and Spanish. Since the launch, the survey has been translated and made available in 5 additional languages: Icelandic, Italian, Polish, French and German; Rumanian, Finnish and Portuguese language versions will be available soon.

A respondent can access the survey by a personal link (providing an e-mail address) or a general link (no e-mail address is necessary). To date, respondents from 21 countries have participated in the survey.

Below is an overview of the number of surveys completed to date for each survey version and language (amount of respondents 12<sup>th</sup> of June 2017 in parenthesis):

<i>Target group</i>	<i>Adults</i>	<i>Carers</i>	<i>Professionals</i>
<i>Language versions available at launch:</i>			
<i>English</i>	40 (22)	13 (7)	10 (9)
<i>Danish</i>	129 (120)	67 (60)	67 (44)
<i>Spanish</i>	11 (6)	46 (19)	22 (13)
<i>Recently released language versions:</i>			
<i>Icelandic</i>	9 (4)	23 (7)	24 (4)
<i>Italian</i>	2 (0)	8 (1)	15 (1)
<i>Polish</i>	7 (1)	7 (0)	9 (0)
<i>French</i>	23 (13)	38 (16)	31 (16)
<i>German</i>	0 (0)	0 (0)	0 (0)

<i>Total</i>	221 (166)	202 (110)	178 (87)
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## **Update on activities:**

The focus of WP3 activities since the last ASDEU update has been preparing the forthcoming language versions (Rumanian, Finnish and Portuguese) for upload into the survey platform and distributing the current available survey versions in each ASDEU country. To help the partners in the distribution process, the Danish site provided materials to use in the distribution and guidance for the distribution process.

Due to the summer holidays and the fact that 3 new translations are soon to be launched, it is possible that the WP3 surveys will be kept open into the autumn 2017.

## **Key learning from activities:**

### ***What worked well?***

- We observed a striking increase in the response rate – especially from autistic adults - after the survey versions were announced by a large Danish autism advocacy organization for people with autism, their families and professionals. It was also important to work with the organization to keep the post in the top or near the top of the Facebook site to keep it visible.
- It is helpful to be responsive to complains/comments and potential difficulties in understanding the questionnaire. We provide contact information on the survey invitation.
- We improved the response rate by adding a general link to enter the survey that did not require an e-mail address.
- Follow up calls to the bigger organisations may be useful as a reminder and a prompt to complete the survey.
- It may be of great importance to indicate how long the survey can be answered.
- It may help to tell or write that we will send the ASDEU report to organizations as soon as it is ready. People may feel more “obliged” to help if they receive something in return.

### ***What could be done differently?***

- Response rates probably reflect the number of contacts and invitations that are made – the more contacts, the higher the response rate.
- Working more closely with sites on strategies for their own country to increase the number of contacts and survey invitations

- Reminders may be helpful – many surveys are partially completed and sending out ‘automated’ reminders to the ‘incomplete surveys’ (can be done automatically by the survey software) may be helpful to raise the number of ‘completed’ surveys

## **Findings and outcomes to-date:**

- WP3 activities and preliminary results of the information searches were presented in May 2017 at the International Meeting for Autism Research (IMFAR; poster) and in Denmark at the annual meeting of the Danish Society for Adolescent Medicine (presentation); and will be presented in a symposium at the European Society for Child and Adolescent Psychiatry in July 2017.
- No survey results analyses have been performed to date since survey data collection is still in progress.

## **Next steps:**

Anticipating final reports and conference.

- The survey data collection is extended, probably until the autumn.
- Analysis of survey results will begin in the autumn for preparation of the draft final report by November 2017.
- Analyses will focus on overall responses by type of respondent in each topic area in the survey, as well as by characteristics of the respondents (e.g., country). Final report will also include results of the WP3 information searches that the sites conducted prior to launch of the survey.