

Work package title: Adults Treatment and Care

Presentation title: *ASDEU WP 3 Progress: Services and care for adults with autism spectrum disorder (ASD)*

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Context:

- There is relatively little knowledge regarding autistic adult services and care or the readiness of communities to provide adult services for persons with ASD in the EU
- WP3 objective is to create a framework for improving services and care for autistic adults in the EU
- WP3 adult services focus areas include:
 - Multidisciplinary approaches to services and care
 - Management of co-morbidity
 - Diagnosis and post-diagnostic support in adulthood
 - Managing major transitions
 - Care for the autistic elder
- WP3 methods include
 - site-specific literature and key informant searches regarding local organization of services and local services policies and recommendations for autistic adults in each participating country
 - on-line surveys of knowledge, experiences and opinions of experts, adult service providers, autistic adults, and carers of autistic adults regarding local current care practices, perceived service gaps, examples of local best practices, and suggestions for improving existing care strategies.

Progress:

- 7 sites have completed report summaries of local organization searches of adult services, including autism-specific features
- 6 sites have completed report summaries of local documentation searches concerning autistic adult services
- 3 versions of on-line surveys (professional, adult with ASD and caregiver versions) are developed and under informant review and pilot testing on-line

Initial findings

- *Literature search:*
 - Research base about services for adults with an ASD is underdeveloped
- *Site-specific reports on information searches:*
 - Variation in public-private balance between AND within countries
 - Private organisations: core knowledge and competence base, and are main providers of services
 - Between and within countries: a) geographic variation in the range of services (tend to cluster in large urban areas), b) may have significant inequalities in the public and private coverage among different regions and c) development and specialisation of the services offered by private organizations may be limited

Key learning:

- **What worked well?**
 - Providing clear guidelines and templates to follow for each site task for the WP were important to assist sites in completing their work
 - Follow-up with sites, 1-1, via telephone or skype meetings, improved sites' understanding of WP tasks
- **What could be done differently?**
 - Improving sites' awareness from the beginning of the scope of the WP tasks ahead
 - Increasing resources for translation of on-line surveys into each ASDEU member language would likely increase surveys response rates and quality of responses

Next steps:

On-line survey

- Finalize on-line surveys (English versions) and distribute to sites for translation into local language, where possible: Oct-Nov 2016
- Sites finalize local distribution plans for surveys: Oct-Dec 2016
- Begin launch of surveys, beginning with English versions and adding other language versions as they become available: begin launch Nov-Dec 2016
- Monitor survey responses and expand survey distribution as needed: Jan-Feb 2017
- Begin preliminary analysis of survey responses: Feb-Mar 2017
- Extract survey response data and perform analysis for final report preparation: April-May 2017

Final report preparation

- Complete site-specific reports from local information searches: Oct 2016-Jan 2017
- Develop final report outline for WP3, including table/figure shells for displaying results: Jan-Feb 2017
- Compile information from site specific reports for final report summary of results: Feb 2017
- Compile results from surveys for final report summary of results: June-July 2017
- Final report writing: March-August 2017