

## Autism Spectrum Disorders in the European Union – ASDEU

### Work package 3. Autistic Adult Treatment and Care

**Title: Main report on good practice examples in adulthood and elderhood - 18.6.18**

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### Background

Due to the limited research attention on adults with autism, regarding identification and diagnosis as well as treatment and care, little is known of the long-term outcomes in adulthood and the factors that influence these outcomes. There is a need to identify best practices for care and support of adults with autism and their families throughout their lives in order to promote good outcomes. The need to improve our knowledge of autism in adulthood is especially critical since the number of diagnosed adults with autism is rising in the wake of the dramatic increase of autism diagnosis in children since the 1990s. ASDEU addresses the knowledge gaps by developing an EU perspective regarding the healthy and positive living of people with ASD. This includes the creation of a comprehensive framework to improve treatment and care and to benefit the quality of life of adult individuals and families affected by ASD. Besides ASDEU, other initiatives include recent reports describing quality standards for health and social services for adults with ASD and associated metrics for evaluation and profiling the needs and gaps in services for adults with autism. Common general themes across these and other reports on the needs of adults with autism include:

- importance of coordinated care through time;
- importance of ASD-specific training and competencies in persons at all organisational levels involved in care of autistic adults
- importance of local strategic plans and a designated local responsible lead over provision of adult autistic services
- inclusion of autistic persons and families in decision-making and processes
- transparent processes for identification, diagnosis and assessment of needs

An important additional step is the identification and development of best practices for implementing these important themes. Achieving this step relies on the exchange of information and expertise and a compilation of knowledge across EU sites.

### Objectives

To create a comprehensive framework to improve adult autistic treatment and care by adopting an adult lifespan perspective. This perspective will address the following integrated specific objectives:

1. Identify best practices suitable for the development of adequate multidisciplinary approaches to address the needs of people affected by ASDs in adulthood.
2. Identify best practices for the management of co-morbidity associated with ASDs in order to avoid hospital admissions.
3. Identify actions improving access to diagnosis and post-diagnostic support when ASD is detected in adulthood.
4. Identify best practices around the management of transitions during adult life, with a special focus on the paediatric to adult care transition and transition due to the loss (due to incapacity or death) of primary care giver
5. Identify best practices for care of elderly autistic people, with a focus on care practices of unique or special relevance for this age group.

## Methodology

The main task was to compile what is understood and what is being carried out in the area of adult autistic treatment and care across ASDEU sites. Special emphasis was on identifying local models of 'best practices' in autistic adult care and support. Two main activities were conducted: an information search and an on-line survey.

The WP3 lead site in Denmark pilot-tested the information search approach prior to distributing the search materials and instructions to other participating sites. To make the searches systematic, feasible, focused and relevant to the WP3 aims, sites were advised to focus their search and search terms, using local specific search terms to accommodate country-specific differences. The information search was used to identify local documentation, web sites, databases, information services, care services, agencies and key persons involved in adult autistic care relevant to the 5 WP3 Objectives. The goal was to improve the understanding regarding the availability of services for autistic adults in each ASDEU participating country. Interviews were requested of key informants and telephone interviews, during which extensive notes were taken, were restricted to approximately 1 hour.

The on-line survey goal was to obtain information on services availability and actual services experiences related to autistic adult care in each participating ASDEU country. Survey questions were based upon a variety of published guidelines and recommendations regarding services for autistic adults. The answer choices were developed to reflect how closely the respondent believed that the local services that they had experienced 'fit' these recommendations. The survey results thus provide a measure of how closely services provision at the local ASDEU level align with published guidelines. Three versions of the survey were developed in order to obtain information about local services from three different perspectives: adults with ASD, family/caregivers of autistic adults and administrators/professionals/service providers for adults. The survey was anonymous and distributed widely through electronic and social media. To facilitate response rates, ASDEU partners were encouraged to translate the survey into their local language (11 language versions were made). Results were based on all responses as of December 2017. Analyses comprised descriptive statistics (e.g., frequencies and percentages of responses to questions). When the sample sizes enabled it stratified analyses were also performed by the autistic person's sex, support needs/ independence level and the specialist area of the professionals e.g. diagnosis, intervention or health/medical. Although not documented in the final report there were differences in the results from Denmark and other countries in various categories. As a result the author calls for further analyses of the data to be carried out to explore "country- and sex-specific variations".

## Results

Information search: A key feature in services organization for autistic adults across all sites appeared to be the relative balance between the public and private sectors in service provision and associated funding specifically for autistic adults' services: who pays and who provides? There appears to be considerable variation both between and within ASDEU countries in the public-private balance. Countries overall vary in the public-private balance in services provision and even within a country, the provision of services specifically for autistic adults is highly variable. That is, the level and range of specific autistic adult services varies widely geographically and the balance between the public and private sectors in autism-specific service provision may vary greatly in different areas. Nevertheless, it appears that over all ASDEU sites, the private sector is largely the core knowledge and competence base regarding autistic adults' services provision and in most instances, it is the main provider of services.

On-line survey: A total of 2009 responses to the survey were analysed for the report: 667 autistic adults, 591 carers and 751 professionals. The Danish language had by far the highest response rate (676 responders) across the three versions of the survey: Respondents across all three versions were primarily women. Approximately 87% of the autistic adult responders answered the survey without any assistance. Half of the carers of autistic adults stated that the autistic adult they cared to had at least some independence, whereas the other half stated that the autistic adult required a high level of support. This suggests that the carers' adults' level of functioning was somewhat lower, in general terms, than that of the autistic adult responders. About half of the professional responders reported on their experience in adult medical-type services (e.g., diagnosis, interventions and health characteristics). The others elected to report on their experience in non-medical services such as: housing, employment and social services. Most of the professional responders had a non-medical background and had been working in adult services for 6 to 10 years and longer.

The final report summarises key findings relevant to each WP3 Objective and describes areas of improvement and recommendations. Overall, the survey results provide a rich overview of many facets of the state of autistic adult services and care in the EU. By design, the survey results highlight where there are differences between the published guidelines for services and care for autistic adults and what is actually experienced by users and providers. For many areas of adult services, the alignment of local services with published guidelines is quite good, (e.g., recommendations for the diagnostic process) although for many others the alignment is much poorer (e.g., recommendations regarding post-diagnostic support; adolescent to adult transition). Notably, it was clear that knowledge of good services models that work well for autistic adults was generally low (i.e., many responders did not know of any good local models for specific types of service). ASD diagnosis and residential services areas had the highest number of proposed good local models, while the healthcare and adolescent-adult transition services areas had the lowest. The survey results thus highlighted discrepancies between services recommendations and what is actually experienced at the local level and, therefore, serve as a guide for where to focus effort concerning autistic adult services in future work.

Some results also highlighted differences in views between autistic adult and carer responders versus professional responders. For example, in the section regarding the "health behaviours" of autistic adults, it was notable that the adults with autism and carer respondents' views compared to the perceptions of professionals differed widely at times. For example, around 50% of carers felt that the adult they supported would struggle in the "ability to recognize and report health problems or pain or an unusual diet". However, there were only a few professionals who believed that these behaviours were more common in autistic adults compared to non-autistic adults. The authors noted that differences in results like this across the three respondent groups indicate that it is important to query all three groups to get the full picture of the experience of autistic adults of services in the community.

**Other topics** in this report that might be of interest are: autism diagnosis and interventions, use of residential services, managing transitions and health and co-morbidity.

**Limitations of the data** – One limitation that was discussed, for example, was the fact that the survey results were derived from a convenience sample and not based on a scientific sampling frame. Therefore, the results may be best viewed as a 'robust' pilot study, providing an overall impression of the state of autistic adult services across different areas of the EU addressed by the 5 WP3 Objectives. The conclusions and recommendations to be drawn on the basis of the work may serve as guide for designing future systematic studies addressing specific topic areas in autistic adult services of the participating countries.

## **Concluding remarks on the survey**

“The conclusions and recommendations drawn on the basis of the survey should be used for designing future systematic studies addressing specific topic areas in autistic adult services”.

**List of appendix**

There is a comprehensive list of 78 appendices detailing all aspects and processes of this research. This list is worth a glance in order to see the work and processes undertaken in order to produce these data.