

Work package title: *Early detection, diagnosis and evidence-based intervention*

Presentation title: *ASDEU WP 2 Progress: Early detection, diagnosis and evidence-based intervention in Europe*

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Context:

- The social and communicative difficulties are detected and diagnosed at a very advanced age in a significant proportion of children with ASD in the EU.
- There is little information on how families access to resources of diagnosis and early intervention for children with ASD in EU
- The main WP2 objective is to create a guidance document on early screening, diagnosis and intervention, including the possible identification of parameters, risk factors and biological markers; the current best practices within this topic; and a proposal on training modules on early detection diagnosis and intervention.

- WP2 intends
 - To know what the best experiences on early detection, diagnosis and early treatment that can be applied within the context of the EU.
 - To know the point of view of families and professionals on early detection, diagnosis and early intervention
 - Make a proposal on training modules in the field of early detection, diagnosis and early intervention for people with autism

- The methods being used in WP2 are:
 - Systematic reviews of literature, with special emphasis on randomized controlled trials and studies in the European Union context;
 - Qualitative methods aimed at knowing the point of view of families and professionals in relation to issues of detection, diagnosis and early intervention
 - The two methods used are focus groups and surveys, which involved families and professionals

Progress:

- 1.423 screening studies have been reviewed, 15 of them met the selection criteria and were selected. Of those 15 studies, 8 have been carried out in Europe, applying five different instruments for screening. Of the 15 studies, half of them report outcomes such as specificity and sensitivity, which offer a better understanding about how well the screening and early detection device is performing
- 2.808 early intervention studies have been reviewed, and so far we have selected 72 studies analyzing comprehensive programs, and 228 studies examining programs focused on specific difficulties.
- There have been 20 focus groups dedicated to analyzing early detection and diagnosis, in which participated 155 people (professionals and families) in 11 different European countries.
- There have been 9 focus groups on early intervention in which 71 people participated (professionals and families) in 9 different European countries.
- Two surveys on screening, diagnosis and early intervention are being developed, which will be launched in the next three months. A survey is aimed at families and other is for professionals.

Initial findings

- *Literature search:*
 - The M-CHAT/M-CHAT-R and the SACS are used in the studies that report more results and screening procedures (explained with transparency), making these the most recommended screening tests.
 - Another fact is that, none of the studies follow up the full sample of negative cases or a true random sample, this fact makes difficult to have an accurate measure of the proportion of false negative cases in a population sample
 - Lastly, most of the screening studies have been conducted from a research background and not from a daily clinical experience, what complicate the generalization of results in public health systems

- *Focus Groups:*
 - The focus groups highlighted deficiencies in services early detection and diagnosis, either for lack of human and material resources as well as lack of time.
 - Other recurring limitations were
 - The differences between areas of the same countries,
 - The difficulty of detecting the first symptoms.
 - Professionals emphasize the importance and need for training
 - Families considered a major problem the delay in the initiation of treatment, and treatment limitations associated with low intensity and the short time that professionals can devote to children with ASD during the early development phase.

Key learning:

- *For the screening programs:*

1. To build a better coordination between research and clinical practice
2. To develop good strategies to better detect false negatives cases

We propose the following strategies:

- Implementing systematic processes
- Collecting the necessary data
- Adjusting screening processes to the clinical environment
- Involving the screening within the health system protocols.

The final objective has to be make the ASD screening, be a part of the public health system, as a public concern and not just a research issue.

- To improve the strategies for detecting false negatives cases, through actions such as:

- Coordinating with other early intervention services, with the objective of finding missing cases
- Increasing the age range of follow-up for the screening programs, in order to detect later presentation of symptomatology

- *For early detection:*

- Professionals ask for improvements in the procedures and more training
- Families ask for greater Involvement of professionals and the need of cover geographical locations distant from urban areas

What could be done differently?

- *Having worked more together with partners in developing the strategy for achieving greater involvement during project implementation*
- Have had more resources for developing working materials in the different languages of the partners. This would improve the involvement and tasks would be made more quickly.

Next steps:

- Finalize on-line surveys and distribute to sites for translation into local languages. Nov 2016
- Launch of surveys. Dec 2016
- Monitor survey responses. Jan 2017
- Analysis of survey responses. Mar 2017
- Final report preparation. May 2017

The final recommendations will be presented to the European commission and the national decision-makers during the final workshop (Oct 2017).

Link to slides: