

Workpackage progress update for ASDEU website – July 2017

WP2: Early detection, diagnosis and evidence-based intervention in Europe

Author: Ricardo Canal-Bedia

Update on activities:

In this workpackage we are working to achieve our main objective, which is none other than to provide relevant scientific information that helps families, professionals and policy makers to learn about good practice on how to design programs for early detection, diagnosis, and early intervention with children with ASD. We continue to work on the systematic review of published experiences on these aspects, selecting the critical elements that will serve to provide a set of useful criteria that will go into a guidance document on early screening, diagnosis and intervention to assure best outcomes, including the possible identification of parameters, risk factors and biological markers.

In this effort we also want to take into account the views of families of young children with ASD living in Europe and the opinions and experiences of European professionals working with children with ASD. To know the point of view of families and professionals we have launched a qualitative study based on focus groups and a European survey.

With regard to the study with focus groups, the general objective has been to obtain information on concerns, interests, and ideas on best practices that families and professionals may have regarding early detection and intervention around ASD. A total of 226 participants took part in this activity, distributed in 29 focus groups: 20 focused on the topics of early detection and diagnosis, and 10 on the early intervention. In total, 10 countries have participated in the study.

In relation to the European survey, currently we have open a [survey about early intervention, diagnosis and intervention](#), in which more than 2,077 people have already participated (parents and professionals) and on which we will give an account in an upcoming newsletter. We encourage all families and professionals in Europe to respond to this important survey.

These two studies aim to collect information to help develop viable proposals in the European context on methods for early detection, diagnosis and early intervention. For this purpose we consider that it is important to collect information and discuss those experiences that the people involved (families of young children with autism and professionals working in this field) have had in relation to these aspects. We need to know which the most satisfactory experiences are, and what aspects should be taken into account to improve the procedures for early detection, diagnosis and treatment.

Finally, we are working on a program of training modules on early diagnosis and intervention, which will be aimed at policy makers, therapists, and healthcare providers who care for children under the autism spectrum. These training modules will also be intended for professionals and paraprofessionals working in early detection and intervention in Europe, as it will provide them the necessary knowledge and tools to help them make conscientious, evidence-based decisions about efficient ways of implementing screening and intervention programs. Furthermore, these programs will provide professionals and carers alike with ASD-specific, cost-effective detection and intervention strategies. The training will provide frameworks and application, from theory to practice, giving participants the opportunity to

explore their practice and how they need to tailor their support to meet the needs of children and adults with autism.

Key learning from activities:

What worked well

- An important network of collaboration between groups of researchers working in the different countries of the project, focusing on improving the quality of life of people with autism, is being stabilized and strengthened.
- Up to now, more than a thousand European families have contacted this WP2 to contribute their experiences and opinions on the early detection, diagnosis and early treatment of children with ASD.
- Progress is being made in the development of a European initiative on early autism that did not exist until now, which promotes a greater awareness of the needs and challenges that European society must face in the immediate future in relation to this important issue.
- There is increasing awareness of the importance of families, professionals and policy makers supporting the development of systematic and coordinated experiences of autism care at an early age

What could be done differently

- Greater emphasis should be placed on finding studies in Europe focusing on basic research on new risk markers at very young ages.
- Qualitative studies (focus groups and surveys) should have sought greater involvement of politicians responsible for legislative development for the improvement of services for individuals with developmental disabilities.
- Greater involvement of parents' and professionals' organizations should be sought in the development of initiatives because children they care for will be the main recipients of the results of this project.

Findings and outcomes to-date:

At this point, results have been achieved that emphasize the importance of early detection to improve prognosis, as well as the need for efforts in this field to promote new experiences of early detection within the protocols of the health system of each country. Such experiences must be coordinated with other early intervention services and should strive to broaden the age range of follow-up the screening program.

In relation to early intervention, we are analyzing the effectiveness of the various early intervention Comprehensive Treatment Models, as well as studies on treatments focused on specific difficulties (in communication, imitation, play, etc.) of children with Autism Spectrum Disorder. Our preliminary thoughts are that scientific literature indicates that *Comprehensive Treatment Models*, such as ESDM, TEACCH, LEAP, PACT, have positive outcomes on ASD severity, behavioral and social problems among young children with Autism. Also some treatments *Focused* on specific difficulties, all of them with a strong base in applied behavioral analysis, obtain very satisfactory results. Both in the Comprehensive Treatment Models and in the Focused ones, high intensity interventions, intervention duration, and parent involvement seem to play an important role in intervention positive outcomes. In most studies, however, there is a lack of data reporting children's characteristics, ASD symptomatology and intervention costs.

From the focus groups study the main results are that early intervention programs should be accessible to the entire population by facilitating access to families with fewer economic resources and those residing in geographically remote areas; institutions should support the development of training programs for professionals and specialists in diagnosis and early intervention; and collaboration and information to families is a key aspect both for detection and diagnosis and for the development of effective early treatments

Next steps:

Before the summer we will send the first draft of the training modules to partners for comment and will formulate proposals that will form the basis of the document on which we will work in the last months of this year.

In the next two months we will finalize the data extraction from the different systematic reviews currently underway and we will prepare the corresponding report.

After the summer we will analyse the data obtained through the surveys, and we will present the report on these findings at the conference scheduled for the end of the study in early 2018.

By the end of the year we will complete the first draft of the documents: a) Current best practices on early detection and intervention in EU Member States; b) Guidance document on early screening, diagnosis and intervention to assure best outcomes; and (c) Training modules on early diagnosis and intervention.