ASDEU: Guidance report on early screening, diagnosis and intervention to assure best outcomes, including the possible identification of parameters and risk factors and biological factors.

Background

There is no doubt that the prevalence of ASD has steadily increased over the past 30 years (US Preventative Services Task Force, 2015). Regardless of the possible causes for such increase, one of the consequences acknowledged internationally is that healthcare systems will have to be structured and organised accordingly to address the needs of the growing population of children diagnosed with ASD. Therefore, there is an imperative necessity to know and reflect on current screening, diagnosis and treatment strategies as a way to find effective solutions to guarantee that children with ASD, and their families, receive the required attention in order to achieve optimal treatment results. One of the main sources of parental stress reported by parents of children with ASD is the lack of adequate professional support (Siu et al., 2016).

Methodology

The guidelines proposed in this document are based on the results obtained by the studies carried out under ASDEU's Work Package 2 (a summary of this report is also available), which is documented below:

- Systematic review of studies on autism early detection programmes in the European context
- Systematic review of biomarkers (an objectively measured characteristic) and non-social markers for the early detection of autism
- Systematic review of studies on early intervention programmes for young children with autism grouped into two lines of research: a) studies on comprehensive intervention programmes; b) studies on intervention programmes focused on specific difficulties
- Study of focus groups with families and professionals on current advances and limitations in the early detection, diagnosis and intervention programmes for autism in the European context
- Survey study aimed at families and professionals about their experiences and points of view regarding the early detection and intervention of autism in Europe.

Findings

Guidelines for improving early detection procedures for ASD

1. In order to develop new screening tools for the early detection of ASD, a prior conceptual analysis of the characteristics of early communication development and social interaction must be made. A thorough review in the scientific literature about the warning signs commonly identified as early indicators of ASD for a given age group is also needed.
2. In the case of using tools previously validated in other studies to implement ASD screening programmes, it is preferable to choose those tools that have demonstrated better

psychometric (a test designed for psychological measurement) and efficacy (the ability to desired result) values.

3. It is recommended to monitor the screening programmes with the intention of being able to confirm the greatest possible number of detected cases and to prevent the increase of false positives and false negative cases.

4. It is recommended to develop protocols and best practice clinical guidelines, based on empirical research, to promote the use of reliable detection and diagnostic tools, to guide training programmes for professionals, to inspire collaboration between health and education sectors, and to promote comparable activities between regions and countries.

5. Before implementing a system of early detection in a specific area, it is recommended to study the context and the target population in order to analyse the problems that stem from implementing an early detection programme for ASD. Whilst estimating the reach and effect of the programme.

6. It is recommended to provide specialised training for all professionals involved in the implementation of early identification and diagnosis procedures. It is also important to offer families training as they are often the first to express concerns regarding their child's development.

Guidelines for improving diagnostic procedures for ASD

1. Professionals should follow evaluation protocols that have been accepted and recommended by the scientific community as the "*gold standard* for diagnostic confirmation".

2. It is best professional practice to involve the family in making decisions and monitoring the diagnostic process. It is also essential to provide them with information and guidance as these actions improve the performance and results of the process.

3. A multidisciplinary team for diagnostic evaluation and good coordination between the different agencies/institutions responsible for carrying out the detection and diagnosis guarantees more reliable and satisfactory results.

Guidelines for improving early intervention procedures for ASD

1. Professionals should use intervention evidence-based programmes that have been identified as successful programmes for children with ASD**.**

2. Families must actively participate in the intervention process.

3. Early intervention programmes should commence as soon as possible. It is recommended to start the programme immediately a problem has been detected in the child's development and specifically design the programme to meet the child's needs in the presence of a formal ASD diagnosis.

4. It is recommended to adapt early intervention programmes to meet the personal characteristics of each child with ASD. The number and length of intervention sessions needs to be proportional and designed to meet the needs of each child, increasing the number and duration of sessions whenever possible and appropriate.

5. Collaboration between the education, public and private health systems together with research teams is recommended to ensure constant improvement and development in early intervention practices and the professionals involved, as well as in personal training networks.

6. The public system must guarantee high quality and universal early intervention for all children with ASD. It is imperative that low-income families need to be guaranteed equal access to available assistance and resources for their child with ASD. It is essential that equitable services are available in all geographical areas not just in big cities as is often the case currently.