

Autism Spectrum Disorders in the European Union – ASDEU. Summary of Final Report WP2. Current Best Practices on Early Detection and Intervention in EU Member States taking into account Gender Difference

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Objectives of the Research

- 1) To review Autism Spectrum Disorder (ASD) early detection and intervention work in EU Member States
- 2) To take into account good practice.
- 3) To take into account gender differences.
- 4) To take into account the demands of professionals in this area.
- 5) To take into account the needs children with ASD and their families.
- 6) To “present a global vision of best practices at the international level, and therefore, results from other continents are reported”.

See **Appendix 1** for more information regarding the objectives of this research. For details regarding the utilised methodology see **Appendix 2**.

Key Findings

The key findings are presented in the sections of: Literature Review, Survey Questionnaire and Focus Groups.

Three literature reviews and one meta-analysis were conducted. These were broken down into the following main areas

1) Review of current best practices on early detection in the EU Member States.

Six main studies published in English 1992–2015 on ASD Screening at early years (aged 14-36 months) within the general population. In the studies chosen there was a big difference in prevalence rates. For example, a study in the Netherlands (2006) found 5.6 per 10,000. However data from a 2010 study in Belgium estimated the cases of ASD to be 60.22 per 10,000. This fits in the same estimation as the UK based study (2000) which found 57.9 cases per 10,000. This difference in prevalence could be down to a high drop-out rate, a low participation rate or no procedures in place to check for accurate classification or for double negatives. The authors of the literature search are critical of the studies that are used in terms of the lack of socioeconomic information of their participants. It was felt that such data could have offered important information in terms of the participants’ ability to access and engage with services.

2) Review of current best practices on identification of parameters and biomarkers for diagnosis and early detection of ASD in the EU Member States.

5388 studies were identified in this area but after processing, including removing duplicates, reading the title/abstract and then fully reading 486 documents a **total of 133 were chosen** for this section. It was suggested by 32 of the studies included that the overall size of the brain was bigger as well as some other structural differences among people with ASD. Immune function deficiencies were demonstrated in 26 studies. Other findings were only supported by a limited number of studies.

3) Review on current best practices on identification of non-social behavioural signs for diagnosis and early detection of ASD in the EU Member States.

The initial search identified 4267 studies. Of these 3333 were excluded at title/abstract level 43 studies read as full text and 29 studies were then included in the study. Attention and visual processing differences were highlighted in 14 studies: this suggested “Attention disengagement problems at 12 months are predictive of an ASD diagnosis at 24 months or 36 months”. There is a suggestion that “atypical play at 6, 9, and 18 months could be a factor”. However, the authors of this literature search stress that more research is needed in this area before firm conclusions can be drawn.

4) Review on current best practices in ASD early intervention in the EU Member States.

A total of 2695 studies were identified in the preliminary search, after the selection process a total of 67 studies were left. Focused and comprehensive intervention practices that have shown greater efficacy in-group design studies are the ones aimed at the development of social and communicative skills with a behavioural methodology applying naturalistic techniques based on knowledge of early childhood development. On the other hand, single case studies provide evidence of efficacy in procedures with a behavioural component such as ABA or PRT. Studies with both group and single case design have demonstrated that active parental participation in the intervention increases treatment effectiveness. Increasing the hours of intervention or the number of sessions can produce benefits in the effects of the intervention.

Focus Groups: 226 participants from 10 countries formed 29 focus groups. 20 groups focussed on early detection and diagnosis, whilst the other 9 concentrated on early intervention. The participants consisted of parents of children with ASD, as well as professionals (paediatricians, caregivers, nurses and early intervention specialists with direct contact with children under 6 years old). The groups are categorised geographically into: Northern Europe, Western Europe, Southern Europe and Eastern Europe.

Participants throughout the four regional areas largely believed that early detection is more common now because professionals and parents generally have greater knowledge and understanding of ASD. The groups also stated that there was more ASD training required among education and “social” professionals. There was also great emphasis regarding regional inequality in terms of resource allocation and access to specialised professionals. “Professional” members of the focus groups spent time discussing “detection and diagnostic procedures”, whilst “family” group members spent a greater amount of time on issues such as “limitations and perceived changes”. Different countries had different lead organisations responsible for detection and diagnosis i.e. health or education. It was felt that in some areas where both “Health” and “Social” organisations were involved that there could be a delay in detection: connected to this group members fed-back that there is a need to “foster coordination amongst professionals from different institutions”. In Eastern Europe the problem of “geographical dispersion” was highlighted as a major issue: at times forcing families to travel away from home in order to access diagnosis and early intervention support. In some rural areas there is also still some “shame” associated with visiting a child psychiatrist.

Surveys: There were separate surveys for families and for professionals. However, they both included the sub-headings of: Background, Detection, Diagnosis and Early Intervention. The survey “will serve to develop criteria to improve the support given to children with ASD”. There was a total of 2032 participants from 24 countries. The two groups have a similar average age (50.8 / 45.8 years) and are mainly females (85.4% / 92.3%). The family group accounted for 64% of responders; of which 95.3% consisted of parents. The 786 individuals in the professional survey consisted of: 37% who work in mental health services such as psychologists and psychiatrists. This is followed by 30% of professionals from health services such as paediatricians and nurses.

The family group was requested to score a list of questions from “1” meaning “nothing” to a high of “6” meaning “a lot”. In only two areas of this section was a score above 4 obtained. These were in the areas of:

- i. *“Were you informed about your child’s evaluation results?”*
- ii. *“Did they take time to speak to you about your child’s problems?”*

Both these areas score slightly over 4, with females scoring a little higher than males on both occasions. The lowest score given by males and females was to the question: *“Were you given the opportunity to make decisions about the usage of different assessments?”* Females scored this at approximately 2.8 and males 3.2 approx.

The survey found that the average age, by families, for detecting ASD behaviours in their children was 25.8 months. However 43.2% of professionals responded that detection occurred between 24-36 months. Interestingly a very similar figure of family members 42.6% believed there were signs of ASD behaviours between 0-18 months. This inconsistency continued within the area of diagnostics e.g. 39.3% of professionals believed that there were delays of between 3-6 months. Whilst 68.8% of caregivers perceived that the delay was over 6 months.

Other Observations

The methodology utilised for this research can be found in **appendix 2**. The authors of this study seem very hopeful regarding the potential effects that it could have on people with ASD, their families and professionals. This attitude gives the research a positive feel to it rather than the usual “dryness” that surrounds many academic studies. The full document is also broken down into many different sections so that accessing a few pages of a specific interest area is a simple task. Having the triple approach to this research i.e. literature search, focus groups and survey has generated a formidable amount of data, not only collected, but also carefully considered in terms of thousands of research projects gathered to enable such an extensive review of the literature in this area.

There is a useful section on guidelines for improving early detection (p.101); early diagnosis (p.110) and early intervention (p.115).

Selected conclusions:

- i) **Early detection and diagnosis:**
 - Most studies reviewed consented that universal ASD screening aided the identification of children with an ASD at an earlier age.
 - Lack of evidence regarding the benefits of early care-treatment as this would call for Randomized Control Trials which would be an ethical minefield as would need some children not to receive intervention.
 - Half of all participants (professionals and parents) claimed a delay of 6-months plus, particularly when needing a diagnosis.

- Most professionals use the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview Revised (ADI-R) for ASD symptoms; the most widely used intelligence scale is the Wechsler Preschool & Primary Scale of Intelligence (WPPSI) and Vineland Adaptive Behaviour Scale (VABS)
- The later a child is diagnosed and detected the more negatively the process is experienced by the family- therefore it is necessary that all children are seen expeditiously.

ii) Early intervention:

- The effectiveness of interventions are increased measurably with parental involvement.
- The more hours of intervention the more positive the results. However, there is not the data currently available to suggest the optimal number of hours.
- Families need appropriate support and information from the outset as it is imperative that they are best positioned to offer lifelong support to the child.
- Approximately 50% of parents and professionals experienced a delay for treatment between 1-3 months.

All conclusions can be found p.75-p.81 of the study.

Appendices

Appendix 1

“With the purpose of reporting the best practices in screening and early intervention in the EU Member States, and taking into account gender as well as the demands of professionals and families of children with autism spectrum disorders (ASD), different studies were carried out. However, it was also intended to present a global vision of the best practices at the international level, and therefore, results from other continents are reported”.

Appendix 2

METHODS

Three systematic literature reviews and meta-analyses were conducted. One of them corresponding to the tools and procedures for detecting cases of children with ASD, while the other two corresponding to early intervention services, one for comprehensive treatment models and the other focused intervention practices. In addition, qualitative research has been carried out, such as focus groups and interviews with stakeholders and administrative leaders in the field of health, social and education services to collect data in countries where there are ASD screening programmes and in countries where there are none. Knowing the opinions of the families and professionals from the EU Member States who work with children with ASD is essential for reporting current best practices. With this objective, a survey was conducted where participants could evaluate detection, diagnosis and early intervention services. Furthermore, having knowledge of the services that families are receiving through the different professionals will allow us to compare this information to the data retrieved from the systematic literature reviews/meta-analyses and focus group interviews regarding effective interventions. In addition, the evaluation of services by the different participants directly involved in the process of detection, diagnosis and intervention of children with ASD will reveal what are the needs and interests demanded by these good practices for the improvement of existing services.

Appendix 3

Tasks for early detection and diagnosis

1. To collect information on the age of identification and diagnosis of ASD cases in the Member States, the proportion of both boys and girls in each age group, the demographics of families, as well as their ethnicity will be taken into account to examine whether there are inequalities for access to diagnostic services and early intervention programs.
2. To compare the current organisation of detection, surveillance mechanisms, and diagnostic methods in the pilot areas. The comparison will include the procedures for detecting ASD in the pilot areas.
3. Information on national guidelines, rules, laws and documentary resources for early detection of developmental disorders and ASD will be collected.
4. Information about the families' and professionals' point of view on existing detection procedures and/or developmental surveillance, and diagnostic practices will be collected.
5. In those countries where a specific ASD screening program/study is currently underway, data for a detailed description of the procedure will be collected.