

Work package title: WP1: Prevalence and related social and economic costs

Presentation title: ASD Prevalence Study in Portugal

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Update on activities:

- Região Centro was selected to develop the prevalence study in Portugal for the following reasons: 1) Região Centro includes 31.3% of mainland Portugal and 23.7% of its population; the total number of 7-9 years children attending regular schools in Região Centro in 2014/2015) was 81.921; 2) The Pediatric Hospital in Coimbra is the reference pediatric hospital in Região Centro, will have the clinical registers of a large percentage of ASD children and has strong ties with hospitals and schools/special education teams in região centro; 4) There are no special education schools in Região Centro; integration in regular schools with special education support is the norm, and there is a network of educational support services available for children with special education needs, that includes “Units of structured education for support and inclusion of students with ASD” or Units of structured education for support and inclusion of students with multideficiencies or congenital blindness/deafness”. ASD children were attending 111 public schools with these units.
- The screening procedure, including the Teacher Nominated Form (TNF), was piloted in a number of regular schools known to have children with ASD as well as children with other neurodevelopmental problems; for this the TNF was translated, and, after piloting, adapted to fit specificities in Portugal. Overall 17 public schools and 2 private schools were piloted. Initial contact was by mail or email, followed by phone calls; TNFs were returned by email. All public schools participated, but the 2 private schools did not respond. After the first 7 schools were piloted, the TNF had to be adapted for correct understanding and autonomous filling by teachers. Overall, all children with ASD were correctly identified, with 3 characteristics most frequently signaled by teachers; children with other neurodevelopmental problems were also nominated, but 1 characteristic was most frequently signaled by teachers (the forced question). The most frequent characteristics for ASD children were “Cumbersome social interaction” and “Lack of flexibility – routine adherence”.

Key learning:

What worked well

The pilot study was fundamental to improve the school contact and procedure, and to adapt the TNF. Ministry of Education provided detailed files with demographic data and school information and locations.

What could be done differently

Private schools are likely to need more effort in terms of phone calls and visits to participate, although personal contacts were also needed for public schools to correctly follow the procedure and teachers to fill out the TNF. This needs to be taken into account. The TNF collection system also needs improvement, possibly more contacts by phone, as it took a long time. The “forced question” was removed from the TNF, as it lead to many false positives. The time needed to obtain authorizations from Ethical Committees, the National Data Protection Agency and the Ministry of Education was completely misjudged, as it took a year, and needs to be taken in account when planning the study.

Next steps:

Oct 2016 - First school contact

Nov 2016 - Second school contact

Nov 2016 - Response collection and organization
Jan 2017 - Checking clinical registries
Feb 2017 - Contact families
Apr 2017 - Child assessment
Jun 2017 - Data analysis