

## **ASDEU – mid-programme news**

### **Prevalence and related cost**

#### **Update on activities:**

The studies considering prevalence fall into two types: those identifying children on the autism spectrum aged 7 to 9 in schools; and those using existing registries of children in the same age range with an autism diagnosis.

#### **School-based studies**

These studies are taking place across 23 areas in eight different countries: Spain (2); Italy (4); Poland (4); Portugal (7); Austria (2); Bulgaria (1); Romania (1, whole country); Ireland (2).

Each country has different educational and health structures and different approaches to working with autistic children. Some have no special educational needs schools, with all children in mainstream education with a variety of models of support. Others have a high proportion of children with an autism diagnosis in specialist schools.

Within these varied structures and systems, all the studies are aiming to work in geographical areas that will elicit good results – in terms of schools' and other professionals' involvement – and which are demographically representative in terms of, for instance, the proportion of children in rural or urban schools and the populations' economic profile.

The method used in the studies is to engage the co-operation of schools and parents in each study area. Children who may be on the autism spectrum are then identified through a combination of nominations from teachers followed by a confirmation from parents of the nominated cases using the social communication questionnaire (SCQ -in two specific areas, information come directly from parents through the SCQ-).

These initial nominations will be validated by specialist teams using standard diagnostic tools, ADOS and ADI-R, as well as an IQ test, among other tools. And, in the Irish studies, there is a further validation exercise to compare parents' and teachers' assessments of the children and check the teacher nomination strategy.

#### **Population-based studies**

The ASDEU programme is also assessing prevalence in two areas in France and nationwide in Iceland, Denmark and Finland, using population registries which include data on children with an autism diagnosis.

These studies are also looking at children aged 7 to 9, and have identified a shared cohort of 8 year olds, born in 2007 and followed through in 2015.

#### **Related social and economic costs**

The research looking at costs will take place across the countries involved in ASDEU and questionnaires have been developed and are being translated to assess the health and social cost of autism. We hope autistic people, their families will participate. You will be able to find out more about these surveys in the next issue of the ASDEU newsletter, due out in January.

#### **Progress and learning:**

Although the findings about prevalence will emerge in the second half of the programme, the school-based studies have already screened over 13,000 children and 2,035 have been nominated as potentially on the autism spectrum, with some preliminary results from Bulgaria, Romania and Italy.

To get to this point, the programme has ensured that the different national registries are learning from each other's practice. For the school-based studies, the researchers have engaged with national and regional government, health and education systems, with schools and individual teachers and parents – all of which is raising awareness of autism spectrum disorder.

The programme is already establishing its legacy, with new autism diagnosis expert teams established in Bulgaria, Poland and Austria. Also, alongside a wide range of information about the programme, the teacher nomination and social communication tools have been translated into eight languages.

**Next steps:**

The first of the questionnaires to establish costs will be launched this month or early in 2017 to start gathering data. (Note: as the cost estimation is affected by variables linked to the health system in each country, the initial survey will only be appropriate for the UK.)

The population-based studies will start generating their results in the coming months, when school-based studies will be completing screening and evaluating and validating their initial screening results.

**[You can find out more about progress from the different prevalence studies on the ASDEU website here.](#)**