

**Work package title:** WP1: Prevalence of ASDs and related social and economic costs

**Presentation title:** **WP1 Progress – Iceland:** Update from studies based on registries or other health info systems

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### **Update on activities:**

#### ***Historical note and changes in the service system***

The first child to be diagnosed with autism in Iceland is thought to have been a 4-year-old boy and this was 1968. From 1970 to 1996, the Dept. of Child and Adolescent Psychiatry (**DCAP**), University Hospital was the only institution providing diagnostic services for autism. The first prevalence study was published 1977, based on the clinical registry of the DCAP. Since 1997, the State Diagnostic and Counselling Centre (**SDCC**) has had the main responsibility of diagnosing autism in children. Previous prevalence studies were based on the records of these two tertiary institutions (Magnússon & Saemundsen, 2001; Saemundsen et al. 2013). However, more children with suspected ASD are now getting diagnostic services outside the tertiary level.

#### ***Development of a new protocol for monitoring prevalence of ASD***

In addition to the SDCC and DCAP we have identified three sources of data, which were all willing to cooperate. Variables were selected on the basis of availability, their descriptive value regarding the service system, quality of diagnostic procedures, and their potential to reflect changes in diagnostic practises over time

#### ***Initial findings***

All cases from the SDCC and the DCAP (“business as usual”) have been collected. Interdisciplinary teams diagnosed ASD in 98% of the cases. The ADOS was used in 96% and the ADI-R was used in 30% of the cases. Of the children diagnosed with ASD at Time 1, 22% were reassessed at Time 2.

### **Key learning:**

#### ***What worked well***

- ASDEU was a platform for the development of a new protocol for monitoring prevalence of ASD in Iceland.
- Considerable time was spent in identifying key stake-holders and informing all parties concerned of the importance of this kind of research.
- The new protocol may become the first step in the design of a central registry for ASD in Iceland.

#### ***What could be done differently***

- We will have to re-examine our list of variables.
- More info is needed on reassessments that lead to a confirmation of ASD diagnosis or not. In the same vein, we need more info on children who did not receive ASD diagnosis at Time 1, but were diagnosed with ASD at Time 2.
- It would strengthen our methodology, if we would screen for ASD in high risk groups (e.g. children receiving special education).

### **Next steps:**

We are in the process of receiving data from two of the three new sources on ASD diagnostics (case finding). Since their databases are developed for different reasons, we have to negotiate for some additional work on their behalf in order to be able to check the validity of the ASD diagnoses. This work is facilitated by the fact that all sources use the same Personal Identification Number System. We estimate that we will have gathered all data by the end of October 2016, and then we would be able to start writing up a paper on the prevalence of ASD in Icelandic 7-9 year-old children based on the year 2015.