

The Hope Project

European Autism Information System

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Project Activities

Work Package Activities and results for the period and plans for the next period

Work Package 1: Coordination of the Project

The first coordination meeting and launch of the European Autism Information System (EAIS) was held on 12 January 2006 at the European Parliament Offices in Dublin. All the Associated Partners and several Collaborating Partners attended; 27 participants in all. The project plans were discussed and a programme of coordination and scientific meetings was agreed. There was media coverage of the launch and articles were published in the Irish national newspapers the following day. A leaflet was produced introducing the project.

The Associated Partners presented their work packages and gave an overview of the work to be carried out. General management and financial procedures to be followed during the course of the project were agreed and detailed minutes were taken of all the proceedings.

Day-to day communication with partners has been maintained by e-mail, post and telephone. This includes sending project details and guidelines on reporting to the partners.

The project leader has met with Partners on several occasions in person, including a coordination visit to Verona with ULSS20 and to France with RHEOP, a collaborating partner. In April, a scientific meeting was held in Verona, which included the participation of experts invited from CDC Atlanta. For these meetings, specific permission was granted by DG-SANCO. These will be further described in other Work Package reports but it also represented an opportunity for coordination with partners.

As a result of the participation of the main partner in the International Autism Epidemiology Network meeting and the International Meeting for Autism Research, both held in Montreal, May 31 – June 3, important contacts were made with different organisations, including Autism Speaks, which has been identified as a potential co-financing partner. Two letters of intention have been accepted for additional funding

for the EAIS pilot studies. Full proposals for these are due in March 07.

The services of a website designed were contracted and the EAIS website is now available at www.eais.eu and partners will be able to use this facility for direct communication in the near future.

The website (deliverable no.3) was expected to be ready in Month 2, but due to the delay in signing the Grant Agreement, this was postponed until the Agreement had been signed.

Work Package 2: Dissemination of the Results

The activities are very much linked to the other packages in the sense that the objective of this work package is to disseminate information about the project and its results which shall be in the form of reports and guidelines. Therefore, as the drafting of these reports and guidelines is ongoing, the main activities foreseen are in the preparatory phase.

In the meantime, activities have focused on disseminating information on the project in general.

To date the following activities have been carried out:

- Research on relevant scientific journals where an article on the project could be published. (See annex 1)
- Research on websites dealing with autism which can be added as links on the EAIS website (See annex 1)
- Research into important scientific events relevant to the subject of autism where a presentation on the project could be made. In this context, an important event has been identified that will take place in Dublin September 2007, namely the Washington Group meeting. In June 2001, the United Nations Statistical Division (UNSD) organised a seminar on the use of the ICF for statistical purposes, in particular, in population surveys. At this meeting, there was an EU coordinated contribution of experts, researchers and statisticians participating in the ESS. The seminar recommended establishing a city group on disability statistics, under the aegis of the Statistical Commission of the UN. The main purpose of the city group was to agree on reference instruments for measuring disability in censuses and population based surveys. The first city group meeting was held in Washington on 18-20 February 2002 and is therefore called the Washington Group (WG). Since then the WG has met 6 times and a 7th meeting will be held on in Dublin on 19-21 of September 2007. Given that one of the objectives of the EAIS projects is to develop mechanisms for obtaining systematic, reliable and consistent data for ASD in Europe, it would be useful to have a slot to present the project on this occasion. ULSS20 Verona is currently looking into this possibility.

In addition to its contractual obligations, discussions are ongoing concerning the preparation of (1) an information/training film (2) an itinerate photo exhibition (3) a project brochure. The project leader is in agreement that Ulss20 Verona should take

responsibility for the preparation of these items with some reshuffling of project funds, subject to approval from the EC. Ulss20 Verona is consulting different companies to obtain quotes for these activities and will submit a draft budget to the Project Leader for approval.

Regarding the film, preparation will begin immediately (subject to confirmation of availability of funds) and it is estimated that it would be ready by December 2007. The film will last approximately 20 minutes and will document the most common early signs of autism (5/6 signs).

Work Package 3: Evaluation of the Project

Evaluation of the project has so far been carried out through coordination meetings and communication with the partners. This Interim Report constitutes the first evaluation report and Associated Partners were asked to contribute to this report according to guidelines sent by the lead partner.

The process of project implementation to date has been focused on establishing the necessary bases for the pilot studies; therefore no data has been generated as yet. When this process is

Work Package 4: Development of a European Network

The development of a European Network for autism is a key component of this project. The name of the network is the European Autism Alliance (EAA) and technical staff, a legal advisor and an expert in autism networking, have been contracted to work on this package with the lead partner. A list of institutions and organisations concerned with autism in Europe has been compiled and will be shown on the web site www.eais.eu. EAA statutes have been drafted; these will be finalised in January.

The launch of the EAA is expected to be in October 2007, instead of November 2006; the reason for the delay in this deliverable is that there were insufficient funds to contract the necessary staff for this work package due to the delayed signing of the grant agreement. It is hoped that during the launch of the EAA, a formal presentation of the EAIS pilot study areas will be made, as it will coincide with the beginning of the pilot studies phase (see Work Packages 6, 7 and 8).

Part of the strategy to achieve sustainability of the EAA after the current project ends, is the formation of a lobbying group of MEPs with a special interest in autism, to promote political support for the EAA and to encourage member states to enrol government bodies in the Alliance. We are also actively campaigning for the adoption of autism as a health priority for the Czech Republic Presidency in 2009.

At the scientific group coordination meeting in Verona in April, the partners agreed a list of eminent scientists in the field of autism as potential members of the Scientific Advisory Panel. Some of the experts suggested have informally agreed to participate in the group and a formal meeting will be arranged for May or June 2007.

Work Package 5: Improvement of Personnel Expertise

For this work package, University College Cork is forming a distance-learning platform. Initial activities include research into existing distance-learning services for autism and contact with the other partners to establish the base for the content of this work package.

Functional guidelines for case definition of autism to be used for the EAIS are being developed following on from discussions at the panel of experts meeting on Autistic Spectrum Disorders, Luxembourg, 28-29 September 06 (hosted by DG-SANCO) where the definition to be used was agreed to be the DSMIV. The functional guidelines are aimed at facilitating information management by data generating institutions, in order to establish a database of autism cases. The case definition guidelines will be the first step in a series of guidelines to be developed in this work package.

Work Package 6: European Population Based Surveillance System for ASD

Aarhus University, the lead partner for this work package, has collected information on existing autism surveillance systems, in conjunction with Instituto Carlos III, the lead partner in Work Package 7, through a questionnaire (Annex 2) which was distributed in August 2006. More information on this is given in the next sub-section on Work Package 7.

Currently this partner is working on the protocol for the pilot study of an ASD surveillance system, which will be submitted early in 2007.

Work Package 7: Characteristics of ASD in Europe

We have developed a WP7 short plan of activities, specifically on designing an ASD prevalence study for Europe. This short plan was presented at the First Coordination Meeting held in Dublin.

We have developed a particular strategy consisting of preparing and distributing a questionnaire among partners for collecting the necessary information for the prevalence study. This strategy was presented to the rest of partners at the Scientific Group Meeting held in Verona.

We designed a questionnaire entitled "***European Autism Information System (EAIS) Project: Design of a Prevalence study. Questionnaire on health care, educational and social facilities and patients' organizations for Autism Spectrum Disorders (ASD)***" (Annex 2). This questionnaire was focused on collecting health, social, educational and parents' associations information for making a viability study of a prevalence pilot study.

We collected the information from the questionnaires that have been sent to us. Then, we taped the information on an ad hoc database and made the first analysis of the results.

We reported preliminary results obtained from questionnaires at the Panel of experts on Autistic Spectrum Disorders meeting held in Luxembourg. At the same time, we presented our results on the population screening programme that we are carrying out in Spain as well as some details of different possibilities of the ASD prevalence study for Europe. Among all participants, agreement was reached on discussing the future prevalence study design with the Scientific Advisory Panel.

We also encouraged all participants in that meeting to collaborate in the prevalence study. After the meeting three more questionnaires were received from different partners. They were saved and analyzed.

Finally, a letter of intent has been sent to Autism Speaks attempting to get more funding for developing the prevalence study in Europe. As a result of having identified other organisations from countries not initially associated to the EAIS project, we have secured their interest in participating in this pilot study. Autism Speaks has approved this letter of intent and we now need to send them a full proposal by March 2007.

Other EAIS researchers have sent another letter of intention to Autism Speaks expanding our initial objectives. Our team has participated in these new proposals sending ideas and suggestions to the project leader.

There have been no particular delays in the development of deliverables in this work package. However, we have introduced two changes:

- a) to discuss the prevalence study design with the Scientific Advisory Panel
- b) To seek more funding to facilitate wider participation in this prevalence study

To finish the prevalence study design

To present this design to the expert panel (Feb, 2007)

To make a prevalence pilot study

To collaborate with other partners in developing the following tasks:

- a) An ASD surveillance systems
- b) Methods for ASD costs
- c) Selecting early diagnosing tools

Under Work package 7, King's College, London is also an Associated partner. Their activities for the period are described below.

The main objective for this reporting period was to finalise the study design to estimate the financial burden of ASD at the European level.

Feedback has been received from partners on their willingness to be part of the prevalence study and by extension the cost of illness study. We are aware that some datasets exist in some partner countries which may be able to provide demographic data and data on service use by children and adults (and possibly their families), and thereby allow estimation of costs and other economic impacts. Possible datasets

identified include the Iserre register in France and the Danish national register. A questionnaire looking at health care, educational and social facilities and patients' organisations for Autism Spectrum Disorders (ASD) designed by colleagues at the Instituto de Salud Carlos III, Madrid, Spain will give an indication of the existence and accessibility of data across the various countries. We are also drafting an economic analysis plan, which will address the issues associated with conducting a cost-of-illness study at the European level. The finalisation of the study design for the financial burden of ASD is contingent on the datasets which exist across countries.

The main activities for King's College London over the next period would be:

- Implementation of Pilot study

The pilot study would seek to estimate the financial burden of ASD across countries that have indicated their willingness to assist with the pilot and have datasets (either national or local) which can be used to extract demographic information and data on health, education and social support services for children, adults and their families. It is likely that access to a range of datasets which focus on health, education and social support for children with ASD may need to be accessed. In this regard, foreseeable activities include:

- Confirmation of and preliminary discussion with pilot sites
- Location of datasets which exist across Europe (from lead and associate partners) which can be used to collect data for the economic study
- Negotiation of access to these datasets
- Finalise the study design for the estimation of the financial burden of ASD at the European level

Collect data on services and support for children and adults with ASD and their families (where available).

Work Package 8: Harmonised Early Detection Tool

The objective of this Work Package is to draw up guidelines for early diagnosis on the basis of a comprehensive analysis of existing tools and methodologies.

To date, the following activities have been carried out:

- Analysis of existing tools for early diagnosis (ADOS, ADI-R, CHAT, M-CHAT, CHAT23, CARS, DSMIV, ICD10)
- Study of the literature that analyses the early signs that focus on the diagnosis of autism (see Annex 3)
- Comparison of the most studied signs in bibliography with the signs in the major diagnostic tools, to find if they were present
- Research in clinical charts of autism centre of the most reported early signs from the parents (50 charts of children under the age of 6))

Following the implementation of the activities mentioned above, the following adjustments were made to the study:

- Instead of comparing the signs identified in literature with the signs in the clinical chart, it was decided that it would be more useful to research in the clinical chart all the early signs reported by the parents. The reason for this modification is due to the fact that with the first approach, not all the signs reported by the parents were identified in literature.

- After the meeting in Luxembourg, it was decided to study ADI-R and ADOS instead of DSM IV and ICD 10, because of their specificity to early detection.

Work Package 9: Increased Public Awareness

Work has been carried out by the lead partner in this work package in the following areas in the Czech Republic; The following report indicates work carried out in the Czech Republic with a view to expanding these activities, together with ULSS20, another Associated Partner, for the production of a short film and potentially for translation and inclusion on the website. The lead partner has sent copies of the materials described below to the main partner, for evaluation at the next coordination meeting.

Leaflet concerning basic information on autism – was distributed to medical doctor (with help of Czech Psychiatric Society J.E. Purkyně and Coalition for Health), to schools and educational institutions, to home for adults and was sent to all MPs and ministers.

DVD information set (four pieces)

- 1: Information about early diagnosis-distributed to specialists in medical science
- 2: Information about schools and educational approach-distributed to schools
- 3: Structured teaching with visual support- distributed to educational institutions
- 4: AUTISTIK-information about NGO. Focus on parents' role in education children with autism. Information about legislation issues etc.

Brochures

Tomas Josis : Behind the Aspergers syndrome gate. (Written by man with Aspergers Syndrome)

Charter of Rights for Persons with Autism – Czech translation with explanation of all topics.

Books

Autism and Play
Autistic thinking

In January, lobbying activity is planned, sending a letter to all members of the Czech Parliament, Ministers and relevant institutions, explaining the problems faced by people with autism and informing about the EAIS project (leaflet). We will appeal for support to get autism as the priority during the the Czech Presidency. In March, there is a meeting planned with the State Secretary for the Czech Presidency.

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