We-S-441a

Resources centers for autism: What for? (Commitments and activities)

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The twenty-six resources centers set up to support children and adults with autism and their families are pursuing the same objectives. But each one, according to regional context, has chosen its own organizational structure and appropriate action strategies. From Toulouse CRA’s example I would like to analyse the clinical and ethical implications of our choices.

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We-S-441b

Research on autism in France: An overview

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Autism and developmental disorders constitute a specific field in child psychiatry research, the priorities being early detection and early interventions. An overview of the scientific activity developed in France, as well as the cartography of the partnership between research teams and regional resource centers, will be presented. These collaborations should support translational studies in main domains: identification of bioclinical markers in the first years of life, development of bioclinical databases, identification of genetic and epigenetic factors, longitudinal long lifespan studies, evaluation of intervention programs and identification of new therapeutic molecular targets.

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ELENA project or how to know more about outcome in autism

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Context. – Only one French cohort on Autism is currently listed in the Epigram database of Iresp (EpiTED, no 01-019). This cohort, formed in 1997, allowed the following of 152 five year-old children during 10 years in order to describe their outcome trajectories and to define models to study their prognosis factors. However, this sample is small, the recruited children had mainly a diagnosis of infantile Autism and data collection did not allow studying biological risk factors. The year 2010 marks the end of the Autism plan in which the creation of a large and pluri-themed cohort allowing follow-up for children with ASD was recommended. In this context, we propose constituting such a cohort with a multidisciplinary approach including the dimensions of health, cognitive psychology, social sciences, new technologies and biology.

Objectives.–

– describe in the developmental and psychosocial clinical fields a population of 1200 children between 2 and 16 years of age with a first diagnostic of ASD in the regional Autism Center (CRA);

– study their evolution over 90 months looking for the determining factors;

– in parallel with the collection of clinical data build a biological data collection.

Innovative aspect.– Its multicentric base due to the participation of every CRA, as well as the Developmental Disorders Centers (CLAD) and the reference centers of mental retardation will create a dynamic of collaboration not seen before in France. The creation of a data bank open to researchers as well as the multidisciplinary and multi thematic collaborations based on a given project will build an environment favorable to translational studies and favor the emergence of an efficient mechanism of research.

Project milestones.– The project will last a total of ten years. The start up phase will cover 12 months and the recruitment of patients a maximum of 24 months followed by 90 months of prospective follow-up (including four standard evaluations every 30 months and annual questionnaires send by the post). It is assumed six months will be needed to produce the final report. Several Work Packages are planned for each milestone and each precise task. The size of the population is estimated to start at 1200 children based on the actives files of the CRA in 2009 in order to obtain a final population of 1000 at the end of the study. This number takes into account dropouts and those who refuse to participate. The recruitment will be carried out in France within the CRA in that the diagnostic means are regionalized. As this will occur during current practice, the CRA will collaborate for the clinical and biological examinations with the CLAD and the centers for mental retardation.

Governance.– The coordination of the project will be assigned to a pilot committee which will validate the rules concerning the use of the gathered data and their publication. This committee will be composed of a coordinator and a group of a dozen person (work package leaders and ANCRRA representatives), will be assisted by a technical team (2 ARC responsible for the national project, 1 data manager and 1 computer technician). A scientific committee (international experts, representatives of the ANCRRA scientific council, work package leaders and representatives of the association of families of patients) will validate the ancillary projects. To make sure the project goes smoothly in each region, a team composed of a study doctor and a TRC will be named by each CRA. This team will work in collaboration with the CLAD doctor responsible in the region concerned. The CHRU of Montpellier being the organizer, the data input, management and data analysis will be centralized there.

Coordination in the framework of existing or future partners.– The project will bring together number teams of clinicians experienced in ASD and researchers in several disciplines with a high level of expertise and tied to the international research network. In the fields of biology the prospect of partnership with industry will lead to the optimization of the technical platform and the ground breaking character of the projects.

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Validation of the instruments: SDQ parent and teacher in eight European countries

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The aims of the presentations are: first, to evaluate internal consistency in a multi-cultural situation of the SDQ parents and teachers; Second, to compare SDQ parents and teachers faced to DAWBA which is a structural instrument used worldly (Goodman et al., 2000); and third, to evaluate influences of seven languages on performance tests. Methods: About 6031 parents and 7321 teachers were recruited randomly in a large school survey in seven European countries. This sample was used to evaluate SDQ internal consistencies. Mean scores distribution, Cross-scale and Inter-rater correlations were calculated. A total of 587 parents and teachers issued from local primary care research centre (GPs or medical centres) were interviewed with the SDQ and the DAWBA in order to evaluate external consistencies. The instruments were administered during a unique session: SDQ was self-administrated and the DAWBA by experienced psychiatrists. Kappa, sensitivity/specificity/negative (NPV) and positive predictive values (PPV) and ROC curve (AUC) were calculated. Results: Cross-scale correlations were mainly better for parents than teachers; in the opposite, Reliability coefficient for SDQ scores was better for teachers than parents, and higher than found in the literature (Goodman, 2001). Externalized problems gave highest inter-rater coefficients on the average, but cultural divergences were found (East VS West part of Europe). When comparing DAWBA to the SDQ teacher/parent, SDQ was more sensitive than specific and any disorders produced an AUC of 0.74 (95% CI: 0.7–0.8), Kappa was on the average. The SDQ more accurately predicts externalized than internalized disorders (AUC 0.8 versus 0.7 and Kappa 0.6 versus 0.4, respectively). Bulgaria was the only country with lower predictability.

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