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Abstracts

1

High-Risk for Autism Infant Sibling Research: Sweden, Europe and the World

Today, many cases of autism can be reliably diagnosed by at age two to three years. Until some 10-15 years ago, it was fairly uncommon for children to get diagnosed with autism before the age of three years, especially milder variants. Even in today's clinical practice, in many cases, especially intellectually able and verbal individuals with ASD, late diagnoses frequently occur. Early autism research is an evolving field of science. Key objectives are fine mapping of neurodevelopmental trajectories and identifying biomarkers in order to improve risk assessment, diagnosis and treatment. In recent years, a growing interest in infant development and early detection of ASD has emerged, mostly driven by the insight that early identification is a prerequisite for early intervention, which itself may improve long-term outcomes for individuals with ASD. Common early signs are primarily delays and alterations in response to name and joint attention and limited or perseverative early play. Nevertheless, many of these signs are neither specific for nor universal to ASD, with low positive predictive values, and a risk for overreferral particularly in case of one stage screening.

Longitudinal studies of high-risk sibling populations provide the potential to generate unique knowledge about the development of autism during infancy and toddlerhood prior to symptom onset, and neurodevelopmental trajectories in general. In this key note, I will give an overview on the state-of-the-art in early autism identification in general and studies of high-risk populations in particular, including recent research and development at the Center of Neurodevelopmental Disorders at Karolinska Institutet in cooperation with the Uppsala Child and Babylab (e.g. using eye tracking, NIRS, standardized scales etc), the ESSEA COST Network (Enhancing the Scientific Study of Early Autism; European Cooperation in Science and Technology; www.cost-essea.com), and "Eurosibs", part of EU-AIMS (www.eu-aims.eu), the largest European autism science network ever, as well as the Baby Sib Research Consortium (BSRC) in North America.

2

Standardized cross-cultural assessment of ability and disability in ASD: The new WHO ICF-CY core sets

Background

The International Classification of Functioning, Disability and Health (ICF) by the World Health Organization (WHO) provides a comprehensive and universally accepted framework to describe health-related functioning. The ICF is based on a bio-psycho-social model, comprising over 1600 categories of functional domains, specifically body functions, body structures, activities and participation and environmental factors. In order to make the ICF more applicable in certain health conditions, so called “ICF core sets”, that is empirically derived condensed versions of the ICF with a high fit for a certain diagnosis and user friendliness for practice have been generated. Core set development is based on a rigorous scientific process including four preparatory studies, each aiming to capture specific perspective on functioning and disability in an international, cross-disciplinary setting: A systematic literature review (research perspective), an expert survey (expert perspective), qualitative study (client and caregiver perspective) and clinical cross-sectional study (clinical perspective). The findings from these studies are evaluated and further compressed by a multi-stage voting procedure during an international consensus conference, resulting in the respective core sets.

Objective

To report the results of the ICF core set consensus conference for Autism Spectrum Disorder (ASD). Preparatory studies had yielded 168 ICF candidate categories for ASD. This evidence was used as a starting point to generate a Comprehensive, a Common Brief, and three age-specific WHO ICF ASD core sets.

Methods

Twenty ASD experts, representing all six WHO-regions and various disciplines, were invited to participate in the 3-day consensus conference. The experts followed a three-stage decision-making and consensus process to decide on the ICF categories that should be included in the ICF Core Sets for ASD. In the first stage, the experts prioritized and selected ICF categories to be included in the Comprehensive ICF core set. The second stage consisted of defining the Common Brief core set for ASD. The third stage involved developing age-specific Brief core sets for ASD: ages 0 to 5 years, 6 to 16 and 16+ years.

Results

Finally, 111 categories were included in the Comprehensive ICF Core Set with 59 categories from the activities and participation component, 31 environmental

factors, 20 body functions and 1 body structure. The Common Brief ICF core set included 46 categories; 17 activities and participation categories, 15 environmental factors and 14 body functions. When defining the age-specific Brief ICF core sets, 14 categories were found to be common in all of the age groups. Thus, these 14 categories were added to the common Brief ICF core set, resulting in a set of 60 ICF categories. Together with the 60 Common Brief set categories, the Brief ICF core set for the 0 to 5 age group consisted of 73 categories, while the 6 to 16 age group had 81 categories and the adult group 79 categories.

Conclusion

When defining the ICF core sets for ASD, a large number of categories were selected across all of the ICF components, supporting the notion that ASD impacts wide ranges of functions and contextual factors in life. From these core sets, assessment tools will be derived for future usage in clinical and research setting as well as health care administration.