UNICEF Global Child Disability Assessment Initiative

BRIEF PROFILE

Dr. Stephen J. Bagnato, Ed.D., Professor of Psychology & Pediatrics at the University of Pittsburgh and the Office of Child Development (OCD) and core interdisciplinary team member at the LEND Center (www.lend.pitt.edu) has been officially invited to serve as part of an expert panel currently working on the development of a manual and package of methodological guidelines, protocols, instructions, tools and training program/materials for an in-depth classification of child disability based on existing “best practice” observational approaches in resource-poor countries. These materials are being developed by UNICEF with inputs from a selected network of international experts. Dr. Bagnato will provide specific expertise to the panel in developing the manual, guidelines, and measurement strategies for global screening and assessment in the area of children’s social-emotional and behavioral functioning.

UNICEF INITIATIVE SUMMARY:

Data collection and research in the area of childhood disability in developing countries has been inadequate to date despite the large impact that disability has on child development, family life, and socio-economic conditions of communities. This is in part due to the lack of an established best method for identifying children with disabilities in this context, as well difficulty in defining and evaluating child disability in resource-poor settings. Different methodologies have been used to collect data in different locations making comparisons across countries problematic.

As the main global advocate for children, UNICEF has a lead role in providing the world with current, high quality information on the health and well-being of children and women across the world. UNICEF is the custodian of one of the largest data collection efforts focused on statistics on children in the world: the Multiple Indicator Cluster Surveys (MICS). As a first step in addressing the need for comparable and reliable data on child disability, UNICEF implemented the Ten Questions Screen (TQ) for childhood disability through MICS since 2000. This screening tool was developed by a team of scientists with the objective of creating a low-cost and rapid method for identifying children in populations where professional resources are extremely scarce.1 By including the Ten Questions Screen, MICS has become the largest source of internationally comparable data on children with disabilities in developing countries. Since 2000, more than 50 MICS surveys have collected data on child disability.

UNICEF methodology to gather data on children with disabilities is currently undergoing a careful process of revision. The objective is to refine the existing screening tool used in the MICS surveys since 2000 and develop a methodology for an in-depth disability assessment. The overall goal is to help countries develop their own disability statistics program for gathering sound and comparable data on child disability in developing countries.

The purpose of this document of methodology is to provide information guidelines, considerations, suggestions, and a general approach for those considering collecting data on children with disabilities. The methods discussed herein
reflect a move away from a medical or diagnostic approach of assessing disability towards one that considers individual functioning as a marker of disability. Within this framework, the purpose of an assessment is to identify children and youth with functional difficulties that might be addressed and managed effectively in the absence of specific medical/diagnostic details or highly technical resources for treatment.

In particular, UNICEF is working on two majors projects for which it requires the support of an international expert:

1) UNICEF is developing a manual for the collection of data on disability in children. The purpose of this document is to provide guidance for those considering collecting data on children with disabilities. The manual discusses conceptual and theoretical issues related to measuring disability and reviews methods that have previously been used to assess disability in children, with particular attention to methods used in low-resource settings. Considerations for designing, planning, and implementing a child disability data collection effort are presented.

2) The second focus of UNICEF’s measurement work is the creation of a package of methodological guidelines, protocols, instructions, tools and a training program/materials for an in-depth assessment of child disability based on existing best practice approaches in resource-poor countries. These materials are being developed by UNICEF with inputs from a selected network of experts. The guidelines utilize the International Classification of Functioning, Disability and Health-Children and Youth version (ICF-CY) as the conceptual framework for an approach to disability where the focus is on activity limitations and barriers and support to participation. The package will include the survey instruments and interview guide, methodological guidelines, training program/materials, staff recruitment guidance, and overall logistics. The interview guide and training program for the stage screening will cover the entire procedure, including the minimum qualifications for the interviewers, the steps to undertake before, during, and after the assessment in order to ensure data quality, how to follow the required ethical codes, and how to guarantee appropriate follow-up if needed. The package will also comprise an analytical framework for the analysis of the findings, including indicators for reporting and main tables, and a strategy for validation and field testing. Recognizing that high-level specialists may be in short supply in some areas, the toolkit is designed to be administered by trained mid-level professionals, such as teachers and community workers, strengthening local capacity for the identification and assessment of children with disabilities.

Dr. Bagnato will serve as a core international panel member and will provide specific expertise in the assessment of children’s functioning in the area of social/emotional/behavioral development. Specifically, Dr. Bagnato will be asked to provide the following:

a. A comprehensive description of the domain (5-6 pages) for inclusion in the manual for the collection of data on disability in children (Chapter 4)
b. A comprehensive review of existing screening and assessment tools in the area of social/emotional/behavioral development (about 5-6 pages) for inclusion in the manual for the collection of data on disability in children (Chapter 6)
c. Suggested tools to be used as part of the methodology for the assessment of child disability
d. A short report (3-4 pages) explaining the rationale for the selected tools
e. Instructions on how to administer the tools that can be inserted directly into the procedures manual (i.e. how to explain the purpose to parents, appropriate approvals, techniques for children with obvious disabilities etc.)
f. A description of the minimum qualifications of field interviewers
g. Principles and recommendations for providing referrals for parents of children determined to have social/emotional/behavioral disabilities that are consistent with cultural and resource considerations
h. Provide a critical analysis of the final complete manual, its content, and process and present this analysis at international meetings.