Title: Family Functioning in Families of Individuals with Down Syndrome from Twelve Countries

Authors: Marcia Van Riper¹, George Knafl²

¹University of North Carolina at Chapel Hill

Introduction: There is growing evidence that many families successfully adapt to the ongoing challenges associated with raising an individual with Down syndrome. However, much of this evidence has come from studies conducted with families of individuals with DS who live in Western countries (Choi & Van Riper, 2016) and samples for these studies have typically been limited to families from a single country. Moreover, in most of these studies, adaptation was assessed at the individual level (i.e., parental well-being), rather than the family level. Therefore, the purpose of this study, guided by the Resiliency Model of Family Stress, Adjustment, and Adaptation, was to examine family functioning in families of individuals with Down syndrome from 12 countries. We also examined the relationship between select family factors (i.e., family demands, family appraisal, family resources, and family problem-solving communication) and family functioning.

Method: Over 3000 parents from more than 50 countries have completed all or part of a survey of self-report questionnaires for our study concerning adaptation and resilience in families of individuals with Down syndrome. For this presentation, we will focus on findings from parents in our 12 main countries (Argentina, Brazil, Ireland, Israel, Italy, Japan, Korea, Portugal, Spain, Thailand, United Kingdom, and USA). Only data from the 1,665 parents with no missing variables for the key variables were used in our analyses. Linear Mixed Models were used accounting for intra-familial correlation and constant variance for parents from the same family.

Results: Mean family functioning scores ranged from 43.9 for the US to 56 for Thailand (with lower scores indicating better family functioning). All the countries except for Thailand had mean scores in the average range for family functioning; a mean score of 56 falls in the increasing problems range. Each predictor had a significant (p<0.001) effect on family functioning in the expected direction. An adaptive modeling process was used to reduce the model with all 10 predictors holding the covariates (gender, parent status, country) and the intercept fixed in the model. Family functioning was significantly better with greater Family Management Ability, greater Mutuality when Partnered, greater Family Hardiness, and more Affirmative Communication and significantly worse with greater Family Strains and more Incendiary Communication.

Discussion: While the experience of raising an individual with Down syndrome includes ongoing challenges, many families adapt well and some thrive. It is critical that health care providers provide accurate information concerning life with DS when they speak with new/expectant parents. Efforts to intervene are likely to be more effective if health care professionals recognize how culture and family factors influence family functioning. More research is needed to understand how social determinants of health, such as culture, societal attitudes towards DS and national approaches to integrating Non-Invasive Prenatal Testing into clinical practice, influence family functioning in families of individuals with Down syndrome.

References: