# Editorial

## Introduction to Special Section on the National Fragile X Survey

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In recent decades, research on intellectual disabilities has increasingly been focused on specific syndromes or etiologies, particularly those of a genetic nature, and away from a focus on IQ-defined groups (Hodapp & Dykens, 1994). Indeed, in much of the research published in the pages of this *Journal* during my tenure as editor, researchers have focused on genetic conditions, such as Down, fragile X, Williams, and Prader-Willi syndromes. This shift in focus has yielded important benefits to the field and clearly documents that different genetic conditions are associated with distinct profiles of behavioral and neurocognitive neurology strengths and weaknesses, different developmental trajectories, and varying constellations of comorbid features and conditions (Dykens, Hodapp, & Finucane, 2000). Most important, research on the behavioral phenotypes associated with these and other genetic conditions has facilitated important discoveries about underlying neuropathological mechanisms and, thereby, potential pharmacological treatment targets (e.g., Hagerman, River, & Hagerman, 2008).

Nevertheless, progress on many of these genetic conditions has been slowed by their relatively low rates of occurrence in the general population, which makes the recruitment of large and diverse samples difficult and costly. Consequently, most behavioral studies of genetic conditions involve small samples of participants recruited from clinics or the community. Limited statistical power and limited or unknown generalizability of findings are, thus, perennial problems in this area of research.

Fragile X syndrome is illustrative of this problem. Despite being the leading inherited cause of intellectual disability, this syndrome is still relatively infrequent, with a prevalence estimated to be as low 1 in 4,000 males and 1 in 6,000 to 8,000 in females (Crawford, Acuna, & Sherman, 2001). Not surprisingly, most behavioral studies of individuals with fragile X syndrome have involved intensely studied and richly characterized, but small, samples of participants. Sample sizes are almost always less than 100 participants and, often, considerably less.

In the following special section, Bailey and colleagues present an alternative approach to studying fragile X syndrome that makes the study of large samples of participants feasible. In particular, they report on the results of a survey of more than 1,200 parents whose families are affected by fragile X syndrome and its associated disorders. Survey methods are not without their limitations, many of which Bailey, Raspa, and Olmstead thoughtfully present in their opening paper to the special section. It is also clear from the papers comprising the special section, however, that a well-conceptualized and implemented survey can (a) provide converging evidence for the findings of more intensive, small sample, behavioral studies and (b) address questions that simply are beyond the scope of most behavioral studies.

After reading some of the early papers to emerge from the Bailey et al. parent survey (e.g., Bailey, Raspa, Olmstead, & Holiday, 2008; Bailey, Raspa, Bishop, & Holiday, 2009; Bailey, Raspa, Bishop, & Olmstead, 2009), I became convinced not only of the importance of the data for understanding fragile X syndrome and its associated disorders, but of the value of the method for addressing questions about other genetic conditions of interest to the readers of the *Journal*. Thus, I discussed with Bailey and his colleagues the idea of submitting several papers about the survey as a special section of the *Journal*. The authors of the four papers in the special section were eventually invited to submit their papers. Each paper underwent peer review and had to stand on its own merits, although it was made clear to the reviewers that each paper was part of a set being considered for this special section.–L. A.



 

## References

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