**THe parent advisor model for research including Parents of Children with Autism**

**Jenna B. Jones, Marcia N. Gragg, & Brianne E. Drouillard**

**University of Windsor**

**Objectives:** A large body of researchhas explored the experiences of parents of children with autism. Participatory Action Research models suggest including representatives from the population being studied in the process of research. The Parent Advisor Model is an innovative approach to research that is consistent with a Participatory Action Research model. In the Parent Advisor Model, parents of young children with autism collaborate with researchers studying this population. Parent Advisors act as representatives to ensure that research being conducted is accessible, relevant, and meaningful to other parents of children with autism. The goals of the present study were to describe the Parent Advisor Model and to gather qualitative information about the experiences of both Parent Advisors and researchers using this model.

**Method:**  A semi-structured interview was conducted with questions assessing the purpose, benefits, and drawbacks of using the Parent Advisor Model. Participants included six mothers of children with autism who have participated as Parent Advisors and six researchers (five psychology doctoral students and one psychology PhD) who routinely collaborate with parents of children with autism in their research. Interview responses were transcribed verbatim and then analyzed using Braun and Clarke’s Thematic Analysis.

**Results:** Initial results described a broad range of tasks that Parent Advisors have participated in, such as designing studies, reviewing materials, recruiting participants, interpreting results, and disseminating findings. As one parent stated, the function of parent advisors is to “give a voice to the other parents and… provide the researchers and professionals with a parent’s point of view.” Parents described benefits such as the opportunity to voice their opinions, develop relationships with researchers, and to learn more about autism and the research process. Researchers described benefits such as gaining a better understanding of parents’ perspectives, enhancing the relevance of research, and improving the quality of research. Benefits to consumers of research, such as improved accessibility, were also described. Parents and researchers identified only minor drawbacks such as the additional time commitment. Advice from both parents and researchers for other researchers planning to use the Parent Advisor Model is also presented. Additional analyses are ongoing.

**Conclusion:** The Parent Advisor Model in autism research allows parents’ voices to be heard, enhances the external validity of research, and improves the overall quality of the methodology and conclusions drawn from studies. Benefits of using this model are presented for the Parent Advisors, researchers, and consumers of research. The results of this study can inform other researchers about how to involve Parent Advisors in future research and to forge positive connections between researchers and parents of children with autism. A limitation is the small sample size, which was addressed through additional data collection.

**Correspondence:**

Jenna Jones, M. A.

Department of Psychology

University of Windsor

401 Sunset Ave.

Windsor, ON, N9B 3P4

jonesjb@uwindsor.ca