

Title –Autism Researched and Autism Lived: A Shifting Paradigm

Program of Study – Psychology

Presentation Type – Poster

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Category – Theoretical Proposal

Abstract: Many researchers devote their lives to studying autism with the hopes of making contributions to the scientific community and to the people most affected by autism. However, scientists may have a very different perspective of the disorder than do people who live and experience it on a daily basis. Autistic self-advocates often sum up this disconnect in the phrase “Nothing about us, without us,” representing the long history of autism researchers failing to include the voices of those who actually have the disorder. For this reason, it is important to address the disconnect between those who research autism and those who live it by first establishing how autism has traditionally been understood within dominant research on the subject. To address this question, a review of the literature was conducted on various topics in autism, especially language and communication, to better understand the assumptions that underlie current research. It was found that much of the research focuses on cures and interventions to reduce autistic behaviors, or on the stressful impact of autism on families. However, a new wave of research is growing out of the autistic self-advocacy movement. More and more researchers are choosing to consider the perspectives of autistic people and to find ways to support them without “curing” them. It is suggested that this change in focus reflects a shift in the underlying paradigm; namely, the belief that the differences displayed by people with autism are not necessarily deficits needing to be fixed. Autism research will hopefully continue

to be conducted in this manner, ensuring that the voices of those being studied are heard and respected. Some families may have internalized the traditional perspective of the experts telling them how to view and treat their autistic children, but others resist the pessimistic view of autism. Over the next year, this researcher intends to gather data from semi-structured interviews to learn more from parents' perspectives of autism and how they learn to communicate with their nonspeaking children.