*"Having my research published through ProQuest allows others to cite my work in their research and opens the door to other studies that will make future changes."* 

 Sandy Weber, thesis author of Remarkable Moments: Communicating Trust in the Relationship Between the Child with Autism

**PROQUEST DISSERTATIONS & THESES** SUCCESS STORY

# Advancing Autism Research by Amplifying Research

How one researcher's decision to disseminate her thesis with ProQuest created new opportunities for people with autism.

Sandy Weber's thesis, *Remarkable Moments: Communicating Trust in the Relationship Between the Child with Autism*, demonstrated autism is caused in part by both physiological and emotional factors. The insights, observations and conclusions resulting from her research continue to have a profound impact on the understanding of autism around the world.

Weber's unique research journey was inspired by personal experience and motivated by the desire to share her discoveries for the benefit of advancing autism research, as well as to improve the lives of individuals with autism.

In an interview, Weber discussed the process that lead to the research and writing of her thesis, as well as why it's important to make her research more widely available to other researchers through ProQuest Dissertations & Theses.



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#### Sandra L. Weber

#### San Diego State University

Master of Arts, Interdisciplinary Studies, 2011

- Title: Remarkable Moments: Communicating Trust in the Relationship between the Child with Autism and the Parent/Caregiver
- **Dedicated to:** Erik N. Weber, J.D., Sandra Weber's accomplished autistic son.



#### A personal connection to autism research

"I am now the parent of an autistic adult," Weber told us. "I was told he would NEVER be more than 18 months old cognitively and when he was 5 that I should put him in an institution to live out his life. I did not do that."

Instead, she took matters into her own hands because no programs were available for autistic children at the time, Weber explained, "My son Erik did not talk until he was 7 years old" she said, but "I worked with him."

"He has been a research subject for University of California San Diego and Caltech since age 14 and has been a keynote speaker for many events in three states on 'living with autism' since 2008," she continued. "Today he specializes in Special Education as a California Bar attorney. By age 28 he had earned a BA, an MA, and a JD!"

Through research, experience and lots of trial and error, Weber not only discovered how to help her son exceed everyone's expectations, she also formed the foundation of her thesis, which has advanced autism research around the globe.

#### The decision to write – and disseminate

As Weber embarked on her work in autism, she was encouraged by her co-workers and other researchers to write a book, but she decided to take the scholarly approach. She believed this path would enable her work to be more effectively disseminated to people working with autistic children.

This approach also enabled her to more easily access and reference the work of other researchers she discovered using ProQuest Dissertations & Theses.

In addition to revealing the physiological and emotional factors that cause autism, Weber's thesis highlights the importance of trust between people with autism and their caregivers. For example, she explored why one therapist might be perceived as trustworthy and another might not be.

Weber found the hormone oxytocin plays a major role in developing a positive relationship – a discovery that became apparent in working with her son. Oxytocin is typically released through affection and social bonding, resulting in a sense of trust and well-being. However, Weber said Erik was at first "tactically defensive" meaning he resisted physical contact.

But by gradually helping him become more comfortable with hugging and other affectionate touches, Erik became able to benefit from the release of oxytocin in this system, and consequently learn how to become better in touch with his emotions.

### The impact of dissemination: changing lives

Weber's academic journey was less motivated by achieving her Master's qualification than to open doors to insights and information about autism that had not been previously explored or disseminated. She wanted the work to help practitioners in the field and enable them to continue with their work by using her dissertation to make the case for funding to conduct additional research.

She said, "I knew I had to make progress with the research studies Erik had been in, brain mapping and all the other procedures, in order to achieve more for other children down the road."

"The alternative is to put these children in group homes," she continued. "Two-thirds of such facilities are understaffed, with poorly trained personnel. Physical abuse is widely suspected. In addition, group homes are underfunded and periodic inspection by licensing agencies usually only takes place every 3 to 5 years."

"Many autistic individuals who manage to complete secondary education are sitting at home without meaningful employment or community interface programs that motivate ongoing learning/training to provide life skills and other educational opportunities to help them integrate more meaningfully into society," she added. Her son, Erik Weber, was recently featured in the A&E Documentary, *The Employables* on this very topic.

She knew a better life and better opportunities awaited people with autism, and she could help them get there by making her research more widely available.

"The greatest thing we can do is to help disabled individuals develop a more neurotypical mindset in order to survive," she concluded. "My goal is to open that door."

Today, Sandy frequently guest lectures at San Diego State University and has worked with and supported the careers of many students who have decided to pursue graduate work in occupational therapy, physical therapy, special education. child life coaching in hospitals, preschool teaching, social work, and pediatrics. These students have often told their professors that the biggest impact on their lives has been the things they learned about child relationship formation from working alongside Erik and Sandy Weber and referencing the background research documented in the respective ProQuest-published thesis. They easily reference the information for themselves and add it to their own research papers, evolving and improving the lives of autistic children and adults. "That was my goal at the outset! Little by little, my son and I have effected meaningful change in the Special Education professional mindset."

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