

Presidential Address, 2019—Family-Based Practices to Promote Well-Being: A Personal Journey of Knowledge Translation

Laura Lee McIntyre, President, 2019–2020

I remember those Thanksgiving dinners growing up. We all sat around the dinner table, enjoying the conversation and company of our family. It was a special time for me. For my cousin though, it was terrible. Everything that was special about holidays was difficult for her. The conversation, the unfamiliar environment, the unusual food, the demands placed on her social communication skills. Holidays were not for her. My cousin, Cindy [pseudonym], could often be found sitting alone, away from others. Sometimes though she would have excruciating meltdowns. I knew it was hard for my aunt and uncle. We all felt helpless and didn't quite know what to do.

I first became interested in developmental disabilities even before I knew exactly what they were. I learned that autism spectrum disorder (ASD) is a neurodevelopmental disorder affecting 1 in 59 people, at least those are our current rates based on the Centers for Disease Control and Prevention (Baio et al., 2018). ASD affects social-communication skills and behavior, and symptoms occur on a spectrum. Some people with autism have average to above average intelligence, while others have intellectual disability. Many people with ASD will require comprehensive supports at home, school, and community settings. The cause of autism is unknown, although genes are implicated. A diagnosis of ASD is made based on behavioral observations and testing and, as of yet, we do not have a blood test or karyotype that confirms diagnosis. We may find in the future that what is being called autism is likely a variety of things with several underlying causes.

The social communication deficits can be challenging, but often what is more devastating and debilitating are the challenging behaviors that often accompany the disorder. People with autism can experience rigid and repetitive behaviors and intense meltdowns, aggression, tantrums, and sometimes self-injury. In comparison to typically developing counterparts, people with autism and other developmental disabilities are three or more

times more likely to develop a severe behavior disorder or significant mental health impairment (e.g., Emerson, 2003).

According to a study by Baker and colleagues (Baker et al., 2003), by the age of 3 years old, children with developmental delay in contrast to their typically developing counterparts, are already experiencing elevated behavior problems as measured by the Child Behavior Checklist (Achenbach, 2000). Comprehensive services at home and school are often required to support children's development and inclusion with their peers.

I saw this firsthand. My aunt and uncle did everything they could for their daughter, including sending her to a special school for children with developmental disabilities across the country. The cost of her high school education was close to that of a 4-year university. My aunt and uncle struggled with the emotional ups and downs of raising a daughter with intellectual disability, including accessing services, and helping to support their daughter as she dealt with a myriad of mental health and academic difficulties. My aunt and uncle were educated and had resources. Even still, they struggled. I often wondered what families did when they did not have the privileges that my family had.

Growing up with a family member with a disability taught me incredible compassion and a desire to work in the field of intellectual and developmental disabilities. After college I went to graduate school thinking that I would be a special education teacher. Once in grad school though, I got bit by the research bug. I knew I wanted to make an impact as a scientist. This love of research led me to my current path—that of a research scientist at the Prevention Science Institute and Professor of Special Education and Clinical Sciences in the College of Education at the University of Oregon. As a graduate student, I first joined AAIDD, where I have been a member for over 20 years.

My research has been heavily influenced by my past, hence the “personal journey of knowledge translation” in the title of this address. I had a desire to work with families who were raising children with intellectual and developmental disabilities and promote positive outcomes for parents and their children. Early on, and right out of my PhD studies, I set out to develop family-centered interventions to help parents develop skills and strategies for parenting their young children with autism and other developmental disabilities.

Back when I started this intervention work, there were very few programs developed for parents to help them learn strategies for managing challenging behavior in their children with disabilities. Anyone who has kids knows how difficult a tantrum can be, but when your child has constant behavior problems, or little things seem to set him off, it can be even trickier. The program I ultimately ended up evaluating was based on Carolyn Webster-Stratton’s Incredible Years Parent Training program. Webster-Stratton, a clinical psychologist up at the University of Washington, designed a program for use with parents who had typically developing children with behavior problems. Rather than re-inventing the wheel, I sought to develop a set of modifications to this intervention that would target the specific needs of parents with children with disabilities, at high risk for emotional and behavioral problems. These modifications are published (McIntyre, 2008a, 2008b) and have served as the basis for much of my current work.

When I first started this work as a brand new assistant professor at Syracuse University, I had no collaborators. It was just me and a handful of PhD students in my lab. These students learned first-hand how to write research grants, partner with community agencies, deliver interventions, and test their efficacy. These PhD students—Leah Phaneuf, Nicole Quintero, Florence DiGennaro Reed, and Leah Wildenger—have all gone on to have wonderful careers of their own and work in hospital, clinic, or academic settings. Much of what we learned initially about how to deliver interventions to families with young children with IDD, we learned together through trial and error and through listening to our family and community stakeholders who were generous with their time and gave us feedback about our work.

The intervention we adapted and delivered to parents was provided in 12 weekly sessions (see McIntyre, 2008b). We used a group format,

bringing together 8–12 parents into a community space, like a church or a preschool. Topics focused on fostering positive parent-child interactions and focused on teaching through play, using behavioral strategies such as praise and rewards to encourage positive child behavior, and using limit setting and other strategies to discourage negative behavior. We taught parents enrolled in the sessions to think about their child’s challenging behavior as a form of communication and to understand the communicative intent of the behavior before developing a plan for addressing the behavior.

Data were collected from families in their homes through structured interviews, child assessments, and videotaped observations of parents and children interacting together. A small randomized controlled trial design was used to test the hypothesis that the Incredible Years Parent Training intervention with modifications for people with developmental disabilities (IYPT-DD; McIntyre, 2008a) was more efficacious than a usual care control condition on reducing child problem behavior and improving parent-child interactions. Families in the experimental group ($n = 24$) received usual care plus the 12-week IYPT-DD. Families in the control group ($n = 25$) received usual care, including early childhood education and related services. Forty-four participants completed the study ($n = 21$ experimental; $n = 23$ control). Results suggested that the parent training intervention, IYPT-DD, was superior to usual care for young children with or at risk for DD in terms of reducing observed negative parent-child interactions (see McIntyre, 2008a). What was so exciting to me about these early findings is that the videotaped observations of parent-child interactions were coded by trained research assistants naïve to the study goals and blind to treatment condition. In other words, the research assistants did not know who was a treatment family versus who was a control family. It is a more objective test of change as a function of treatment than a parent self-report or clinician reflection.

Although our intervention focused on parenting and changing the ways in which parents interact with their children with developmental disabilities, I was ultimately interested in reducing children’s challenging behavior. The hypothesis is that the changes in the child would come as a function of changes in the parenting environment and the micro interactions that parents and children have together. There were similar reduc-

tions in child challenging behavior in the experimental intervention group in comparison to the control group (see McIntyre, 2008b).

On all counts this randomized controlled trial was a success and resulted in new grant applications and new funding opportunities. Often we start small and demonstrate real “wins” in terms of improving lives of children and families, before scaling up. Think PBS before Prime Time!

On a personal note, the finding that I struggled with was the the lack of intervention effects on parenting stress and mental health. We improved parent-child interactions and improved children’s behavior, but we just could not touch stress. This finding left me scratching my head and looking for different ways to intervene.

I am currently working with a colleague, Dr. Cameron Neece at Loma Linda University, who is an expert in mindfulness-based stress reduction for parents of children with developmental disabilities. We are investigating the extent to which directly targeting stress first will lead to better parenting intervention outcomes on child behavioral health. Cameron Neece’s work shows that that following a mindfulness-based stress reduction intervention, parents of children with intellectual and developmental disabilities reduced their stress and depression (Neece, 2014). In order for our work to have maximal impact and directly improve lives, it pays to collaborate and continue to refine our family-based interventions to promote well-being. In this newly funded NIH 5-year longitudinal study, we are working across two sites to recruit a larger and more diverse sample of participants. Our sites are in the Inland Empire region of Southern California and the greater Portland metro area in Oregon. We are delivering interventions in both Spanish and English and are working to optimize family engagement in our interventions through a series of motivational “boosts” designed to correspond to intervention content. Speaking of intervention content, every family enrolled in the study receives 16 weeks of free intervention designed to improve child behavioral outcomes and reduce parenting stress. Stay tuned for the results of our PRO-Parenting study. I am excited to be working with Cameron Neece on this new collaboration.

As I mentioned previously, collaboration is key for us to continue to move the field forward. Over the years that I have been working on developing, adapting, implementing, and evaluating family-based interventions, I was struck by

another realization. This won’t surprise you who are tech savvy, but for me, it was somewhat of a revelation. We live in a world full of technology and more and more of us use technology for things that used to require face-to-face contact. If you don’t believe me, think about the last time you actually went inside a bank or wrote a check. This was months or maybe even years ago for me. Now think of the last time you made an online purchase. For me, this was yesterday, when I realized I needed to make a quick purchase and Amazon was the easiest option. My point is that many of us use technology in our everyday life, yet until recently, I was stuck in the rut of traditional face-to-face delivery of interventions for families. That has recently changed when my colleagues Ann Glang, Shari Wade, Ilka Riddle, and I received a grant from the National Institute of Disability, Independent Living, and Rehabilitation Research to develop, test, and scale up a web-based family-centered intervention for parents of young children with intellectual and developmental disabilities. Our new project “TOTS” (Tiered Online Training and Supports) is building a scalable intervention that provides web-based, highly engaging content to families, based on the interventions we have been delivering for years in-person. The intervention is tiered so that those who need additional resources and supports can receive support from a live coach and/or be referred for more specialized and targeted interventions. We are partnering with two University Centers of Excellence in Developmental Disabilities (UCEDDs)—one in Portland at Oregon Health and Science University and one in Cincinnati at University of Cincinnati and the Cincinnati Children’s Hospital. In the final stage of this research, we are hoping to disseminate our web-based interventions more broadly and work with multiple UCEDDs nationwide. This type of scaling up and knowledge translation is critical so that our evidence-based practices make it into the hands of those who may benefit from this work.

This year’s conference theme is all about knowledge translation and leveraging this knowledge to improve practice, policy, and research. In an ideal world, research, practice, and policy would be inextricably linked. Unfortunately, however, we do not often use research to make a difference in practice, nor do we always consider practice when designing research studies. Similarly, policy does not always consider the lessons we have learned in

research and practice contexts. In AAIDD we are in a unique situation to have a dialogue about how best to move the field forward because we have attendees who work in all of these areas. As an organization, we value the input, critical feedback, and guidance from people with disabilities and their families. Today I challenge you to engage with someone outside your bubble and identify at least one way to include the perspective of someone else in your work. We have students, researchers, self-advocates, family members, practitioners, providers, and policy makers here at the conference. Share your work and tell your story. We are all here for a reason. What's your "why"? For me it's easy. My "why" is Cindy. My family is a driving factor in my work. As a field we must find ways to work together across disciplinary boundaries. It is through collaboration and thoughtful conversations that we can continue to make a difference as a community. Thank you for being here. Thank you for engaging. Thank you for making a difference.

References

- Achenbach, T. M. (2000). *Manual for the Child Behavior Checklist 1½–5*. Burlington, VT: University of Vermont, Department of Psychiatry.
- Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., . . . Dowling, N. F. (2018). Prevalence of autism spectrum disorder among children aged 8 Years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *MMWR Surveillance Summaries*, 67(6), 1–23.
- Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Preschool children with and without developmental delay: Behavior problems and parenting stress over time. *Journal of Intellectual Disability Research*, 47(4/5), 217–230.
- Emerson, E. (2003). Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *Journal of Intellectual Disability Research*, 47(1), 51–58.
- McIntyre, L. L. (2008a). Adapting Webster-Stratton's Incredible Years Parent Training for children with developmental delay: Findings from a treatment group only study. *Journal of Intellectual Disability Research*, 52, 1176–1192.
- McIntyre, L. L. (2008b). Parent training in young children with developmental disabilities: A randomized controlled trial. *American Journal on Mental Retardation*, 113, 356–368.
- Neece, C. L. (2014). Mindfulness-Based Stress Reduction for parents of young children with developmental delays: Implications for parental mental health and child behavior problems. *Journal of Applied Research in Intellectual Disabilities*, 27(2), 174–186.
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- Correspondence concerning this article should be addressed to Laura Lee McIntyre, PhD, BCBA-D, Director, Prevention Science Institute, Professor and Department Head, Special Education and Clinical Sciences, 5208 University of Oregon, Eugene, OR 97403-5208