New Study Puts Parents at Center of Helping Toddlers with Autism

by Sally James

At the heart of helping young children with autism is helping their parents. If parents can understand a new diagnosis and begin to feel empowered to help their own child, a better outcome for that youngster is likely to occur. This kernel is at the center of new research underway by Annette Estes, Ph.D., research associate professor of speech and hearing sciences and a research affiliate at the Center on Human Development and Disability. Estes is also affiliated with the UW Autism Center. The new study builds on several related projects and will try to refine and enhance the way parents are taught to give their own child help, using an evidence-based approach called the Early Start Denver Model (ESDM).

“We already know that the ESDM works when the intervention is provided by trained practitioners at 20 hours a week,” Estes said during an interview. But it is not clear whether the ESDM or other approaches can be used by parents, in their daily activities with children at home, to improve outcomes for very young children. The new study called Parents and Toddler at Home, or PATH, addresses this issue. Funded by Autism Speaks, the PATH study will enroll 24 families in Washington and another 24 families who will go to the MIND Institute at the University of California at Davis. The principal investigators there are Sally Rogers and Laurie Vismara. Results will be combined across the two sites for the final research reports.

Every family who enrolls in the study will receive training in providing ESDM for their newly diagnosed child between 12 and 30 months of age. The ESDM is a developmental, relationship-based intervention that fuses approaches validated by the science of child development and the science of applied behavior analysis. As noted, this model has already been shown to be effective when provided to children at 20 hours a week by trained therapists. However, this study is designed to foster parent use of the ESDM and incorporate a child-centered, responsive interaction style that embeds many teaching opportunities into play. Some of the families will be taught using experimental teaching methods aimed
at making sure parents understand and deliver the intervention consistently and regularly.

Recent randomized clinical trials of parent-implemented intervention, using ESDM and using other approaches, have not shown as much impact on child development as researchers expected. Estes believes that part of the problem may lie in traditional teaching methods used to help parents learn to deliver early autism intervention. It may be especially important to reach parents who may feel ambivalent, who are struggling to learn new skills, or who need help implementing intervention into daily routines at home.

“We went to the literature to study how adults learn best,” Estes said, and the PATH study will reflect a coaching style for teaching parents that has been shown to be effective in other areas. For example, parents will be invited to use more than one style of learning – including a book and web videos. They will also use approaches that put parent motivation and goals at the heart of the program. If the research proves that parent-provided ESDM is effective, there could be several ways to allow for more training in areas without many professionals. One method could be to deliver training to those parents through on-line videos or multimedia materials, work that has already begun with co-investigator Laurie Vismara at the MIND institute.

Besides the potential benefits of parent-delivered intervention, this approach could open up access to evidence-based early intervention to thousands of families who cannot currently find this in their community. Because many communities lack access to professionals, this research “holds the hope of helping parents who don’t have access to teams of intervention specialists,” Estes explained. As of now, most parents who want their children to benefit from early intervention, including the ESDM, have to find a professional to provide it and take their child there for sessions. For many families, there may not be a professional near their home or there may not be the time or money to seek this care.

Estes also believes that there may be a second profound impact. Specifically, parents who implement the intervention appear to experience less increase in their stress level than parents who just take a child to a professional for the intervention. This is something that Estes measured during a recently completed study, which is under review for publication. Her hypothesis is that parents can also achieve a stronger sense of competence about their own parenting if they successfully learn and practice the intervention. Increased parent confidence could improve the developmental and behavioral trajectory of their child, as those parents navigate many future challenges in the family’s path.

Who can participate?

- Children between 12-30 months (symptoms or diagnosis of autism)
- English as primary language
- Families live within 30 min. drive of Seattle UW campus
- Children can move on their own

For more info, call 1-877-408-8922 or write uwautism@uw.edu