Family-Centered Inclusive Practices Represented in Interdisciplinary Clinical Evaluation Reports of Young Children Diagnosed with ASD and other Developmental Disabilities

Cheryl M. Jorgensen, Ph.D., Project Director and Assistant Research Professor, Institute on Disability/UCED, University of New Hampshire

Cabrinni Kulish, M.S., Trainee, New Hampshire LEND Program

The Institute on Disability/UCED (IOD) at the University of New Hampshire (UNH) and the New Hampshire Leadership Education in Neurodevelopmental Disabilities program (NH-LEND) are conducting a research project designed to identify exemplars of family-centered inclusive practices in interdisciplinary clinical evaluation reports for children diagnosed with an autism spectrum disorder (ASD) or other developmental disability between the ages of 18 months and 5 years at the UNH Seacoast Child Development Clinic (SCDC). This program is a clinical component of NH-LEND in partnership with the Children's Hospital at Dartmouth and the College of Health and Human Services at UNH. Professionals and faculty from both UNH and Dartmouth Medical School staff the clinic, and NH-LEND trainees are part of the interdisciplinary team. NH-LEND trainees gain experience in providing family-centered, community-based, culturally sensitive, interdisciplinary services. They also serve in leadership and support roles on behalf of children with disabilities and their families.

Approximately 36% of the 44 children who visit the clinic annually are diagnosed with an ASD. Other diagnoses include developmental delay, cerebral palsy, anxiety, attention issues, sensory issues, to name a few. The typical evaluation involves the family, a developmental pediatrician, a speech and language pathologist, an occupational therapist, a nutritionist, a Family Coordinator, a School Liaison, and NH-LEND trainees. The evaluation process is based on concerns and questions from the family especially, as well as the school and referring professionals. As a result of the evaluation process, families and community providers can expect to:

- Receive information regarding a child's medical, developmental and educational needs, and whether or not a diagnosis is present.
- Receive recommendations for use at home, in the community, or at school to support health, development, and learning.
- Receive guidance regarding expected developmental stages and transitions.
- Learn about medical or related services that may be needed to assist with or ameliorate the identified developmental concerns.
- Learn about sources of family and community support.
- Receive information about development, community resources, and methods for addressing financial concerns or access to care.

The interdisciplinary evaluation may be the first time that families are provided with comprehensive information about their child’s learning and developmental differences. Thus the content of the report that the family receives not only has a significant influence on what the family expects from their child, but what they will advocate for from their local early intervention or school program, and medical providers.
We were interested, therefore, in the findings and recommendations that families are given when their children are evaluated by and receive a report from an interdisciplinary clinical evaluation team.

**What Constitutes a High Quality Clinical Evaluation Report**

Although there are numerous sources for evaluation teams to consult with respect to conducting evaluations for children suspected of having ASD (Committee on Educational Interventions for Children with Autism, 2001; The American Academy of Pediatrics [Johnson & Myers, 2007]); there are few guidelines for how those recommendations ought to be presented in written form to families.

Farrell described some general characteristics of family-centered and culturally competent clinical evaluation reports, although these were not specific to children with autism and related developmental disabilities:

- Language and terminology that is family-centered and accessible.
- Describing children using strengths-based rather than deficit-based language.
- Demonstrating respect for each family’s culture (e.g., ethnicity, race, religion, family constellation).
- Emphasizing optimism for the future and for the child to have a “good life” (Farrell, 2009).

In addition, the following are examples of practices that are correlated with optimal learning and other functional outcomes for children with ASD and other developmental disabilities, and we wondered how these practices might be reflected in clinical evaluation reports:

- Presume competence of all children with respect to communication and learn (Jorgensen, McSheehan, & Sonnenmeier, 2007; Kasa-Hendrickson, 2005).
- Provide access and support for children to make progress in the general education curriculum (Wehmeyer & Agran, 2006).
- Provide all children with a way to communicate about age-appropriate academic and social topics (McSheehan, Sonnenmeier, & Jorgensen, 2008).
- View all behavior as having meaning and employ positive behavior interventions and supports (Lorimer, Simpson, Myles, & Ganz, 2002).
- Provide special education and related services within the context of typical activities and environments (Soto, Muller, Hunt, & Goetz, 2001).
Honor children’s interests and passions in the development of interventions (Kluth, 2008).

**Purposes of the Study**

This study will use qualitative methods to identify exemplars of family-centered inclusive practices in a small sample of clinical evaluation reports. These exemplars might be used as part of LEND training curricula or in personnel preparation programs that prepare physicians, psychologists, educators, speech-language pathologists, occupational and physical therapists, social workers, nutritionists, early childhood educators, and other members of interdisciplinary evaluation teams.

A secondary aim of the research is to provide the NH-LEND trainee with the experience of conducting applied research, a competency within the NH-LEND program. The study has received approval from both UNH and Dartmouth-Hitchcock Medical Center review boards for the protection of human subjects.

**Methodology**

The investigation will begin with an exhaustive literature search for family-centered inclusive practices for children with ASD and related disabilities. Based on a preliminary list of these practices, we will then use an iterative analysis process on a small sample of evaluation reports that includes open coding of exemplars, identifying potential paths of inquiry, applying and comparing promising coding frames, developing selective coding, redefining concepts, recording the data, and further analysis (Jorgensen, McSheehan, & Sonnenmeier, 2007). At the conclusion of the report analyses, representative exemplars of inclusive practices will be chosen.

At the conclusion of the study, the results will be submitted for publication to a peer-reviewed journal and for presentation at the annual AUCD meeting.

**Researcher Profiles**

Cheryl M. Jorgensen, Ph.D., Project Director with the IOD and Research Assistant Professor in the UNH Education Department will be the principal investigator on this study. She has been at the IOD at UNH for 25 years and has experience in conducting qualitative research of a similar nature. She has published in several peer reviewed journals, presented at numerous professional conferences, and written or co-written 4 books.

Cabrinni Kulish, M.S., NH-LEND trainee, will be research associate. Ms. Kulish’s professional experience includes being a parent of two children with special needs, one with ASD. Ms Kulish has sixteen years experience as an advocate for children and their families. Ms Kulish is also on the committee for Independent Living /Work Group of the New Hampshire Commission for Autism Spectrum Disorders. She is a state trainer and speaker for National Alliance of Mental Illness (NAMI) New Hampshire.

The study is supported, in part, by the 2009 Omnibus Appropriations Act, administered by the U.S. Department of Education, to the Institute on Disability’s National Inclusive Education Initiative for Students with Autism and Related Disabilities; and funding from the U.S. Dept, of
Health and Human Services, Human Resources and Services Administration, Maternal and Child Health Bureau, to the NH-LEND program and the NH Seacoast Child Development Clinic.

References


