Celebrating 50 Years

of service to Colorado, the Rocky Mountain Region, and the nation

JFK Partners

SCHOOL OF MEDICINE

UNIVERSITY OF COLORADO

ANSCHEUTZ MEDICAL CAMPUS
Welcome

History of JFK
John Conger

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Welcome

I’m pleased to welcome all of you to our symposium today held in honor of the 50 years of JFK Partners as a program of the University of Colorado School of Medicine. JFK Partners has provided leadership in a number of areas over its 50 year history. In the early years William Frankenburg as Director from 1977 to 1985 defined the need for and responsibilities for Developmental Screening with his work on the Denver Developmental Screening Tool. His emphasis on the need for follow-through after screening is receiving renewed attention with the federal government interagency initiative Birth to Five: Watch Me Thrive (http://www.acf.hhs.gov/programs/ecd/child-health-development/watch-me-thrive) program. With the platform of the JFK Center then known as a University Affiliated Program, Dr. Frankenburg brought developmental screening to the forefront. JFK faculty such as Marilyn Krajicek provided leadership and development regarding early intervention services throughout the 1970s and 1980s. In the late 1980s JFK faculty obtained federal demonstration project funding to develop childcare that was inclusive of children with developmental disabilities.

The 1990s saw considerable expansion of our presence in providing early intervention services and training. Dr. ’s Flynn and Lewis received US Department of Education funds to do faculty development in early intervention for the Western United States. Funding was also obtained to start ENRICH, a transdisciplinary early intervention program. Leadership training grants were obtained from the US Department of Education and the Maternal Child Health Bureau. Interdisciplinary diagnostic services also expanded during this period.

Beginning in 2001 and continuing to the present JFK faculty member Sarah Davidson has led our efforts emphasizing Early Childhood Mental Health in collaboration with other JFK faculty and many community partners. This work began with SAMHSA system of care funding, Project BLOOM. Through this funding we began to offer annual training in DC 0-3 assessment in collaboration with the Department of Psychiatry.

For today’s symposium we have elected to focus on three current but long standing initiatives. Sally Rogers will start us off with her Keynote: Past, Present, and Future of Early Intervention: A View through the Autism Spectrum Disorder Lens. She is followed by a panel of faculty each addressing autism and a co-occurring condition.

Next we will focus on an early intervention services program ENRICH (Enrichment using Natural Resources in the Community and Home) with follow-up videos of children served in ENRICH in the early days.

The third programmatic effort we will focus on is the development of parent leadership. Following remarks from Sue Swenson, Deputy Assistant Secretary, Office of Special Education and Rehabilitative Services, a panel of four mothers who have worked with JFK in the capacity of parent leadership will share reflections on their work.

Our noontime grand Rounds speaker is The Honorable Patrick J Kennedy. Mr. Kennedy is a strong advocate regarding parity and Mental Health treatment. His remarks will focus on both the legacy of PL88-164 signed by President Kennedy in 1963, and the importance of mental health treatment for all.

We will close with remarks from Andy Imparato JD, Executive Director Association of University Centers on Disability and Sandra Friedman, MD, MPH incoming Director of the integrated JFK and Neurodevelopmental Behavioral Pediatrics program.
Over its 50 year history, JFK Partners has contributed to the training of hundreds of professionals and provided assessment and intervention services to thousands of individuals and their families. Those trained represent a number of disciplines that contribute to the diagnosis and treatment of persons with developmental disabilities and their families, not only in Denver and Colorado, but nationally and internationally. In 1964, a multidisciplinary clinic was founded within the Department of Pediatrics at the University of Colorado (CU) School of Medicine. When federal funding through PL88-164 became available to assist in building interdisciplinary clinical training and research centers in developmental disabilities, CU under the leadership of John J. Conger successfully applied, with support from Colorado’s governor and legislature, The Arc of Colorado, and the Joseph P. Kennedy, Jr. Foundation. The JFK Child Development Center and the B.F. Stolinsky Lab building at 8th and Birch, on the former campus was dedicated in 1968.

The rationale for these centers was the need for community-based, as opposed to institution-based, diagnostic treatment centers for children with intellectual and related disabilities. The training philosophy was grounded in the assumption that children and families would benefit from care delivered by professionals who received their training in an interdisciplinary clinical context. The center was organized initially under Dr. Donough O’Brien’s leadership. Dr Joseph Rossi was the first director (1965-1969), followed by John Meier, PhD (1969-1975). William Frankenburg, MD, served as Director (1975-1985) followed by Bonnie Camp MD, PhD (1985-1991).

In 1993 JFK Partners became an interdepartmental program of Pediatrics and Psychiatry. At that time, Corry Robinson, PhD, RN, was appointed as Director. Also within Pediatrics there was the Section of Developmental Behavioral Pediatrics under the direction of Randi Hagerman, MD. The two sections, JFK and Developmental Behavioral Pediatrics, began to collaborate. Their collaboration made it possible to successfully compete for a Leadership Education in Neurodevelopmental Disabilities (LEND) training grant from the Maternal Child Health Bureau.

In 2007, JFK Partners moved to the Anschutz Medical Campus, ED2 South Building, 5th floor. Clinical work however continued at The Children’s Hospital until the new hospital opened in 2008. In 2009, Sandra Friedman, MD, MPH, was appointed Section Head of Neurodevelopmental Behavioral Pediatrics, as well as Associate Director of the LEND and UCEDD core grants. For the past year, since Corry Robinson’s announcement of retirement as Director of the program, the combined faculty and staff of the two sections have been working to create unified clinical, training, research and advocacy programs. As of July 1, 2015 Sandra Friedman, MD, MPH, will become the 6th Director of JFK Partners.
In large measure the fact that the University of Colorado secured federal funding for the program is due to the efforts of John J. Conger, MD. Today’s activities are dedicated in his honor.

John J. Conger, PhD, was a gifted leader who joined the University of Colorado School of Medicine as a Professor of Clinical Psychology in 1953. He dedicated 24 years of his career serving in varying capacities ranging from Chief of the Division of Clinical Psychology to Dean of the School of Medicine, Vice-President for Medical Affairs, and Acting Chancellor of the Health Sciences Center. Dr. Conger also served as Vice-President and Director of the Health Program at the John D. and Catherine T. MacArthur Foundation.

A distinguished scholar and researcher, Dr. Conger focused much of his career on Child Mental Health Policy and the overwhelming gap between diagnosis and treatment of mental health problems. He was the co-author of the most influential textbooks on child and adolescent development of his generation and received an award for Distinguished Contributions to Public Policy for Children from the Society for Research in Child Development.

Dr. Conger received numerous notable awards throughout his career including the University of Colorado Medal in 1986 for outstanding achievement and distinguished contributions to the welfare of the University, the state, and the nation.

In 1992, as Professor Emeritus, he chaired the committee to recruit a new director of the JFK Center, a responsibility which he accepted as a reflection of his continuing commitment to the program he helped to found. In 1998, he again answered a call to assist with JFK Partners 30th anniversary symposium.

A letter from John Janeway Conger at the time of the 30th anniversary.

When the John F. Kennedy Child Development Center was created thirty years ago, our overarching aim - as well as that of members of the Kennedy family - was to focus greater attention than in past years on the challenges and opportunities presented by mental retardation. But we knew that if such an effort was going to have a lasting impact, it would need to be interdisciplinary in nature because of the variety and complexity of skills required. And it would need to involve research, both basic and applied; interdisciplinary training, both of professionals and students; and clinical care and support. This is what the Center set out to do.

While the Center, which we now know as JFK partners, and its many activities have broadened and expanded beyond anything that could reasonably have been anticipated at its founding thirty years ago, it has remained true to its original aims. In a world of constant change and shifting fads, this is a remarkable accomplishment and a cause for celebration. Our hats are off to all those who through the years have worked to make it possible.

Congratulations!
John Janeway Conger
Professor Emeritus of Clinical Psychology and Psychiatry
Former Chancellor,
University of Colorado Health Sciences Center
JFK Partners 50th Anniversary Symposium
Friday, April 17, 2015
## Agenda

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<tr>
<th>Time</th>
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| 8:30-8:45 a.m. | Welcome                                                               | Richard Krugman, MD  
Professor of Pediatrics  
Dean, University of Colorado School of Medicine (1991-2015) |
| 8:45-9:00   | Overview of the day                                                    | Cordelia Robinson Rosenberg, PhD, RN  
Professor of Pediatrics and Psychiatry  
Director, JFK Partners |
| 9:00-10:00  | Keynote: Past, Present, and Future of Early Intervention: A View through the Autism Spectrum Disorder Lens | Sally J. Rogers, PhD  
MIND Institute |
| 10:00-10:15 | Break                                                                  |                                                     |
| 10:15-11:30 | Contributions to Understanding the Complexity of Autism and Neurodevelopmental Disabilities | Panelists:  
Down Syndrome & ASD (Susan Hepburn, PhD)  
Deafness & ASD (Deborah Mood, PhD)  
Medical Issues, Sleep, Nutrition (Ann Reynolds, MD)  
Psychiatric Co-Morbidities (Judy Reaven, PhD) |
| 11:30-12:10 | ENRICH “Reunion Video”                                                 | Larry Edelman, MS  
Renée Charlifue-Smith, MA, CCC-SLP  
Parents |
| 12:10-12:30 p.m. | Lunch – select boxed lunch and return to auditorium for Grand Rounds |                                                     |
| 12:30-1:30  | Grand Rounds: Looking Back, Moving Forward – Celebrating the 50th Anniversary of the University of Colorado School of Medicine’s JFK Partners Program in Developmental Disabilities | The Honorable Patrick J. Kennedy, Former U.S. Congressman  
Founder, Kennedy Forum on Community Mental Health |
| 2:00-2:30 p.m. | History and Contributions in Parent Leadership                         | Sue Swenson, Acting Assistant Secretary, Office of Special Education and Rehabilitative Services |
| 2:30-3:30   | Parent Leadership at JFK Partners                                      | Panelists:  
Jeanette Cordova  
Kristen Kaiser  
Betty Lehman  
Tracy Price-Johnson |
| 3:30-3:40   | Break                                                                  |                                                     |
| 3:40-4:15   | Reflections on 50 Years of Progress                                     | Andrew Imparato, JD, Executive Director  
Association of University Centers on Disability |
| 4:15-4:30 p.m. | What Does the Future Hold?                                             | Sandra L. Friedman, MD, MPH  
Incoming Director, JFK Partners |
Contributions to Understanding Autism: Autism Diagnostic and Intervention Services, Research and Training

When the JFK program at the University of Colorado School of Medicine was started, autism was considered to be a rare disorder. Bernard Rimland’s work suggesting that it was a processing disorder had just been published. DSM criteria had not yet been articulated. In the mid-1980s a focus on autism was introduced at the JFK Center with the work of psychologist Sally Rogers. A preschool program was established. In 1994, diagnostic services were expanded through a contract with Kaiser Permanente Health Plan. Kaiser paid a case rate for evaluations which made it possible to bring on more faculty. Restored Maternal Child Health Bureau funding (LEND) and funding from US Department of Education provided resources for more graduate trainees.

For over 20 years, The Autism and Developmental Disabilities Clinic of JFK Partners, has been serving individuals with developmental disabilities across the life span, from toddlers through adults. Under the initial guidance of Sally Rogers, Ph.D. to the current leadership of Judy Reaven, Ph.D., the A & DD Clinic has offered gold standard diagnostic assessments and evaluations for families across the Rocky Mountain Region. The interdisciplinary faculty of the A & DD Clinic specializes in autism spectrum disorders, and has provided comprehensive evaluations to over 2,000 individuals and their families. Additional assessment services have included numerous discipline specific evaluations for individuals of all ages. Over the years, the A & DD faculty have worked with hundreds of families in a variety of therapeutic contexts, delivering state of the art interventions, across disciplines, in individual, group and family modalities. Interfacing and developing community partnerships has been a cornerstone of the A & DD Clinic, as demonstrated by the many consultative relationships that have been developed with schools and other community agencies across the Denver Metro Area, Rocky Mountain region and beyond.

In addition to the provision of clinical and consultation services, the A & DD Clinic has been a primary resource for pre-professionals across the country interested in interdisciplinary training that is family and person-centered, culturally competent, and community-based. Through the combination of clinical and didactic experiences, JFK clinical training addresses the critical values, knowledge and skills necessary to build inclusive communities for people with developmental disabilities and their families. Hundreds of professionals have received their clinical training through the A and DD Clinic. Many of these professionals are now serving individuals with developmental disabilities and their families, in their own communities in a variety of capacities – from academic settings, to hospitals, schools, community centered boards and private practices.

Now, after decades of working in close collaboration, JFK Partners (JFK), University of Colorado School of Medicine and the Child Development Unit (CDU), Children’s Hospital Colorado are integrating our two nationally recognized programs. This integration will allow JFK and CDU to operate under the same organizational umbrella. Both programs are committed to continue to provide the same level of service excellence to our families and community partners, whether it is advocacy, clinical, research or training related. Interdisciplinary assessments and training will remain in their current form, as JFK faculty and staff continue to provide cutting-edge clinical and training experiences to our community.
Past, Present and Future of Early Intervention: A view through the ASD lens.
Sally J. Rogers, Ph.D.

Two years after President John F. Kennedy signed PL88-146 authorizing University Affiliated Programs to increase services and research involving developmental disabilities, Life Magazine published a cover story on Ivar Lovaas’s UCLA autism intervention study, bringing autism and the challenges it creates for children and families into the public eye. Fifty years later, early autism intervention is the topic of laws, lawsuits, and hope. The powerful effects of high quality early intervention delivered in the first few years of life provide new ideas about the multiple mechanisms underlying developmental and behavioral impairments associated with early ASD and other neurodevelopmental disorders. This keynote will; (1) describe and illustrate the kinds of gains that high quality intervention can facilitate in young children with ASD; and other developmental disabilities; (2) identify treatment elements common to the most successful early intervention approaches, both in developmental delays and in ASD, highlighting research from the Early Start Denver Model (Dawson and Rogers 2010); and (3) consider ways to increase the reach and quality of early intervention services to young children with ASD and other disorders.

Sally J. Rogers is a developmental psychologist, Professor of Psychiatry and Behavioral Sciences, and Director of Training and Mentoring at the MIND Institute, University of California Davis. She has been the principal investigator of several autism research programs, including a ten year CPEA program project from NICHD and two NIMH/NICHD funded Autism Centers of Excellence (ACE) network projects, both involving a multisite randomized controlled trial of an infant-toddler treatment for autism. She is also the director of an NIMH funded T32 interdisciplinary postdoctoral training grant for interdisciplinary autism research. She has carried out major clinical and research activities involving autism at the national and international levels, including past vice presidency and presidency of the International Society for Autism Research, associate editor of the journal Autism Research, member of the Autism Speaks Global Autism Public Health Initiative, fellow of the American Psychological Association and the Association for Psychological Science, and a member of the Autism, PDD, and other Developmental Disorders workgroup for the DSM 5. She has received many awards of her teaching, research, and clinical contributions, including the UCDavis School of Medicine Research Award in 2008 and the John W. Jacobsen Career Award from the American Psychological Association.

She received her Ph.D. from Ohio State University, with a specialization in Mental Retardation and Developmental Disabilities. She has spent her career studying cognitive and social development in young children with disabilities. She has published over 200 papers, chapters, and books on topics including cognitive development in children with profound intellectual disability, cognitive and social development of blind infants, and symptoms of toddlers with Fragile X Syndrome, as well as numerous papers on clinical and developmental aspects of autism. She has made seminal contributions to the study of imitation in autism research. Her current research focuses on developing effective interventions for infants and toddlers with autism that families and community professionals in a wide range of communities can deliver.

In addition to research, she is also a mentor to many graduate and postgraduate scholars and clinicians, and is herself a clinician, providing evaluation, treatment, and consultation for infants and young children and their families. The intervention model that she first developed with colleagues at University of Colorado School of Medicine, and then elaborated with Geri Dawson and colleagues at the University of Washington, and her own team at University of California Davis — is internationally known and was recognized by Time.com and Autism Speaks as one of the 10 main medical breakthroughs of 2012. The treatment manual, Early Start Denver Model for Young Children with Autism: Promoting Language, Learning and Engagement, and instrumentation for this approach have been translated into many languages and are being used across the globe. The self-help treatment manual for parents, An Early Start for your Child with Autism, was awarded the #1 Consumer Health publication of 2012 by the American Journal of Nursing.
Co-Occurrence of Down Syndrome and Autism Spectrum Disorder: Implications for Assessment & Intervention
Susan Hepburn, Ph.D.

Down syndrome is one of the most common developmental disabilities with a known genetic etiology. For decades, clinicians and researchers identified sociability (or an inherent motivation to interact with other people) as a relative strength for persons with Down syndrome. However, as we now know, there is variability within the behavioral profiles (or “phenotypes”) of individuals with any genetic condition, and not all individuals with Down Syndrome demonstrate intact sociability. In fact, approximately 18% of children with Down syndrome meet diagnostic criteria for co-occurring Autism Spectrum Disorder (ASD), which is much higher than is observed in typically-developing children and those with many other developmental disabilities (DiGuiseppi et al., 2011; Warner, Moss & Howlin, 2014).

Children with both conditions show increased rates of problem behaviors (e.g., self-injury, aggression) at home and at school and are often educated in more restrictive environments than their peers with Down syndrome without ASD (Hepburn & MacLean, 2008). Communication development is usually impaired significantly in children with Down syndrome and ASD (Capone, 1999), and there is a need to investigate the efficacy of communication interventions that focus on strengthening communicative intent and nonverbal communicative behaviors, such as gestures, shared eye contact and shared affect (Fidler, Philofsky & Hepburn, 2010). There is also evidence that instructional techniques that promote learning of academic and functional skills in children with Down syndrome (without ASD) are markedly less effective in students with both conditions, thus new instructional techniques are greatly needed to foster learning for youth with co-occurring Down syndrome and ASD (Froehlke & Zaborek, 2013).

In this presentation, we will discuss the impact of this complex co-occurrence of developmental disabilities. We will then synthesize the existing research on assessment and intervention for individuals with co-occurring Down syndrome and Autism Spectrum Disorder and will identify next steps for research, treatment and family support.

Susan Hepburn is an Associate Professor in the Departments of Psychiatry and Pediatrics at the University of Colorado at Denver. She is a licensed clinical psychologist and has extensive experience working with families of children with Autism Spectrum Disorders and other developmental disabilities. Dr. Hepburn is the Director of Research for JFK Partners, the University Center for Excellence in Developmental Disabilities for Colorado, and is active in the Leadership Education in Neurodevelopmental Disorders (LEND) program. Her research focuses on co-occurring conditions in persons with developmental disorders and developing and testing psychosocial interventions for youth with complex needs.

References Regarding Down syndrome and Autism


Autism Spectrum Disorder among Children who are Deaf and Hard of Hearing: Current Practice and Future Directions
Deborah Mood, PhD

Children who are Deaf or Hard of Hearing (D/HH) appear to be diagnosed with an autism spectrum disorder (ASD) at similar, if not higher, rates than hearing children (Szymanski et al., 2012; Hitoglou et al, 2010). Other reports have also found that the rate of hearing loss in clinical samples of individuals with an ASD is higher than in the general population (Rosenhall et al., 1999). Children who are both D/HH and have ASD may have unique challenges in learning and development.

Although the rate of ASD among children who are D/HH has generally been reported to be higher than in the general population, the diagnostic process and availability of interventions to address communication challenges are severely lacking. To date, there are no tools that have been validated for use with children who are D/HH, and tools that are considered the “gold standard” for assessing ASD may be problematic when applied to this population (Mood & Shield, 2014). Appropriate diagnosis is further complicated given that differing structures of spoken and signed languages may lead to different linguistic manifestations of ASD (Shield, 2014). Whereas the adoption of universal newborn hearing screening has led to earlier identification and intervention for hearing loss, due to these diagnostic challenges ASD is often identified later in the D/HH population (Meinzen-Derr et al., 2014), resulting in delayed access to appropriate intervention and poorer outcomes.

The current presentation will briefly describe movement toward a best practice clinical approach for assessing ASD among children who are D/HH. Implications of the dual diagnosis for intervention will be discussed.

Deborah Mood earned her doctorate in school psychology from the University of Northern Colorado. She also holds a specialist degree in school psychology and master’s degree in developmental psychology from Gallaudet University. She completed a LEND psychology postdoctoral fellowship at JFK Partners, University of Colorado School of Medicine, after completing an APA accredited psychology internship at the University of Minnesota. She is currently a licensed psychologist with the Child Development Unit at Children’s Hospital Colorado. She specializes in working with children who are deaf and hard of hearing as well as children with a variety of developmental disabilities including ASD. Current research projects focus on the complex comorbidity of autism spectrum disorders among children who are deaf and hard of hearing.

References Autism and Children who are Deaf and Hard of Hearing
Co-occurring Medical Conditions in Children with Autism Spectrum Disorders: A Focus on Sleep Problems

Ann Reynolds, MD

Children with autism spectrum disorders (ASD) and children with developmental disabilities (DD) often have co-occurring medical conditions. Medical conditions reported to have a higher prevalence in children with ASD and/or DD include, but are not limited to, sleep problems, gastrointestinal dysfunction, and feeding/nutrition concerns. These conditions can often be overlooked in children with ASD or DD which can have a negative impact on the quality of life of the child and the child’s family.

The prevalence of sleep problems in children with ASD has been reported to be 50-80% in comparison to 9-50% in children with typical development (Krakowiak, 2008; Richdale, 2009; Souders, 2009). These sleep problems can have an impact on the child’s daytime behavior and the parent’s level of stress (Honomichl 2002; Quine 1991; Goldman 2009; Didde 2001). The etiology of sleep problems in children with ASD is multifactorial (Reynolds 2011). There are behavioral and psychiatric differences in children with ASD which can impact sleep, such as difficulty with transitions and anxiety. There is also mounting evidence that there may be physiological differences which may play a role, such differences in melatonin metabolism (Veatch 2014, Melke 2008, Tordjman 2012). Co-occurring medical conditions such as constipation, gastroesophageal reflux, or eczema may also play a role in sleep problems.

Research regarding treatment of sleep problems in children with ASD and DD has shown that sleep education paired with behavioral strategies modified for children with ASD or DD can be helpful in treating sleep problems (Malow, 2014, Johnson, 2013, Jan 2008). Melatonin can be helpful for treating difficulty initiating sleep in children with ASD and DD (Braam 2009, Malow 2011, Damiani 2015). A practice pathway for identification and management of sleep in children with ASD has been published (Malow 2012). Significant progress has been made in understanding the etiology and potential treatments of sleep issues in children with ASD over the past 15 years. However, there is still much more work to do, especially to address issues of sleep maintenance/night waking.

The presentation will briefly review prevalence, impact, identification, etiology, complexity, and management of sleep issues in children with ASD.

Dr. Ann Reynolds is a Developmental and Behavioral Pediatrician at Children’s Hospital Colorado and an Associate Professor of Pediatrics at the University of Colorado Denver. She has a long standing interest in co-occurring medical conditions in children with developmental disabilities (DD) and autism spectrum disorders (ASD). She and Dr. Terry Katz created a clinic for children with DD/ASD to evaluate and treat sleep issues. Dr. Reynolds is an Investigator in the Study to Explore Early Development (SEED) and is currently evaluating the prevalence of sleep and gastrointestinal issues in children with ASD and DD in comparison to children with typical development. She has also been involved in research studies designed to evaluate treatments for sleep issues in children with ASD and to describe nutritional status of children with ASD.

References regarding Autism and Medical Conditions


Co-occurring Psychiatric Symptoms in Children and Adolescents with Autism Spectrum Disorders: Implications for Identification and Treatment.

Judy Reaven, Ph.D.

Recent research has consistently indicated that children and adolescents with autism spectrum disorders (ASD) are at increased risk for developing co-occurring mental health symptoms (de Bruin et al., 2007; Hepburn et al., 2014; Leyfer et al., 2006; Simonoff et al., 2008). As many as 70% or more of youth with ASD may experience significant mental health symptoms and between 40-50% of youth may meet criteria for two or more psychiatric conditions (Leyfer et al., 2006; Simonoff et al., 2008). When these disorders are present, they may be more functionally impairing than when these same disorders occur in youth without ASD (Joshi et al., 2010). In fact, anxiety symptoms can interfere significantly with an individual's ability to participate in home, school, and community activities (Russell & Sofronoff, 2005). Youth with significant anxiety symptoms are at risk for serious educational problems, later underemployment, substance abuse, and other psychiatric problems (Velting et al., 2004). Anxiety problems can be especially “debilitating” to individuals with ASD (Greig & MacKay, 2005), by adversely impacting school performance, peer relationships, family functioning, and further exacerbating the core-deficits of ASD (Bellini, 2004; Sze & Wood, 2007). Accurately identifying the co-occurrence of psychiatric symptoms in individuals with ASD may be quite challenging.

Cognitive-behavioral treatments (CBT) are frequently used for typically developing children and adolescents with anxiety symptoms, with very good success (Compton, et al., 2004; Velting et al., 2004; Walkup, et al., 2008). Over the past 10 years, there has been much interest in using modified CBT programs to target anxiety symptoms in children and adolescents with ASD. Beginning with a series of case studies and small group studies, the field has quickly moved to randomized controlled trials. Youth with ASD and anxiety have demonstrated significant reductions in anxiety symptoms following participation in modified CBT approaches (e.g., Fuji et al., 2012; Reaven et al., 2012; Storch et al. 2013; Sung et al., 2011; White et al., 2013; Wood et al., 2009).

The current presentation will briefly review the Facing Your Fears program of research, (family focused group CBT treatment for managing anxiety symptoms in high-functioning youth with ASD), highlighting the core components of the manualized cognitive behavioral group treatment approach. Results of the treatment studies to date will be provided as well as implications for future clinical and research directions.

Judy Reaven, Ph.D. is an Associate Professor of Psychiatry and Pediatrics at the University of Colorado School of Medicine and is the Director of the Autism and Developmental Disabilities Clinic of JFK Partners, a University Center of Excellence in Developmental Disabilities. She received her B.A. from Vanderbilt University, and her M.A. and Ph.D. in clinical psychology from the University of Missouri – Columbia. She has worked in the field of developmental disabilities as a clinician, researcher and educator since 1985. Clinical and research interests include the co-occurrence of mental health symptoms in children and adolescents with autism spectrum disorders, including the development of an evidenced-based treatment intervention for anxiety symptoms in children with ASD (Facing Your Fears: Group Therapy for Managing Anxiety in Children with High-Functioning Autism Spectrum Disorders; Reaven et al. 2011). She has co-authored a number of peer-reviewed publications and book chapters. Dr. Reaven has been the Primary Investigator on grants funded by private foundations dedicated to autism research (CAN, Autism Speaks, OAR) including PI on a federally funded project (NIMH) exploring the initial dissemination of the Facing Your Fears treatment program.

References regarding Autism and Co-occurring Psychiatric Symptoms


Book chapters:


Books:

Contributions to Early Intervention Services
Throughout its history, JFK has played an instrumental role in defining and demonstrating recommended practices in early intervention for young children with developmental disabilities and special health care needs. In the early years JFK faculty in Nursing and Physical Therapy provided therapy services and conducted many workshops on early intervention. Training in developmental screening and assessment were also a main feature of work in the early years. In the 1980s a preschool for children with autism was started. In the late 80s with federal demonstration grant funding an inclusive childcare center was developed on site. Following this demonstration, inclusive childcare options increased throughout the metro area.

Center for Family and Infant Interaction
In the mid-1990s Joy Browne brought the Center for Family and Infant Interaction to JFK Partners. The purpose of the Center for Family and Infant Interaction is to promote the best outcomes and relationships between families and their infants, particularly those infants who have developmental challenges and/or special health care needs. The Center addresses this purpose through education, consultation, research, and support of professional/parents collaboration. Infants and their families who begin their lives in intensive care nurseries benefit from this program. The activities of the Center have been funded through a variety of sources including the Colorado Department of Education, Newborn Hope, Inc., Children’s Hospital Colorado, the Maternal Child Health Bureau, and the US Department of Education, Office of Special Education Programs.

The goals for the Center for Family and Infant Interaction:
• to provide quality training, consultation, and leadership to professionals and parents who care for infants born prematurely or with special needs, both in hospitals and communities;
• to promote education, support, and leadership among families who have experienced or are experiencing newborn intensive care or hospitalization;
• to conduct research that contributes to The body of knowledge regarding infants and families, particularly those born prematurely or with special needs;
• to promote collaborative relationships among parents, professionals, and community providers in supporting families and infants.
Sharing these mission and goals are the five programs of the Center

The Colorado NIDCAP® Training Center trains and certifies professionals from newborn intensive care units (NICUs) and individualized developmental assessment and intervention using Newborn Individualized Care and Assessment Program (NIDCAP®) approach.

The BABIES and PreSREPS Program which provides continuing education and developmental care concepts and interventions to community professionals who assist infants and families who transition from NICU to home.

The Fragile Infant Feeding Institute is a weeklong program that trains NICU to

1. implement developmentally supportive and family centered care;
2. community professionals to refer infants and their families to appropriate community support services;
3. integrate community professionals into the work of the NICU collaborative teams; and
4. intervention for families whose infants and young children have feeding challenges.

Early Intervention ENRICH (Enrichment using Natural Resources in the Community and Home)

In 1994 the ENRICH program was started with demonstration grant funding from the US Department of Education. ENRICH (Enrichment using Natural Resources in the Community and Home) was developed as a transdisciplinary intervention.

ENRICH focuses on providing early intervention services that are transdisciplinary in nature, focuses on functional outcomes, and includes education of parents and other providers in strategies that support children’s participation in their families’ every day routines at home and in the community. Federal grants, state contracts, and fee for service provided the support for these efforts. Following the initial demonstration project funding we received outreach funding to train transdisciplinary teams throughout Colorado. In addition to demonstrating and evaluating delivery of functional outcome oriented therapy services this training focused on efforts to identify ways to improve service delivery systems. Specific areas addressed included funding mechanisms, lack of critical knowledge and skill among therapists, lack of access to necessary specialized equipment, and shortages of personnel.

Additional demonstration project funding allowed for expansion of ENRICH services to place a specific focus on social emotional and infant mental health concerns and consultation to support inclusive childcare.

Since 1994 ENRICH and associated programs provided opportunities for practicum experience for well over 150 trainees from many disciplines. While trainees primarily come from occupational, physical and speech therapy disciplines, early childhood educators, nurses, pediatricians, psychologists, and social workers have all participated in practica in ENRICH.

The ENRICH Early Intervention “Reunion Videos”

The ENRICH Early Intervention team has been supporting the learning and development of infants and toddlers in Colorado since 1994. As with most age-eligible early childhood services, over the years our practitioners lose touch with children and families who graduate from the program. The “Reunion Videos” project re-connects with families who received early intervention services as long as 20 years ago. In these videos the families look back at archival photos and videos and discuss what early intervention services meant to them, which aspects of the services were most useful, and what has happened since. Additional videos will be added.
Kirby and Kendi Hylton
A Reunion with Jennifer (run time 14:08)
In this video Kendi and Kirby Hylton tell the story of Jennifer’s hemispherectomy. They also discuss what they found most useful about the early intervention services they received over 10 years ago for both of their children and how things have progressed since then.

Senator Irene Aguilar, MD and Thomas Bost, MD
A Reunion with Amy (run time 14:46)
In this video Senator Irene Aguilar, MD and Tom Bost, MD tell the story of the birth of their twin daughters. They also discuss what they found most useful about the early intervention services they received for Amy 20 years ago and the philosophies they adopted that continue to enable them to maintain the quality of life they desire for their family. The video also features an interview with Amy’s identical twin, Meg.

Larry Edelman is a Senior Clinical Instructor at JFK Partners in the Department of Pediatrics in the University of Colorado School of Medicine. As an ongoing consultant to the Colorado Department of Education’s Results Matter Initiative and the California Department of Education’s Desired Results access Project, Larry assists with the development of approaches to assessment, child and family outcomes measurement, professional development, technical assistance, and dissemination. Larry has worked with hundreds of early childhood, educational, disability, and health agencies in more than 45 states and abroad as a professional development and technology specialist. He has authored, edited, and produced hundreds of professional development programs, materials, and videos that have been adopted throughout the United States and internationally. Currently, the emphasis of Larry’s work is on the use of digital video, video conferencing, and other technology to enhance early childhood services, professional development, technical assistance, and dissemination activities. See: http://www.cde.state.co.us/resultsmatter/RMVideoSeries and http://draccess.org/videolibrary/

Renee Charlifue-Smith is a Senior Instructor, Department of Pediatrics, University of Colorado School of Medicine. She has been with JFK Partners since 1990 where she is the Speech-Language Pathology Discipline Director for the Leadership Education in Neurodevelopmental Disabilities (LEND) Program and she is the ENRICH Early Intervention Team Coordinator, which has provided services and training since 1994. Renee has been the speech-language pathology consultant on a variety of federally funded projects and grants and she currently is a clinician on the Study to Explore Early Development (SEED). Her areas of specialization include screening and assessment of young children, caregiver coaching, routines-based intervention, transdisciplinary teaming, and autism spectrum disorder. Renee completed an Irving Harris Mid-Career Fellowship in Infant Mental Health and Child Development and she is trained in the Early Start Denver Model (ESDM), Hanen approach (It Takes Two to Talk, More Than Words, Learning Language and Loving It), and Prompts for Restructuring Oral Muscular Phonetic Targets (PROMPT) technique.
The Honorable Patrick J. Kennedy
Former United States Representative, Rhode Island;
Co-Founder, One Mind, and Founder, Kennedy Forum

The last piece of legislation signed by President John F. Kennedy was the Community Mental Health Centers and Mental Retardation Facilities Construction Act of 1963. This legislation authorized “University-Based Centers on Intellectual Disabilities” throughout the United States, and marked the beginning of a dramatic nationwide improvement in the quality of staff training, services, and research. JFK Partners, the University-Based Center at the University of Colorado, was one of the very first such Centers established in the nation and now is celebrating its 50th anniversary. The Honorable Patrick Kennedy, mental disability rights advocate, former US congressman, nephew of President Kennedy and son of Senator Ted Kennedy, Founder of the Kennedy Forum and Co-Founder, One Mind, will share reflections with us on the tremendous legacy of the landmark 1963 legislation in Colorado and throughout the United States.

Representative Patrick Kennedy served 16 years in the U.S. House of Representatives, and is predominantly known as author and lead sponsor of the Mental Health Parity and Addiction Equity Act of 2008. This dramatic piece of legislation provides tens of millions of Americans who were previously denied care with access to mental health treatment.

Rep. Kennedy is the co-founder of One Mind, a national coalition seeking new treatments and cures for neurologic and psychiatric diseases of the brain afflicting one in every three Americans. One Mind is dedicated to dramatic enhancements in funding and collaboration in research across all brain disorders in the next decade. This historic grassroots endeavor unites efforts of scientists, research universities, government agencies, and industry and advocacy organizations not only across the country, but throughout the world. Rep. Kennedy is bringing everyone together to design the first blueprint of basic neuroscience, to guide efforts in seeking cures for neurological disorders affecting Americans.

Rep. Kennedy is also the founder of The Kennedy Forum. The Forum’s mission is to unite the nation’s health care system and rally the mental health community around a common set of principles: fully implement the 2008 parity law, bring business leaders and government agencies together to eliminate issues of stigma, work with providers to guarantee equal access to care, ensure that policymakers have the tools they need to craft better policy, and give consumers a way to understand their rights.

Rep. Kennedy has authored and co-sponsored dozens of bills to increase the understanding and treatment of neurological and psychiatric disorders, including the National Neurotechnology Initiative Act, the Genomics and Personalized Medicine Act, the COMBAT PTSD Act, and the Alzheimer’s Treatment and Caregiver Support Act.

Rep. Kennedy is a winner of the American College of Neuropsychopharmacology Distinguished Service Award, the Society for Neuroscience Public Service Award, the Peter C. Alderman Foundation Humanitarian Award, Centennial Award from the Clifford Beers Foundation, the Autism Society of America Congressional Leadership Award, the Depression and BiPolar Support Paul Wellstone Mental Health Award, the Epilepsy Foundation Public Service Award and has been recognized by many organizations for his mental health advocacy including the Society of Biological Psychiatry, and The Association for Medical Education and Research in Substance Abuse (AMERSA).

He is also founder of the Congressional Down Syndrome Caucus and the 21st Century Healthcare Caucus, as well as an honorary advisor to SAM-Smart Approaches to Marijuana.

Parent Leadership

Contributions to Parent Leadership

Parent Leadership is a defining feature of the development of programs for individuals with developmental disabilities. With the passage of the Developmental Disability Act (Developmental Disabilities Services and Facilities Construction Amendments of 1970, PL 91-517) it became possible to grow the network of University-based programs so that eventually every state and territory had one. It was parent leaders such as Elizabeth Boggs who were instrumental in working with Senator Edward Kennedy to craft the Developmental Disabilities Act Amendments and the term developmental disabilities (http://www.acl.gov/programs/aidd/dd_history). In our case here in Colorado it was Chief Justice Luis Rovira, who had a daughter with a developmental disability, who was instrumental in assisting with state funding for the JFK Child Development Center.

As the network of university programs grew through the 70s, 80s, and 90s the role of parents on the faculty of these programs grew as well. University of Nebraska Meyer Rehabilitation Institute may have been the first program to bring a parent onto its faculty based upon her qualifications as a parent leader. This parent leader, Patty McGill Smith, went on to become leader of the National Parent Network and then became, Assistant Secretary of Office of Special Education and Rehabilitation Services in the late 1980s.

In late 1980s the Administration on Developmental Disabilities (Now Administration on Intellectual and Developmental Disabilities), appointed parents and self-advocates to peer review site visit teams. By the mid-1990s parents became a “required discipline” for successful MCHB LEND grantees. Some parents who came into this role had other professional credentials however their faculty role and identity was as a parent.

In 1993 Tracy Price Johnson joined the faculty of JFK as coordinator of a special project designed to introduce students of the health sciences programs on campus to individuals with disabilities. While this special project ended, introducing students from medicine, nursing, physician assistants, physical therapy to families and individuals with developmental disabilities as a key part of their curriculum, continues to be present.

Shortly after Tracy joined the faculty a number of other parents joined the faculty in part-time positions with the NICU Consortium (Suzanne Smith Sharp) and in the Early Childhood faculty Institute (Linda Frederick, Anita Wagner).

In 1994 funding from US Office of Special Education to prepare therapists in early intervention greatly expanded training at JFK. The core curriculum typically had 20 trainees a year participating. The early intervention program of the Colorado Department of Education also believed in parent leadership and offered stipends of $4000 for a year so that parents could take the graduate course work alongside physical, occupational and speech therapists, nurses, psychologists and social workers. Many of these parents went on to become staff in Colorado’s Early Intervention Part C program. Their presence in class always enriched the dialogue.

Over the years a number of parents have been on faculty in a specific role on a special project. Christy Blakely was coordinator of Project Participate. Her background as a special educator and also as a parent of a daughter with cerebral palsy made her ideal for the project. Betty Lehman served as part-time faculty on a project that focused on understanding how to best leverage funding for therapy Harriet Austin served as coordinator for the Autism Treatment Network project and parent faculty of the LEND grant. Kit Hovey was parent advocate for the Autism and Developmental Disabilities Clinic for many years. Current parent faculty include Tracy Price Johnson and Kristen Kaiser who came onto faculty following completing of a LEND fellowship as a parent.

Parents as faculty have become an integrated aspect of JFK Partners program. Depending upon their background and interests they serve as teachers, researchers and advocates.

History and Contributions in Parent Leadership

Sue Swenson, Acting Assistant Secretary, Office of Special Education and Rehabilitative Services

Ms Swenson is currently the acting Assistant Secretary for the Office of Special Education and Rehabilitative Services (OSERS) at the U.S. Department of Education. She serves as the principal adviser to the U.S. Secretary of Education on matters related to the education of children and youth with disabilities, as well as employment and community living for youth and adults with disabilities. The mission of her office is to provide leadership to achieve full integration and participation in society of people with disabilities by promoting inclusion, ensuring equity and creating opportunities for people with disabilities.
In addition to serving as OSERS Acting Assistant Secretary, Swenson is also Deputy Assistant Secretary for OSERS, a position she has held since August, 2010. During this time, Swenson also served for one year as the acting Director of OSERS’ National Institute for Disability and Rehabilitation Research (NIDRR). Besides OSERS, Swenson served a previous administration as the Commissioner for Developmental Disabilities in the U.S. Department of Health and Human Services. Prior to OSERS, Swenson also served as CEO of The Arc of the United States and Executive Director of the Joseph P. Kennedy, Jr. Foundation.

Sue Swenson got involved with disability advocacy because her middle son, Charlie, had profound disabilities. She was active in the Minneapolis schools as well as in state and federal policy while working as a professional services marketing director before being named a Kennedy Fellow in the U.S. Senate in 1996. She was educated at the University of Chicago and earned an AM there as well as an MBA at the University of Minnesota.

**Reflections from JFK Parent Faculty and Consultant**

**Jeanette Cordova**

Jeanette has over 20 years’ experience in nonprofits and over ten years in advocating for children with disabilities. Jeanette is Puerto Rican American and has lived in Colorado for about 22 years. Prior to that she was born in NYC and raised in Miami, Florida. Jeanette graduated December 2014 with her Bachelor of Science in Human Services with a concentration in nonprofit and minors in Psychology and Spanish.

Jeanette is the proud mom of a 13 year old teenage boy who is chromosomally enhanced and has a lot of charm to spread around. Jeanette knows first-hand the challenges and wonderful journey it is being a parent of a child with different abilities. In addition to being a mom, Jeanette has volunteered her time as an Educational Surrogate Parent for the Colorado Department of Education over the past 6 years. She provides advocacy for children with disabilities whose parental rights were severed and need a representative in their Individualized Education Plan meetings.

Jeanette is a current member of the Mill Levy Advisory Committee of the Rocky Mountain Human Services. She is also a member of the Phi Theta Kappa International Honor Society, Psi Beta National Honor Society in Psychology, and Human Services Organization at Metropolitan State University of Denver.

Jeanette worked at The Arc Arapahoe & Douglas, Denver Metro Community Parent Resource Center, and Rocky Mountain Down Syndrome Association (formerly Mile High Down Syndrome Association). Through her work at RMDS, Jeanette started the first Spanish speaking support group for parent of loved ones with Down syndrome in Denver which is still running today “Cromosoma Del Amor”.

Jeanette accepted the position of Executive Director of El Grupo VIDA, the only Spanish speaking organization supporting Hispanic/Latino individuals with disabilities and their families in the state of Colorado. She has developed and maintained relationships with Spanish speaking community in the area of disabilities. El Grupo VIDA and JFK Partners partnered on two grants that will help families of loved ones with Autism Spectrum Disorder.

**Kristen Kaiser**

When all of our 3-year old triplets were receiving early intervention for Autism, my family was overwhelmed and at a loss for how to move forward. For us the challenge was not only learning how to engage fractured systems of care, but also ensuring that each child received intervention tailored to their specific needs. We needed a team that could work with us as a family, yet see each child as an individual. Through the Children with Autism Waiver, JFK partners worked with us in our home for 2 years, teaching us skills that were life changing for us as parents, and ultimately altered the trajectory of our children’s development. Our children are 11 years old now, and only one still has a diagnosis of ASD.

Through my experiences, I became passionate about supporting other parents. I trained in neurodevelopmental disability in advocacy, systems of care, and research as a LEND Parent Fellow at JFK Partners. I founded The Living Spectrum, a non-profit support organization for parents of children with ASD serving families in the Metro Denver area and the rural mountain communities in the Roaring Fork Valley. I am currently an
Instructor/LEND Parent Faculty at JFK Partners, and participate in a number of state-level, interagency committees. I also have a background in marketing and communications, with over 15 years of experience in managing technical projects and strategic planning. I received a BA in English from University of California Santa Barbara, a Masters in Liberal Arts from Harvard University Extension School, and I am currently working on an MPH at the Colorado School of Public Health.

Betty Lehman

By my son, Eli’s, sixth birthday, he had 36 medical diagnoses, one of which was autism. The true tragedy was not simply Eli’s health and development, but that I had to devote as much time to navigating and fighting the system as I did to taking care of my son.

To create a more just, responsive, and humane world for Eli - and all Colorado families with children with special needs - I became a statewide leader for change. Working within the Colorado early intervention system, public and private health insurance industries, and disability initiatives and medical practices, I successfully:

- Spearheaded 14 Colorado statutes to improve the quality of life for people with disabilities and their families
- Served as the Executive Director of the Autism Society of Colorado
- Chaired the Colorado Autism Commission and the Colorado Division of Insurance Consumer Council

Now I share the wisdom I gained on my journey with parents and guardians of children with special needs who are also determined to build a brighter future for their loved ones.

Tracy Price-Johnson

Tracy began her work in 1993 at JFK Center coordinating the Project Access funded as a special initiative from what was then the Administration on Developmental Disabilities grant which provided training to future healthcare providers in working with individuals with disabilities and their families. These trainings continue today with many healthcare disciplines and with several hospitals.

Tracy is the single parent of two children, Hayley and Hayden. Hayley had significant health and surgical needs and utilized therapy services like PT, speech language and audiology. Hayley passed away in 2004 and her legacy continues in the work done with JFK and Children’s Hospital on behalf of children with disabilities.

Tracy’s work continues with the JFK Council comprised of individuals with disabilities, family members and community advocates to support JFK’s programs and projects. She also teaches in the Physician Assistant Program at the University of Colorado as well as advocacy work with the Pediatric Residents in better understanding the needs of families who have children with disabilities and complex medical issues. In addition, she is the Department of Pediatrics liaison for senior faculty. She also works with healthcare ethics in the Denver area as well as serving on the Board of Directors for The Hayley House, a respite and palliative care program for children with special needs and The Children’s Treehouse Foundation which provides support for children whose parents are undergoing cancer treatment.
Reflections on 50 Years of Progress

Andrew Imparato, JD, Executive Director Association of University Centers on Disability

As director of the Association of University Centers on Disabilities, Andrew Imparato will share his reflection and celebrate the accomplishments of the past 50 years for persons with disabilities. He has had the privilege of visiting many of the centers around the country so his perspective is broad. He will also speak to the work that still needs to be done as AUCD and its family of centers moves into the future.

Andrew Imparato has served as executive director of the Association of University Centers on Disabilities (AUCD) since September, 2013. As a disability rights lawyer and policy professional with more than two decades of experience in government and advocacy roles, Imparato has worked with bipartisan policymakers to advance disability policy at the national level in the areas of civil rights, workforce development, and disability benefits. Prior to coming to AUCD, he was senior counsel and disability policy director for Senator Tom Harkin on the US Senate Committee on Health, Education, Labor and Pensions. Before that, he spent 11 years as President and CEO of the American Association of People with Disabilities, a national membership organization working to grow the political and economic power of the disability community. Imparato’s perspective is informed by his personal experience with bipolar disorder.

Since joining AUCD, a national network of over 100 university-based programs that conduct research, training and advocacy to improve the quality of life of children and adults with disabilities, Imparato has helped the organization broaden the scope of its advocacy and expand its leadership capacity. Imparato is currently serving on two bipartisan panels developing recommendations for reform of the Social Security Disability Insurance program and has spearheaded a national “Six by ‘15” campaign designed to leverage next year’s milestone anniversaries of the Americans with Disabilities Act and the Individuals with Disabilities Education Act to focus public attention on the areas where the disability community wants to see more progress. This campaign has been endorsed by over 140 disability organizations.

Imparato’s work has been recognized by the Secretaries of Health and Human Services and Transportation, the US Junior Chamber of Commerce, the National Council on Independent Living, the National Association of the Deaf, and the Osteogenesis Imperfecta Foundation. He has testified nine times before Committees of the US Senate and House of Representatives and has been interviewed on a wide range of disability issues by national television, radio and print media. He cultivates grassroots activism on social media and is known for seeking out and mentoring emerging leaders with disabilities. He co-authored articles that have been published in the Stanford Law and Policy Review and the Milbank Quarterly, and wrote a chapter on the Supreme Court’s disability rulings in The Rehnquist Court: Judicial Activism on the Right (Hill & Wang 2003). Imparato graduated summa cum laude from Yale College and with distinction from Stanford Law School. He lives in Baltimore with his wife Betsy Nix and their 15 year-old son Nicholas.
What the Future Holds

Sandra L. Friedman, M.D., M.P.H., Professor

Dr. Friedman joined the University of Colorado School of Medicine and Children’s Hospital Colorado in September 2009 as Section Head of Neurodevelopmental and Behavioral Pediatrics. She also serves as program director of Developmental and Behavioral Pediatrics fellowship program, accredited by ACGME in 2010. Prior to coming to Denver, she had been a staff physician at The Children’s Hospital Boston (CHB) and faculty at Harvard Medical School (HMS) for 16 years. She is a developmental pediatrician who has been involved in developmental assessments and management of children with a wide range of developmental problems and special health care needs. She functioned as program director for the Neurodevelopmental Disabilities residency program at CHB and HMS. She also was Director of Pediatric Training for the Leadership Education in Neurodevelopmental Disabilities program at CHB and the Institute for Community Inclusion. She has presented at multiple local and national conferences, and provided technical assistance to national and international organizations. She has published journal articles, abstracts, book chapters, and co-edited a book on end-of-life care as it pertains to people with IDD. Her research has also focused on developmental and medical outcomes of children born with congenital diaphragmatic hernia, autism spectrum disorders, and children with special health care needs. She has served on the board of directors of the American Association on Intellectual and Developmental Disabilities and on the executive council of the Committee on Children with Disabilities of the American Academy of Pediatrics. Her major areas of scientific interest are children with special health care needs, end-of-life care, and autism spectrum disorders.

Collaborative Partnerships

The multifaceted work of JFK Partners is built on a foundation of collaborative relationships with local, statewide, and national government agencies, private foundations, hospitals, institutions of higher education, advocacy organizations, support groups, individuals with disabilities and families of children with special needs and disabilities. JFK Partners benefits from approximately 3 million dollars in federal funding annually. Many of JFK Partners’ activities are enriched through partnerships with Colorado public and private state level agencies and organizations. These linkages include partnerships and consortiums and coalitions, joint programs, and contractual agreements.

Over the years JFK Partners has worked closely with various programs from a range of Colorado colleges and universities including Colorado State University, Denver University, and Colorado community colleges. Collaborative efforts with other University of Colorado Anschutz Medical Campus programs include:

- Intellectual and Developmental Disabilities Research Center (IDDRC);
- Kempe Children Center;
- Program in Healthcare Ethics, Humanities and Law;
- National Resource Center for Health and Safety in Childcare;
- School of Medicine Department of Family Medicine and Rehabilitative Medicine
- College of Nursing

A primary purpose of the core funding that JFK receives from the Maternal Child Health Bureau with the Leadership Education in Neurodevelopmental Disabilities (LEND) grant, and Administration on Intellectual and Developmental Disabilities with the University Center of Excellence in Developmental Disability Education, Research and Services grant is to use the funds to collaborate to maximum impact. Over the years these have been numerous projects funded by a variety of federal and Colorado agencies.

In 2001 funding from the Center for Disease Control and Prevention in collaboration with the Colorado Department of Public Health and Environment allowed faculty to expand from clinical and training emphasis to engaging in research as well. The CDPC funding was to participate in multi-site case control and surveillance projects. However the funding also permitted each site a special study. This support launched investigations into co-occurring psychiatric conditions and problems with sleep and gastrointestinal problems. Initial funding from the CDC and then funding from NIH resulted in development of a manualized
intervention for anxiety disorders, Face Your Fears. It also put the center in a position to become part of the Autism Treatment Network. We also completed successfully for CDCP funding to investigate the co-occurrence of Down syndrome and autism. This work is an excellent example of how clinical and research work can inform one and other. We are now funded for version 2 of the Case Control study: Study to Explore Early Development and a new round of surveillance work under ADDM (Autism Developmental Disability Monitoring) looking at four-year-olds in addition to eight-year-olds. Most recently School of Public Health doctoral candidate Norbert Soke completed a dissertation on co-occurrence of Self Injurious Behaviors and Autism.

Frequently a project creates new opportunities for other efforts. Project BLOOM, funded by SAMHSA through the Colorado Department of Human Services created opportunities to further training and service development in Infant Mental Health. We are currently collaborating with The Arc’s of Colorado and the Autism Society of Colorado on implementation of the Colorado Autism Commission Strategic Plan. CANDO, (the Colorado Collaborative for Autism and Neurodevelopmental Disabilities Opportunities). CANDO meets quarterly on the Anschutz Medical Campus and by webinar and is open to all interested. These quarterly meetings have become a vehicle for examining many issues of concern for people with autism and developmental disabilities. The collaborative partners in CANDO worked on the “Gap Analysis”, a project to focus attention on the grave problems faced by individuals with autism or intellectual disabilities and their families in access to mental health services in Colorado. Details of this project supported by funding from the Colorado legislature through the Colorado Department of Human Services can be found at: http://tinyurl.com/coloradoGAP. It appears as though this project will provide some strategies to improve access to mental health care for individuals who are dually diagnosed.

Carolyn DiGuiseppi, Epidemiologist and Pediatrician is leading a recently funded MCHB R40 grant in collaboration with JFK Partners faculty, Denver Health, Rocky Mountain Human Services, and El Grupo Vida. This project is designed to facilitate screening for autism and assisting with referral to early intervention services. A problem of lack of follow-up of children with positive screens has been documented nationally and locally. Staff on Project Salsa (Screening and Linkage to Services for Autism) will assist families in getting from positive screening to enrollment and maintenance in early intervention services.

Colorado Parent Mentoring in an MCHB funded R-40 grant that developed strategies to assist families receiving an autism diagnosis in understanding services and supports. Components of the project include both emotional support from a parent when a child has been diagnosed at least two years earlier and educational support through a series of group trainings. Both groups of parents, newly diagnosed and those providing mentoring benefitted from the project. The program is currently being translated and adapted for monolingual Spanish-speaking families.

Over the years, there have been many fruitful collaborations and partnerships that have created mutual benefit for the agencies and more important for the families served and the professionals who have participated as trainees. The wonderful support received for this event is testimony to the mutual benefits of these collaborations.
Upcoming Events

15th Annual Coleman Institute Conference for Cognitive Disability and Technology
October 15, 2015 | Broomfield CO
“Inequality and the Rights of People with Cognitive Disabilities to Technology and Information Access”
Keynote Speaker: Timothy P Shriver, PhD, Chairman of Special Olympics, co-founder and chair of the Collaborative for Academic, Social and Emotional Learning (CASEL) and best-selling author of Fully Alive: Discovering What Matters Most.
www.colemaninstitute.org   Email: Colemaninstitute@cu.edu

JFK Partners 3rd Annual Autism Spectrum Disorders Conference
Friday, October 2, 2015 | Aurora CO
“Unstuck and On Target: Improving Executive Function, On-Task and Flexible Behavior in Children with ASD”
Speakers: Lauren Kenworthy, PhD and Laura Anthony, PhD, Children’s National Health Systems, Washington, DC

More info forthcoming at www.jfkpartners.org under Events.
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1. The Sie Foundation donated $4,000 to be used as scholarships for parents, self-advocates and teachers to attend the Symposium. This generous donation was made in honor of Betty Lehman for her years of advocacy on behalf of individuals with Autism.
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