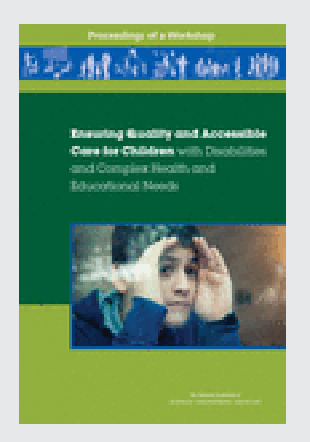

Ensuring Quality and Accessible Care for Children with Disabilities and Complex Health and Educational Needs: Proceedings of a Workshop

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and
Health and Medicine Division

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This Proceedings of a Workshop has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the Report Review Committee of the National Academies of Sciences, Engineering, and Medicine. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published proceedings as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the charge. The review comments and draft manuscript remain confidential to protect the integrity of the process.

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Although the reviewers listed above provided many constructive comments and suggestions, they were not asked to endorse the content of the proceedings nor did they see the final draft of the proceedings before its release. The review of this report was overseen by Patrick H. Deleon, F. Edward Hebert School of Medicine and the Graduate School of Nursing, Uniformed Services University of the Health Sciences. Appointed by the National Academies, they were responsible for making certain that an

independent examination of this proceedings was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this proceedings rests entirely with the rapporteur and the institution.

The National Academies' planning committees are solely responsible for organizing the workshop, identifying topics, and choosing speakers. Its forums and roundtables do not issue, review, or approve individual documents.

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1

Introduction and Overview of the Workshop

Children with disabilities and complex medical and educational needs present a special challenge for policy makers and practitioners. These children exhibit tremendous heterogeneity in their conditions and needs, requiring a varied array of services to meet those needs. Uneven public and professional awareness of their conditions and a research base marked by significant gaps have led to programs, practices, and policies that are inconsistent in quality and coverage. Parents often have to navigate and coordinate, largely on their own, a variety of social, medical, and educational support services, adding to the already daunting financial, logistical, and emotional challenges of raising children with special needs. The unmet needs of children with disabilities and complex medical and educational needs can cause great suffering for these children and for those who love and care for them.

To examine how systems can be configured to meet the needs of children and families as they struggle with disabilities and complex health and educational needs, the Forum on Promoting Children's Cognitive, Affective, and Behavioral Health held a workshop in Washington, D.C., December 9-10, 2015, titled "Ensuring Quality and Accessible Care for Children with Disabilities and Complex Health and Educational Needs." The goal of the workshop was to highlight the main barriers and promising solutions for improving care and outcome of children with complex medical and educational needs. Presentations and discussions among the workshop participants examined prevention, care, service coordination, and other topics relevant to children with disabilities and complex health and educational needs, along with their families and caregivers. More broadly, the forum seeks actionable understanding on key research questions for enhancing the evidence base; promoting and sustaining the quality, accessibility, and use of relevant programs and services; and informing relevant policy development and implementation. By engaging in dialogue to connect the prevention, treatment, and implementation sciences with settings where children are seen and cared for, the forum seeks to improve the lives of children by improving the systems that affect those children and their families.

This summary of the workshop should not be seen as the conclusions of the workshop participants as a whole. Rather, it recounts the points made by workshop presenters and participants as a way of exploring the many issues surrounding children with disabilities and complex health and educational needs and their families and caregivers. Many individuals and groups are involved with these issues, including patient groups, health care professionals, government officials, policy makers, and community members. By working together, these individuals and groups can enhance the health and well-being not only of children with disabilities and complex conditions, but also of all children.

ORGANIZATION AND MAJOR THEMES OF THE WORKSHOP

The workshop consisted of a keynote address and four panel presentations, followed by a final session in which the moderators of the preceding sessions and reporters from three breakout sessions revisited some of the major themes that arose during the workshop.

The workshop began with a panel of three individuals and family members affected by disabilities and complex health and educational needs, who described their greatest challenges and how they have worked to overcome those challenges (Chapter 2). The need for a variety of coordinated services was mentioned by several of the panel members, including services that need to be available in educational settings but often are not. Another common theme was the challenges posed by transitions in care, whether because a family moves, a child becomes an adolescent or an adolescent becomes an adult, or a complex condition changes over time.

Chapter 3 summarizes the keynote address by Maureen Durkin, a codirector of the Center for Pediatric Traumatic Stress at the Children's Hospital of Philadelphia and A.I. duPont Hospital for Children in Delaware. She noted that the prevalence of childhood disabilities has risen dramatically in recent decades in the United States, in part because more children are surviving childhood illnesses and disabilities that they would not have survived in the past. Also, the prevalence of mental disabilities has been rising faster than that of physical disabilities, and disparities in prevention and treatment have caused the prevalence of disabilities to vary among population groups.

Chapter 4 considers the implications of serious medical conditions for behavioral health. For example, the psychological and physiological responses of children and their families to pain, injury, medical procedures, and invasive or frightening treatment experiences can manifest as traumatic stress that can seriously impair a child's or family's functioning. Both community supports and family resilience can reduce the behavioral health consequences of serious medical conditions, but achieving these objectives requires coordination among systems that do not always work well together.

Chapter 5 presents the observations of a panel that looked at developmental disabilities arising in childhood, with a particular focus on autism. Every child and family is different, observed the speakers on this panel, which means that interventions need to be personalized or tailored for individuals and sites. Moreover, policies that have increased access to services have not necessarily increased the quality of those services, panel members said.

Chapter 6 looks at older youth who have serious behavioral health conditions, including depression, bipolar disorder, and schizophrenia. Early intervention has the potential to reduce disability for these conditions, speakers on this panel observed, reducing hospitalizations and increasing the rates of participation in work and school. In addition, coordinated approaches that span mental health issues, substance abuse, and educational deficits can address the combination of issues that these young people and their families face.

Chapter 7 considers a topic that the forum had not explored in a workshop before—the role of the media in shaping public perceptions and misperceptions of children with disabilities. The media can help individuals, families, and communities communicate their needs, the speakers on this panel said. Stories on children with disabilities can educate, illuminate, and inform. The media also can help convey the message that disabilities are not inherent in an individual but arise through the interaction of that individual with his or her physical and social environment.

Finally, Chapter 8 features the reflections of the panel moderators on the workshop. Care coordination, community engagement, early interventions, and prevention were all highlighted by several speakers, as were the benefits that would be expected to follow from a White House conference on children and the establishment of a federal children's office in the near-term future. Box 8-1, in this chapter, provides a summary of suggestions for future actions made by speakers throughout the workshop.

2

Perspectives from Individuals and Family Members

The workshop began by hearing from individuals and family members affected by disabilities and complex health and educational needs. They described their greatest challenges and how they have worked to overcome those challenges. They laid out what they thought should be done to help people with disabilities lead fulfilling and productive lives. A particular focus of their comments, as noted by panel moderator Stephen Shore, clinical assistant professor at Adelphi University, was "the importance of community—of advocates, of parents, of professionals. We all need to work together, because we can do so much more working in collaboration than any of us do alone."

CARING FOR A CHILD WITH SPECIAL NEEDS

Jackson was born a few weeks early but was pronounced a perfectly healthy and normal baby boy. As his mother, J-Jaye Hurley, said at the workshop:

> He was happy, typically developing, meeting milestones, saying "Hi da-da." At age 19 months, he developed a serious case of RSV [respiratory syncytial virus] and pneumonia and ended up being hospitalized for 8 days with fevers over 106 degrees. He was never the same again. He went from playing appropriately with his toy tool bench to mouthing the hammer and spinning the nails. At age 2, he was diagnosed with autism spectrum disorder [ASD]. I remember wondering what it was that we had done wrong or had missed, or why the doctors had told me he was just fine all the way up until the time that he wasn't.

Hurley began to study Jackson's condition on the Internet. He was enrolled in an early intervention program at an autism center, and he participated in the center's language and learning clinic for 2 years. He relearned several words that he had lost and was making academic progress. "We were hopeful for his future," said Hurley:

> Unfortunately, at age 6, Jackson had another serious bout with pneumonia, more high fevers, more hospitalizations. After that illness, he had a second serious developmental regression, and he has never recovered any of the skills that we had spent almost 4 years learning. He has not spoken another word since the second regression.
>
> This one hurt worse than the initial diagnosis. I didn't know why or how this could happen. We had done the therapies they told us to do. We had enrolled him in special needs pre-K. We had spent hours at our home doing services and therapies. It was devastating.

After much more study, testing, and visits to physicians, it was determined that Jackson, in addition to autism, has mitochondrial disease, which explains his developmental regressions and autism symptoms following his illnesses. He also has complex partial epilepsy, hypogammaglobulinemia immune deficiency, and a lifelong genetic pain disorder that had him screaming in pain for 3 years until the disorder was diagnosed and medicines to treat it were begun:

> He has intellectual disabilities and sensory issues. He breaks out in random mast cell activation rashes every few weeks. He has ADHD [attention deficit hyperactivity disorder], MTHFR [methylene tetrahydrofolate reductase] mutations, a blood disorder, an autonomic dysfunction. In a word, he has a lot.
>
> Over the years, friends and strangers said, "How do you guys do it? I could never be a special needs parent." The answer is simple. I do it because Jackson is my son. He is my child, plain and simple, just like your child is yours. I'm a special needs mom because my child is very special.

Jackson's original diagnosis led Hurley to become involved in Autism Speaks, and in 2011, she became the organization's southeast regional autism response team coordinator. After spending years being her own son's advocate, she has been able to help other parents navigate the complex systems involving health care and education. The autism response team helps families connect with local resources and provides support through daily phone calls and e-mails:

> I have been in this position now for 5 years next month, and I love it. I remember not knowing where to turn or who to contact when Jackson was first diagnosed. Autism Speaks family services provides help and guid-

> ance for individuals with autism and their parents in accessing services, waivers, and advocacy throughout the lifespan. Our small eight-person team responded to more than 47,000 calls and e-mails in 2014 alone. That is a lot of people who need help. My job has also opened my eyes to the disparity of many families across the country who do not have the advantages of living in a metro area and are facing financial, language, or socioeconomic barriers.

Over the years, Jackson's family faced many barriers in getting Jackson what he needs. When he was first diagnosed, his developmental pediatrician prescribed 40 hours a week of applied behavior analysis (ABA) therapy for him, but the family's insurance did not cover the therapy and they could afford only 4 hours a week. At age 8, their insurance coverage changed and finally began to cover the treatments. He now receives 25 hours of weekly in-home therapy, though these services would have been invaluable before, said Hurley.

Hurley observed that they have tried many different treatments for Jackson over the years, but ABA therapy has been by far the most successful. Medicaid has been mandated to cover these treatments, but most states, including the state of Georgia, have yet to implement this. Yet Jackson will need these treatments for the rest of his life, Hurley noted.

A great challenge for their family has been Jackson's safety:

> Jackson is completely nonverbal, and while we work on learning safety signs through his school and home ABA programs, he is still very naïve when it comes to safety. He does not understand traffic or danger or strangers. He is attracted to ponds and pools. He cannot answer you when you call his name. He likes to disrobe and take off all his clothes, including his coats and shoes. As parents, our main job is to keep our child safe, so this presents in the form of 24/7 monitoring and stress for my husband and me. We have a nightly lock-down system of our house, multiple cameras, door and window alarms. We constantly have to say, "Okay, he's going upstairs, do you have an eye on him?" or "Honey, I need to take a shower, your turn, you have eyes on him." The stress this causes is something most people cannot understand unless you have a child who elopes, but it's not just Jackson. There are thousands of families just like mine.

Autism Speaks has partnered with the National Center for Missing and Exploited Children to provide grants for swimming safety lessons and fencing for Jackson. He needs Project Lifesaver, which is a nonprofit organization that works on tracking technology for the search and rescue of individuals with cognitive disorders, to come to the Hurley's county, but funds are not available for that, his mother said. Parents often call Autism Speaks because school districts are not taking seriously their concerns of elopement (wandering or running from supervision). Communities need to focus their efforts on providing safety training, funding for GPS devices, and insurance coverage for these devices, said Hurley, since wandering is now a medical diagnosis:

> Jackson has gotten out of our house several times over the years. He walked out of our garage 2 years ago. He was missing for almost 30 minutes. We had to call 9-1-1. He was found naked in a neighbor's backyard. It was the longest 30 minutes of my life, and it was all because we forgot to hit the garage button once.

Access to quality health care has been another challenge for the Hurleys. They live in a metro area, but finding medical providers who are trained to understand and support individuals with autism and their families has been difficult. They have heard such comments from medical professionals as, "He can't talk, really? Like at all?" or "This boy has ants in his pants. Can you please tell him just to sit still for me just for 5 minutes?"

> My biggest pet peeve is when doctors don't talk to my son but they talk over him, like he's not in the room. Our medical professionals are only as good as their training, so I feel it is vital that all staff in medical offices and hospitals be given proper training annually.
>
> On the flip side of this, we have encountered great service providers. One time Jackson was having a very hard time and was hiding under the table, and his neurologist got down and examined him on the floor in the corner of the room because he didn't want to upset him any further. Many parents that I talk to at work have had positives and negatives, but it seems we hear more about the negatives, so hopefully any discussion going forward about these will support training for all medical staff.

Autism Speaks often gets calls from families who say that they are unable to get treatments covered, or that because of an age cap, the treatments have stopped. In part because of Autism Speaks' advocacy on the issue, more states and companies are covering medically necessary treatments for autism, Hurley noted.

The Hurleys have had positive experiences in their public schools. Jackson has been in a self-contained autism classroom since the age of 3. His teachers work on life skills and make community trips; his school nurse has received training for mitochondrial disease; and his speech therapist started a buddies group just for Jackson. Many families that call the autism response team are not as fortunate, said Hurley, and Autism Speaks provides special education advocacy resources every day, especially for those in rural communities or who have language barriers. Most families want to work within their school districts to receive the services that their child is entitled to under section 504 of the Rehabilitation Act (which requires school districts to provide a "free appropriate public education") and the

Individuals with Disabilities Act (IDEA). As with medical staff, training is essential for educators to help their special students achieve success, said Hurley.

Hurley receives lots of help from her friends. One morning she met at a local restaurant with other parents who were dealing with similar issues. As she recounted, "I went home and told my husband, 'I've found my people. They get it. I didn't have to explain, there was no judgment. It was wonderful.' When families call the autism response team, I always encourage our new families, 'Try to find some other family or a parent in your community, whether it's in your child's class, or it's through an online support group, someone to be able to share these experiences.'"

When Jackson was diagnosed in 2007, there was less awareness and acceptance for children with autism. Now that he is 10, tolerance, understanding, and acceptance have grown tremendously, said Hurley. Jackson has participated in a special needs swim team, sensory movies, and autism days at an amusement park and zoo. He was a surfer for autism and stood up on a surfboard this year. With 1 in every 68 children being diagnosed with ASD, everyone now knows someone who knows someone with autism, Hurley observed:

> Jackson Hurley is the very definition of a child with complex medical and educational needs. He requires 24-hour care and supervision. He cannot be left unattended for even a few minutes. He will continue to require long-term care as he enters puberty and transitions into adulthood. My husband and I fully anticipate that our son will live with us for the remainder of our lifetime.
>
> Jackson is the reason why all medical insurances should provide meaningful coverage throughout the lifespan of the individual with autism and other medical needs. Jackson is the reason why we need better safety and wandering resources and supports in all of our communities. Jackson is the reason that our teachers and our medical staff require better and ongoing training. Jackson is the reason why our community will become more tolerant and accepting. He will continue to make his slow and steady progress. He is now finally communicating via his talker, an aug comm device, that our insurance and Medicaid provided for him. In fact, just this year he has learned to type his initials on his talker, he uses it to answer yes and no, and he can tell us when he needs to use the restroom. He also can tell us if he is upset, sleepy, or wants to go for a ride. These are big things, huge. He is trying to find his voice again.
>
> I will always believe in my son and his ability to learn and grow. He makes me laugh. He loves to be tickled by his little sister. He is a terrific swimmer who loves to go on boat rides and jump on trampolines. He has noise sensitivity and wears noise-canceling headphones most of the time, yet he loves to turn up his beloved Elmo's World full blast on his iPad.

> When he was born, I thought Jackson was going to change the world. I believe he still is. He has changed me. Because of him, I will fight and learn and advocate for Jackson and for the millions of families just like mine, because he is very, very special and I am his special needs mom.

GROWING UP WITH COMPLEX HEALTH NEEDS

Jill Plevinsky, founding chair of the Patient Advisory Council for ImproveCareNow, was diagnosed with Crohn's disease about 20 years ago, when she was 7 years old. Crohn's disease is a chronic autoimmune condition that can cause inflammation anywhere along the digestive tract, resulting in abdominal pain, fatigue, fever, diarrhea, growth delay, and weight loss. As Plevinsky noted, inflammatory bowel disease (IBD), including Crohn's disease and ulcerative colitis, can be particularly severe when diagnosed in childhood. Treatments can include a combination of routine endoscopic procedures, immunosuppressive medications, surgical procedures, and lifestyle modifications. She explained:

> When I was diagnosed with IBD, I was pretty lucky. My pediatrician had specialized in gastroenterology in his fellowship [and] recognized that my symptoms warranted a colonoscopy pretty much immediately. I was quickly referred to Children's Hospital of Philadelphia. I was lucky to live in a suburban area at that point, but not all patients are as lucky as I was. It often takes years of misdiagnosis of things like functional abdominal pain, food allergies, eating disorders, growth delay, or stomach infections before a proper diagnosis is reached and treatment can begin. This is where awareness becomes key.
>
> As I went through elementary school and middle school, my disease course waxed and waned, as it goes through periods of remission and flare-ups. As my disease got worse, my medication regimen became more complicated. I began to suffer more side effects from steroids and more frequent infections from those immunosuppressive drugs prescribed with, of course, the best of intentions to control my symptoms. I was pretty sick. But I didn't want to be treated that way. Most importantly, I wanted to keep up with my school work. . . .
>
> At the time, my mom worked in special education and was very aware of how I could access accommodations through the medical 504 plan. [She advocated] on my part for a plan that would allow me to freely use the bathroom, have extra time on tests, and extended time on other assignments. This plan was very useful for me when a complicated surgery the summer before my freshman year kept me out of school for 2 months and in the hospital. My teachers came to the house, under my 504 plan, to make sure that I didn't fall behind.

Throughout her childhood and adolescence, Plevinsky said her parents encouraged her to become involved with activities through the Crohn's and Colitis Foundation of America (CCFA), which is the largest nonprofit organization supporting research, education, and social supports for people with IBD in the United States. She has attended Camp Oasis, a week-long camp for children with IBD, which became the inspiration for her master's thesis (Plevinsky and Greenley, 2014). She has participated in education events and fundraising walks. She benefited from the social support of other children with IBD, while her parents benefited from meeting the parents of other children with IBD, she said.

In college, Plevinsky served as founding chair of the CCFA's National Council of College Leaders, which brought together college students with IBD from across the United States to cover the gap in services for those 18 to 22 years old. She said that having a community of peers who were going through similar experiences was extremely helpful:

> As my involvement with CCFA increased, so did my social network of patients with IBD. I realized that there were so many stories—this disease is not the same in any two people, and every case is so unique. What struck me the most was how we all benefited from connecting with one another and sharing those stories. Because of my obvious millennial status, we use a lot of Facebook and Twitter to stay in touch.

Toward the end of her undergraduate training, she was contacted by a pediatric psychologist she had known through the CCFA about joining a collaborative called the Collaborative Chronic Care Network. The idea behind the network was to improve chronic illness care systematically using quality improvement science, with IBD care as a test case. At the first design meeting she attended in 2009, she was surrounded by parents, nurses, Web designers, testing experts, and people from many other fields, all of whom listened to each other and formed a true collaborative. What became the organization ImproveCareNow has grown to encompass 83 participating care centers, 730 physicians, and 25,000 patients, which encompasses 40 percent of all pediatric patients with IBD. The collaboration has helped improve remission rates over time through better treatments, greater awareness, and institutional buy-in. It has recently prioritized the psychosocial aspects of IBD, including medication adherence, transition readiness, and psychosocial functioning. Yet Plevinsky noted:

> My own personal transition to adult care was not smooth. It took about three tries to get to the right physician, which is pretty common. We did a study of young adults with IBD, . . . and it's rare that they stick with the first doctor they see. There's a lot of hesitation to leave their pediatric

> providers, because there's a lot of attachment that happens there. This is a pretty universal experience. . . . One of the patients I interviewed said that she was afraid of becoming just a number when switching to the adult setting, as opposed to being familiar with her pediatric institution (Plevinsky et al., 2015).

When surveyed, physicians tend to think that young adults with IBD are not prepared to be seen by an adult provider, reported Plevinsky (Hait et al., 2009). Physicians say that young adults with IBD do not have the necessary health literacy or self-management skills. "We need to do a better job there," she said. Some pediatric hospitals have good partnerships with adult institutions, including transition clinics that allow for a smoother transition, but that is not widespread. "That's something we could work on as well," she noted.

Due to better technologies, education, and awareness, Crohn's disease is being diagnosed at younger and younger ages, even in infants, said Plevinsky. However, insurance coverage and the cost of medications remain major problems for many patients with IBD. Also, many families are unaware that students with IBD have access to medical 504 plans, said Plevinsky. They are unsure how to access the services, unsure with whom to talk, and not sure what to ask, which is why awareness, education, and self-advocacy are critical.

From a systems perspective, having everyone working together and on the same page is invaluable, Plevinsky observed. "We can't overestimate the importance of community. Whether it's advocacy, parents, education, government, we all need to work together," she noted. All are united by the desire to reduce suffering and increase the potential for leading fulfilling and productive lives.

At the time of the workshop, Plevinsky was in her 3rd year as a doctoral student training to become a clinical pediatric psychologist and was doing research on the readiness of adolescents and young adults with IBD who are transitioning to adult care. Items that remain of concern to her and to the IBD community are awareness, advocacy, and the issues facing adolescents and young adults with IBD, she said. She noted that, after years of lobbying, the Senate passed a resolution supporting the goals of a Crohn's and Colitis Awareness Week, which had ended just a few days before the workshop. Greater recognition of IBD, a strong online social media presence, advocacy organizations, regular conferences, and efforts to improve care from the bottom up and the top down are all yielding progress, she concluded.

TREATING EARLY PSYCHOSIS

"Nothing focuses the mind more than having your first-born child diagnosed with paranoid schizophrenia," said Victoria Costello, a parent advocate and science journalist with the *Public Library of Science*:

> In the course of the following 10 years, I had a dual track. One was, of course, survival and searching for care for my son. The other was as a researcher focused on, as the subtitle of the book I eventually wrote puts it, "A Mother Uncovers the Science Behind Three Generations of Mental Illness." My focus became currently available research and treatment, as well as what I discovered to be the greatly untraveled ground of connecting family history to current mental disorders that cross multiple generations in families.

At the age of 16, her son Alex had lost his ability to finish a sentence, get even half a night's sleep, or face his peers at school. His father tended to classify his behavior as teenage defiance, but the family had no information with which to make decisions, according to Costello. Fortunately, the family lived in Los Angeles, and Alex was persuaded to go to the Neuropsychiatric Institute at the University of California and be diagnosed:

> The words are etched in my memory forever. "He has paranoid schizophrenia. His condition is complicated by his recent use of marijuana and methamphetamine, but the underlying symptoms of paranoia and delusion are clearly present. I'd like to keep him here for a month to stabilize him with an antipsychotic medication." Every single one of these words is terrifying to a parent.

At that time, not many psychiatrists would have given Alex that diagnosis, Costello said, partly because his symptoms did not totally fit the diagnosis. But human beings do not always tidily fit into categories, she pointed out, and without a diagnosis, parents often are left without insurance coverage and are on their own in putting together treatment plans.

In deciding what to do for her son, Costello talked with many parents and physicians, including the medical director of a clinic that treats 16- to 30-year-olds presenting with symptoms of early psychosis. He told her that the problem with the current diagnostic standard is that it waits until dysfunction has been present for 6 months before confirming schizophrenia:

> The message to parents and patients is all too often, "Let's wait this out. You're either going to fall off a cliff or you'll be OK, we're not sure which." The real question should be: How can clinicians reduce the risk of conversion while minimizing the risk and burden of any treatments?

As a leader of the early intervention movement for psychosis, Costello participated in an effort to get early psychosis included in the Fifth Edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5). In the process, she often heard the objection that formalizing the condition would create a bonanza for the pharmaceutical industry and that patients would pay a high price in terms of adverse effects, costs, and stigma:

> The basic view is that if we call it what it is, we risk stigmatizing patients, and therefore the better option is to not treat. [But] the real issue here is under-treatment, not over-treatment, and the stigma needs to be challenged.

Costello lauded the effects of a 1 percent tax on high-income earners in California that was targeted for a mental health services fund. Those tax dollars supported early psychosis clinics and peer support programs that would not have been funded otherwise. Though there have been efforts to raid the fund, it has been available for the past decade and has led to valuable services.

Costello also advocated against what she described as an anti-pharmaceutical attitude. Medications were the only recourse for her family, and both she and her younger son have been treated for depression.

Early psychosis is still not in DSM-5, Costello noted, and many parents are still on their own. But parents can be their children's best advocates, because they know their children best. Parents can keep up with research. They can work to reduce the gap that exists between new findings and practice. They can share information about things that work, such as medications that some physicians may not be willing to prescribe. They can help counter common misperceptions, such as the idea that children and adolescents did not have these kinds of problems in the past:

> They were there. They were the class clowns, they were the juvenile delinquents, they were the drop-outs, they were the kids who quit school at 14 or 15 because they weren't doing well. There was no diagnosis, there was no treatment.
>
> My final message, which I share with everyone, is that treating earlier is better than waiting too long. In the course of having my son treated—who is fine and symptom free today—early diagnosis and early treatment worked. He is always going to be an eccentric and unusual young man, but he is absolutely fine. . . . We are a typical family dealing with a set of issues that are very common.

NAVIGATING THE SPECTRUM OF AUTISM

During the discussion session, the moderator of the panel, Stephen Shore, spoke about his own experiences with autism. He was born at a time when a diagnosis of autism was "tantamount to a life sentence to an institution," he said. But his parents accepted him for who he was while recognizing that they had a lot of work to do for him to lead a fulfilling and productive life. They advocated on his behalf, convinced the school to take him in, and implemented what today would be called an intensive home-based early intervention program emphasizing music, movement, sensory integration, narration, and imitation. "It was up to them to figure out what needed to be done," he said. "It was almost as if they were general contractors in setting the stage for getting intervention at a time when the concept of early intervention did not even exist."

At 18 months, he was severely affected, but by age 4, speech had begun to return, and he returned to the school that had previously recommended institutionalization. His parents began imitating him, which made him aware of them in his environment and led to a stronger relationship between them. His parents supported his interests, whether it was astronomy, earthquakes, collecting sea shells—"whatever it was, it seemed like my parents were also interested."

He also moved along the autism spectrum over time, which is common, Shore noted. As the brain matures, as individuals become more self-aware, and as interventions have their effects, people change. For example, Shore is sensitive to overhead recessed lights, so he wears a hat with a brim to shield his eyes. People have unlimited potential no matter what their condition, he observed, "so it's up to us to find ways to help that person find ways to access that potential."

As Shore said, people with autism, IBD, schizophrenia, or other conditions look the same as everyone else, but there are differences in neurology and physiology that are not visible and are the source of stigma. "The more work that we can do to increase understanding and learn how to work with these conditions, the better off we'll be," he said.

SUPPORTING PARENTS AND OTHER FAMILY MEMBERS

A topic that was extensively discussed during the question-and-answer session was how to address the needs of parents and other family members who are caring for children with disabilities and complex health and educational needs. As Thomas Boat from the Cincinnati Children's Hospital Medical Center pointed out, 40 percent of mothers, for the first 3 years after a child is diagnosed with cystic fibrosis, are clinically anxious or depressed, along with almost 30 percent of fathers. Many parents need help to stay well themselves, he observed.

Hurley responded that health care providers need to give parents information about resources in an area, including organizations of other parents dealing with similar issues. For instance, Autism Speaks encourages doctors' offices to have parents call the organization to get information and support. "If a doctor could say, 'These are some local areas of support, these are programs in your area where you can get involved so you're not so alone,' that would be huge," she said.

Costello noted that many parents do not diagnose their own disorders until their children's conditions are diagnosed, and they realize that they have had the same symptoms. In the original psychiatric interview for her son, she realized that she had to do something about her own depression, but she was unable to get help from her son's psychiatrist because she was not his patient. With mental disorders, "it's not that hard to have a referral list ready," she said, since mental disorders are so often a family issue rather than an individual issue.

The panelists also spoke positively about paid positions for navigators to help families work with the health care system. Many of these navigators are parents who have received training and have become part of the system, which gives them special insights into the issues families face. Navigators and other guides to the system also can help parents arrange and coordinate the multiple forms of assistance that a child might need.

3

Disability Names and Numbers

In the keynote address at the workshop, Maureen Durkin presented an overview of disability data, definitions, and research gaps. Most important, the prevalence of childhood disabilities has risen steadily in recent years, she observed, which has major implications for policy and practice.

TRENDS IN THE PREVALENCE OF U.S. CHILDREN WITH DISABILITIES AND COMPLEX NEEDS

One of the greatest U.S. public health achievements of the past century was the reduction in infant mortality. In 1915, 10 percent of children born did not live to their first birthday. A century later, according to data from the Centers for Disease Control and Prevention, only 6 of every 1,000 children die before the age of 1—a rate of 0.6 percent (Hoyert and Xu, 2012). Deaths of children from 1 to 4 years of age also have fallen dramatically, noted Durkin, from 2 percent in 1900 to 0.0255 percent (Child Trends Databank, 2015).

In contrast, the percentage of children with disabilities and complex needs has been rising in recent decades, though these data are less certain than the data on childhood mortality. Since the 1950s, the National Health Interview Survey has been asking parents about activity limitations in their children. In 1960, parents reported that less than 2 percent of children had an activity limitation due to a chronic health condition. According to the most recently available data, from 2011, the percentage had quadrupled to 8 percent (see Figure 3-1). One problem with these data is that they are based on household surveys and do not include children living in institu-

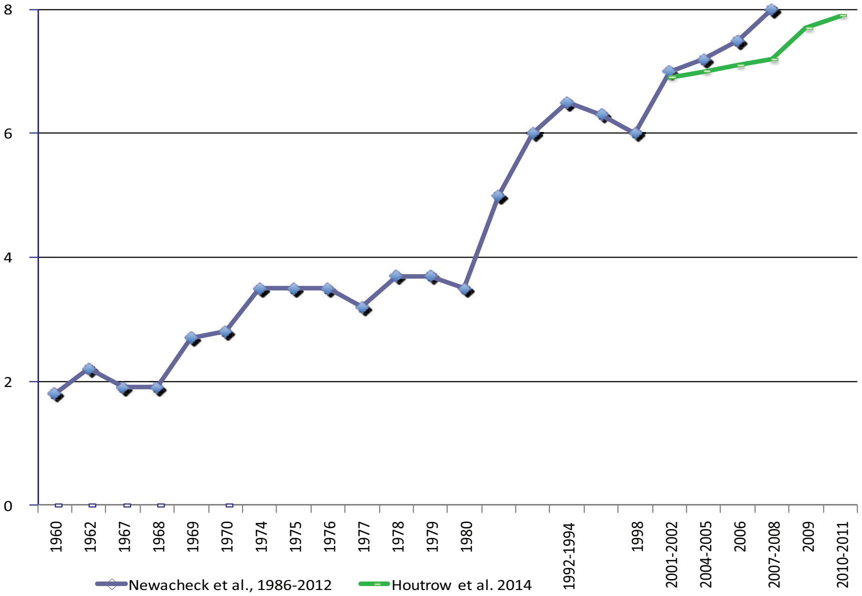

FIGURE 3-1 The percentage of children with activity limitations due to health, based on parent reporting, has quadrupled over the past five decades.
SOURCE: Durkin (2015). Available: http://sites.nationalacademies.org/dbasse/bcyf/dbasse_170078 [September 2016]. Data from Halfon et al. (2012) and Houtrow et al. (2014).

tions. Some of the rise could be due to the fact that the percentage of children living in institutions has declined over the years. Also, the wording of the questions has changed somewhat across survey years, which may have contributed to the rise. Nevertheless, said Durkin, "there's no doubt that the improvements in survival, especially of children with special health care needs, during this time period have contributed to increases in prevalence." As an example she cited Down syndrome, which is a common cause of developmental disability and complex health and educational needs. In 1960, the average life expectancy for a child with Down syndrome was estimated at about 10 years; today, due to advances in health care and other services, it is about 60 (Leonard et al., 2000). "It's not unusual now for individuals with Down syndrome to graduate and go into the workforce," said Durkin. "This is a huge change."

Usually in epidemiology, a rising prevalence rate of something is a bad thing. But a rising prevalence of disabilities caused by a reduction in mortality is a good thing, Durkin observed, and it is occurring throughout the world. "In a way it is a sign of progress in a country when the prevalence of disability is increasing," she said.

Many other data sources reflect the same trend of increasing disability rates among young people. According to the National Health Interview Survey, the percentage of children with developmental disabilities has risen since the 1990s, with the greatest increases in autism and attention deficit hyperactivity disorder (Boyle et al., 2011). Data from the Children with Special Health Care Needs (CSHCN) survey also show an increase in the number of children with special health care needs, from about 13 percent in 2001 to about 20 percent in 2011-2012 (Bethell et al., 2002). Furthermore, the needs have shifted from physical disabilities more toward mental health conditions and behavioral disorders (Houtrow et al., 2014).

Reports on special education since the 1970s show that the percentage of children qualifying for special education services nationally has increased from about 8 percent to 13 percent today (Scull and Winkler, 2011). The number of children with disabilities receiving Supplemental Security Income more than tripled from 1991 to 2011 (Tambornino et al., 2015). Furthermore, this increase is not due entirely to more children living in poverty, which is a condition of receiving Supplemental Security Income. Controlling for poverty, the percentage of children with a disability who received Supplemental Security Income was less than 3 percent in 1991 and has risen to about 8 percent, again with the prevalence of mental disabilities rising faster than physical disabilities (National Academies of Sciences, Engineering, and Medicine, 2015).

The prevalence of autism spectrum disorder (ASD) also has risen dramatically since 2002 in the United States (see Figure 3-2). The highest prevalence is in white children, with a lower prevalence in African American and Hispanic children. Across ethnic and racial groups, ASD is found at higher prevalences in higher-income families than medium- and lower-income families (see Figure 3-3). "That's one of the questions that we may address in this workshop," said Durkin. "Is it true that it's occurring more in children of high socioeconomic status, or is this a disparity because higher-income children with autism are the ones getting access to services? If the latter, then we might need to do something to make sure that the children in greatest need are actually being identified and getting access to services."

SOCIAL CONTRACT THEORY AND UTILITARIANISM

Turning to the underpinnings of the policies directed toward children with disabilities and complex health and educational needs, Durkin explained that two traditions of thought, each extending hundreds of years into the past, shape current thinking.

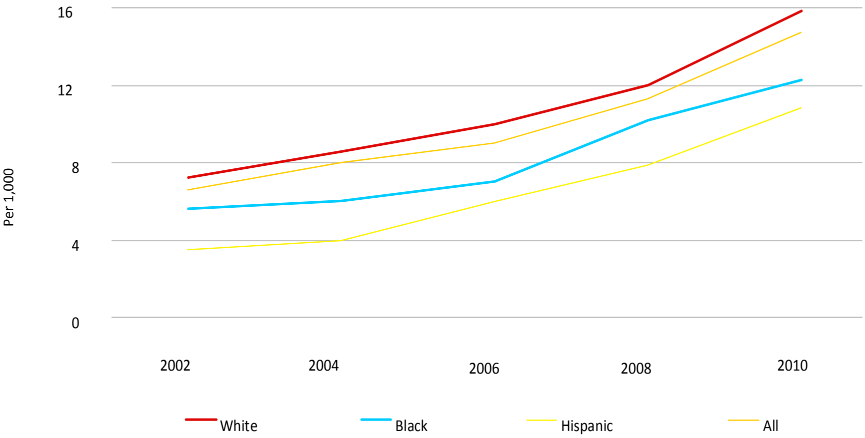

FIGURE 3-2 The prevalence of autism spectrum disorder has grown since 2002. SOURCE: Durkin (2015). Available: http://sites.nationalacademies.org/dbasse/bcyf/dbasse_170078 [September 2016]. Data from the Centers for Disease Control and Prevention (2014).

Utilitarianism focuses on cost effectiveness: How can limited resources be allocated to maximize happiness and well-being for the population overall? From a utilitarian perspective, which calls for the greatest good for the greatest number, a system with high inequality, health disparities, and suffering of a minority, including people with disabilities, may be acceptable if it produces maximum benefit for the population overall.

Contractarianism emphasizes implicit social contracts, Durkin said. From this perspective, everyone must give up something in exchange for social protections. As philosopher John Rawls pointed out, this tradition posits that if people do not know what position they are going to occupy in society, rational people will choose policies that benefit the least advantaged, perhaps including those with disabilities and complex health and educational needs.

A contemporary example of utilitarianism is the use of disability-adjusted life years to estimate the social value of different health interventions. This approach can devalue people with disabilities, Durkin observed, if it holds that they are not as valuable to society as people without disabilities. Another example would be a program that excludes people with disabilities in order to reach more people, because most do not have disabilities.

Under a contractarian approach, the range of inequality is generally narrower than under a strictly utilitarian approach, she pointed out. Inequality still exists, but the extremes on both the high side and the low side are less severe. This approach is consistent with many U.S. policies directed

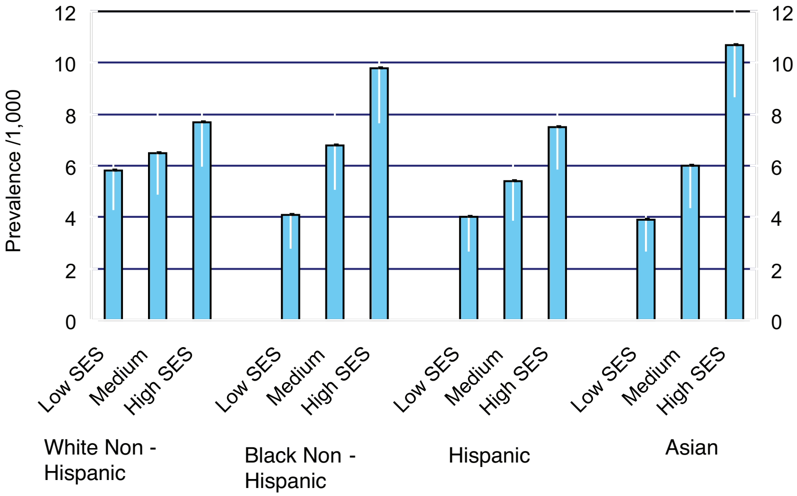

FIGURE 3-3 The prevalence of autism spectrum disorder is higher in families with higher socioeconomic status (SES).

NOTE: Based on the Autism and Developmental Disabilities Monitoring Network, data from 12 U.S. states with a population of 557,689 8-year-old children in 2002, including 3,680 with autism spectrum disorder.

SOURCE: Durkin (2015). Available: http://sites.nationalacademies.org/dbasse/bcyf/dbasse_170078 [September 2016]. Data from Durkin et al. (2010).

toward children with special needs. As early as 1931, at the White House Conference on Child Health and Protection, President Herbert Hoover said, “Children are our most precious possession. The Children’s Charter was written by 3,500 experienced men and women, after many months of study. It condenses into few words the fullest knowledge and the best plans for making every child healthier, safer, wiser, better and happier. These plans must be constantly translated into action” (Hoover, 1931). A specific policy from the Children’s Charter (White House Conference on Child Health and Protection, Committee on the Infant and Preschool Child, 1931) recommends, “for every child who is blind, deaf, crippled, or otherwise physically handicapped, and for the child who is mentally handicapped, such measures as will early discover and diagnose his handicap, provide care and treatment, and so train him that he may become an asset to society rather than a liability. Expenses of these services should be borne publicly where they cannot be privately met.”

More recent examples of contractarianism include the expansion of the Supplementary Security Income Program to children with disabilities in 1974, the Individuals with Disabilities Education Act (IDEA) of 1975 and 1990, and the Americans with Disabilities Act (ADA) of 1990. The contractarian approach is also evident internationally in the U.N. Conventions on the Rights of the Child (CRC) and on the Rights of Persons with Disabilities. For example, article 23 of the CRC states, "A mentally or physically disabled child should enjoy a full and decent life in conditions which ensure dignity, promote self reliance, and facilitate the child's active participation in the community." The preface of a 2015 report from the National Academies of Sciences, Engineering, and Medicine also expresses a contractarian approach (National Academies of Sciences, Engineering, and Medicine, 2015): "Children with disabilities in the United States, particularly those with mental, emotional, or behavioral disorders, are deserving of the highest level of planning and implementation for family support programs. Both at-risk families and society as a whole stand to benefit." From this perspective, Durkin observed, people with disabilities are not viewed as objects of charity, medical treatment, or social protection, but as subjects with rights.

This perspective recognizes that health has multiple determinants and that much more than just medical care affects the functioning and well-being of people with disabilities. It calls for a restructuring of society to be more inclusive and accepting of people with disabilities for them to be able to achieve their ultimate capabilities.

It remains to be seen whether implementation of the Affordable Care Act will take a more utilitarian approach, Durkin noted. How can more be done with less? How can this be done most efficiently? The needs of children and families with special health care needs might not be met under such a system, she said, unless special efforts are made to do so.

DEFINITIONS OF DISABILITY AND RESEARCH GAPS

Definitions of disability in policies differ. The ADA defines disability as a physical or mental impairment that substantially limits one or more major life activities of an individual, with an expected duration of not less than 6 months.[1] The Supplemental Security Income Program defines disability as "a medically determinable physical or mental impairment, which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months."[2] The CSHCN states that disability is consequence based and characterized by the need for or use of health care or special education for chronic conditions.

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[1] ADA Amendments Act of 2008, PL 110-325 (S 3406), 42 U.S.C. § 12102.

[2] Social Security Act, Title II, § 223(d)(2)(A), and Title 16, § 1614(a)(3)(B).

4

Children with Serious Medical Conditions and the Behavioral Health Implications

Serious medical conditions have many implications for the behavioral health of children with those conditions and for their families and caregivers. As such, consideration of these conditions involves many of the broad themes discussed at the workshop, including a two-generational approach toward children and their families, the need for measures of health and well-being, and the benefits of working simultaneously across disciplines and conditions.

A panel of four speakers at the workshop considered the intersections between medical conditions and behavioral health. Two of the speakers looked at specific conditions—medical traumatic stress and asthma, which should be considered "as exemplars," according to the panel's moderator, Mary Ann McCabe of the George Washington University School of Medicine and George Mason University, "since the lesson [from these examples] would hold true for diverse conditions." The other two speakers looked more broadly at issues of social integration and care coordination for children with complex health needs.

PEDIATRIC MEDICAL TRAUMATIC STRESS AND ITS IMPACT ON FAMILIES

When children have a serious illness or condition, they tend to have developmentally shaped, emotional reactions such as anxiety, depression, or behavior problems, explained Anne Kazak, codirector of the Nemours Center for Healthcare Delivery Science, codirector of the Center for Pediatric Traumatic Stress at the Children's Hospital of Philadelphia and A.I. duPont

Hospital for Children in Delaware, and professor of pediatrics at the Sidney Kimmel Medical School of Thomas Jefferson University. Mothers, fathers, and other caregivers, along with siblings and other family members, also can have a range of reactions, including traumatic stress responses. Preillness functioning tends to predict longer-term outcomes, Kazak noted, and social isolation is a predictor of worse outcomes. The majority of children and families are resilient, but many have psychosocial concerns that can affect the course of treatment.

Kazak focused on traumatic stress responses, which she described as a set of multiple psychological and physiological responses of children and their families to pain, injury, medical procedures, and invasive or frightening treatment experiences. Many aspects of illness and injury are stressful, but some are potentially traumatic, and traumatic stress and associated emotional reactions can have effects that seriously impair a child's or family member's functioning.

Traumatic stress is marked by symptoms that result in distress and may impair certain aspects of functioning, such as re-experiencing, arousal, and avoidance. It differs from post-traumatic stress disorder (PTSD) by focusing on the symptoms, whereas PTSD is a diagnosis of psychopathology.

Medical events can lead to traumatic stress in a number of ways. They can challenge beliefs about the world being a safe place. They can create a realistic or subjective sense that a child could die. Medical treatments can be frightening. "When we work in medical settings, we sometimes forget how overwhelming and stressful all the high-tech intense medical treatments and equipment can be," Kazak said. A child or family member may feel helpless or uncertain about the course or outcome of an illness or condition. Treatment can cause pain, the observation of pain in others, and exposure to other children who have died. Finally, people have to make important treatment decisions at times of great distress.

Four meta-analyses have uncovered several risk factors for PTSD after acute trauma with medium and large effect sizes, including subjective life threat; acute post-traumatic stress in children or adults; depression and anxiety in children; low social support; and maladaptive coping strategies, such as social withdrawal, avoidance, or thought suppression (Alisic, 2011; Cox et al., 2008; Kahana et al., 2006; Trickey et al., 2012). With childhood cancer, evidence of PTSD or post-traumatic stress symptoms is very common at diagnosis and during early treatment, with 40 to 50 percent of parents qualifying for acute stress disorder. This continues during long-term survival, with the mothers and fathers of childhood cancer survivors having elevated rates of post-traumatic stress symptoms compared with controls (Kazak et al., 2004). Nearly all families have at least one member who meets one of the diagnostic criteria for PTSD, Kazak said.

The normal course of reaction to a traumatic medical experience is that the stress goes up and then plateaus before beginning to decline, become chronic, or even increase (see Figure 4-1). But for some resilient families, stress plateaus at a lower level and begins to decline more quickly than for the average family. These resilient families may need less targeted or clinical treatment and may be well served by universal treatments that provide education and family-oriented support (see Figure 4-2).

Kazak and her colleagues have developed the psychosocial assessment tool (PAT) that can be used to screen a family for psychosocial risk (www.psychosocialassessmenttool.org). Available in a variety of languages, it has been used in research and clinical care at 77 U.S. sites in 33 states since 2007 and in 30 international sites. The screening tool does immediate risk scoring and generates family-centered reports to support decision making and communication. For example, across 6,500 administrations of the PAT, 55 percent of families were determined to need only universal supports, while 34 percent were determined to need targeted interventions and 11 percent were deemed to need clinical treatment.

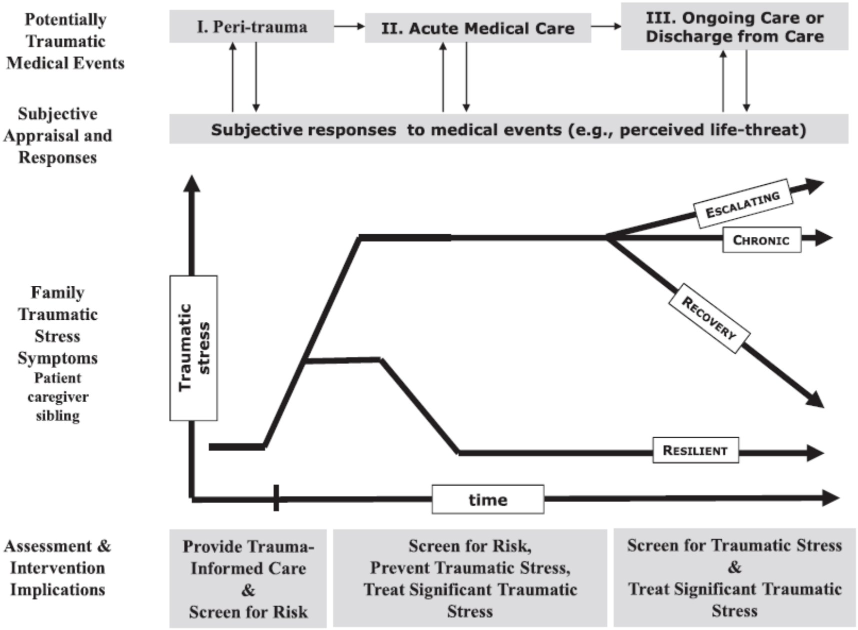

FIGURE 4-1 Some families have more resilient subjective reactions and appraisals of medical events, while others experience escalating, chronic, or gradually recovering levels of traumatic stress.
SOURCE: Price et al. (2016). Reprinted with permission from Oxford University Press.

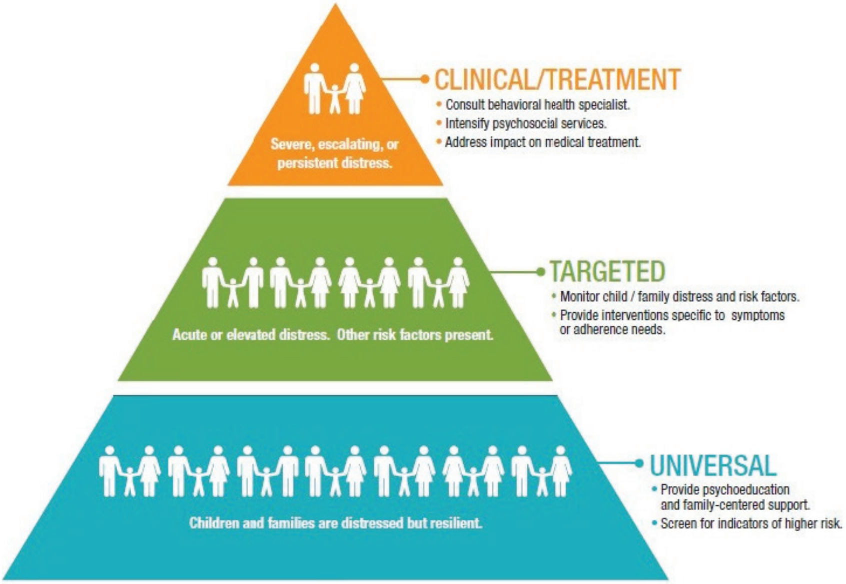

FIGURE 4-2 A pediatric psychosocial preventive health model (PPPHM) identifies three levels for addressing traumatic stress in the pediatric health care setting.
SOURCE: Reproduced with permission from the Center for Pediatric Traumatic Stress (CPTS) at Nemours Children's Health System ©2011. All rights reserved. The PPPHM may not be reproduced in any form for any purpose without the express written permission of CPTS. To obtain permission to use the PPPHM, contact Anne Kazak at anne.kazak@nemours.org.

Kazak and her colleagues also have been working to develop better ways of assessing the strengths and trajectories of families. Children live and interact in families or other systems, and these systems influence every aspect of their lives, she pointed out. Families are the key to participatory research, patient engagement, and outcomes.

Kazak also noted that they have developed an intervention model that integrates behavioral therapy and work with families around symptoms of traumatic stress. People are being trained in the model, and the use of technology is being considered for greater integration. Additional models exist that would make it possible to do larger studies across different systems.

The PAT has been adapted for different groups, though it is still an instrument under development, Kazak noted. Some people have used it clinically as well as in research, but it is only a screening tool, and additional procedures are needed to follow through and offer families and other groups the right care.

The Website for the Center for Pediatric Traumatic Stress, which is part of the National Child Traumatic Stress Network, provides a health care toolbox that helps children and families cope with illnesses and injuries (see https://www.healthcaretoolbox.org [September 2016]). After the ABCs of medical care are addressed (a traditional mnemonic referring to airway, breathing, and circulation), providers need to think about the DEFs (distress, emotional support, and family). The DEFs of trauma-informed care, said Kazak, are reduce distress, provide emotional support, and remember the family. The site has abundant resources and connections to training programs for health care providers, including nurses. As the Website points out: “You are not alone: Child life, social work, and psychology departments at your hospital can help. You are not helpless: Research shows that dealing with the stress of this experience now can minimize PTSD for everyone in the future.”

MANAGING ASTHMA

Asthma is a chronic inflammatory disorder of the airways, and it is a major public health concern for pediatric populations. It causes 14 million missed days of school annually, and 13.5 percent of all pediatric hospitalizations are for asthma (Denlinger et al., 2007; Moorman et al., 2011; Akinbami et al., 2012).

Asthma is not curable but it is manageable, said Robin Everhart, assistant professor of psychology at Virginia Commonwealth University. However, families can be hard-pressed to minimize exposure to asthma triggers, recognize symptoms, and manage medications. Pediatric asthma also occurs at very different rates in different population groups. It is higher among African American and lower-income groups than in other racial, ethnic, and income groups (see Figure 4-3). These pediatric asthma disparities are “multidetermined,” with several domains that overlap and help to predict the occurrence of disparities (Canino et al., 2006). In the domain of individual characteristics, inherent factors include genetic and biological factors, while modifiable factors include beliefs about asthma and medications, illness management, and psychological stress within families, such as stressors related to living in poverty. In the domain of environmental and contextual factors, indoor allergens, outdoor allergens, pollution, and environmental stresses all influence pediatric asthma disparities. Within the health care system, insurance coverage and reimbursement practices affect asthma disparities, as do such factors of the system as provider cultural sensitivity, workforce diversity, the use of evidence-based care, workload, and available resources. Finally, the provider’s characteristics can have an effect, including race and ethnicity, training, and beliefs and stereotyping in the provider-patient interactions. “We hear a lot from kids that maybe

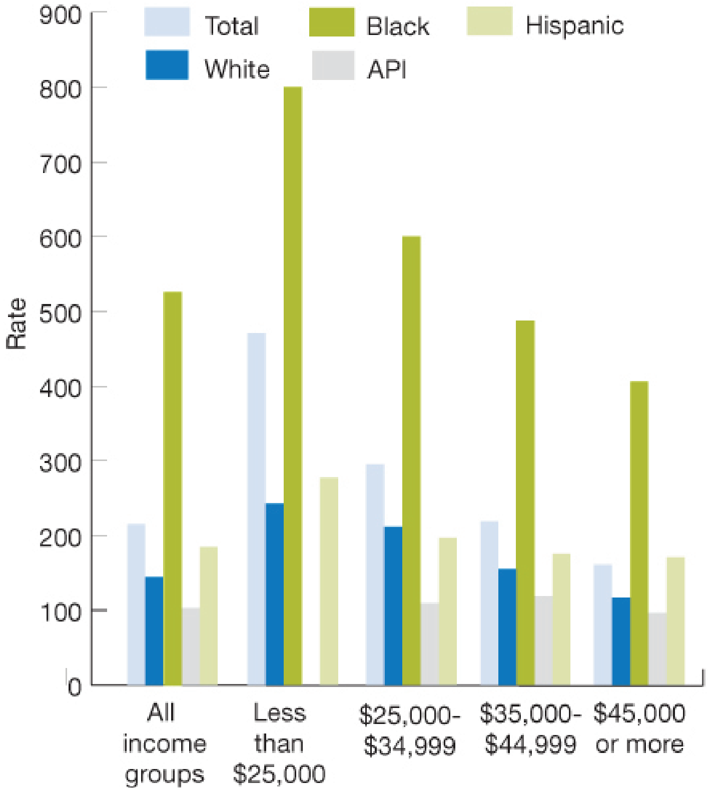

FIGURE 4-3 Pediatric asthma emergency department admissions rates per 100,000 population are stratified by race and ethnicity and by area income.
NOTE: Rates are shown as the median income of the zip code of residences. API = Asian-Pacific Islander.
SOURCE: Agency for Healthcare Research and Quality (2005).

they don't trust their provider, or there's something about the way that their provider interacts with them that makes them not want to talk," she said.

Everhart's work is centered on Richmond, Virginia, which "is one of the most challenging places to live if you have asthma," she said. The pediatric asthma hospitalization rate in Richmond is more than twice the overall Virginia average. Many families live in poverty, and environmental pollution is a factor. Though many families are resilient and are succeeding, others struggle to handle preventive and acute symptom management.

Everhart has used two broad approaches to the development and refinement of interventions. One, known as ecological momentary assessment (EMA), uses smartphones to survey parents regularly over the course of a day on such factors as sleep, asthma symptoms, and neighborhood stress. EMA reduces recall bias, since parents are remembering what has happened in the past few hours rather than the past few weeks. “Using EMA, we’re hopefully able to get a better picture, an accurate representation, of what’s happening on the family’s end,” she said. The second approach is a community-based needs assessment, which gathers information from caregivers, children, schools, and other stakeholders to develop a program to help children with asthma.

The Childhood Asthma in Richmond Families Study looked at children with persistent asthma and their caregivers in 61 families. Ninety percent were African American, 55 percent had yearly incomes below $19,000, and 82 percent of children had one or more emergency department visits in the previous year. Using EMA, the study found that on days when caregivers reported feeling less comfortable in their neighborhoods or less able to control child asthma at home, they reported more daily asthma symptoms in the children. “There may be violence in the community, there may be some safety concerns,” said Everhart. “Oftentimes, cognitive and emotional resources are spent on some of those safety concerns at the expense of more disease-related management behavior.”

The Asthma in the Richmond Community (ARC) project had the goal of conducting a community-based needs assessment to inform the development of a randomized clinical trial to decrease asthma morbidity among urban children ages 5 to 17. It allowed Everhart and her colleagues to meet with stakeholders, run focus groups, and learn from the community about what families need and how evidence-based interventions can be adapted for those families. A caregiver and youth advisory group consisting of three parents and three children with asthma met with the research team monthly to bring a community perspective to such instruments as focus group scripts and community surveys. In addition, a group of community residents were trained in data collection so that they are able to analyze data.

Themes emerging from the focus groups have centered on visits to the emergency department, insurance coverage for asthma medications, adherence to daily controller medications, and other people understanding the seriousness of asthma. For example, the focus groups have revealed that visits to the emergency department are not as stressful for children and families as is generally presumed. “There are some real reasons why some families are choosing to access the emergency room,” said Everhart, which requires rethinking some of the existing strategies around asthma management. Similarly, the focus groups have revealed why adherence rates are not as high as would be expected. She explained, “Families understand the need to take a daily controller medication yet they’re not able to, and we’re working with them on why that might be.” Regarding the seriousness of asthma, some teachers might not appreciate that wearing strong perfume is harmful, or students might not appreciate that smoking around classmates with asthma can worsen their condition.

Everhart concluded with several take-home messages. A child's community, including its strengths and weaknesses, needs to be taken into account, she said. In addition, a focus on families is important, including caregiver health and psychological well-being. Finally, meeting the needs of the family is critical: "What is it that you need, and how could we help you?"

INCLUSION TRAINING FOR PROGRAMS THAT SERVE CHILDREN WITH DISABILITIES

Torrie Dunlap, chief executive officer of Kids Included Together (KIT), was a drama teacher who expected to spend her life teaching children tap dance and musical numbers. As she recounted, when she was the education director at a youth theater company, a mother called and told her that she would like her child with Down syndrome to be in an acting class. "As a 22-year-old with no prior experience with disability, I kind of panicked. I didn't know what to say to her," she recalled. "I was afraid. I didn't think I could do it. I didn't know what an acting class with a child with Down syndrome could look like." She asked the mother for help and was referred to KIT, a nonprofit organization that works to facilitate inclusion for children with all types of disabilities. "That experience changed my life," Dunlap said. "It also changed the theater company where I worked. It was a transformational experience for all of us. We began to get good at this and began to include children with a wide range of disabilities, including very significant disabilities, in theater programs. We were all fundamentally changed by the experience of having children with disabilities in our programs."

After several years working with KIT as a client, Dunlap was hired as a part-time program coordinator, funded by a small grant in 2003. KIT was founded in 1997 when a woman who had polio left a large bequest to the Jewish Community Foundation in San Diego so that children with disabilities would be better served in the community. The foundation also hired a woman named Gayle Slate, the mother of a child with cerebral palsy who had experienced considerable exclusion, who was committed to including children with disabilities in their communities. Beginning with an inclusive summer camp, KIT evolved to have the mission of teaching inclusive practices to organizations that serve children.

The organization's goals are rooted in the Americans with Disabilities Act, "but we are not the ADA police," said Dunlap. "We do not go in and tell people what they're doing wrong, or at least we say it nicely if we do." Its vision is a world where inclusion is the norm, not the exception, and it acts as a friendly and helpful guide on the path to inclusion. Its goals are to change the way people think about disability and make sure that every place where children want to go in a community is prepared to meet their diverse needs. As Dunlap said, a specific diagnosis is less helpful than information on how the program can support the child's individual needs.

KIT uses a blended learning model, including live and online training, to teach and build capacity in child and community-based programs like preschools, summer camps, afterschool programs, sports leagues, and scouting. A team of highly skilled trainers delivers in-person training and classroom consultation. KIT offers access to on-demand online information and operates a call center staffed by inclusion specialists. "Teachers can call when they have a problem and say, 'A mom is coming in tomorrow. I don't know what to say.' 'A child in my class did this, and I didn't know what to do,'" Dunlap explained. KIT tries hard to find the "early adopters," people who might not have much experience or knowledge but are interested and curious. These individuals become "foot soldiers" for the organization because they bring the rest of an organization and other organizations along. "The unit of change is the people, because the organization is very hard to change," she said.

The 2011 *World Report on Disability* (World Health Organization and World Bank, 2011) stated, "Children with disabilities are among the world's most marginalized and excluded children." As Dunlap said, society places a huge stigma on families who have children with disabilities, which makes it difficult for many families to access community-based supports, especially families with limited incomes and resources. Research has shown that inclusion of children with disabilities in an activity has benefits for everyone, including measurable gains in social skills, academic development, communication, confidence, autonomy, and even test scores (Division for Early Childhood and National Association for the Education of Young Children, 2009).

In accord with KIT's theory of change, people who learn to include children with disabilities become advocates for those children in their communities and take more of a leadership role. They teach others to see disability as a difference and not a deficit. When people adopt a strengths-based model, "they accept disability as a natural part of human existence," Dunlap said. "They begin to see [the] barriers that we've created, and they figure out how to knock down those barriers to participation."

KIT also asks providers to see what children can do to realize their potential and to hold all children to much higher expectations. "Low expectations is a huge problem in our field, which is why we have a dropout rate for students with disabilities that is two times higher than for students without disabilities," according to Dunlap. During the training process, providers have opportunities to reflect on their unconscious biases, which can help shift their mindset. "This is often a very powerful experience for the people that we teach," she observed.

Each individual taught by KIT can reach an average of 17 children per year, or 300 children over the course of their career. They also can influence other providers by mentoring and coaching their peers and colleagues. With 300 program sites served in San Diego County, 220 national programs currently being served, 49 programs being served internationally, and 22,620 learners, KIT has the potential to reach more than 380,000 children. “That looks impressive, but I tell you it’s really not,” said Dunlap. “The need is so much greater. We are working to scale our organization to be able to serve many, many more people.”

KIT also advocates for children with disabilities. It was involved in a recent policy brief on the inclusion of children with disabilities in high-quality early childhood programs. KIT is a special consultant to the Economic and Social Council of the United Nations and does training for military child and youth programs on 245 military bases around the world. It works with the U.S. Department of Education, the federally funded 21st Century Community Learning Centers programs, YMCAs, Boys and Girls Clubs, 4H Programs, and Girl Scouts. “When providers have the training and support that they need, they are capable of meeting the needs of children with diverse abilities,” said Dunlap.

IMPROVING SERVICE DELIVERY FOR FAMILIES OF CHILDREN WITH COMPLEX MEDICAL NEEDS

In its report *Children’s Health: The Nation’s Wealth*, a National Research Council and Institute of Medicine committee stated that, “Children’s health should be defined as the extent to which an individual child or groups of children are able or enabled to (a) develop and realize their potential; (b) satisfy their needs; and (c) develop the capacities that allow them to interact successfully with their biological, physical, and social environments” (National Research Council and Institute of Medicine, 2004). This definition is much broader than what is used in health care systems today, said Amy Houtrow, associate professor and vice chair in the Department of Physical Medicine and Rehabilitation for Pediatric Rehabilitation Medicine at Children’s Hospital of Pittsburgh. “I want us to use that frame when we talk about medical complexity,” she said.

Contextualizing the lives of children includes considering their experiences with poverty, adverse childhood experiences that might be multigenerational, their ability to function in schools and in the community, and the resources to which they have access in their communities. In addition, they might have experiences with the foster care system, the juvenile justice system, or law enforcement. “If your teenager is one who frequently elopes because they have autism, it might be the police officer or your good neighbor who's your first responder—not necessarily the emergency room," said Houtrow.

As the health care system is refined, revised, and transformed, different families will have different needs, but there are some consistent themes, said Houtrow. Families want simple and straightforward access to needed services. They do not want to spend a lot of money out of pocket. Families who have children with complex needs often suffer from work loss and limited social engagement and opportunities. The health care system needs to focus on these broader disadvantages, not just on biomedical metrics that can be measured, Houtrow insisted. "Families are concerned about whether they'll keep their job because they came in late again because they had to take care of their child," she said. "They might not have a home next month. Some of these basic necessities need to rise to the forefront when we think about transformational change in the health care system."

As with families, one-size solutions do not fit all children. A 15-minute appointment in a pediatrician's office is not going to be sufficient for a child with complex needs, Houtrow observed. Families may not be able to get time off to go to the doctor. It can be very difficult simply to make an appointment by phone. Other ways of accessing 15 minutes of information or advice, such as telemedicine or a home visit, might have a greater impact on a child and family than an office visit, yet the health care delivery system is not pliable enough to successfully offer these types of services.

Systems of care consist of groups of related parts that either work well together or do not work well together, said Houtrow. Some of these parts are in the health care system, such as clinics and hospitals, but others are not, such as schools and other community resources. Today, different care systems do not necessarily talk or work with each other, she continued, noting "sometimes they're in opposition with each other, and sometimes there are limitations on how you can access them."

As Houtrow put it, an important aspect of promoting health and well-being is having disparate care systems "become good neighbors." That requires being coordinated within systems and among systems, which requires communication. Today, many physicians still send and receive information by fax machines, and medical record systems do not necessarily communicate with each other, much less with schools or other community resources. She noted

> As a pediatric rehabilitation medicine provider, I see my primary job as living solidly in a healthy neighborhood that makes connectivity happen. I can't speak enough to the value of being able to do clinics in a school with the physical therapist, occupational therapist, teacher, and speech therapist for a child with disabilities. I get to hear what's happening every day by the people who get to do it every day. . . . When we think about delivering

> high-quality care, we have to potentially be breaking down walls—those walls can be barriers that don't allow us to communicate by phone or electronically, or they can be actual physical walls.

Team-based care for children with complex conditions can be multicoordinated, intercoordinated, or transcoordinated. In the first, many disciplines are working together in the same setting at the same time, though they have different goals. In the second, communication about goals allows team members to work together toward common goals. In the third, disciplinary boundaries are blurred to better achieve shared goals and produce synergies. In transdisciplinary team-based care, "sharing goals, at the knuckles of the intersection between disciplines, is often the best way to keep the ball in the air," said Houtrow.

Part of team-based care is care coordination. In a complex health care system, care coordination involves having someone who knows about what a child's needs are, knows what a family's lived experience is, knows what challenges they face, and helps access aspects of care in the health care system and outside of it. The center of team-based care and care coordination remains the child and family, but the dynamic nature of childhood and social life is taken into account in improving systems of care, said Houtrow. From this perspective, the important question is whether children are able to participate in day-to-day life in the way that they want to, "being happy, healthy, and well," said Houtrow. Thinking about the whole child requires cutting across disciplines and breaking down silos.

The detailed structure of a care team also can differ. For example, a pediatrician may provide a medical home for a child with a disability, but when pediatricians are faced with health care needs that exceed their capability to manage, they may turn to a comanagement strategy where a subspecialty group takes the lead along with a pediatrician. Another model is where specialty clinics act solely as consultants but do not take over the management of care. A care manager can be in a primary care setting or a tertiary care setting.

A medical home model is especially attractive because it can optimize services for children, especially if services are collocated, with behavioral health services, legal services, and social services nearby. In this mode, a general pediatrician can be the coach or leader of a team that includes many different providers.

The model can also depend on the availability of resources in communities. In a city without a good bus system, a family might not be able to reach a tertiary care provider, while a primary care provider may be nearby. In addition, a care management strategy for a cystic fibrosis program might look different than the care management strategy for children with spina bifida, who may have many more providers and more opportunities for surgical intervention.

As demonstrated by previous presentations at the workshop, many opportunities exist to disseminate and replicate excellent programs, Houtrow concluded. But success requires communication and coordination as well as dissemination.

INSURANCE COVERAGE FOR CHILDREN WITH COMPLEX MEDICAL NEEDS

A prominent topic that arose in the discussion session involved reimbursement for children with complex medical conditions. As Edward Schor of the Lucile Packard Foundation for Children's Health pointed out, the health care reimbursement system is designed for acute care, but disabilities and complex needs are chronic issues and out of sync with reimbursement. Also, good measures of individual or family functioning do not exist, even though such measures could help make the case to payers to cover a service on cost-effectiveness grounds. Similarly, McCabe noted that some patients with attention deficit hyperactivity disorder have insurance policies that consider it an educational problem and will not cover it.

On this topic, Houtrow lamented the dichotomization between physical health or medicine and behavioral health, which is also embedded in payment structures and policies. "Although we would like to consider the whole child, we're often facing barriers related to whether there's a carve-out where those services can be provided, or the stigma associated" with a condition, she said. This contributes to fragmented care that is not coordinated or organized in a way that is easy to access and to use.

Also, different families need different things at different times. As such, people from outside a health care system might be leading the team serving a child's and family's needs, such as someone from a foster care agency. "When you play on a team, you aren't always holding the ball, but you need to be always ready to take it, and you need to know how to help the other people drive the ball forward," Houtrow said. Everyone has various sets of skills and strengths that children will need at different times and different places.

Ongoing changes in the health care system, such as the move to measure quality and the move away from fee-for-service care, have associated risks for children with disabilities. But there are also opportunities to learn from these different models as reform continues, Houtrow added. Today, health care providers have to maintain large volumes of patients to survive financially, which makes it difficult to serve children with complex needs. That points to the need for continuous insurance that protects families from unmet needs and does not cost too much. "We have a lot to think about—

not only payment reform for the physician, but structural reform for how we make sure that coverage is delivered," Houtrow said.

Schor also pointed out that getting a team to be physically located together is complex, especially when teams need to form and re-form for children and families with different needs. As Houtrow said, people need to understand their roles and skill sets. "It often comes down to face-to-face communication so that people know what they're expected to do, what their shared responsibility is, and how they are achieving shared goals. . . . It's very tough, and the way we do it clinically is face-to-face every week," she said.

5

Early Identification and Interventions for Developmental Disabilities Emerging in Childhood

Speakers on the next panel considered a variety of factors affecting a particular set of conditions: developmental disabilities emerging in childhood, with a particular focus on autism. Settings, approaches, funding, families, research, practice, and policy are all important dimensions of interventions for these conditions, observed moderator Craig Newschaffer, and all of these dimensions need to be considered to get a full picture of the potential of those interventions.

ENSURING QUALITY AND ACCESSIBLE CARE

Heather Johnson, acting director and chair of the Family and Women's Health Nurse Practitioner Programs at the Uniformed Services University of the Health Sciences (USUHS) Daniel K. Inouye Graduate School of Nursing, talked not only about her experiences as a family nurse practitioner but about her experiences as the mother of a son on the autism spectrum. Her son was born a few weeks early, and other than wanting to be swaddled in his swing rather than lying flat in his crib, he was a typically developing baby. But between his 15- and 18-month pediatric visits, he did not seem to be developing language in the same way that other children were doing. The family's pediatrician thought that he was just developing slowly and that Johnson might be overly concerned because she was a nurse practitioner trained to detect problems. But a month after his 18-month visit, Johnson called the Babies Can't Wait system in Georgia, where the family was living at the time, and, after an assessment, was told that her son did need services.

Speech services were not available through Babies Can't Wait, so the family needed to work through their insurance company to secure services and had to take at least 1 hour off from work 3 days a week to drive their son to his appointments. Similar arrangements were made for a special education teacher to come to his daycare program for a half-hour twice a week and for appointments with a developmental pediatrician, though the closest such specialist covered by their insurance was more than a 2-hour drive.

When the family moved to the Washington, D.C., area, Johnson lined up a new set of services ahead of relocating, but because of administrative insurance complications, the family had a significant lapse in care while they waited for a new referral. Meanwhile, their son's new school system wanted to do a parallel set of evaluations while they were trying to access care. "It was very challenging, [but] we did learn a lot from the process," Johnson said.

One complication was that many services in the Washington, D.C., area are cash-only practices. "You have to be able to keep your practice afloat, [but] there's no cloud where money comes from," she said. When getting a referral to see a speech therapist or occupational therapist in the area, they had to decide whether to get on waiting lists for a therapist who would take their insurance or pay out of pocket and hope to get reimbursed. Parent and family support systems also were often cash practices, or insurance would not cover benefits for families. Driving distances did not correspond to driving times in their new home. "It might be a 20-mile drive, but it's an hour to get there," she remarked.

Johnson drew several lessons from her family's experiences. First, she warned against a cookie-cutter approach to health care. Even though autism is now much more widely recognized and treated, treatment still often consists of 30 minutes a week of speech therapy and 30 minutes a week of occupational therapy despite the distinct needs of the patient. "We're forgetting that everybody is an individual," she said. Evidence-based practice does not just mean using practices that are based on good evidence but using evidence to inform clinical practice. Incorporating the individual characteristics of patients and family members is fundamental to evidence-based practice.

The preparation of clinicians, and especially their training to be culturally competent when treating people with disabilities, is another major consideration, she said. For example, the nurse practitioner students at USUHS receive training on typical and atypical development, 504 plans, individualized education programs, individual family service plans, and advocacy for children.

Another lesson is that parents have a major role as advocates and not just bystanders, Johnson said. In particular, primary care physicians can help parents become advocates for their children.

Schools and education systems provide health care services to help children access a free and appropriate education, but a paradigm shift is needed so that the education and health systems can work seamlessly together, Johnson said. Parents could be partners in this collaboration to reduce fragmented and redundant care, for example, decreasing the need for parallel evaluations and focusing on the same problem. “That’s something we really need to address,” she said.

BRIDGING THE GAP BETWEEN RESEARCH AND PRACTICE

The Los Angeles Unified School District is the second largest school district in the country. Three-quarters of its students are Hispanic, many of whom are English learners, and 80 percent are on free and/or reduced-price lunch. The school district has 14,000 children with autism spectrum disorder (ASD).

Connie Kasari, professor of human development and psychiatry at the University of California, Los Angeles (UCLA), does research in the school district on novel interventions for students with ASD. She began her presentation by emphasizing that public schools should be places without disparities in services. Yet white students, who make up only 9 percent of the student body, represent 30 percent of the ASD population in Los Angeles public schools. “Disparities are real,” she said. “That’s very concerning to those of us who are trying to do research in schools and to bring evidence-based practices to those settings.”

She moved on to three issues involving research. First, a huge gap exists between research and practice, she observed. Researchers might perfect an intervention in a laboratory and roll it out to a community. But most children with a disability have never been in a research study, partly because many children with comorbidities are excluded from research studies, and most interventions developed for children with disabilities have never been tested in any controlled way. “The evidence base doesn’t really reflect most children in the community,” she said.

Deployment-focused models may help, where an intervention is tested with participants within the context, such as homes or schools, for which the intervention is intended and by people, such as parents or teachers, who are intended to deliver the intervention. In addition, interventions need to be tested against usual care, she said, “because if you don’t find differences, we don’t need to change usual care.” However, as was pointed out during the discussion period, usual care as the comparison to evidence-based practice can be uninformative. A complication for research is that access to services is variable across the United States. If research is being conducted over multiple sites, some sites may have fairly good access to services, while others have poor access. In addition, different places may be more or less willing to adopt practices backed up by evidence. Usual care must be carefully considered as a comparison to evidence-based practice.

The second issue Kasari emphasized is that a single treatment is not effective for all. Many children need a combination or sequence of interventions. Methodologies need to be personalized or tailored for individuals and for sites through such approaches as sequential multiple-assignment randomized trials to see what works for which children, she said. Children who are not responding then can be provided with an increased dose, switched onto another intervention, or given a combination of interventions. "Our goal is to have all children make progress. . . . These kind of models could help us think this through," she said.

The third issue she mentioned is that sustainability is often poor. Partly, training models tend to be complicated, and implementation fidelity is often low. One way to address this issue is to think about the "active ingredients" of effective treatments, she suggested. These active ingredients may be reflected in modules or targeted treatment strategies that can be applied more flexibly than multicomponent, comprehensive treatments. Knowing what elements of an intervention make it effective can inform implementation strategies and likely lead to greater sustainability of an intervention.

Another way to increase sustainability is to foster academic-community partnerships, she said. Equitable relationships between community partners and researchers can increase the feasibility and acceptability of sustainable models. As Kasari said, "It's not easy, it takes a lot of time, yes, but it's worth it."

TREATING PROBLEM BEHAVIORS

Although estimates of prevalence vary (Emerson et al., 2011), problem behaviors are more common in individuals with ASD than same-age peers, observed Nathan Call, director of the Severe Behavior Program at the Marcus Autism Center in Atlanta. Common problem behaviors include aggression, tantrums, self-injury, disruptive behavior, property destruction, pica (the persistent eating of nonnutritive items), elopement (wandering or running from supervision), and encopresis (incontinent bowel movements). Call showed several examples at the workshop, including a heartbreaking example of a boy who engaged in self-injury in the form of head hitting, averaging about 8,000 blows to his head per 6-hour therapy day. Though his hands were padded, he had blinded himself in both eyes through repeated blunt force trauma that disconnected his retinas. "These are behaviors that can have a significant effect," said Call. They "are the number one causes for seclusion, restraint, overmedication, and isolation, in many cases both academically and residentially."

Problem behaviors also negatively affect almost every facet of a caregiver's daily life. These effects include poorer family functioning, lower marital satisfaction, higher rates of problem behavior in siblings, parental unemployment, and a significant increase in total lifetime costs of care (Caicedo, 2014; Davis and Gavidia-Payne, 2009; Hall et al., 2012; Hartley et al., 2012; Hastings, 2007; Sikora et al., 2013). Families, he related, "report to us that they don't leave their home, and that caregivers cannot work because they're taking care of their child."

The current state of treatment for problem behaviors is inadequate, Call said. Treatment is often limited to crisis stabilization, with a short-term and usually pharmacologic focus. Many families do not have access to services that can address the problems in a meaningful way. Families may wait for a crisis to occur and then call first responders who are not well equipped to deal with these behaviors. "We have patients who get tazed and have had all kinds of run-ins with juvenile justice," he said. "They end up being dropped off in an emergency room, or if they are lucky, they end up in an inpatient or residential psychiatric center."

The Severe Behavior Program at the Marcus Autism Center focuses on producing long-term effects, which requires several treatment components, said Call. The first is function-based treatments. Behavioral treatments for problem behavior that are based on the type of problem behavior, such as aggression or self-injury, are largely hit-and-miss. "They work for some kids but not all, or they work some of the time but not all of the time," he explained. Treatment components based on the purpose the behavior serves for the individual—that is, its "function"—are consistently more effective (Campbell, 2003; Heyvaert et al., 2014). He gave as an example two children who engage in self-injurious behavior, like head hitting. One may be hitting himself because he has learned that it will make people back away, whereas another might engage in the behavior because it is stimulatory and part of the repetitive nature of ASD. "Why would we expect the same treatment to work with behaviors that have completely different etiologies?" asked Call. In fact, Call and his colleagues are attempting to move pharmacologic treatment toward the same approach.

A second factor behind successful long-term outcomes is a level of service that fits where the individual falls on the continuum of severity. Tertiary care is for the most severe behaviors, which tend to be less prevalent. It requires a high investment of resources, and relatively few providers are able to deliver this care. However, many individuals are at risk for these behaviors, and if the need for intensive services can be avoided, it should be, Call observed. A group of his colleagues have developed a parent training program that is universal for children who are at risk for more significant problem behaviors, such as children who are engaging in tantrums.

Treatment of problem behavior exhibited by children with autism and other developmental disorders has generally taken one of two perspectives that have tended to be distinct in the past. One is applied behavior analysis, which tends to focus on the most severe cases, uses highly individualized treatment components, and emphasizes the basic mechanisms behind specific treatments and internal validity. The other is rooted in clinical psychology and focuses on less severe cases, group designs, manualized interventions, exportability, and external validity. There is a significant opportunity to build upon the strengths of both approaches by bridging the divide between these perspectives and answering questions on each side using whatever methods are most appropriate.

Between universal and tertiary care are individuals who have moderate intensity conditions with prevalence between the highest severity and lowest severity cases. A treatment model for these cases uses master's-level clinicians who can provide in-home community-based services to address problem behaviors. These individualized treatments focus on a handful of specific caregiver priorities and have been shown to be successful, according to Call.

All of these treatments are mediated by caregivers, Call noted, which means that caregivers have to be able to implement the treatment. This requires both buy-in and training. Although parents tend to say they will do anything to make a problem behavior get better, they can have second thoughts when they learn what they have to do. Call and his colleagues have done research into factors that affect whether caregivers follow through with treatments, such as how long it takes for a treatment to have the desired outcome and how hard a treatment is to implement. For example, the longer a treatment takes to have an effect, the less value it has for caregivers. The goal, he said, is to customize treatments not just for the child but for the family to take into account how sensitive they are to delays in outcomes or the effort the treatment requires.

Call also observed that dealing with a problem behavior is only part of the puzzle for these families. Many have a host of other issues with which they must deal, such as poverty, underemployment, lack of social supports, or barriers to treatment success. The Severe Behavior Program at the Marcus Autism Center does preadmission assessment of the home environment and identification of barriers to treatment success, with care coordination to provide wrap-around services. A problem, he acknowledged, is that care coordination is generally unreimbursed. "It isn't something that we can continue to do forever. This is something that we cover through philanthropy, but not a lot of programs are going to be able to do the same," Call said.

Finally, he observed that a major barrier to effective treatment for problem behaviors is the limited number of providers. Not many people have the level of expertise to address severe problem behaviors. This is another reason to emphasize prevention, said Call: "to do more up front, when kids are younger, smaller, when these behaviors can be managed much more easily, and to invest more resources into those types of interventions to prevent the long-term need." Intensive services will always be needed, but caregivers and health care providers both would prefer to treat children before they have lengthy histories of problem behaviors.

The prevention-based model has been conducted in clinics, but the Marcus Autism Center also has been developing a telehealth-based model in which families drive to a satellite clinic and receive the same training via video link. In the secondary care model, families download a free smartphone app so that care can be maintained from the clinic to the home. Families receive coaching in their homes from a therapist located in the center. However, this, too, is not a reimbursed service, and the regulations surrounding such care are not clear. For example, it is not clear how this service would be provided over state lines. "This is just one more area that needs to be clarified," Call said.

IMPROVING THE QUALITY OF POLICIES

A variety of policies, from the Community Mental Health Act and Medicaid in the 1960s to the Mental Health Parity Act and the Affordable Care Act in the past decade, have affected people with ASD, noted David Mandell, associate professor of psychiatry and pediatrics at the University of Pennsylvania's Perelman School of Medicine. "What these things do is open doors," said Mandell. "In a lot of ways they have been very successful."

These policies and interventions have greatly increased access to care. The number of children with a diagnosis of autism served through the special education system has risen dramatically, to 8.2 percent of all special education students. The number of children with autism who are served through the Medicaid system has similarly expanded. Laws or guidelines that require pediatricians to screen for autism and other developmental delays have led to more screening ("although not as much as we would like," said Mandell), and more children have been identified. While autism insurance mandates have not had the effect that was hoped in increasing access within the private insurance market, they have increased the number of children in private insurance who are identified with autism.

At the same time, a wealth of new interventions has improved communication, adaptive behavior, and social behavior (Weitlauf et al., 2014), Mandell said. At least in a laboratory setting, these interventions have demonstrated their potential to create profound changes for children with autism.

However, this increase in access and the creation and testing of these interventions have not resulted in a commensurate increase in quality or important outcomes, Mandell continued. For example, according to data from a Pennsylvania survey in which parents were asked if their child had ever been psychiatrically hospitalized, children in later birth cohorts had a higher risk of hospitalization than children in earlier birth cohorts (Mandell, 2008). "We are psychiatrically hospitalizing more young children now than we were a decade ago," said Mandell.

Data from the U.S. Department of Education reveal that more children are in more segregated environments in public schools than in the 1990s, after a trend toward greater inclusion in the prior years. Furthermore, the effects of community intervention on children with autism are, according to Mandell, "woefully small." The effect size of usual care on improving cognition is just 0.26, and the effect sizes on adaptive behavior, improvements in social ability, and improvements in communication are also small. "Whatever we're providing in community care is not meeting the benchmark that we've established in efficacy trials. There is something that is lost in translation about what we know works in efficacy trials versus what we are doing in communities," he said.

In a research project in the Philadelphia school district, Mandell and his colleagues compared two interventions to each other. When teachers implemented the interventions the way they were designed, one intervention showed much better outcomes than the other. "But the most startling statistic to me was the one about fidelity," he continued. Teachers were implementing about half of the components of these interventions, despite extensive training and support.

This experience led to the use of findings from social psychology to think about practitioner behavior change. In particular, Mandell's group borrowed from the Theory of Planned Behavior, which states that intentions—the degree to which an individual plans to execute a particular behavior—are the strongest predictors of that behavior. Intentions are in turn affected by attitudes, norms, and self-efficacy. The most common strategy to get practitioners to change their behavior (namely, increase their use of evidence-based practice) is to train them. "If the use of the desired practice does not increase, we train them some more," said Mandell. "We think of it as a skill deficit that we are going to improve, but the reality is that it often isn't." Policies usually offer little support or incentive in this area, given that they dwell on access without mentioning the need for practitioners to use evidence-based practices.

The comprehensive interventions that make up the bulk of tested interventions generally involve complex repertoires of behaviors. Especially for school-age children, the use of visual schedules, positive reinforcement, one-to-one instruction, and data collection form the backbone of interventions that can help children with ASD, Mandell said. His team has found that to affect behavior change among practitioners, these intervention components must be introduced and supported individually. He and his colleagues initially focus on positive reinforcement and schedules, getting buy-in from participants before moving on to one-to-one instruction and data collection.

Mandell said his take-home message was that it is practitioners' behaviors that result in a change in child outcome, so policies need to be focused on what practitioners should do. He said questions that should guide these policies are: Are the desired behavior changes clear? Who are the people whose behavior needs to change? Are the resources available to change? Is the behavior intrinsically reinforcing and, if not, what incentives should be put in place to change behavior? What is the short-term and long-term implementation policy? How can a policy and the behavior changes it seeks be made sustainable?

APPROACHES AND COMPARISONS

A major topic of conversation during the discussion session was how to identify practices that are effective with ASD and how to implement those practices more widely. Comparisons of interventions to each other or to usual care can be difficult to interpret for several reasons. One issue is that a particular intervention can be effective with some children but not others. Also, as Mandell said, in randomized trials in which a university-based intervention is compared to treatment as usual, it can be hard to distinguish between the effects of the treatment per se and the effects of having skilled clinicians deliver the intervention.

In response to a question about the National Database for Autism Research (NDAR) developed by the National Institutes of Health, Johnson pointed out that one of the difficulties with the database is the lack of people who can translate information into practices that can be implemented in schools, homes, and communities. Mandell added that NDAR has "beautiful clinical characterization" for understanding clinical features of people with autism, but "if you want to look at trajectory and treatment effects, it's not a good database." One problem he identified is that a standardized set of instruments does not exist for measuring treatment components or fidelity of implementation. A better approach might be to look at moderators and mediators of treatment effects across interventions, he suggested.

Different approaches to autism treatment tend to emphasize different treatment components and outcomes, such as observable behaviors of children versus their level of functioning and that of their families. For example, in the case of the boy hitting himself in the head, a 60 percent reduction in self-injurious behavior would be less meaningful than a measure of the family's functioning, said Call. The boy's mother "told us that the only way that she could keep him from hitting himself in the head [was] to sit by his side and restrain him all day long. She didn't take showers very often, she didn't cook meals, she didn't have very much quality of life at all. So for that mom a treatment goal would be, I need to be able to cook a meal, I need to be able to go to the store. Those are meaningful treatment goals, and when you approach it in that way, when that's what you are working toward, that changes everything else," he said.

The implementation of a particular approach is also critical, said Mandell. Two different approaches to autism treatment may be similar in essence, but the implementation of the approaches differs, which in turn has an influence on outcomes. For that reason, he said, different strategies "all should be at the table."

Outcomes are in turn related to the evidence base supporting an approach. An intervention may produce an effect but not a meaningful outcome, said Kasari. Yet reimbursement may hinge upon this effect. "I don't get reimbursed," she pointed out, "but I do care that something has a meaningful outcome and that can be implemented by somebody who can get the outcome to happen." To this, Johnson observed that "I do care about reimbursement because otherwise I can't live" while agreeing that "this is a really great point, because what is evidence, and is all evidence the same?" For example, Johnson continued, specific reading interventions might improve phonemic awareness or fluency, "but what we don't have is meaningful data showing that this intervention or this combination of interventions improves the ability to read, including understanding and being able to articulate back to somebody what was read."

Call pointed out that caregivers are highly constrained by the options that are available to them. They tend to put much of their effort into well-known interventions that they consider effective while also devoting some time to less substantiated approaches. "Caregivers are making rational choices within the sphere of information that they have. When we give them good information about treatments, they make rational choices," he said. However, when they do not have good information, they tend to make much worse choices.

A fundamental question, observed Kasari, is whether to incentivize particular practices or particular outcomes. Incentivizing outcomes assumes that people know what they should do or that there is not enough evidence to choose a particular practice. But with practices that do have evidence to support them, teachers, for example, might be expected to justify why they are not using those practices. From that perspective, case management might include doing quality assurance and improvement with care providers, with the collection of data to determine what to incentivize.

On the issue of outcomes, Mandell pointed to the examples set by the pediatric oncology and cystic fibrosis communities. Within each research and practice community, different treatment sites agreed on a common set of outcome measures and committed to sharing data so that everyone can learn from each other's practices. The challenge for the autism community is agreeing on the important outcomes not only within the medical setting, but also within the other settings in which children live, including their schools and homes. "We need to think about how to pull those groups together to have a common voice to create the same kind of successful networks that we see for condition-specific networks," Mandell said.

6

Early Identification and Interventions for Youth and Adolescents with Serious Behavioral Health Conditions

Mental health and substance use disorders often arise early in adolescence and young adulthood. Earlier interventions are better than waiting until the condition has developed, yet many years can go by before people with these very serious conditions receive treatment. Common reasons for this lack of treatment include problematic access to medical care, incorporating the priorities of families in care decision making, and the transition from child-focused treatment to adult treatment settings.

A panel of four speakers looked at several of these disorders, including depression, bipolar disorder, and schizophrenia. All pointed to the need for early identification and treatment, which also has been gaining increased attention within the federal government and state governments. As moderator Kirsten Beronio of the U.S. Department of Health and Human Services noted, her department has been focusing on getting services and supports to people with mental health and substance use disorders. "There's a lot of interest within the administration right now in thinking about those issues and redirecting some of the resources we have toward earlier intervention," she said.

EARLY INTERVENTION IN BEHAVIORAL HEALTH CONDITIONS

Clinical staging is widespread in medicine. It informs prognosis, clinical course, and treatment, including personalized care. It places an individual on a probabilistic continuum of increasing potential disease severity, from increased risk to prodome, first episode, first recurrence, and persistent illness.

In mental health, the natural history of a disorder also can move through a predictable temporal progression, said Mary Fristad, professor and vice chair for research and academic affairs in the Department of Psychiatry and Behavioral Health at Ohio State University's Wexner Medical Center. Provision of timely and stage-appropriate treatment can modify the individual's pattern of disease progression. Prognosis is generally more favorable with earlier diagnosis and intervention, as earlier treatments often have a more favorable risk-benefit ratio than those used later. (However, she noted, a caveat to keep in mind is that childhood onset can also confer greater genetic or other risk.) In particular, risk-staging provides a rationale for early intervention in depression, bipolar disorder, and schizophrenia, which are three of the four most burdensome problems in people ages 10 to 24 (Gore et al., 2011). "This notion of staging can really make a difference," she said.

Vallarino et al. (2015) reviewed 29 studies to develop an evidence map of what is known about psychosocial interventions to change the early-stage course of bipolar disorder. They found that most treatments show greater effects on depressive symptoms than manic symptoms. This study did not find any major differences between bipolar-specific and transdiagnostic treatments. The evidence map in this study was hampered by lack of a uniform staging model to select patients, Fristad noted. Specific targets were not specified, such as the sleep-wake cycle or cognitive-emotional regulation. Also, comorbid problems were not well articulated, such as substance use, physical health issues, or inactivity. But the most serious drawback, said Fristad, is that the study considered only adolescents, not younger children, even though treatments often need to start in preadolescents. "We need to think younger than the teenage years. That's not early enough if we want early intervention," she said.

According to Birmaher and Brent (2007), major depressive disorder has prevalence in any given year of about 2 percent. By age 18, however, the cumulative risk is 20 percent. The prevalence for dysthymic disorder is 0.6 to 1.7 percent. For subsyndromal depression, where some meaningful symptoms of depression are causing some functional impairment, the prevalence is 5 to 10 percent. "It's a real problem, and it's not an uncommon problem," said Fristad.

Depression in youth is linked to significant functional impairment, including risk for disruptive behavior and substance use disorders (Lewinsohn et al., 2003; Birmaher and Brent, 2007). In addition, recurrence rates are high: 40 percent in 2 years and 70 percent in 5 years. Between one-quarter and one-half of depressed children will develop a bipolar spectrum disorder within 2 to 5 years, explained Fristad.

Van Meter et al. (2011) did a meta-analysis of 150 psychopathology epidemiology studies from the past 50 years, 12 of which included mania or bipolar disorder, and found a prevalence rate of 1.2 percent for bipolar I, which is characterized by full mania but not necessarily full depression. For bipolar spectrum disorders, the prevalence was 1.8 percent in children from the ages of 7 to 21 and 2.7 percent in adolescents 12 and older. These rates are roughly comparable between the United States and other countries—1.7 percent in the United States for bipolar spectrum disorder versus 1.9 percent in the other five countries in the study. Rates are also comparable over time. "It has not increased over time, despite what people think," Fristad said.

In a review of evidence-based psychotherapy for bipolar disorder, Fristad and MacPherson (2014) looked at interventions for which the level of evidence is well established, probably efficacious, possibly efficacious, and experimental. Family psychoeducation and skill building was highest ranked, but no psychosocial treatment attained the highest category. Two randomized controlled trials have been conducted with children at high risk for bipolar spectrum disorders. Nadkarni and Fristad (2010) did a study of 165 children, 37 of whom had depression with transient manic symptoms. Eight sessions of psychoeducational psychotherapy for 8- to 12-year-olds with mood disorders found, at 12 months, a fourfold difference in conversion to bipolar spectrum disorder, with 16 percent who received psychoeducation psychotherapy converting compared with 60 percent conversion in those who had not yet received psychoeducational psychotherapy. In another study, Miklowitz et al. (2013) studied 40 high-risk children between 9 and 17 years of age and had similar results with a 12-session family-focused course of therapy. They found that those in the family-focused treatment had more rapid recovery from mood symptoms, more weeks in remission, and more favorable manic symptom trajectories. Miklowitz et al. (2014) also found, in a different study of high-risk 12- to 35-year-olds, greater improvement in attenuated positive symptoms at 6 months. "If you put these three studies together, it suggests that we can potentially alter the staging with early intervention," said Fristad.

Fristad also mentioned an intervention involving omega 3. Lin and Su (2007) found a significant antidepressant effect of omega 3 in adults with both depression and bipolar depression. In a 12-week randomized controlled trial followed by 40 weeks of follow-up, Amminger et al. (2010) found that the conversion to psychotic disorder was significantly lower in those who received 12 weeks of omega 3—a 5 percent conversion compared to a 27.5 percent conversion. Even 7 years later, in a follow-up that reached almost 90 percent of the 81 participants, they found decreased risk of progression to psychotic disorder, slower conversion times, lower psychiatric morbidity, and lower antipsychotic prescriptions in those who had received the 12 weeks of omega 3. Though these results may seem "too good to be true," said Fristad, "possibly treatment occurred during a critical developmental period, preventing changes associated with increases in striatal dopamine. It's a hypothesis that clearly needs replication."

Fristad and her colleagues have been conducting trials that use omega 3 plus psychotherapy trials, where children got both interventions, one intervention, or neither. Subjects had a reduction in depressive symptoms when they received the combination of omega 3 plus psychoeducational psychotherapy. The therapy also produced a small but measurable effect for manic symptoms. In addition, the combination of interventions produced decreased depressive symptoms in endogenously depressed children, decreased behavioral symptoms in depressed children, and improved executive functioning in children with mood disorders.

These studies are small and need to be replicated, said Fristad. But they "suggest that there's something there," she added. "Low-risk interventions such as psychotherapy or nutritional interventions may alter the progression of illness."

RECOVERY AFTER AN INITIAL SCHIZOPHRENIA EPISODE

Schizophrenia is a disabling disorder that is characterized by impaired contact with reality, diminished motivations and sense of purpose, and social withdrawal. It usually begins in late adolescence or early adulthood, just as people are launching themselves into independence and adult functioning. Most people in the United States who develop schizophrenia are ill anywhere between 1 and 3 years before treatment is initiated. During that period tremendous disability can accrue. Between 80 and 90 percent of people with schizophrenia are unemployed (Marwaha and Johnson, 2004). In any given year, between 15 and 20 percent of individuals with schizophrenia in the United States are homeless (Folsom et al., 2005), while 15 percent of state prisoners and 24 percent of jail inmates report symptoms that meet criteria for a psychotic disorder (James and Glaze, 2006). Individuals with schizophrenia die anywhere from 8 to 10 years earlier than people in the general population, often from treatable medical conditions such as cardiovascular disease (Druss et al., 2011). In addition to the personal suffering, the burden on family members is high, as are the overall health care costs. In 2005, these were estimated to be $63 billion annually in both direct and indirect costs (Wu et al., 2005).

"Some of these poor outcomes are a consequence of the way that schizophrenia has been treated in the United States," said Robert Heinssen, director of the Division of Services and Intervention Research at the National Institutes of Mental Health (NIMH). Until recently, treatment generally focused on managing psychotic symptoms and using rehabilitation therapies to try to establish people in settings outside of hospitals. It tended not to focus on helping people find work or achieve personal goals or reach high levels of independence. But, by the mid-2000s, lessons from Australia, Canada, Denmark, Sweden, and the United Kingdom showed that intervening very close to the onset of psychosis could give people much greater levels of symptomatic recovery and functional capacity. NIMH became interested in seeing whether this early intervention approach could be applied in the community treatment system common in the United States.

In 2008, NIMH launched the Recovery After an Initial Schizophrenia Episode (RAISE) Project, challenging investigators to develop and test interventions, in community settings, to treat first-episode psychosis. NIMH funded two studies both designed to maximize the external validity and utility of their findings. The RAISE Implementation and Evaluation Study (RAISE-IES) was an implementation study conducted with the commissioners of mental health of New York and Maryland as partners. That program studied the barriers to implementing a treatment program for first-episode psychosis and examined strategies that could surmount the barriers and make the intervention delivery feasible.

The RAISE Early Treatment Program (RAISE-ETP) was a national randomized controlled trial involving 34 sites in 21 states. These sites had no prior experience with first-episode psychosis care and no affiliation with academic research institutions, but did have real-world clinicians who were trained to deliver the treatment.

"We learned a lot," said Heinssen. First, the quality of care in those community treatment settings before people entered the study was worse than was assumed. People had long periods of time where they were not treated (Addington et al., 2015). Second, medications prescribed were not consistent with evidence-based guidelines (Robinson et al., 2015). Finally, very few people had integrated psychiatric and medical care, and they had cardiometabolic health risks associated with premature mortality (Correll et al., 2015).

The RAISE-ETP study evaluated a coordinated specialty care treatment program (NAVIGATE) that combined stage-specific pharmacologic therapy with recovery or resilience oriented or psychotherapy based in cognitive behavioral treatment principles. A family education component engaged family members, and employment and education supports sought to return people to their preferred work or education situations.

The results of the trial were published shortly before the workshop (Kane et al., 2015). Results showed that the experimental intervention was highly engaging. After 1 year, about 80 percent of individuals enrolled in treatment were still in the treatment and, after 18 months, 70 percent were still enrolled, even though some people were beginning to leave the program and move into other treatment settings. This was a much higher level of engagement than in the typical community care condition, Heinssen noted.

The primary outcome measure was quality of life, which is a composite measure that captures symptoms, interpersonal functioning, engagement in community activities, and some important psychological characteristics such as curiosity, motivation, interest, and emotional engagement. Individuals who received NAVIGATE achieved a significantly greater rate of recovery compared with community care. The effect size was modest, 0.31, which Heinssen characterized as a level of improvement that would be noticed by mental health professionals and family members. However, when the duration of untreated psychosis was taken into account, the situation became quite different. People who had a duration of untreated psychosis of less than 18 months showed much greater improvement than people with a longer duration of untreated psychosis. This effect size was 0.54, “something that would be noticed by friends, by teachers, and by the individual themselves,” added Heinssen.

“The bottom line of the study,” said Heinssen, is that “it’s not enough just to offer the right thing; you need to offer the right thing at the right time.” In response to early results from the study, Congress allocated an additional $25 million for first-episode psychosis treatment programs to the Substance Abuse and Mental Health Services Administration (SAMHSA) through the community mental health services block grant. Congress also directed NIMH and SAMHSA to work together to provide guidance to the states that would use the “set-aside” funds to allow this type of treatment to be broadly implemented.

In addition, RAISE-IES, had developed a number of turnkey products, and these resources were made available, at no charge, to state administrators who were planning to use the mental health block grant dollars to support this kind of treatment.

Before the study was conducted, only two states—Oregon and California—were delivering this kind of coordinated specialty care treatment program widely. Following the set-aside mental health block grant program, NIMH is projecting that 32 states and 120 clinics will be offering first-episode psychosis treatment programs, although Heinssen said, “I’m anticipating that we’ll end up with more than 32.” In addition, in October 2015, the Centers for Medicare & Medicaid Services released guidance to state Medicaid directors that endorsed coordinated specialty care, the kind of treatment tested in RAISE, as an evidence-based treatment for first-episode psychosis.

A common estimate for the amount of time it takes for original research to enter into clinical practice is 17 years (Balas and Boren, 2000), Heinssen noted. RAISE took only 7 years from the release of the statement of work to changing practice. “We consider this to be a big win,” he said. “We haven’t solved the whole problem, but we feel we’ve achieved significant traction in a relatively short period, and we’ll be building on that as we go forward.”

IMPLEMENTING COORDINATED SPECIALTY CARE SERVICES IN NEW YORK

Lisa Dixon, professor of psychiatry at Columbia University Medical Center, offered several insights generated by the implementation of the RAISE program in New York State. She was part of the RAISE Connection Program, which was a partnership between the states of New York and Maryland and NIMH. Given the success of the program, the New York State Commissioner of Mental Health found money to invest in the delivery of first-episode services to the citizens of New York. As Dixon said, this was a good example of the kind of experimentation that goes on in states and can provide a model for programs elsewhere.

Early attention was given to the program's name. Psychosis or schizophrenia are frightening words for people and could scare them away, said Dixon. The program thus became OnTrackNY, which was described as "an innovative treatment program for adolescents and young adults who recently have had unusual thoughts and behaviors or who have started hearing or seeing things that other people don't. OnTrackNY helps people achieve their goals for school, work, and relationships."

The care model consisted of a team-based approach with specific evidence-based components, including case management, supported employment and education, psychotherapy, family education and support, pharmacotherapy, and primary care coordination. Core functions of team members included specialized training, community outreach, client and family engagement, mobile outreach, and crisis intervention services.

The promotional material was focused on early identification and early treatment (see Figure 6-1). The program implementers worked with young people and family members to develop some of the outreach material. For clinicians, they sought to frame mental health recovery for young people by asking them to:

- contextualize first-episode psychosis within age-appropriate questioning about a young person's role in life;
- help clients formulate an understanding of what the problem is and how clinicians can be part of the solution;
- adopt the client's metaphor or explanation of illness to explore goals;
- reduce stigma;
- emphasize resilience and an active individual recovery journey; and
- provide the same recovery messages to a client's support network.

A major principle in setting up the system was to start small and expand wisely. To build on existing strengths, they drew on the evidence-

FIGURE 6-1 A public service ad for OnTrackNY seeks to reach out to those who have experienced the early symptoms of psychosis.
SOURCE: Durkin (2015). Available: http://sites.nationalacademies.org/dbasse/bcyf/dbasse_170078 [September 2016].

based-practice training center that Dixon was leading. They also developed a leadership group with diverse stakeholders. They connected with families, consumers, clinicians, and payers, which in this case was the state. They also considered the overall needs of the population. Schizophrenia is a relatively high-prevalence but low-incidence condition, with an average of about 10 to 12 new cases per 100,000 per year, said Dixon; "it's not something that is going to be commonly seen in middle school or high school." The appearance of just a few new cases every year requires a team-based model to deal with both high-density and low-density population centers.

The program implementers created a pilot to gather experience from four fully funded teams. They did not worry about which services were billable and which were not billable, since some would be covered and others not in the traditional framework. The program initially was limited to the downstate area to capitalize on the population density and cultural variability in that area and also to facilitate training. Four different types of programs were chosen to host the pilot: a state program, a city program, a private nonprofit program, and a hospital-based program, "because we wanted to see how this would flourish or not in these different settings," she explained. Included ages were 15 to 30, which helped bridge the adolescent-adult divide.

A particular focus was outreach, "because of course we want to get into people's homes and into schools in order to get the earliest possible identification and referral," Dixon said However, research had indicated that at least half the bottlenecks to care occur in the mental health system, so outreach also was focused on the system itself. It sought to serve people within 2 years of onset, whether insured or not insured. The treatment component continued to evolve, since, as Dixon said, "the science is moving forward even as we are implementing it, . . . and we wanted the program to live and breathe as new science occurred." Outcomes and performance expectations were measured from the beginning.

Of the 223 OnTrackNY enrollees through October 2015, the mean age was 20, and about one-fifth were under age 18. The mean length of time between the onset of psychosis and treatment was about 5 months. It has been a racially and ethnically diverse group, with 48 percent covered by Medicaid and 41 percent having private insurance. The program has produced substantial and consistent reductions in hospitalization and increases in the rates of participation in work and school, according to Dixon.

The success of the approach led to several policy advances, including an increase in the Community Mental Health Block Grant Program by $24.8 million, the allocation of funds for first-episode psychosis programs, and new guidance from NIMH and SAMHSA for states regarding effective programs for first-episode psychosis. New York State received support to enhance the participation of youth, focus on reaching more underserved individuals, and address issues of cultural competence such as enhancing the LGBTQ focus and use of social media. The program also expanded from the downstate area throughout the state.

The program has had challenges in bringing on new sites. One such challenge has been staying in sync with the Medicaid transformation toward managed care in New York State. The treatment model also has continued to evolve, with a particular focus on peer support. The program has devoted attention to transitions, follow-up, and community outreach. Major questions have included how many people can be served with a limited staff, how long the program should last, and what should happen next.

"We have benefited from the RAISE initiative," concluded Dixon. "The time is right, given the science and given the expertise in implementation, to expand and sustain resources for individuals with first-episode psychosis."

An interesting conversation arose in the discussion period about insurance coverage for OnTrackNY enrollees. Medicaid covers the program, but private insurance does not always provide coverage. Dixon said that information is being gathered for those enrollees who are being covered by private insurance, and this information is being compiled for presentation to other insurers to "try to get them on board." In addition, in New York State, most Medicaid managed care insurers have both public and private products, which could help coverage crossover.

Heinssen pointed out that when the Centers for Medicare & Medicaid Services (CMS) endorsed this as an evidence-based treatment, it created opportunities for CMS to discuss the treatment with private insurers. "CMS is the 800-pound gorilla in the room," he observed. "If they say, 'We're going to do it,' it makes it harder not to go forward on the private side." Keeping children on their parents' policy until age 25 and the preexisting conditions provisions in the Affordable Care Act also work in the direction of greater buy-in, he said.

A MODEL FOR CHILDREN INVOLVED IN BOTH CHILD WELFARE AND JUVENILE JUSTICE

In a population of young people studied by Herz (2014), 10 to 29 percent of youth ages 8 and older in child welfare were subsequently arrested. Similarly, among juvenile justice referrals, two-thirds had some sort of child welfare history. Research has long indicated that this crossover population is more likely to suffer from trauma and adverse childhood experiences, said Shay Bilchik, founder and director of the Center for Juvenile Justice Reform at Georgetown University's McCourt School of Public Policy. But only recently has it become clear that members of this population are often retraumatized by experiences with the child welfare and juvenile justice systems. "We need to think more systemically about how we pull all this together," said Bilchik. "There needs to be a very targeted conversation [about] what our research tells us about effective interventions."

Bilchik cited five factors that shape the experiences of this "dually involved" population with the child welfare system: (1) the type of child welfare placement [25% of the children who crossover live in group homes], (2) placement instability, (3) persistent or only in adolescence maltreatment, (4) the absence of positive attachments, and (5) education instability. They also tend to have academic and behavioral problems at school; high rates of mental health and substance abuse problems; and families with a history of criminal behavior, mental health, and/or substance abuse problems. Research points to "the hopelessness that this population faces, and their families struggle with, including the depression that can mount from that," he said.

The model he and his colleagues have developed sought to bring these systems together in different ways. The core elements of the model are

- identification
- equitable treatment
- family teaming
- information sharing
- coordinated case assessment, planning, and management
- evidence-based services
- trauma-informed care
- judicial administration
- permanency

The key implementation factors focus on family teaming, coordination, and permanency, said Bilchik. For example, the child welfare and juvenile justice systems often do not know that children are involved with both systems, let alone the underlying behavioral health issues—substance abuse, mental health, or educational deficits—a child might have. Family teaming is designed to bring people together around children in a holistic way to help them and their families navigate the systems they encounter and achieve better outcomes. Information sharing makes it possible to share information across systems and, when done well, build trust that the information will not be misused. Coordination of assessment, planning, and management can lead to the use of evidence-based strategies and trauma-informed care. He queried, "How does the court system integrate itself so we're not seeing families docketed in one system on Monday and another system on Thursday, where one judge is in tune with the behavioral health issues but another is looking at punitive accountability and sanctions?" Finally, permanency implies sustained relationships and support for young people and families that last beyond a program or system intervention.

The model they are using seeks to reduce juvenile justice penetration, the unnecessary use of preadjudication detention, the rate of recidivism, and re-entering the child welfare system from the juvenile justice system, noted Bilchik. To accomplish these goals, the model seeks to increase information sharing, the family voice in decision making, family and youth engagement, joint assessment and case planning, coordinated case management, behavioral health treatment, presocial bonds, and diversion.

The outcomes of this approach are "startlingly good," said Bilchik. "We see systems changing behavior, setting up new policies and practices that they then train their staff and practitioners around, and developing performance and quality assurance measures to make sure they're actually doing what they said they would do."

As Bilchik said in response to a question, "If the families are not there, if the families are not centrally involved, you're not going to end up being successful." Distrust that has been built up in families over time needs to be overcome. In the same way, the workforce needs to be respectful of the voices of families.

SYSTEMIC IMPROVEMENT

During the discussion period, a topic that arose was how to support a variety of initiatives in a variety of places as the research evidence becomes available to justify particular approaches. Heinssen pointed out that NIMH is following up on the findings he described in areas that indicate the potential for greater improvement. For example, NIMH has funded eight additional studies that are looking for practical strategies for reducing the duration of untreated psychosis. Besides identifying problems and doing research to solve them, NIMH is "keeping the engagement between the science and policy makers who are already engaged in the problem," he added. NIMH has channeled information on the results of its studies to a number of public and private organizations. "The way we're going to keep the momentum going is by continuing to add to the knowledge base and feeding the knowledge back to the policy making process," Heinssen said.

Dixon added that funding can be structured to apply resources efficiently in a community over time. However, she also warned about funding individual disorders and not thinking more carefully about the overall needs of entire populations.

Bilchik returned to the importance of the school system. Educators need to be at the table, he said, so that they can team up with people from other systems and identify the needs of children rather than pushing those children away. Children need mental health services, but they also need "a level playing field" in the educational environment, he stated. Schools could pull back from extreme suspension and expulsion policies if they understood more about the context for a child's behavior, he noted. Other agencies also could help create a safety net in the school environment to support children so they can be successful. In this way, education could become a key element of a broader case plan to support children.

7

Media and Public Perceptions and Misperceptions of Children with Disabilities

In the final panel of the workshop, five presenters examined a topic that has often been discussed by the Forum on Promoting Children's Cognitive, Affective, and Behavioral Health but has not been explicitly addressed in one of its workshops: the perceptions and misperceptions of children with disabilities that are created by the media. A panel of people in the communication sciences, journalism, and the media looked at how to frame issues and how to construct messages so that people will hear them, understand them, and act on them. As moderator Donald Wertlieb of the American Orthopsychiatric Association and Tufts University observed, the notion of disability has been changing in recent decades from the property of an individual to a property of the social, emotional, and physical environment. The media have helped and can continue to help shape skills, knowledge, and attitudes that reflect this new understanding of disability.

OVERCOMING THE STIGMA OF MENTAL ILLNESS

Science journalist Victoria Costello, who also spoke earlier in the workshop (see Chapter 2), focused on the theme of stigma, based on her book that discusses the various disorders that her family has experienced over three generations (Costello, 2012). During her book tour, she said, "it was striking how powerful it was for people, for other parents especially, to hear someone talking about their story." Personal stories help break down the stigma that surrounds these conditions, said Costello, because "they can relate to you as a person, as a parent, and then that helps them imagine that they can own up to what's going on in their households."

Costello worked on the board of the Mental Health Association of San Francisco. Some of the money generated by California's 1 percent tax on millionaires was spent on research into stigma. For instance, a study by Corrigan (2001), using 150 community college students as subjects, found that education had some impact on changing attitudes, one-on-one contact had more impact, and protests had no impact. Another study at King's College (Mehta, 2015) also found that education had a small but statistically significant effect, while one-on-one and Internet contact had a moderate impact. In that respect, said Costello, Internet contact proved to be "more intimate than, say, watching a television show about people."

Costello also pointed to the excellent care that she and her son received at a community mental health center. "These psychiatrists knew exactly what you were saying. They were the best people we dealt with," she said. Sometimes expertise is more readily available in that kind of setting than with clinicians covered by private insurance, where it can be difficult to get appointments and guarantee coverage.

MAKING AUTISM VISIBLE

Steve Silberman, a former science writer for *Wired* and the author of the book *NeuroTribes: The Legacy of Autism and the Future of Neurodiversity*, pointed to the rise of the autism advocacy movement as one way of understanding public perceptions of autism and other conditions (Silberman, 2015). In January 1962, a small group of parents in London began meeting in the kitchen of Helen Allison to form a new organization that they initially called just "The Project." They were told by other parents that the chances of getting the organization off the ground were slim. Their children's disability, they were told, was too rare and obscure to justify launching a new organization. The few psychologists and pediatricians who had heard of autism felt confident that they would get through their entire careers without seeing a single case. Furthermore, said Silberman, the prevailing theory at the time among psychiatrists and medical professionals was that parents themselves were to blame for causing this condition in their children by being cold and overly ambitious. Women who had college degrees, instead of being stay-at-home mothers, were particularly suspect, he recounted. But the group persisted, and the Society of Autistic Children, now known as the National Autistic Society, was born.

The group decided that working with the media was part of their core mission. Their children's condition was considered so rare that little scientific research had been done on it, and most lay people were unaware of the desperate need of these children and their families for support and services. In fact, said Silberman, throughout the 1960s and 1970s, autistic children were often sent to institutions, and their parents were told to remove their pictures from the family albums and never speak of them again.

A couple of months before the official launch of the society, Allison appeared on a popular BBC program called "Women's Hour" to talk about her son Joe. "The mailroom at the BBC filled up with letters, which was one of the first signs that autism was not as rare as clinicians had been insisting for more than 20 years," Silberman said. That fall a feature article on autism appeared in the London newspaper *The Evening News*. It bore the unfortunate headline "Children in Chains," Silberman reported, but it alerted the many other parents of autistic children that they were not alone.

A counterpart organization launched in the United States in 1965. An early organizer was Ruth Christ Sullivan, who Silberman said was a gifted community organizer who knew how to advocate for public policies that would benefit all children. At one point, Sullivan saw a script for a movie about an intellectually disabled man with unusual skills, which became the movie *Rain Man*. "In retrospect, *Rain Man* looked like a cliché," said Silberman. "But at the time it was a breakthrough to see an autistic person on the screen, and it was seen all over the world." As Silberman pointed out later in the workshop, the best approach is often to encapsulate a complex systems problem within a story. "Human interest stories are in general the most powerful vehicle for expressing complex systems issues, because then you don't have to argue theoretically that you need to make complex systems change. You can show this is the problem, and then you open it out to the larger systems issues," he said.

Another important event was the broadening of diagnostic criteria in the *Diagnostic and Statistical Manual of Mental Disorders*, which had the effect of more people receiving a diagnosis. At the same time, clinical instruments for screening for autism became available, and the mistaken idea that vaccines cause autism was circulated in the media. "This perfect storm of things happened that created the spike in diagnoses that started in the late 1990s," said Silberman. Autism organizations began speaking of an epidemic, which had the effect of terrifying parents. "Many studies of disabilities have shown that parental stress and suffering depends on parents' subjective views of their children's disability," said Silberman. "Children can have very serious impairments, but if their parents have a more positive view of the condition [and] have faith in their children's potential, they suffer less and make better decisions about their children's future." Yet the traditional way of gaining policy makers' attention and raising money has been to prey on parental fears of an epidemic. Silberman said, "The problem is that fear is an excellent way to raise money, and it's an excellent way to motivate policy makers, but it's not an excellent way to raise children."

Silberman pointed out another issue, which is that the criteria for autism were restricted to children for many years and only became available to adults in the 1990s. The prototypical image of someone with autism is a child, and the vast majority of autism organizations all over the world almost exclusively use pictures of children on their Websites. "The problem with that is that it tends to obscure the fact that autism is a lifelong disability that requires lifelong support and accommodations," said Silberman. "If we frame a condition like autism as exclusively a problem of children, then we create a larger problem in society. In that sense, autistic adults have been rendered doubly invisible."

CONVEYING ISSUES THROUGH STORIES

In 2015, Susan Lanzoni, a historian of science and medicine, wrote an article about her experiences caring for her 11-year-old son, who has type 1 diabetes (Lanzoni, 2015). He was attending an overnight school outing in western Massachusetts to learn about farming, and Lanzoni had to attend the outing as well to test his blood sugar at various intervals, assess his activity levels, count his carbohydrates before meals, set his infusion pump, and monitor him at night. "Yet I was also trying to be invisible," she recounted, "because what 11-year-old wants his mom coming by and chasing after him."

Part of the article's intention was to publicize type 1 diabetes, an autoimmune disease that accounts for about 5 percent of diabetes cases. Children with the disease are totally dependent on injected insulin or insulin delivered through an insulin pump. Most people know much less about type 1 diabetes, Lanzoni said, noting "when you hear about diabetes in the press, it's about type 2, and type 1 gets lost."

In writing the piece, she thought a lot about media representations and how to portray a child with a chronic condition. She wrote it as a vignette of a particular situation that occurs every day; according to Lanzoni, "this brought it to life within the context of a story." But even as a single vignette, the story brought together questions of family, schools, and communities. Sometimes parents have to work with school nurses or other staff members to train them in how to manage a condition in a communal setting. In other cases, schools have rejected children who need special attention, saying that they do not have the staff to do special monitoring or care. "We certainly have had camps that have said, 'Sorry, we just can't take you,'" she said.

She also mentioned her son's preferences. At first she was reluctant to name him in her writing, but he said that he wanted his name in the article. "I was pleasantly surprised, but it made me think a lot about his own perceptions of himself," said Lanzoni. "He's at an age where he wants to be just like the other kids, so he tries to hide his machinations with the pump as much as possible." At the same time, as he moves into adolescence, he is going to be taking on more of his own care and presenting himself to others. "That's something else to think about, with kids having their own voices and being able to tell their own stories in their own ways," she said.

APPEALING TO EMOTION AT THE AD COUNCIL

The mission of the Ad Council is to identify a select number of significant public issues and stimulate action on those issues through communications programs that make a measureable difference in society, said Tony Foleno, senior vice president for research at the Ad Council. Since the 1950s, it has done work on forest fires, polio, pollution, discrimination, drunk driving, crime, seat belts, AIDS, domestic violence, recycling, texting and driving, bullying, and, since 2008, autism.

Foleno said that he has been at the Ad Council for 14 years, and his job now is unrecognizable from what it was when he started. Partly the changes are due to the proliferation of media, including online media. Partly they are due to what he called "message clutter" caused by the number of different organizations that are vying for the public's attention. And partly they are due to an explosion of data with which to analyze and plan media campaigns.

But certain principles remain the same, he stated. The first is that appealing solely to logic never works. "The most effective campaigns . . . tell a story and tell it in an emotional, compelling way," he said. All of the Ad Council's successful campaigns have an emotional component, he said. "It could be fear, but more likely it's going to be joy or celebration or some sort of inspiration."

A second principle is that the message needs to be simple and clear. "The public doesn't care about the complexities," he said. "They want to know what they can do about it right now." One of his most difficult tasks, said Foleno, is to persuade scientists, environmentalists, public health professionals, and other professionals to narrow down their message to a single clear compelling idea.

Foleno pointed to several approaches that work. The first is to do as much research as possible on a topic. "The more homework you do in the beginning, the more literature that you can refer to, the more primary research you can do," the better, he said. Listening to the people you are trying to reach is another component of research, he said. "We need to understand and have a sense of empathy, whoever that audience might be, however different they might be from us."

Another route to success is to strive for measurable objectives. During the kickoff meetings, Foleno said he asks, "A year from now, what do we want to be talking about?" Objectives give a campaign the momentum it will need.

People who receive a message need to feel a personal connection to the content, Foleno observed. "It should feel like, 'Oh, that's for me.'" Messages also need to travel through a broad and deep media mix, he said, including social media and on-the-ground resources.

Foleno played three video clips that the Ad Council had prepared for Autism Speaks. Directed toward parents, they emphasize early interventions for young children. The first and oldest ad spot was accompanied by photographs of the singer Toni Braxton (Ad Council, 2008):

> The odds of this daughter of a clergyman spending 11 weeks at number one on the U.S. singles charts: 1 in 19 million. The odds of going on to win seven Grammy awards: 1 in 1.4 million. The odds of having a child diagnosed with autism: 1 in 68. I'm Toni Braxton, and I encourage you to learn more at autismspeaks.org/signs.

The second and more recent spot was accompanied by video of a boy playing:

> Maybe he's really focused. Maybe he likes spinning the wheels. Maybe he just loves trucks. Maybe he's just being a boy.
>
> Preoccupation with objects is one early sign of autism; learn the others today. The sooner it's diagnosed, the better.

The third and most recent spot was accompanied by an animation of a boy:

> This is a story of a boy who is very sensitive to lights and sounds. So he built secret hiding spaces where nothing could get in. The boy didn't like looking people in the eye. It made him feel uncomfortable. One day he found out he had something they called autism. His family got him help, and slowly he learned how to live with it better.
>
> Early intervention can make a lifetime of difference. Learn the signs at autismspeaks.org.

This campaign "has been a homerun for the Ad Council," said Foleno. About 4.5 million visitors have come to the Autism Speaks Website for learning the early signs of autism, "which is a huge number." Almost half of the targeted parents have seen the campaign or recognized it. Even more important, the percentage of parents who have talked to a health care professional about the possibility of autism has doubled from 8 to 16 percent.

Foleno acknowledged the power of language in messages. For example, the phrase "learning disability" places the disability with the learner rather than with the interaction between the learner and the environment. Using language that acknowledges an issue rather than a problem allows more empathy for the people affected by that issue. He said, "Empathy is the key to all of this. It's not understanding who you're trying to reach but who you're trying to help." The Ad Council's own thinking has undergone a progression on this topic, as evidenced by the changes in the three ad spots Foleno showed. Rather than playing on the ominous undertones of parental fear, the most recent spot emphasized the perspective of someone with autism, which is more likely to produce empathy. "As our understanding evolves, so does our creative work," said Foleno.

These campaigns can be expensive, Foleno acknowledged in response to a question. "There's a misperception, particularly in government and public health circles, that you could save a lot of money and still be as effective if you just build a Facebook page and tweet a bit. That's not the case. There's a reason why major advertisers spend billions of dollars every year in the United States, not just on social and interactive [media] but on broadcast as well," he said. The Ad Council relies on donated media—each campaign gets about $30 million across media platforms per year in media donations—and is currently near capacity for the campaigns it can produce. "The media community is not set up to do public service; they're set up to make money, and the competition for time and space is tremendous," he said. At the same time, he pointed to state and local organizations with limited budgets that have still been quite impactful. "But the fact of the matter is that it does cost quite a bit," he concluded.

OVERCOMING OBSTACLES TO FUNCTIONING

Emily Willingham's grandmother, who died the year before the workshop at age 91, lived for 60 years with multiple sclerosis. Whenever she encountered an obstacle in her environment that hampered her need to function, she modified the environment so that she could do what she needed. "She ran a school on her own for about 20 or 30 years," said Willingham. "There wasn't a single thing she couldn't do, because she consistently modified her environment to fit her function. I've never forgotten that."

Willingham is also the mother of three sons, two of whom have special needs. Her oldest son is autistic, and when he was diagnosed in 2004, Willingham adopted the same attitude her grandmother had. "I was going to create an environment for him that would allow him to function and still be who he is. So that's what we did. He is now at a prep school and won a championship grade-level match in chess last year for the state of California. . . . He continually surprises me, even though I have high expectations of him and always have," she said.

The environment determines disability, not the person, said Willingham. As a result, people have an obligation to create an environment that is functional for everyone.

As a developmental biologist, university teacher, and freelance writer, Willingham has thought and written about perceptions of disability in the media, including social media. In the past, people with autism have been characterized as "being toxic, or kidnapped, as monsters, as needing to be institutionalized," she observed. "The parents of these people have been characterized as refrigerator mothers. . . . Because of the fear that these perceptions have created, there has been an enormous focus on putting money toward a cure, instead of modifying the environment as much as it could be modified for existing people who are autistic."

Since her son was diagnosed and she became deeply involved in the autism community, Willingham has noticed a distinct change in attitudes toward autism. Not coincidentally, this also has been the period when social media has arisen. "We have seen Facebook, we have seen Twitter, we have seen Tumblr," she said. "It's not just that it lets parents connect. It lets autistic people connect as well, in ways that demonstrate that they have capacities that people had not previously realized they have. It gave them an outlet, it gave them a tool. It modified their environment to show their function. I think that's critical."

The language with which people talk and write about autism also has changed, she said. Style guides no longer let writers use the word "suffer" or "afflicted" in talking about people with autism. Stories about autism include quotations not just from parents but from people with autism as well. "Those people have voices as well, and they get to use them, they get to speak for themselves," Willingham stated.

Willingham urged people to stop defining high functioning and low functioning as the ability to speak. Speaking "is not reflective of cognition in any way, and never has been," she said. Someone may need support in a particular area, but that does not mean that they are low functioning. "I've had clinicians ask me, in front of my son, 'So is he really high functioning?' And I have always turned to him and said, 'Well, baby, are you?' so that he can answer that question for himself," she said.

Social perceptions shape individual perceptions, she noted, and the destigmatization of autism has led not just to awareness but to acceptance. She said, "Once we clear the way, we clear the stigma, we clear the blame, we say these people are people who have voices that they can use if you give them the right tools, these are people who can read what others write about them. Once we recognize that, . . . we don't have to dismiss their positives and their potential."

IDENTIFYING WITH A DISABILITY

An interesting discussion arose among the panel about the extent to which people acknowledge and thereby identify with their disabilities. As Silberman pointed out, "some people cannot hide their disabilities. But the process of deciding to be who you are is very powerful and important."

When one person acknowledges that he or she is clinically depressed, others feel empowered to do so as well, he pointed out. Similarly, journalists who have autism spectrum disorder (ASD) have become more willing to say so in their writing.

In the past 25 years, autistic identity and culture have developed, he said. This “allows young children and adolescents to have visible role models, which is very important and which they never had in previous generations.” In addition, an entire ecosystem has grown up of autism Websites, blogs, and other venues where autistic people can talk with each other. The development of an identity has been accompanied by considerable tension and conflict—for example, the extent to which a “cure” for autism should be emphasized—but, he said, “for the most part it has been a tremendously encouraging thing, particularly for young autistic people. They not only get the sense that they have the chance to maximize their potential, [but] they have mentors within the autistic community.” In his book, Silberman writes about engineers who realized as adults that they are autistic and that the people they had been mentoring were probably young autistic people. “Intertribal mentoring is a really powerful thing, and that’s what’s happening,” he said.

This issue comes up in the language used to refer to people with disabilities and complex health and educational needs. For example, Lanzoni objected to the use of the word “diabetic,” because it defines a person by a medical condition, reducing a person with a complex identity to a narrow disease category. “There are a multitude of voices even within what you might call a category of disability or a spectrum,” she said. “The more we can get out there, it seems to me, the better able we’re going to be to hear that diversity.” Her son tries not to draw attention to himself, but as he has approached adolescence he has been more willing to “come out, in a sense, and say, ‘This is a part of who I am.’” It is an identity too complex to be captured by the word “diabetic.”

Silberman pointed to a different aspect of language, which is that many people with ASD want to reclaim the word “autism” as part of their identity. He has a tendency to use the adjective “autistic” rather than the person-first “person with autism.” The usage is analogous to the homosexual community, in which “gay people took back words like ‘queer’ as badges of pride. For many people with autism, the word ‘autistic’ is a badge of pride,” he said.

Similarly, Foleno pointed to the work on addiction done by the Ad Council, where organizations like Alcoholics Anonymous emphasize the need to acknowledge that someone is an alcoholic first and everything else follows. “It’s deliberately reductionist,” Foleno said.

Amy Houtrow of Children’s Hospital of Pittsburgh said, as someone who participates in and has studied the disability rights movement, “person-first language still reminds us in an important way to make sure we're destigmatizing, and not just labeling." At the same time, part of destigmatization is the ownership of a condition, she commented.

These differences also appear within particular communities, such as the deaf community. As Willingham pointed out, within disability communities, some people are focused on a cure for a disability, while others are fighting for the right to be the way they are.

Costello added that everyone has to manage his or her own mental health, and mental health does not stay static. Some disorders are more familiar, such as depression or anxiety, but most people are going to have a mental health issue at some point in their lives, she said. "As with other medical illnesses, psychiatric illness is a nearly universal experience."

Silberman added that most people will be disabled at some point in their lives, with the extent of their disability changing over time. In that respect, the autism rights movement has close ties to the disability rights movement.

Houtrow made the same point about disability. As she explained, "Many of you are wearing eyeglasses. You have visual impairment. If I took your eyeglasses away from you, you would no longer be accommodated. Some of you may not be able to drive a car. Some of you might not be able to read. Some of you might not be able to find your way to the bathroom because your visual impairment is that severe. So there is always going to be an interaction between the person and their environment that creates disability."

As pointed out by other speakers, disability is universal. "It has affected each and every one of us," said Houtrow. "Every single one of us has had a cold and has been stuck in bed feeling terrible, not being able to do day-to-day activities. It happens all the time. If we can just own that disability is a part of everyone's life, it will become less stigmatized."

8

Breakout Groups and the Reflections of Moderators

In the final session of the workshop, representatives from three breakout groups reported back on the main topics of discussion during the workshop's breakout session. Finally, the moderators of each panel and breakout group reporters reflected on the major themes that emerged from the workshop. In addition, Box 8-1 at the end of this chapter lists suggestions for future actions made by speakers earlier in the workshop.

MOVING FORWARD WHEN THE EVIDENCE BASE IS LACKING

One breakout group looked at how to think about interventions when the evidence base is incomplete. C. Hendricks Brown of Northwestern University, who reported back for the group, emphasized the importance of integrating services with research, which can help address the lack of an evidence base. For example, the split within the federal government of research and mental health services "has caused serious problems," he said, "and it's time to reshape that." Integrating the two can both improve research and provide the best services possible, Brown said.

Emily Lichvar of the Substance Abuse and Mental Health Services Administration (SAMHSA), who also reported back for the group, pointed out that many evidence-based practices are targeted toward specific groups, thresholds, or diagnoses. If these practices could be extended to other populations or individuals who are in an earlier stage of a disorder, the practices could have more widespread benefits and could be studied in a broader context. In addition, the origins of many mental health problems are in childhood, she pointed out. Screening and early interventions thus may be able to prevent later problems that emerge in adolescence and young adulthood while also adding to the evidence base.

Group members discussed the fact that parents have opportunities to learn about research projects and get involved in those projects to take advantage of those interventions, even if not all the components of an intervention are offered at all times. However, both research and services require getting and maintaining the attention of policy makers to ensure funding for complex medical and educational needs. These goals hinge in part on public perceptions of these conditions (see Chapter 7).

The group also discussed the advantages and disadvantages of a reliance on specific diagnoses. A diagnosis identifies people with a prognosis, which can cause stigma and discrimination, but it also provides a name for a person's condition. In addition, some conditions have been "medicalized," when, often, different kinds of interventions are needed to relieve suffering, members of this breakout group observed.

COMMUNITY ENGAGEMENT AND PARTNERSHIPS

Kelly Kelleher of the Research Institute at Nationwide Children's Hospital and Angela Lello of Autism Speaks reported back for the group on community engagement and partnerships for development and implementation of solutions. Members of the group observed, first, that there is no single definition of a community. Attempting to define a community by a diagnosis runs up against the fact that needs, preferences, opinions, and languages all vary even within a single diagnosis. Rather, communities take shape naturally and have overlaps and shared areas of concern with other communities, as in a multidimensional Venn diagram.

In that case, to build capacity in communities to reduce risk and enhance access to care, multiple communities need to engage with children and families with disabilities, Kelleher and Lello reported. This requires ongoing education and resources for the members of these diverse communities, and particularly for those communities that do not usually engage with people affected by disabilities. Resources might include, for example, information about the key opinion leaders in different communities, including the disability community, and how to engage with those individuals.

Kelleher and Lello also noted that existing resources and models of community and family engagement can be adapted for work with disabilities. However, responses to disability need to be reactive and flexible to meet the needs of diverse communities.

One issue is what are the big questions that communities are facing, they noted. Where is the overlap among these issues, and are there common solutions that would help address these issues?

OVERCOMING BARRIERS TO COLLABORATION

The third group included participants in both the workshop and in a 2-day meeting preceding the workshop titled "Designing Systems That Work for Children with Complex Health Care Needs" sponsored by the Lucile Packard Foundation for Children's Health. Edward Schor of the Lucile Packard Foundation, who reported back for the group, pointed out that a theme of both meetings was the need to overcome barriers to good quality care, prominently including barriers to collaboration. "The care of any complex, chronic condition is going to require multidisciplinary approaches, and yet we have substantial barriers, both in practice and policy, that interfere with that kind of collaboration," said Schor. A particularly difficult collaboration is with the education system, yet this collaboration is essential once children reach school age. Schools "need to come to appreciate how important it is to collaborate with all the rest of the systems that are serving children and families," Schor noted.

In general, members of the breakout group said the social determinants of health need to be factored directly into health care systems, not addressed as an afterthought, Schor reported. These social factors are often the primary determinants of not only whether people can access care, but also whether they benefit from the care that they can access. Members of the group also asked whether insurance is the right way to address chronic illness and preventive services. Insurance was designed to respond to rare and unanticipated events. But disabilities and complex health and educational needs are not rare and self-limiting; they are chronic and expansive. "Are there different, not just payment strategies, but financing strategies, that we ought to be considering, that will allow us to provide the services that are needed?" Schor asked.

Change often originates at the local level, Schor observed. An innovation happens locally and is identified as a best practice, the change then moves to the state level, and the state serves as a laboratory for federal policy. "It's unusual for federal policy to lead; it usually follows," he observed. Intentionally tracking innovations at the local and state level therefore can be a valuable spur to policy change, even as broader efforts to change federal policy continue.

Finally, Schor pointed to the need to "follow the dollars." In California, for example, developmental services are provided by 21 independent contractors. If two children with identical problems, one black and one white, go into the same center, the white child gets twice as many services as the black child, he said, "and these are by people who want to do the right thing." The problems caused by funding and health care disparities will need continuing attention, he said.

COORDINATING SYSTEMS OF CARE

In the session where panel moderators joined the breakout group reporters to reflect on the main messages emerging from the workshop, Deborah Klein Walker returned to a theme that arose in several panels: the need for care coordination among systems. The underlying question, she said, is who is responsible for the health of children, including those with complex medical conditions. In many states, systems come together to provide a loosely coordinated system of care for children. However, that system breaks up when children become adolescents and adults. "I don't have the answer, but if we can't solve those bigger policy issues of the points of accountability at the federal and state level, . . . we've lost it," she said.

Parents, families, and communities are key to a more cohesive system, she said. The United States has never made a commitment to fully fund health care for everyone who needs it, and today's emphasis on health equity highlights the needs that are going unmet. "How do we come together to build that kind of system?" she asked. People in the states want to make this happen for children and adolescents, but "it takes leadership at the federal level, and right now that's a big issue."

As one way to improve cohesion, Stephen Shore pointed to the parent skills training that Autism Speaks supports in low-resource areas. This initiative takes a lot of time and effort, he said, but research on the efficacy of such programs might point in productive directions. Also, experiences in the autism community could be disseminated to other parts of the disability community. "We're a community here, all of us in this room. What can we do to reach out to learn what other people are doing?" he stated.

Several of the other moderators commented on the need for a unified front. For example, Mary Ann McCabe pointed to the funding silos within the federal government as an impediment to greater cohesion. "Even the journals and such are siloed in a way where somebody in one area will be very unlikely to learn about integration in another," she said. Shore observed that advocates cannot be stymied by federal bureaucracies and siloed departments, or "we'll be back talking about this decade after decade." Keynote speaker Maureen Durkin said that even at the federal level, there is no incentive to work together for children. Instead, funding streams are more incentivized to work separately and competitively.

Walker observed that disability affects all social groups, "so it shouldn't be one of those things that we can't come together on." But the American public needs to know more about disability, she said. Advocacy groups could send unified messages, with champions leading the way toward change, as champions at the federal, state, and local level have done in the past. "There is strength in coming together and advocating for similar things," she suggested.

Strengthening the link between disabilities and disparities is another way to foster change, Walker said. "Disability is a health disparity and should be on the health equity agenda in this country," she said, as reflected by the designation of disabilities as a source of health inequities by the Centers for Medicare & Medicaid Services. People with disabilities have a history of exclusion and discrimination, they have population-level differences in health outcomes, and those differences are preventable and unjust, Walker said.

She added that prevention of disability influences everyone, not just individual groups. The United States spends $3 trillion on a health system that is responsible for only a small fraction of the health of the population. Investing in the social determinants of health could boost education, employment, and health simultaneously. "That's where true prevention is," she stated.

One obstacle to prevention, Walker continued, is the Office of Management and Budget's requirement that federal funding show a return on investment within 3 years. With children, a return on investment may not materialize until 10 years later. As a result, she said, children "do not get the focus or the understanding that they need in a lot of the legislation or in the funding models." A logic model could identify intermediate outcomes on the way to an ultimate outcome, but, she asked, "is that really realistic?"

On the subject of coordination, Lichvar asked whether public schools are currently equipped "from an infrastructure perspective, or from a staffing perspective, to meet the needs of children with complex medical and health and mental health problems." Teachers are focused on trying to bring all of the 30 or more students in their classroom up to an adequate level on tests, and adding more responsibilities to their jobs may not be possible. "My brother is a third grade teacher," she said, "and he has 30 students in his class. Eight of his 30 students have various accommodations, and, to be quite frank, he is not meeting those accommodations, it's physically not possible. . . . He wants to meet the needs, he's agreed to meet their needs, they all have Individualized Education Programs, it's in writing, he has to report on all of this, but it's quite simply not happening." One possible approach at the school or county level may be to do something like case management, but schools are not equipped to meet these needs today, she said.

Kelleher observed that the parents and families who are able to advocate for their children with schools and other institutions are the ones with resources. "We don't see that among people without resources. These kids are disproportionally trucked in to foster care and other situations if they have medical complexity and multiple disabilities, and there's nobody advocating for them," Kelleher noted.

OPTIONS FOR PREVENTION AND TREATMENT

Several speakers in the workshop's final session also raised issues involving prevention and treatment choices. For example, Craig Newschaffer pointed to the tension between targeted and universal programs, adding that the two approaches are not necessarily antagonistic. Programs aimed at a group at the extreme of a distribution can serve a much larger population if they are designed to do so, which would also break down barriers among groups.

In addition, he mentioned the importance of developing alternative outcomes as one way to close the gap between research and practice. For example, measures of implementation fidelity, changes in the classroom, or enhanced parental decision making could be used to shape policy.

Forum member David Hawkins of the University of Washington pointed to the role of primary care and schools in delivering preventive interventions to parents and children. "It's important to think about both improving parenting skills in the whole population as well as ensuring that those parents who are dealing with even more difficult problems have the tools and skills they need," he said. The challenge, said Hawkins, is to be able to provide a service without a diagnosis and to someone who is not the patient. "We need to get that to be something that is acceptable and legitimate to do—and legal to do." McCabe similarly pointed out that many of the incentives in place today are based on an adult model and do not adequately recognize the importance of childhood and life course health development.

As Shore observed, "primary care pediatrics is as close as we can come . . . to a universal infrastructure that can reach all families. It's far more pervasive than organized child care." The problem is that most pediatricians are not well prepared to offer preventive services.

Shore suggested another approach. "Obstetricians routinely ask women pregnant with their first baby, 'Where are you going for your prenatal classes?' That's not thought of as a pejorative or stigmatizing question. That's just part of the system. I think pediatricians ought to be asking first parents, 'Where you are going for your parenting education?'" Today, many parents do not have access to parenting education programs, Shore acknowledged. "But if we had universal parenting education as an accepted thing that you do when you're a first parent, we could make some real progress on preventing some of the things we've been discussing today."

Newschaffer also identified the prenatal period as a period of risk for many of the conditions discussed at the workshop, including, possibly, schizophrenia and autism. "There's a lot going on there that we don't fully understand if we're thinking about prevention."

At the same time, McCabe added, interventions cannot take the route of blaming parents, despite the good evidence for parenting programs as interventions for disruptive behavior disorders. Blaming is why parents do not get these services. “We can’t do a mass campaign to tell parents that they’re the answer because they’re the problem. It’s not going to fly. We have a lot of work to do to figure out how to communicate all we know and the urgency of it, and help families see it as a supportive move and not that they are the cause.”

A WHITE HOUSE CONFERENCE AND FEDERAL CHILDREN’S OFFICE

Finally, the moderators noted that, at several points during the workshop, several speakers and participants called for a new White House conference on children, the last of which was held in 1971, and for the establishment of a federal children’s office in the near-term future. Such steps would make it possible to reach out to other people and “go beyond talking to ourselves,” said McCabe.

BOX 8-1
Suggestions by Workshop Presenters for Future Actions

In addition to the workshop participants who spoke in the final session, the speakers on previous panels expressed ideas that have implications for future actions. The following list recapitulates suggested actions from earlier in this Proceedings of a Workshop:

- Better preparation of adolescents through education in health literacy and self-management skills would improve the transition from pediatric to adult care. (Plevinsky)
- Parents can reduce the gap between research and practice by sharing information, advocating for resources, and countering misconceptions. (Costello)
- The provision of information and other resources to parents by health care organizations can increase cooperation among families and between families and providers. (Hurley)
- The education of children with disabilities and complex health and educational needs in inclusive settings can benefit children both with and without disabilities. (Durkin)
- Better ways of assessing the strengths and trajectories of families could lead to interventions that improve their ability to cope with the symptoms of traumatic stress. (Kazak)

continued

BOX 8-1
Continued

- Similarly, ways of assessing and taking advantage of the strengths and weaknesses of communities can help care providers meet the needs of families. (Everhart)
- The proper training and support of care providers would improve the provision of care for children with complex needs and their families. (Dunlap)
- Increased communication and coordination among care organizations could help accommodate the many differences among children and families. (Houtrow)
- Cultural competency is an important skill for clinicians and other health care providers who work with children who have disabilities and complex health and educational needs. (Johnson)
- Equitable relationships between community partners and researchers can increase the feasibility and acceptability of sustainable research and care models. (Kasari)
- A level of service that fits where an individual falls on the continuum of severity can contribute to successful long-term outcomes. (Call)
- Introducing and supporting the components of interventions separately can help change behaviors among care providers. (Mandell)
- Earlier diagnosis and intervention can modify patterns of disease progression. (Fristad)
- In particular, intervening close to the onset of psychosis can provide greater levels of symptomatic recovery and functional capacity. (Heinssen)
- Outreach to individuals and families can increase early identification and treatment. (Dixon)
- Children involved in both the child welfare and juvenile justice systems often have attributes that require targeted interventions. (Bilchik)
- Though campaigns to raise awareness of a condition often invoke fear, a more positive view of a condition tends to lead to better decisions. (Silberman)
- Personal stories of individual children and their families can raise much broader issues involving treatments and other interventions. (Lanzoni)
- New forms of media, including social media, allow for greater personal connection to the content of media messages. (Foleno)
- Reducing the stigma associated with a condition can lead not only to greater awareness, but also to greater acceptance of that condition. (Willingham)

References

Ad Council. (2008). *The Odds of Having a Child Diagnosed with Autism—Toni Braxton.* Available: https://youtu.be/XxCgtLyyGB8 [June 2016].

Addington, J., Heinssen, R.K., Robinson, D.G., Schooler, N.R., Marcy, P., Brunette, M.F., Correll, C.U., Estroff, S., Mueser, K.T., Penn, D., Robinson, J.A., Rosenheck, R.A., Azrin, S.T., Goldstein, A.B., Severe, J., and Kane, J.M. (2015). Duration of untreated psychosis in community treatment settings in the United States. *Psychiatric Services, 66*(7), 753-756.

Agency for Healthcare Research and Quality. (2005). *National Healthcare Disparities Report, 2005*. Rockville, MD: U.S. Department of Health and Human Services.

Akinbami, L.J., Moorman, J.E., Bailey, C., Zahran, H.S., King, M., Johnson, C.A., and Liu, X. (2012). Trends in asthma prevalence, health care use, and mortality in the United States, 2001-2010. *National Center for Health Statistics Data Brief, 94*, 1-8.

Alisic, E. (2011). *Children and Trauma: A Broad Perspective on Exposure and Recovery.* Utrecht, Netherlands: Labor Grafimedia BV.

Amminger, G.P., Schäfer, M.R., Papageorgiou, K., Klier, C.M., Cotton, S.M., Harrigan, S.M., Mackinnon, A., McGorry, P.D., and Berger, G.E. (2010). Long-chain omega-3 fatty acids for indicated prevention of psychotic disorders: A randomized, placebo-controlled trial. *Archives of General Psychiatry, 67*(2), 146-154.

Balas, E.A., and Boren, S.A. (2000). Managing clinical knowledge for health care improvement. In J. Bemmel and A.T. McCray (Eds.), *Yearbook of Medical Informatics 2000: Patient-Centered Systems* (pp. 65-70). Stuttgart, Germany: Schattauer.

Bethell, C.D., Read, D., Stein, R.E., Blumberzg, S.J., Welzls, N., and Newacheck, P.W. (2002). Identifying children with special health care needs: Development and evaluation of a short screening instrument. *Ambulatory Pediatrics, 2*(1), 38-48.

Birmaher, B., and Brent, D. (2007). Practice parameter for the assessment and treatment of children and adolescents with depressive disorders. *Journal of the American Academy of Child and Adolescent Psychiatry, 46*(11), 1503-1526.

Boyle, C.A., Boulet, S., Schieve, L.A., Cohen, R.A., Blumberg, S.J., Yeargin-Allsopp, M., Visser, S., and Kogan, M.E. (2011). Trends in the prevalence of developmental disabilities in US children, 1997-2008. *Pediatrics, 127*(6), 1034-1042.

Caicedo, C. (2014). Families with special needs children: Family health, functioning, and care burden. *Journal of the American Psychiatric Nurses Association, 20*(6), 398-407.

Campbell, J.M. (2003). Efficacy of behavioral interventions for reducing problem behavior in persons with autism: A quantitative synthesis of single-subject research. *Research in Developmental Disabilities, 24*(2), 120-138.

Canino, G., Koinis-Mitchell, D., Ortega, A.N., McQuaid, E.L., Fritz, G.K., and Alegría, M. (2006). Asthma disparities in the prevalence, morbidity, and treatment of Latino children. *Social Science and Medicine, 63*(11), 2926-2937.

Centers for Disease Control and Prevention. (2014). Prevalence of Autism Spectrum Disorder among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010. *Morbidity and Mortality Weekly Report, 63*(SS02), 1-21.

Child Trends Databank. (2015). *Infant, Child, and Teen Mortality: Indicators on Children and Youth*. Available: http://www.childtrends.org/wp-content/uploads/2012/11/63_Child_Mortality.pdf [June 2016].

Correll, C.U., Detraux, J., De Lepeleire, J., and De Hert, M. (2015). Effects of antipsychotics, antidepressants and mood stabilizers on risk for physical diseases in people with schizophrenia, depression, and bipolar disorder. *World Psychiatry, 14*(2), 119-136.

Corrigan, P.W., River, L.P., Lundin, R.K., Penn, D.L., Uphoff-Wasowski, K., Campion, J., Mathisen, J., Gagnon, C., Bergman, M., Goldstein, H., and Kubiak, M.A. (2001). Three strategies for changing attributions about severe mental illness. *Schizophrenia Bulletin, 27*(2), 187-195.

Costello, V. (2012). *A Lethal Inheritance: A Mother Uncovers the Science Behind Three Generations of Mental Illness*. Amherst, NY: Prometheus.

Cox, C.M., Kenardy, J.A., and Hendrikz, J.K. (2008). A meta-analysis of risk factors that predict psychopathology following accidental trauma. *Journal for Specialists in Pediatric Nursing, 13*(2), 98-110.

Davis, K., and Gavidia-Payne, S. (2009). The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities. *Journal of Intellectual and Developmental Disability, 34*(2), 153-162.

Denlinger, L.C., Sorkness, C.A., Chinchilli, V.M., and Lemanske, Jr., R.F. (2007). Guideline-defining asthma clinical trials of the National Heart, Lung, and Blood Institute's Asthma Clinical Research Network and Childhood Asthma Research and Education Network. *Journal of Allergy and Clinical Immunology, 119*(1), 3-11.

Division for Early Childhood and National Association for the Education of Young Children. (2009). *Early Childhood Inclusion: A Joint Position Statement*. Chapel Hill: University of North Carolina, FPG Child Development Institute.

Dixon, L. (2015). *Implementing Coordinated Specialty Care Services: From RAISE Connection to OTNY and Beyond*. Presentation at the Workshop on Ensuring Quality and Accessible Care for Children with Disabilities and Complex Health and Educational Needs, Washington, DC. Available: http://sites.nationalacademies.org/dbasse/bcyf/dbasse_170076 [June 2016].

Druss, B.G., Zhao, L., Von Esenwein, S., Morrato, E.H., and Marcus, S.C. (2011). Understanding excess mortality in persons with mental illness: 17-year follow-up of a nationally representative U.S. survey. *Medical Care, 49(*6), 599-604.

Durkin, M. (2015). *Disability Names and Numbers: Challenges and Opportunities in Nosology, Epidemiology, and Equity/Disparity*. Presentation at the Workshop on Ensuring Quality and Accessible Care for Children with Disabilities and Complex Health and Educational Needs, Washington, DC. Available: http://sites.nationalacademies.org/dbasse/bcyf/dbasse_170078 [June 2016].

Durkin, M.S., Maenner, M.J., Meaney, F.J., Levy, S.E., DiGuiseppi, C., Nicholas, J.S., Kirby, R.S., Pinto-Martin, J.A., and Schieve, L.A. (2010). Socioeconomic inequality in the prevalence of autism spectrum disorder: Evidence from a U.S. cross-sectional study. *PLoS One, 5*(7), e11551.

Emerson, E., Einfeld, S., and Stancliffe, R.J. (2011). Predictors of the persistence of conduct difficulties in children with cognitive delay. *Journal of Child Psychology and Psychiatry, 52*(11), 1184-1194.

Folsom, D.P., Hawthorne, W., Lindamer, L., Gilmer, T., Bailey, A., Golshan, S., Garcia, P., Unutzer, J., Hough, R., and Jeste, D.V. (2005). Prevalence and risk factors for homelessness and utilization of mental health services among 10,340 patients with serious mental illness in a large public mental health system. *American Journal of Psychiatry, 16*(2), 370-376.

Fristad, M.A., and MacPherson, H.A. (2014). Evidence-based psychosocial treatments for child and adolescent bipolar spectrum disorders. *Journal of Clinical Child and Adolescent Psychology, 43*(3), 339-355.

Gore, F.M., Bloem, P.J., Patton, G.C., Ferguson, J., Joseph, V., Coffey, C., Sawyer, S.M., and Mathers, C.D. (2011). Global burden of disease in young people aged 10-24 years: A systematic analysis. *Lancet, 377*(9783), 2093-2102.

Hait, E.J., Barendse, R.M., Arnold, J.H., Valim, C., Sands, B.E., Korzenik, J.R., and Fishman, L.N. (2009). Transition of adolescents with inflammatory bowel disease from pediatric to adult care: A survey of adult gastroenterologists. *Journal of Pediatric Gastroenterology and Nutrition, 48*(1), 61-65.

Halfon, N., Houtrow, A., Larson, K., and Newacheck, P.W. (2012). The changing landscape of disability in childhood. *The Future of Children, 22*(1), 13-42.

Hall, A.G., Bouldin, E.D., Andresen, E.M., and Ali, A.K. (2012). Maintaining employment among caregivers of individuals on a Medicaid waitlist for services. *Journal of Disability Policy Studies, 23*(2), 121-128.

Hartley, S.L., Barker, E.T., Baker, J.K., Seltzer, M.M., and Greenberg, J.S. (2012). Marital satisfaction and life circumstances of grown children with autism across 7 years. *Journal of Family Psychology, 26*(5), 688-697.

Hastings, R.P. (2007). Longitudinal relationships between sibling behavioral adjustment and behavior problems of children with developmental disabilities. *Journal of Autism and Developmental Disorders, 37*(8), 1485-1492.

Herz, D. (2014). *Building A Multi-Systems Approach: Defining and Identifying "Crossover Youth."* Module presentation from the Juvenile Justice and Child Welfare: Multi-System Integration Certificate Program, Center for Juvenile Justice Reform, Washington, D.C.

Heyvaert, M., Saenen, L., Campbell, J.M., Maes, B., and Onghena, P. (2014). Efficacy of behavioral interventions for reducing problem behavior in persons with autism: An updated quantitative synthesis of single-subject research. *Research in Developmental Disabilities, 35*(10), 2463-2476.

Hoover, H. (1931). Letter endorsing the Children's Charter, April 7. Available: https://research.archives.gov/id/187089 [June 2016].

Houtrow, A.J., Larson, K., Olson, L.M., Newacheck, P.W., and Halfon, N. (2014). Changing trends of childhood disability, 2001-2011. *Pediatrics, 134*(3), 530-538.

Hoyert, D.L., and Xu, J. (2012). Deaths: Preliminary data for 2011. *National Vital Statistics Reports, 61*(6), 1-51.

James, D.J., and Glaze, L.E. (2006). Mental health problems of prison and jail inmates. *Bureau of Justice Statistics Special Report*. Available: http://www.bjs.gov/content/pub/pdf/mhppji.pdf [June 2016].

Kahana, S.Y., Feeny, N.C., Youngstrom, E.A., and Drotar, D. (2006). Posttraumatic stress in youth experiencing illnesses and injuries: An exploratory meta-analysis. *Traumatology, 12*(2), 148-161.

Kane, J.M., Robinson, D.G., Schooler, N.R., Mueser, K.T., Penn, D.L., Rosenheck, R.A., Addington, J., Brunette, M.F., Correll, C.U., Estroff, S.E., Marcy, P., Robinson, J., Meyer-Kalos, P.S., Gottlieb, J.D., Glynn, S.M., Lynde, D.W., Pipes, R., Kurian, B.T., Miller, A.L., Azrin, S.T., Goldstein, A.B., Severe, J.B., Lin, H., Sint, K.J., John, M., and Heinssen, R.K. (2015). Comprehensive versus usual community care for first-episode psychosis: 2-year outcomes from the NIMH RAISE Early Treatment Program. *American Journal of Psychiatry, 173*(4), 362-372.

Kazak, A.E., Alderfer, M., Rourke, M., Simms, S., Streisand, R., and Grossman, J.P. (2004). Posttraumatic stress symptoms (PTSS) and posttraumatic stress disorder in families of adolescent childhood cancer survivors. *Journal of Pediatric Psychology, 29*, 211-219.

Lanzoni, S. (2015). An overnight field trip with my son—and his diabetes. *Cognoscenti*. Available: http://www.wbur.org/cognoscenti/2015/07/07/parenting-a-child-with-type-1-diabetes-susan-lanzoni [June 2016].

Leonard, S., Bower, C., Petterson, B., and Leonard, H. (2000). Survival of infants born with Down's syndrome: 1980-1996. *Paediatric and Perinatal Epidemiology, 14*(2), 163-171.

Lewinsohn, P.M., Pettit, J.W., Joiner Jr., T.E., and Seeley, J.R. (2003). The symptomatic expression of major depressive disorder in adolescents and young adults. *Journal of Abnormal Psychology, 112*(2), 244-252.

Lin, P.Y., and Su, K.P. (2007). A meta-analytic review of double-blind, placebo-controlled trials of antidepressant efficacy of omega-3 fatty acids. *Journal of Clinical Psychiatry, 68*(7), 1056-1061.

Mandell, D.S. (2008). Psychiatric hospitalization among children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38*(6), 1059-1065.

Marwaha, S., and Johnson, S. (2004). Schizophrenia and employment: A review. *Social Psychiatry and Psychiatric Epidemiology, 39*, 337-349.

Mehta, N., Clement, S., Marcus, E., Stona, A.-C., Bezborodovs, N., Evans-Lacko, S., Palacios, J., Docherty, M., Barley, E., Rose, D., Koschorke, M., Shidhaye, R., Henderson, C., and Thornicroft, G. (2015). Evidence for effective interventions to reduce mental health-related stigma and discrimination in the medium and long term: Systematic review. *British Journal of Psychiatry, 207*(5), 377-384.

Miklowitz, D.J., Schneck, C.D., Singh, M.K., Taylor, D.O., George, E.L., Cosgrove, V.E., Howe, M.E., Dickinson, L.M., Garber, J., and Chang, K.D. (2013). Early intervention for symptomatic youth at risk for bipolar disorder: A randomized trial of family-focused therapy. *Journal of the American Academy of Child and Adolescent Psychiatry, 52*(2), 121-131.

Miklowitz, D.J., O'Brien, M.P., Schlosser, D.A, Addington, J., Candan, K.A., Marshall, C., Domingues, I., Walsh, B.C., Zinberg, J.L., De Silva, S.D., Friedman-Yakoobian, M., and Cannon, T.D. (2014). Family-focused treatment for adolescents and young adults at high risk for psychosis: Results of a randomized trial. *Journal of the American Academy of Child and Adolescent Psychiatry, 53*(8), 848-858.

Moorman, J.E., Zahran, H., Truman, B.I., and Molla, M.T. (2011). Current asthma prevalence—United States, 2006-2008. *Morbidity and Mortality Weekly Report, 60*(1), S84-S86.

Nadkarni, R.B., and Fristad, M.A. (2010). Clinical course of children with a depressive spectrum disorder and transient manic symptoms. *Bipolar Disorders, 12*(5), 494-503.

National Academies of Sciences, Engineering, and Medicine. (2015). *Mental Disorders and Disabilities Among Low-Income Children*. Washington, DC: The National Academies Press.

National Research Council and Institute of Medicine. (2004). *Children's Health, The Nation's Wealth: Assessing and Improving Child Health*. Committee on Evaluation of Children's Health. Board on Children, Youth, and Families, Division of Behavioral and Social Sciences and Education. Washington, DC: The National Academies Press.

Plevinsky, J.M., and Greenley, R.N. (2014). Exploring health-related quality of life and social functioning in adolescents with inflammatory bowel diseases after attending Camp Oasis and participating in a Facebook group. *Inflammatory Bowel Diseases, 20*(9), 1611-1617.

Plevinsky, J.M., Gumidyala, A.P., and Fishman, L.M. (2015). Transition experiences of young adults with inflammatory bowel diseases (IBD): A mixed-methods study. *Child Care, Health, and Development, 41*(5), 755-761.

Price, J., Kassam-Adams, N., Alderfer, M.A., Christofferson, J., and Kazak, A.E. (2016). Systematic review: A reevaluation and update of the integrative (trajectory) model of pediatric medical traumatic stress. *Journal of Pediatric Psychology, 41*(1), 86-97.

Robinson, D.G., Schooler, N.R., John, M., Correll, C.U., Marcy, P., Addington, J., Brunette, M.F., Estroff, S.E., Mueser, K.T., Penn, D., Robinson, J., Rosenheck, R.A., Severe, J., Goldstein, A., Azrin, S., Heinssen, R., and Kane, J.M. (2015). Prescription practices in the treatment of first-episode schizophrenia spectrum disorders: Data from the National RAISE-ETP Study. *American Journal of Psychiatry, 172*(3), 237-248.

Scull J., and Winkler, A.M. (2011). *Shifting Trends in Special Education*. Washington, DC: Fordham Institute.

Sikora, D., Moran, E., Orlich, F., Hall, T.A., Kovacs, E.A., Delhaye, J., Clemons, T.E., and Kuhlthau, K. (2013). The relationship between family functioning and behavior problems in children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 7*(2), 307-315.

Silberman, S. (2015). *NeuroTribes: The Legacy of Autism and the Future of Neurodiversity*. New York: Penguin.

Tambornino, J., Crouse, G., and Winston, P. (2015). *National Trends in the Child SSI Program*. Assistant Secretary for Planning and Evaluation Research Brief. Washington, DC: U.S. Department of Health and Human Services.

Trickey, D., Siddaway, A.P., Meiser-Stedman, T., Serpell, L., and Field, A.P. (2012). A meta-analysis of risk factors for posttraumatic stress disorder in children and adolescents. *Clinical Psychology Review, 32*(2), 122-138.

Vallarino, M., Henry, C., Etain, B., Gehue, L.J., Macneil, C., Scott, E.M., Barbato, A., Conus, P., Hlastala, S.A., Fristad, M., Miklowitz, D.J., and Scott, J. (2015). An evidence map of psychosocial interventions for the earliest stages of bipolar disorder. *Lancet Psychiatry, 2*(6), 548-563.

Van Meter, A.R., Moreira, A.L., and Youngstrom, E.A. (2011). Meta-analysis of epidemiologic studies of pediatric bipolar disorder. *Journal of Clinical Psychiatry, 72*(9), 1250-1256.

Weitlauf, A.S., McPheeters, M.L., Peters, B., Sathe, N., Travis, R., Aiello, R., Williamson, E., Veenstra-VanderWeele, J., Krishnaswami, S., Jerome, R., and Warren, Z. (2014). *Therapies for Children with Autism Spectrum Disorder: Behavioral Interventions Update*. Rockville, MD: Agency for Healthcare Research and Quality. Available: http://www.ncbi.nlm.nih.gov/books/NBK241444/ [June 2016].

White House Conference on Child Health and Protection, Committee on the Infant and Preschool Child. (1931). *"The Children's Charter" Recognizing the Rights of Children*. Available: https://research.archives.gov/id/187089 [June 2016].

World Health Organization and World Bank. (2011). *World Report on Disability*. Available: http://www.who.int/disabilities/world_report/2011/report.pdf [June 2016].

Wu, E.G., Birnbaum, H.G., Shi, L., Ball, D.E., Kessler, R.C., Moulis, M., and Aggarwal, J. (2005). The economic burden of schizophrenia in the United States in 2002. *Journal of Clinical Psychiatry, 66*(9), 1122-1129.

Appendix A

Workshop Statement of Task

ENSURING QUALITY AND ACCESSIBLE CARE FOR CHILDREN WITH DISABILITIES AND COMPLEX HEALTH AND MEDICAL NEEDS

Statement of Task: An ad hoc steering committee will plan a 2-day open, interactive public workshop featuring presentations on prevention, care, and service coordination for children with disabilities and complex health and educational needs. The committee will identify specific topics to be covered at the workshop, select and invite speakers and other participants, and moderate the discussions. A brief summary and a full-length summary of the workshop presentations and discussions will be prepared by a designated rapporteur in accordance with institutional guidelines.

Appendix B

Workshop Agenda

Ensuring Quality and Accessible Care for Children with Disabilities and Complex Health and Medical Needs

December 9-10, 2015

The National Academies Keck Center
500 Fifth Street, NW
Washington, DC 20001

AGENDA

Day 1: Wednesday, December 9, 2015

8:30 a.m. Welcome and Workshop Overview

8:45 a.m. Introductory Session, "Perspectives from Individuals and Family Members"
Moderator: Stephen M. Shore, Ed.D., Adelphi University
- J-Jaye Hurley, Parent Advocate and Autism Response Team Coordinator, Autism Speaks
- Jill Plevinsky, M.A., Founding Chair, Patient Advisory Council, ImproveCareNow
- Victoria Costello, M.F.A., Parent Advocate, Science Journalist, and *Public Library of Science*

10:00 a.m. Keynote Presentation, "Disability Names and Numbers: Challenges and Opportunities in Nosology, Epidemiology, and Equity/Disparity"
Moderator: Deborah Klein Walker, Ed.D., Abt Associates and American Orthopsychiatric Association
- Maureen S. Durkin, Ph.D., Dr.P.H., M.P.H., University of Wisconsin–Madison

11:00 a.m. Panel One, “Children with Serious Medical Conditions and the Behavioral Health Implications”
Moderator: Mary Ann McCabe, Ph.D., ABPP, George Washington University School of Medicine, George Mason University

- Anne E. Kazak, Ph.D., ABPP, Nemours Children’s Health System and Sidney Kimmel Medical School of Thomas Jefferson University
- Robin S. Everhart, Ph.D., Virginia Commonwealth University
- Amy J. Houtrow, M.D., Ph.D., M.P.H., Children’s Hospital of Pittsburgh of UPMC
- Torrie Dunlap, CPLP, Kids Included Together

1:30 p.m. Panel Two, “Early Identification and Interventions for Developmental Disabilities Emerging in Childhood”
Moderator: Craig J. Newschaffer, Ph.D., Drexel University

- Heather Johnson, DNP, FNP-BC, FAANP, Uniformed Services University of the Health Sciences Graduate School of Nursing
- Nathan A. Call, Ph.D., BCBA-D., Marcus Autism Center, Emory University School of Medicine
- Connie Kasari, Ph.D., University of California, Los Angeles
- David S. Mandell, Sc.D., University of Pennsylvania School of Medicine

3:15 p.m. Panel Three, “Early Identification and Interventions for Youth and Adolescents with Serious Behavioral Health Conditions”
Moderator: Kirsten Beronio, J.D., Office of the Assistant Secretary for Planning and Evaluation

- Mary Fristad, Ph.D., ABPP, Ohio State University Medical Center
- Robert K. Heinssen, Ph.D., ABPP, National Institute of Mental Health
- Lisa Dixon, M.D., M.P.H., Columbia University Medical Center and New York State Psychiatric Institute
- Shay Bilchik, J.D., Georgetown University Center for Juvenile Justice Reform

4:45 p.m. Armchair Discussion/Reflections from Moderators (full group Q and A)
Moderator: Maureen S. Durkin, Ph.D., Dr.P.H., M.P.H., University of Wisconsin–Madison

5:30 p.m. Closing Remarks and Adjourn

Day 2: Thursday, December 10, 2015

8:30 a.m. Welcome, Brief Recap of Day 1, and Overview for Day 2

8:45 a.m. Panel Four, "Media and Public Perceptions/Misperceptions of Children with Disabilities"
Moderator: Andy Shih, Ph.D., Autism Speaks, and Donald Wertlieb, Ph.D., American Orthopsychiatric Association and Tufts University

- Steve Silberman, Science Writer and Author of *NeuroTribes: The Legacy of Autism and the Future of Neurodiversity*
- Susan M. Lanzoni, Ph.D., Historian of Science and Writer, Harvard University
- Victoria Costello, M.F.A., Parent Advocate, Science Journalist, and *Public Library of Science*
- Tony Foleno, M.A., The Ad Council
- Emily J. Willingham, Ph.D., Freelance Writer

10:30 a.m. Interactive Breakout Group Sessions (unavailable to Webcast audience)

- Group 1: Considerations for when an evidence base is lacking
  Moderator: C. Hendricks Brown, Ph.D., Northwestern University, and Emily Lichvar, Ph.D., Center for Mental health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services
- Group 2: Community engagement and partnerships for development and implementation of solutions
  Moderator: Kelly J. Kelleher, M.D., The Research Institute at Nationwide Children's Hospital, and Angela Lello, M.P.A., Autism Speaks

- Group 3: This breakout group is offered to participants of both the December 7-8 "National Symposium on Designing Systems That Work for Children with Complex Health Care Needs" and the December 9-10 "Workshop on Ensuring Quality and Accessible Care for Children with Disabilities and Complex Health and Medical Needs"
  Moderators: Andy Shih, Ph.D., Autism Speaks, and Ed Schor, M.D., Lucile Packard Foundation for Children's Health

11:45 a.m. Report-back from breakout groups

12:45 p.m. Workshop Reflections

1:00 p.m. Adjourn Workshop

Appendix C

Biosketches of Workshop Speakers and Moderators

Kirsten Beronio is director of the Division of Behavioral Health and Intellectual Disabilities Policy in the U.S. Department of Health and Human Services' (HHS) Office of the Assistant Secretary for Planning and Evaluation. In this role, Beronio advises agency leadership on mental health and substance use disorder policy issues regarding the implementation of new programs and new legislative requirements, oversight of existing HHS programs, development of regulations and subregulatory guidance, and issuance of public statements. She also designs and oversees research projects by contractors addressing current federal mental health and substance use disorder policy issues. Beronio was previously vice president of public policy and advocacy at Mental Health America. She received her J.D. from Georgetown University.

Shay Bilchik is the founder and director of the Center for Juvenile Justice Reform at Georgetown University's McCourt School of Public Policy. Prior to joining Georgetown, Bilchik was the president and chief executive officer of the Child Welfare League of America. Earlier, Bilchik was the administrator of the Office of Juvenile Justice and Delinquency Prevention in the U.S. Department of Justice, where he advocated for and supported a balanced and multisystems approach to attacking juvenile crime and addressing child victimization. Bilchik was also an assistant state attorney in Miami, Florida, from 1977 to 1993, where he served as a trial lawyer, juvenile division chief, and chief assistant state attorney. He earned his B.S. and J.D. degrees from the University of Florida.

C. Hendricks Brown is professor in the Departments of Psychiatry and Behavioral Sciences, Preventive Medicine, and Medical Social Sciences in the Northwestern University Feinberg School of Medicine. He also holds adjunct appointments in the Departments of Biostatistics and Mental Health at the Johns Hopkins Bloomberg School of Public Health as well as the Department of Public Health Sciences at the Miller School of Medicine at the University of Miami. He directs the Center for Prevention Implementation Methodology for Drug Abuse and Sexual Risk Behavior and a study funded by the National Institute of Mental Health to synthesize findings from individual-level data across multiple randomized trials for adolescent depression. He is also the codirector of the Prevention of Youth Violence Center. Recently, his work has focused on the prevention of drug abuse, conduct disorder, depression, and suicide.

Nathan Call is director of the Severe Behavior Program at the Marcus Autism Center. He completed a predoctoral internship at the University of Iowa Hospitals and Clinics Center for Disabilities and Development, and he completed a postdoctoral fellowship at Marcus Autism Center and Emory University. After working as an assistant professor at Louisiana State University from 2004 to 2006, he returned to Marcus Autism Center. His current research interests include the assessment and treatment of severe behavior disorders. His interests also include identifying the basic behavioral mechanisms that influence the occurrence and maintenance of problem behavior, and developing clinical methods that incorporate these mechanisms into the assessment and treatment of problem behaviors. He received his doctorate in school psychology from the University of Iowa.

Victoria Costello combined her experience dealing with family mental illness and a science journalism career to author *A Lethal Inheritance: A Mother Uncovers the Science Behind Three Generations of Mental Illness*. She has served as a board member for the Mental Health Association of San Francisco, and currently as community editor for the *Public Library of Science*, where she edits a blog network aimed at translating biomedical research for a broad readership.

Lisa Dixon is a professor of psychiatry at the Columbia University Medical Center and the director of the Division of Mental Health Services and Policy Research within the Department of Psychiatry. She also directs the Center for Practice Innovations (CPI) at the New York State Psychiatric Institute. As CPI director, she oversees activities for the New York State Office of Mental Health in implementing evidence-based practices for people diagnosed with serious mental illness. She also leads OnTrackNY. Her grants have focused on improving the quality of care for individuals with serious mental disorders with a particular emphasis on services that include families, reducing the negative impact of co-occurring addictions and medical problems, and improving treatment engagement and adherence.

Torrie Dunlap is an educator who found her life's purpose when she taught a theater class for children that included a boy with Down syndrome, which connected her to the work of Kids Included Together. She started as a volunteer for the national nonprofit and is now chief executive officer. She is a regular contributor to the advocacy Website Think Inclusive, and the SWIFT schools blog SWIFTtalk and also was a frequent guest host on the podcast The Inclusive Class. She is a certified professional in learning and performance and in 2013 was selected as a social innovation fellow at Stanford's Graduate School of Business.

Maureen Durkin is a professor of Population Health Sciences and Pediatrics, an investigator with the Waisman Center, and principal investigator of the Wisconsin Study to Explore Early Development of Autism Spectrum Disorder, all at the University of Wisconsin–Madison. Her research interests include the epidemiology, prevention, antecedents, and consequences of neurodevelopmental disabilities and childhood injuries. She has collaborated in the development of cross-cultural methods for behavioral and developmental screening and assessment and methods for the surveillance of childhood injuries, and she has directed international studies of the prevalence and causes of childhood disabilities and mental health disorders in low-resource settings. She has also directed cohort studies of the neuropsychological outcomes of neonatal brain injuries associated with preterm birth and with metabolic disorders detected on newborn screening. She holds an undergraduate degree and Ph.D. in anthropology from the University of Wisconsin–Madison and M.P.H. and Dr.P.H. degrees in epidemiology and postdoctoral fellowship training in psychiatric epidemiology from Columbia University.

Robin Everhart is an assistant professor in the Department of Psychology at Virginia Commonwealth University and a licensed clinical psychologist. Her program of research is focused on understanding childhood chronic disease management from a family systems perspective, particularly within the context of urban and cultural stressors and primarily related to pediatric asthma. She incorporates a focus on quality of life, health disparities, caregiving, and family-based models of care. She is also leading a National Institute of Health-funded community needs assessment in the Richmond area that will inform the development of a larger clinical trial to reduce pediatric asthma disparities. In maintaining her broader interest in child health psychology and families, she has also published and presented research on adherence in pediatric cystic fibrosis.

Tony Foleno is the senior vice president for research at the Ad Council, where he advises the strategic planning of more than 40 public service communications campaigns. He also oversees campaign evaluation, establishing key performance indicators and the tools for measurement. He has conducted numerous studies on best practices in social marketing and public service communications. He cochairs the Ad Council Research Committee. Prior to joining the Ad Council in 2002, he managed projects at Public Agenda, a nonpartisan public opinion research organization. He is a graduate of Swarthmore College and holds an M.A. in sociology from Columbia University.

Mary Fristad is professor and vice chair for research and academic affairs in the Department of Psychiatry and Behavioral Health at the Ohio State University (OSU) Wexner Medical Center. She also holds appointments in Psychology and Nutrition and is the associate director for research at the OSU Center for Integrative Health and Wellness. She is board certified in clinical psychology and clinical child and adolescent psychology. Her current National Institute of Mental Health (NIMH) grant is in its 10th year examining the longitudinal course of manic symptoms in youth. She recently completed two NIMH-funded randomized, controlled trials of omega 3 fatty acids (n3) and individual-family psychoeducational psychotherapy in youth with depressive and bipolar spectrum disorders. Currently, her group is completing a long-term follow-up of participants from those trials, including testing for a genetic marker that may indicate who is more likely to be responsive to n3. She received her doctorate from the University of Kansas after completing her clinical internship at Brown University.

Robert Heinssen is director of the Division of Services and Intervention Research at the National Institute of Mental Health (NIMH), which he joined in 1999. He is NIMH science officer for the North American Prodrome Longitudinal Study and study director for the Recovery After an Initial Schizophrenia Episode initiative. From 2008 to 2010, he played a pivotal role in launching the NIMH-Army Study to Assess Risk and Resilience in Service Members. Between 2004 and 2012, he served as a major in the U.S. Army National Guard and deployed to Afghanistan in 2010 as a member of the U.S. Army Joint Mental Health Advisory Team. He earned a doctoral degree in clinical psychology from Catholic University of America. A board-certified, licensed clinical psychologist, he completed a clinical fellowship at McLean Hospital/Harvard Medical School and residency at Chestnut Lodge Hospital.

Amy Houtrow is an associate professor and vice chair in the Department of Physical Medicine and Rehabilitation for Pediatric Rehabilitation Medicine at Children's Hospital of Pittsburgh. She also serves as the chief of its Pediatric Rehabilitation Medicine Services. She completed her residencies in physical medicine and rehabilitation and pediatrics at Cincinnati Children's Hospital and the University of Cincinnati Medical Center in 2005. She is board certified in both disciplines with subspecialty certification in Pediatric Rehabilitation Medicine. From 2005 to 2012, she was assistant professor of clinical pediatrics at the University of California, San Francisco. Her main clinical focus is caring for children with disabling conditions. Complementing her clinical focus, her research focus is on optimizing health services for children with disabilities, with an emphasis on recognizing the impact that raising children with disabilities has on families and on developing channels to improve service delivery to reduce disparities. She has a master's in public health from the University of Michigan, an M.D. from Michigan State University, and Ph.D. in medical sociology from the University of California, San Francisco.

J-Jaye Hurley joined Autism Speaks Family Services in 2011 as the southeast regional autism response team coordinator. She also provides special education support and resources to parents to empower them to be the best advocates they can be for their child. She is herself an advocate for her son, who has complex medical and educational needs. She graduated with a B.A. from the University of Mississippi.

Heather Johnson is a family nurse practitioner and retired Air Force lieutenant colonel. She is the acting director and chair of the Family and Women's Health Nurse Practitioner Programs at the Uniformed Services University of the Health Sciences Daniel K. Inouye Graduate School of Nursing. She helps families navigate the complex health care and education systems for children with special health care needs, and she integrated curriculum specific to this population into Family, Women's Health and Psychiatric Mental Health Nurse Practitioner education. She partnered with the National Center for Disaster Medicine and Public Health on projects to create multidisciplinary education initiatives for vulnerable populations in disasters and maintains an active clinical practice at the Walter Reed National Military Medical Center Cabrera Family Health Center.

Connie Kasari is professor of human development and psychiatry at the University of California, Los Angeles (UCLA). She is a founding member of the UCLA Center for Autism Research and Treatment. Her research aims to develop novel, evidence-tested interventions implemented in community settings. Her recent projects include targeted treatments for early social communication development in at-risk infants, toddlers and preschoolers with autism, and peer relationships for school-aged children with autism. She received her Ph.D. from the University of North Carolina at Chapel Hill and was a National Institute of Mental Health postdoctoral fellow at the Neuropsychiatric Institute at UCLA.

Anne Kazak is is codirector of the Nemours Center for Healthcare Delivery Science and codirector of the Center for Pediatric Traumatic Stress at the Children's Hospital of Philadelphia and A.I. duPont Hospital for Children in Delaware. Kazak is a licensed psychologist and a professor in the Department of Pediatrics at the Sidney Kimmel Medical College of Thomas Jefferson University in Philadelphia and adjunct professor of psychology at the University of Delaware. She is editor in chief of *Health Psychology* and *American Psychologist*. She received an undergraduate degree at Smith College and Ph.D. in clinical-community psychology from the University of Virginia, and she completed her internship training at Yale University School of Medicine, Department of Psychiatry.

Kelly Kelleher is director of the Center for Innovation in Pediatric Practice and vice president of Health Services Research at the Research Institute at Nationwide Children's Hospital. He is also professor in the Department of Pediatrics of the Ohio State University College of Medicine. A pediatrician by training, his research interests focus on accessibility, effectiveness, and quality of health care services for children and their families, especially those affected by mental disorders, substance abuse, or violence. He has a longstanding interest in formal outcomes research for mental health and substance abuse services. He earned his M.D. from the Ohio State University.

Susan Lanzoni is a historian of science and medicine based in Cambridge, Massachusetts, where she teaches in the Division of Continuing Education at Harvard University. She was previously a resident fellow in the Newhouse Humanities Center at Wellesley College and a visiting scholar at the Massachusetts Institute of Technology. She specializes in the history of psychiatry, experimental psychology, neurology, and the mind sciences, and she is completing a book about the cultural history of empathy from aesthetics to neuroscience. She received her Ph.D. in history and philosophy of science from Harvard University.

Angela Lello is director of Housing and Community Living and a member of the Family Services and Federal Advocacy teams at Autism Speaks. She is a policy expert in Medicaid and long-term care, as well as the mother of a child with autism. She began her career as a policy advocate at an independent living center in Austin, Texas, where she also conducted policy analysis for the Texas Department of Aging and Disability Services. She then directed and managed public policy and public information for the Texas Council for Developmental Disabilities. In 2011, she was named a Joseph P. Kennedy Jr. Foundation public policy fellow and had placements within the U.S. Senate and the U.S. Department of Health and Human Services. She holds a B.A. from Abilene Christian University and an M.P.A. from the Lyndon B. Johnson School of Public Affairs at the University of Texas at Austin.

Emily Lichvar is an applied developmental psychologist and a public health adviser in the Child, Adolescent and Family Branch of the Center for Mental Health Services in the Substance Abuse and Mental Health Services Administration (SAMHSA). She provides program oversight, guidance, and leadership to grants, contracts, and cooperative agreements that utilize a system-of-care approach to better serve children and adolescents nationwide. Prior to joining SAMHSA, she held academic appointments at Washington State University and Manhattan College. Additionally, she served as coinvestigator on a National Institute of Drug Abuse-funded study aimed at integrating pharmacological and behavioral interventions for substance-using adolescents with co-occurring attention deficit and hyperactivity disorder. She received her B.A. in psychology from University of Delaware, M.A. in clinical psychology from Teachers College, Columbia University, and Ph.D. in applied developmental psychology from Fordham University.

David Mandell is associate professor of psychiatry and pediatrics at the University of Pennsylvania's Perelman School of Medicine, where he directs the Center for Mental Health Policy and Services Research. He also is associate director of the Center for Autism Research at the Children's Hospital of Philadelphia. The goal of his research is to improve the quality of care individuals with autism receive in their communities. He cochaired the Commonwealth of Pennsylvania's Autism Task Force from 2003 to 2006 and consults with Philadelphia agencies to help them develop appropriate policies to meet the needs of people with autism. He currently serves as a member of the U.S. Department of Health and Human Services Interagency Autism Coordinating Council. He holds a B.A. in psychology from Columbia University and a doctorate of science from the Johns Hopkins School of Hygiene and Public Health.

Mary Ann McCabe is associate clinical professor of pediatrics at the George Washington University School of Medicine and affiliate faculty in applied developmental psychology at George Mason University. She is also a clinical psychologist and consultant in independent practice. She is president of the Society for Child and Family Policy and Practice and a member of a task force on integrated care for the Society of Pediatric Psychology. Her areas of research and writing have focused on neuropsychological and behavioral sequelae of medical treatments in children, as well as minors' capacity for involvement in decision making about medical and mental health treatment and research. She earned her Ph.D. in clinical psychology from Catholic University of America.

Craig Newschaffer is founding director of the A.J. Drexel Autism Institute at Drexel University and a professor in the Department of Epidemiology and Biostatistics at the Drexel University School of Public Health. He is an epidemiologist whose main research focus is the discovery of modifiable autism risk factors. He has directed an NIH Autism Center of Excellence (ACE) project, been a site principal investigator on other major autism epidemiology initiatives, and led an NIH-funded project testing streamlined approaches to ASD case confirmation for epidemiologic research purposes. Newschaffer is also a fellow of the American College of Epidemiology, vice president of the International Society for Autism Research, associate editor of *Autism Research*, and interim associate dean for research at the Drexel University School of Public Health.

Jill Plevinsky is a third-year doctoral student in the clinical psychology program at Rosalind Franklin University of Medicine and Science. Her research interests include understanding barriers to various domains of self-management in adolescents and young adults with inflammatory bowel diseases, including medication adherence, risk-taking behaviors, and the transition to adult care. She has lived with Crohn's disease for the past 20 years and, through her involvement in the Crohn's and Colitis Foundation of America, Collaborative Chronic Care Network (C3N Project), and ImproveCareNow, has advocated for and spoken on behalf of young people with IBD.

Edward Schor is senior vice president for programs and partnerships at the Lucile Packard Foundation for Children's Health. Previously he was a vice president at The Commonwealth Fund, where he directed the State Health Policy and Practices program and the Child Development and Preventive Care program. A pediatrician, he has held a number of positions in pediatric practice, academic pediatrics, health services research, and public health. He received postdoctoral training in social and behavioral sciences and has a special interest in the social determinants of child health and family functioning. He is editor of the book *Caring for Your School-Age Child* and has chaired both the Committee on Early Childhood, Adoption and Dependent Care and the national Task Force on the Family for the American Academy of Pediatrics. He has been a member of the faculties of several major university medical schools and schools of public health.

Andy Shih is senior vice president of scientific affairs at Autism Speaks. He oversees the public health portfolio, which includes Autism Speaks' Global Autism Public Health Initiative. He and his team serve as technical advisers to ministries and other government agencies by facilitating multi-stakeholder collaboration and sourcing needed content expertise and other technical resources. His research background includes published studies in gene identification and characterization, virus-cell interaction, and cell-cycle regulation. Prior to focusing on Autism Speaks' public health/international development efforts, he oversaw the organization's investments in genetics, environmental sciences, epidemiology, and assistive technologies.

Stephen Shore was diagnosed as a child with "atypical development and strong autistic tendencies." He is now a professor at Adelphi University, where his research focuses on matching best practice to the needs of people with autism. In addition to working with children and talking about life on the autism spectrum, he presents and consults internationally on adult issues pertinent to education, relationships, employment, advocacy, and disclosure. He is president emeritus of the Asperger's Association of New England and former board member of the Autism Society. He serves on the boards of the Asperger Syndrome and High Functioning Autism Association, the Autism Services Association, and other autism-related organizations.

Steve Silberman is an award-winning science writer. He is the author of *NeuroTribes: The Legacy of Autism and the Future of Neurodiversity*. His TED talk, "The Forgotten History of Autism," has been viewed more than 1 million times and translated into 25 languages. His writing on science, culture, and literature has been collected in a number of major anthologies.

Deborah Klein Walker is vice president and senior fellow at Abt Associates. She is a public health leader and behavioral science researcher with more than 40 years of experience developing and implementing programs and system change, research, evaluation, policy analysis, and consulting on child and adolescent health issues. Before joining Abt Associates, she was the associate commissioner for programs and prevention at the Massachusetts Department of Public Health and a faculty member at the Harvard School of Public Health and Graduate School of Education. She is the current president of the American Orthopsychiatric Association and board member of Family Voices and a past president of the American Public Health Association and the Association of Maternal and Child Health Programs. She earned a B.A. degree in psychology from Mount Holyoke College and Ed.D. and Ed.M. degrees in human development from Harvard University.

Donald Wertlieb is past president of the American Orthopsychiatric Association and current president of the Partnership for Early Childhood Development and Disability Rights. He is professor emeritus and former chair of the Eliot-Pearson Department of Child Development at Tufts University. Internationally, his work emphasizes collaboration in the development of mental health and integrated human services frameworks, with particular attention to fostering resiliency for children and families placed at risk. He is a pediatric psychologist whose major research interest has been in understanding the complex processes by which children and families cope with stressors. He earned his Ph.D. in pediatric psychology from Boston University.

Emily Willingham is a research scientist and freelance writer. Her writing focuses on health, especially mental health and neurobiology, and debunkery, particularly as it pertains to controversial issues around autism, genetically modified organisms, parenting, and vaccines. She has taught students of all ages, primarily as a university instructor in scientific writing and biology, focusing on physiology, developmental biology, genetics, and general science. She earned her bachelor's degree in English and Ph.D. in biological sciences at the University of Texas at Austin and completed a postdoctoral fellowship in urology at the University of California, San Francisco.