

P R O C E E D I N G S

Building the Capacity of Service Delivery Systems for Children and Youth with Disabilities and Special Health Care Needs

State of the Science Conference

WASHINGTON, DC • MARCH 18-19, 2004



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THE CONSORTIUM FOR CHILDREN AND YOUTH WITH DISABILITIES AND SPECIAL HEALTH CARE NEEDS
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FUNDED BY

The National Institute on Disability and Rehabilitation Research (NIDRR)
Office of Special Education and Rehabilitative Services (OSERS)
United States Department of Education

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Introduction

The Consortium for Children and Youth with Disabilities and Special Health Care Needs is one of 40 national Rehabilitation Research and Training Centers (RRTC) sponsored by the National Institute on Disability and Rehabilitation Research (NIDRR), a program within the United States Department of Education's Office of Special Education and Rehabilitative Services (OSERS).

The Consortium brings together researchers, clinicians, policy analysts, and families of persons with disabilities from four nationally known organizations: the Georgetown University Center for Child and Human Development, the Heller School for Social Policy and Management at Brandeis University, the Institute for Child Health Policy at the University of Florida, and Family Voices.

One of the mandates of NIDRR to each RRTC program is to sponsor a State of the Science (SoS) conference in the third year of the grant cycle. This conference enables policymakers, professionals, and family members involved with key issues in the field of children and youth with disabilities and special health care needs to share information, identify key issues to address, and chart a course for future collaboration.

The Consortium's State of the Science conference was held March 18-19, 2004 in Bethesda, MD. It brought together over 70 researchers, academicians, clinical practitioners, policy leaders, adult and youth advocates, and family members of children and young people with disabilities. The purposes of the two-day meeting were to:

- ◆ Learn what research is saying about the barriers that children and youth with disabilities and special health care needs face when trying to access health and rehabilitative care.
- ◆ Identify practices that make it easier to gain access to services.
- ◆ Set a research and practice agenda aimed at improving access to care for children and families.

Over the past two decades, there have been tremendous shifts in policy and service delivery for children with disabilities and their families. This shift has been based on a consensus among policymakers, providers, advocates, researchers, and families that: 1) children with special health care needs require a range of services and supports that are best delivered within their families and communities, and 2) these services are more effective and efficient when service systems and agencies are coordinated and organized to provide a system of care that is culturally competent and family centered.

The challenge involved in making this consensus become a reality for children with special health care needs and disabilities is complex. The advent of managed care, fragmentation among agencies and providers, and difficulties with knowledge transfer have contributed to the slow implementation of strong community-based systems of care for these children and their families.

The Consortium and the State of the Science conference address three critical areas needed to improve rehabilitation outcomes for children and youth with disabilities and special health care needs:

1. Access to and financing of appropriate health and rehabilitation services for children with special health care needs.
2. Transition of children with disabilities from child to adolescent to adult health care systems.
3. Use of technology as a tool to increase personal independence and promote access to care.

This document summarizes the presentations and discussions of the Consortium's State of the Science conference and outlines recommendations for future action.

The March 2004 State of the Science conference, entitled *Building the Capacity of Service Delivery Systems for Children and Youth with Disabilities and Special Health Care Needs*, could not have been accomplished without the coordinated efforts of the Consortium partners, especially Toby Long and Maria Woolverton from Georgetown University, Marji Erickson Warfield of Brandeis University,

Robert Gibson of the University of Florida, and Rebecca Goniwich from Family Voices. For all their efforts in planning this event, thank you. Also deserving of very special thanks is Tammy Edwards of Georgetown University. Tammy's patience, diligence, and attention to detail was critical to the organization of this meeting.

Phyllis R. Magrab, Ph.D.

Principal Investigator, The Consortium for Children and Youth with Disabilities and Special Health Care Needs

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January 2005

The Consortium

Phyllis R. Magrab, Ph.D.

Principal Investigator

The Consortium for Children and Youth with Disabilities and Special Health Care Needs

The mission of the Consortium is to improve rehabilitation outcomes for children and youth with disabilities and/or special health care needs through focused and applied research, targeted training for professionals and others involved in care, and active dissemination of our work. All our activities are fueled by a commitment to make a positive difference in the lives of children with special health care needs, their families, and the service providers who support them.

Our work focuses on five critical areas: how children and their families **access** needed health and rehabilitation services, how **managed care practices** affect the quality and quantity of services provided, the special problems experienced as children become adolescents and **transition** into the adult health care system, the promise of **assistive technology** to increase personal independence and autonomy, and the potential of **telerehabilitation** practices to bring state-of-the-art care to all segments of our society.

Linking our different organizations and the projects we pursue is a shared conviction that children with special health care needs require and deserve a range of services and supports that are best delivered within their families and local communities. We also recognize that as children with special needs mature and their needs change, our service systems must be responsive to those changes. Additionally, we share an excitement about the enormous potential of technology to broaden the horizons of people with disabilities and improve their access to rehabilitation services.

The Consortium is honored to be one of 40 Research Rehabilitation and Training Centers funded by NIDRR. We welcome you to visit our website at http://gucchd.georgetown.edu/programs/consortium_for_children

Building the Capacity of Service Delivery Systems For Children and Youth with Disabilities and Special Health Care Needs

Phyllis R. Magrab, Ph.D.

Principal Investigator, The Consortium for Children and Youth with Disabilities and Special Health Care Needs and Director, Georgetown University Center for Child and Human Development Washington, D.C.

As host of this State of the Science conference, I welcome you to *Building the Capacity of Service Delivery Systems for Children and Youth with Disabilities and Special Health Care Needs*.

The dual purpose of this conference is to give researchers, practitioners, consumers, and policymakers an opportunity to identify and examine state-of-the-art knowledge about access to care for children with disabilities and special health care needs and to develop recommendations for a future research agenda that aims to improve access to a system of care for these children.

We hope that through sharing information we can learn how access to services for children with special health care needs can be improved and we can identify ways that service providers can increase both the quality and coordination of the services they deliver. This dialogue among advocates and organizations involved with children who have disabilities is needed because in all too many cases services for children with disabilities and special health care needs are fragmented and under-funded—or not funded at all. We must continue to work together to improve access to services that make it possible for these children to grow and thrive in their home communities.

The Consortium was formed in the year 2000. It brings together four groups dedicated to improving the lives of children and youth with disabilities. The

work that began with each separate organization has evolved into an integrated program that is studying a variety of factors that influence access to care for children with disabilities. During the next two days of the State of the Science meeting, members of the Consortium will be presenting key findings from our research. Our work across projects has shown us that there are two areas that are of particular importance: 1) incorporating family members as well as older youth and adults with disabilities as partners in planning and evaluating the services they receive, and 2) recognizing the importance of culture by designing services that respect and embrace the approaches and attitudes of people from various cultures around our country.

The agenda for the next two days brings together a variety of perspectives on the three focus areas of the Consortium. It is our hope that through a rich dialogue we all will:

- ◆ Learn from our research findings more about the barriers that children and youth with disabilities and special health care needs face when accessing health and rehabilitative care and the practices that promote access to care, and
- ◆ Frame a research and practice agenda aimed at promoting access to care for children and youth with disabilities and special health care needs.

Again, welcome to our conference!

Accessing Care: The NIDRR Perspective

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As someone with a disability, I can speak personally about gaps in services—the cracks in the road—that young people and their families face. Because of my own experience, NIDRR, under my leadership, has a strong consumer focus as well as a family-driven agenda. Furthermore, this agenda strives consciously to include the full range of individuals with disabilities in our work—children, youth, and adults with mental health needs as well as cognitive and developmental disabilities alongside those who have physical and other challenges.

The last 25 years have brought many successes in the field of delivering services to children and youth with disabilities and special health care needs. However, challenges remain. Organizations involved with these children and youth need to pay attention to six key areas:

1. **Early intervention**—getting appropriate assessments early on, educating parents about issues relevant to their child’s disability as well as their growth and development potential, and giving family members the resources they need to create a strategic plan as their child moves towards adulthood.
2. **Prevention of secondary results of disability** such as excluding young people with special needs from typical life experiences.
3. **Expanding the use of assistive technologies** to help young people with disabilities go to school and ultimately move with their peers from

elementary to secondary to post-secondary studies, and then to employment. Also, to find and fund technologies that support healthy living such as respirators at night, which make it possible for a child or adult to operate successfully during the day. Assistive technology is an important way to enable the disabled.

4. **Employment.** Seventy percent of adults with disabilities who are able to seek work are not employed. We need to find ways that their abilities can be put to productive use whether it be by doing tele-work from home, by holding a part-time job, or by working full time.
5. **Research that is consumer and family driven** as well as sensitive to the interests and attitudes of cultural and ethnic groups.
6. **Attention to transition and life-span issues** for children with disabilities as they become youth and then adults, and thus need to move from the pediatric to the adult medical care and social service systems.

The work of this Consortium and their colleagues that will be shared today and tomorrow is a beginning for all of us in creating an agenda of research, service, and policy. I know that the work you do over the next two days will be fruitful, and I wish you well.

Thank you all for the work that you do for children and families.

Best Practices in Service Delivery and Research that Can be Used as Building Blocks to Improve Care for Children and Youth with Disabilities

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Good afternoon and welcome to the Consortium's inaugural State of the Science conference. As a consumer with a physical disability, a clinician, and a researcher on disability issues, I would like to focus my presentation on three topics:

- ◆ **Best practices** for working with children and youth who have disabilities and with their families
- ◆ **Research** issues related to definitions and measurements in the field of disabilities, and
- ◆ **Access to care**

My perspective on access to care and the service delivery system for individuals with disabilities was created by my own story. At age 15 I survived a car accident, which left me with severe spinal cord injuries. With the support of rehabilitation services, I moved from complete dependence on others to being able to care for myself, return to high school, drive a car, and finally to build a career and family. My rehabilitation ultimately laid the groundwork for me not only to cope with my loss, but also to build a new life with an entirely different premise: that my disability could be a valued part of my identity.

Ten years later, I returned to rehab, this time in another facility and this time not as a client but as a trained social worker. This hospital, as it turns out, did not have a gym (the nerve center of my initial rehab hospital), there was no department of therapeutic recreation, the mental health department had been downsized, and the length of stay for clients was half of what I had received as a young adult. Changes in

health care payment systems and health care service delivery philosophy were the root of these changes:

- ◆ The managed care system of payment had taken hold, limiting funding of services through care management, and
- ◆ A new health/rehabilitation philosophy was emerging, requiring documentation of medical necessity for care to continue. This meant that in order for care to proceed, continuous, measurable improvement in functional skills had to be demonstrated. This philosophy takes the position that if a child or adult isn't improving, he or she should be discharged. For a disability advocate, for parents, and for many providers, however, that is the point when *more* rehabilitation services or a different type of rehab or a different level of intensity would be needed, not less.

The contrast between these two facilities and the care provided highlights the areas in which improvements in services for children and adults with disabilities are needed.

The Medical Home

One "best practice" that has emerged from the 1990s is the concept of "medical home." This is neither a house nor a hospital, but rather an approach used by service providers to assist consumers in coordinating a comprehensive system of services and supports. The concept of medical home emerged from the efforts of very dedicated family advocacy organizations, the maternal and child health community, and the

American Academy of Pediatrics. A medical home has the following elements:

- ◆ **A medical specialist or primary care provider** who is well acquainted with the child, the family, and their service needs serves as the lead coordinator and takes responsibility for ensuring that appropriate care is found, provided, and coordinated.
- ◆ **Care is family-centered.** In this model of care, the family and child sit at the center of the medical home. Information about specialty care and other needed services is provided to the whole family, and decisions are made with the child and family as active participants in the process. Efforts are made to ensure that care from all providers is coordinated reducing the burden on families.
- ◆ **Care is defined broadly—and goes beyond medical.** A medical home is considered a component of a system of care. In a system of care the medical/health needs of an individual with a disability are addressed in relation to the early intervention, education, child-care, mental health, financing, rehabilitation, social service, and home health needs provided by public and private community agencies. Depending on the needs of the child and family, foreign language services may also be part of the system of care. In essence, physicians and their staffs are asked to go far beyond the medical care they are trained to provide. And if physicians are asked to take on these expanded duties, they must be given the training, staffing, and—perhaps most importantly—the time to do so, or else the medical home approach will be an un-funded mandate.

Disability Research

One of the challenges of research in the field of disability is how to conceptualize and measure a population with such a broad range of health care and other needs. Using the federal Maternal and Child Health Bureau's (MCHB) definition of children with special health care needs (Box 1) makes it possible for researchers to generate estimates of a population, not only on a demographic basis, but also on the

BOX 1

Children with special health care needs are those children and youth who “have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who require health and related services of a type or amount beyond that required by children generally.”

MCHB, U.S. Department of Health and Human Services (HHS), 1998

basis of the use and cost of medical services, access to services, and barriers to obtaining health care.

Screeners and algorithms based on this definition are available for use with national health surveys, helping researchers to delineate service needs as well as the realities of service provision to this population. Because this definition is now in place, researchers have a consistent language for children with disabilities and children with special health care needs (CSHCN). This definition has been adopted as MCHB/HHS' policy related to CSHCN. It has also been incorporated into Healthy People 2010¹, HHS' goal statement within the first decade of the 21st century, and into HHS' response to President George W. Bush's New Freedom Initiative², which sets as a national goal community living for all people—young and old—with disabilities. Ultimately, using this definition has helped practitioners, insurers, and policymakers focus on the large picture: how to meet the service needs of children when those needs are ongoing and extensive.

Although having MCHB's definition in place is both timely and helpful, the breadth of the definition leads to inconsistencies in the estimation of the population of individuals with disabilities. As few as 10 percent and as much as 40 percent has been estimated as being the number of children that can be categorized as children with special health care needs. Including children with a broad range of needs and conditions such as mental retardation, asthma, and hearing impairments leads to this variability. Thus, although there are times when studying the aggregate is necessary and needed, to truly understand the functional needs of children it may be more valid to study the variability inside the big tent, such as differences in transition to adult health care for children with mental retardation versus physical

¹For a full description of HHS' Healthy People 2010 initiative, visit www.healthypeople.gov

²Visit the New Freedom Initiative's website at: www.hhs.gov/newfreedom

disability, or differences in care coordination among children with asthma and children with cerebral palsy. Two factors influence our ability to do this. First, we need solid theory, grounded in the daily experiences of children and families, to help us chart the relationships among chronic health conditions, functional impacts, and the barriers children encounter in the health system, in the educational environment, and in the community. Second, research must take into consideration that disability is not a fixed state. A disabling condition continually changes and evolves. Also, not all children with the same condition experience the disability in the same way. A disability is not something one is—or is not. Instead, it is a set of characteristics everyone shares to varying degrees and in varying forms and combinations. Thus our methodological conception must take all these factors into consideration.

Finally, in regards to research the importance of context cannot be underestimated. While differences among diagnostic codes may provide us with valuable information, we may indeed find that the rich differences between young people and adults with various disabilities come from social, environmental, educational, socio-economic, racial, or cultural factors.

In sum, approaches used in research need to be conscious and intentional about what they are trying to study—similarities among the large group of children with disabilities or differences between individuals that make up this group.

Access to Care

The Consortium has found that many of the access-to-care difficulties that parents report stem from having to navigate their way through the multiple systems in which their children are embedded. The boundaries between what is health care, what is educational care, and what is home care are unclear. Also unclear are things such as how that care is provided, in what setting, under whose responsibility, and with whose dollars. All of this can be almost too daunting for many parents to sort out. Our research shows us that outright unmet needs for services are more rare than are the hassles and problems families face along the way to obtaining services.

Still, access-to-care problems do exist. Some come from the nature of a child's health condition. For

example, parents of children with conditions that affect their behavior have higher rates of reported access problems than parents who have children with other kinds of special health care needs. Access problems also are more prevalent for those families seeking home health care services than for those families needing specialty physician services or speech, occupational, or physical therapy.

Additional access problems are now being caused by the exploding national debt, a weakened economy, significant shortfalls in state budgets, uninsured families, reductions in many private health plan benefits, cuts in some of the most important funding streams that maintain a safety net for children, program enrollment limits, program cuts, and federal cuts in Medicaid monies that States have been counting on. Thus the influence of public policy on service delivery systems must also be taken into consideration.

At the same time as people are searching for ways to build the capacities of the service systems that exist for children, other forces are eating away at them. One thing that researchers can do in this situation is to follow these developments and document with rigor and objectivity any losses that occur in access to care.

The good news is:

- ◆ We have, in fact, begun to do a good job of documenting and refining best practices for working with children and youth with special health care needs and disabilities.
- ◆ We now have nationally representative data that can help us study multiple aspects of these children and their families.
- ◆ We have a clearer picture of both the success and failures of our systems of care.
- ◆ We are struggling with some of the right questions, such as how to best centralize and coordinate the services these children need when we also need to decentralize them into community settings.

The bad news is:

It is hard to know how to help these systems do more at a time when they are being given less to work with. This is the challenging topic that this State of the Science conference has the opportunity of tackling.

Financing and Availability of Health Care Services for Children with Special Health Care Needs

Access to Health Care Services for Children with Disabilities and Special Health Care Needs

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The Maternal and Child Health Policy Research Center in Washington, D.C. regularly conducts qualitative work to assess access to coverage and access to care by children enrolled in the United States' State Children's Health Insurance Program (SCHIP, Box 1). This presentation describes the Maternal and Child Health Policy Research Center's recent research examining SCHIP's benefit coverage and its implementation of the SCHIP program.

BOX 1

The State Children's Health Insurance Program (SCHIP) extends government funded insurance coverage to low-income children whose family's income is too high to qualify for Medicaid. Within SCHIP, states have two options. They can either extend Medicaid eligibility to this group of children or they can enroll these children in a separate, state-designed insurance plan. When states use the first option, then all Medicaid policies for children apply. Under the second option, states develop an insurance plan modeled after the insurance plan available to government workers in that state. In those states, families have to determine each state's coverage policies.

We started by "creating" 12 hypothetical children with a range of physical, developmental, emotional, and behavioral health conditions (Table 1) in order to examine the adequacy of the benefits covered in the 36 states with separate (non-Medicaid) SCHIP programs (Fox, Limb, & McManus, 2003). The hypothetical case descriptions included medical histories and service utilization profiles for children with 12 different chronic conditions, representing both high- and low-prevalence conditions among children at various ages. To determine the extent of coverage that would be available for each child's recommended services in a given state, we analyzed: the availability of the benefit; limits on coverage by day, visit, or funding; limits on the nature and scope of coverage; applicable condition exclusions; and the child's eligibility for any special wraparound programs or specialty managed care organizations (MCOs) that would enhance benefit coverage in the regular SCHIP program. Coverage of recommended services for each child was then judged to be full, partial, or not covered at all.

Our analysis reveals that despite concerns that separate SCHIP programs would look like conventional private coverage and be insufficient to

meet the service requirements of children with special needs, they actually provide fairly generous coverage. In fact, 5 of the 12 hypothetical children would have full coverage of all needed services in more than 75 percent of the states. Nonetheless, children with complex mental health, developmental, or dental problems would have more variable coverage because of their more intense service requirements and also because of some states' policies of imposing visit limits on behavioral health services, putting monetary limits on dental services and not covering orthodontia, and excluding coverage for ancillary therapies that are not for recovery from an illness or injury. Still, even the adolescent with co-occurring disorders would have full coverage of all his mental health services in 26 states, the child with ADHD would have full coverage in 20 states, and the adolescent with anorexia nervosa would have full coverage in 21 states.

That's the good news: SCHIP benefits are comprehensive. But coverage is just one component of access. We do not know how children in these states receive services—whether managed care plans authorize needed services; whether covered medications are on different plans' formularies; whether there are sufficient numbers of pediatric providers (sub-specialists, mental health professionals, ancillary therapy services, home health care providers, and durable medical equipment suppliers) to provide covered services; how children access specialty programs such as the wraparound program in Connecticut or the specialty MCO in Florida; or how the tracking of cost sharing works and whether children really are protected from burdensome cost sharing by caps on expenditures.

Understanding these access components involves talking with all the various stakeholders: state officials, managed care plan representatives, providers, and families. In 1998 and 1999, we went to five states (California, Connecticut, Maryland, Missouri, and Utah) to look at how implementation of the SCHIP program, then just in its infancy, was affecting children with special needs (Fox, McManus, & Limb, 2000). We met with the SCHIP program director and senior staff, with the medical director and other key staff from the two

managed care organizations with the largest SCHIP enrollment, with key staff from their behavioral health subcontractors or the state's behavioral health plan, with a variety of physical and mental health care providers, and with families with children enrolled in the program.

Findings from this study reveal that children with special needs usually receive the services they require, but problems exist with respect to provider availability and service authorization. Also, accessing needed services for mental health and developmental conditions was often far more difficult than accessing services for physical conditions.

Two of the study states, California and Connecticut, have wraparound programs for certain children with special health care needs: those with serious physical disabilities and those with mental health conditions. By talking with providers, plan representatives, and families, we discerned that plans in California were often confused about wraparound program eligibility, which resulted in over-referral to the wraparound services designed for children with physical disabilities. We also found that there were staff shortages in both the physical and mental health wraparound programs and insufficient financing for the service system infrastructures. Although problems were fewer in Connecticut, plans there, too, were confused about when to refer a child.

Access to pediatric subspecialty care was sometimes difficult in the five states, not because of limited benefits or MCO authorization policies, but because of provider shortages in SCHIP subspecialty networks, resulting in long delays for appointments, most commonly for pediatric neurologists and orthopedists. Across all five SCHIP programs, mental health providers reported a severe shortage of participating psychiatrists in all communities, and plans reported relying heavily on licensed clinical social workers and lesser-trained therapists to treat SCHIP participants.

With respect to ancillary therapy services, the states all had different benefit policies, with the Medicaid expansion programs having the most generous benefit. Despite these differences, all the

TABLE 1: THE HYPOTHETICAL CHILDREN

This table presents 12 hypothetical children created by the Maternal and Child Health Policy Research Center as a way of examining the adequacy of benefits covered in the 36 states that have separate (non-Medicaid) State Children's Health Insurance Programs (SCHIP). These children are intended to represent a range of typically occurring physical, developmental, emotional, and behavioral health conditions.

Rosita, age 18 months with recurring acute otitis media, requires coverage for acute care visits to the primary care physician (PCP); influenza immunization; visits to an ear, nose, and throat specialist and to an audiologist; ambulatory surgery; and short-term medication.

Anna, age 30 months with cerebral palsy and seizure disorder, requires coverage for acute care visits to the PCP; visits to an orthopedist and neurologist; laboratory tests; extensive speech, physical, and occupational therapy visits; orthotics; a fitted stroller; and long-term medication.

Emily, age 5 with spina bifida, requires coverage for routine immunizations; visits to a neurologist, urologist, physiatrist, and orthopedist; emergency room visits; shunt replacement surgery; inpatient hospitalization; home health nurse visits; medical supplies; a wheelchair; and long-term medication.

Duane, age 7 with ADHD and sensory integration and motor planning dysfunction, requires coverage for an acute care visit to the PCP; long-term outpatient mental health visits, including group and family therapy; a neuropsychological evaluation; occupational therapy visits; and long-term medication.

Sam, age 10 with step 3 asthma, requires coverage for acute care visits to the PCP, allergist; influenza immunization; emergency room visits; spirometry; a peak-flow monitor; spacers; a portable nebulizer; and long-term medication.

Tiffany, age 12 with multiple dental caries and malocclusion, requires coverage for X-rays; numerous fillings; root canal therapy and a stainless steel crown; medications; and orthodontia.

Kate, age 14 with anorexia nervosa, requires coverage for an acute-care visit to the PCP; adolescent medicine specialist visits; inpatient hospitalization; extensive mental health services, including partial hospitalization; individual, group, and family therapy; nutritional counseling; and long-term medication.

Carlos, age 14 with injuries from a motor vehicle accident, requires coverage for an acute care visit to the PCP; orthopedist visits; emergency room visit; X-rays; inpatient hospitalization; orthopedic surgery; restorative physical and occupational therapy visits; and short-term medications.

Nikki, age 15, suicidal with major depressive disorder, requires coverage for an acute-care visit to the PCP; an emergency room visit; extensive mental health services, including inpatient hospitalization and individual and family therapy; and long-term medication.

Cindy, age 16 with a history of sexually transmitted diseases, requires coverage for gynecologist visits; short-term psychotherapy visits; and medication, including Depo-Provera.

Paul, age 16 with major depressive disorder, requires coverage for an acute care visit to the PCP; short-term outpatient mental health visits; and medication.

Ricky, age 17 with substance abuse disorder and bipolar disorder, requires coverage for a visit to the PCP for medical monitoring; an emergency room visit; extensive substance abuse and mental health services, including inpatient hospitalization; residential treatment services; partial hospitalization; mental health therapy; substance abuse counseling; and long-term medications.

participating MCOs relied on medical necessity guidelines that basically limit services to children with impairments due to serious medical conditions or injuries that would improve significantly from therapy within a relatively short amount of time. Children with serious medical conditions, spina bifida, cerebral palsy, or cleft lip and palate, would receive ancillary therapies, but most children with developmental disabilities would be referred to schools or regional service centers.

Likewise, regardless of the generosity of the mental health benefits covered, access to outpatient mental health services was often hampered by plans' gate keeping and referral systems, which often required obtaining prior authorization from the behavioral health plan. Mental health providers also complained about the treatment plan documentation required to obtain ongoing treatment and about the fact that not all mental health diagnoses were considered acceptable. The majority of the plans we interviewed would not authorize therapy for children with emotional problems associated with a complex physical condition, children with ADHD, or children with conduct disorder or oppositional defiant disorder.

It is hoped that this presentation provokes thinking on the complex issue of access to care. Our work on SCHIP benefit coverage and implementation of the SCHIP program tells us that coverage is only one of many pieces that affect access to care, although it is an extremely important piece. We must go beyond assessing coverage to peeling back the onion even further in order to assess availability of qualified providers, treatment planning documentation and authorization policies, definition of medical necessity, and limitations based on disability categories. The need to create a system that allows for individualization through flexibility continues to be critically important if we are to build strong and responsive local systems of care for children with special health care needs and disabilities.

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Accessing Care: Challenges and Opportunities

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The work of the Brandeis component of the Consortium has been to determine factors that influence access to pediatric and rehabilitation services for families of children with disabilities. I would like to share our findings regarding this work in three areas: 1) the challenges confronted when trying to study access to pediatric and rehabilitation services for children with special health care needs, 2) the various ways a select group of recent studies has met these challenges, and 3) opportunities for studying access issues in the future.

Challenges in Studying Access

Four main challenges face us when studying the issue of access to care for children with disabilities. The first involves **defining children with special health care needs**. As Steve Gulley pointed out earlier, the Maternal and Child Health Bureau has developed the most widely accepted definition (McPherson, et al., 1998). This definition identifies children with special health care needs as being those “who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.” This is a broad definition since it includes both actual conditions that individuals have or are at risk for having as well as the health and related services that they may require. The challenge for researchers is to operationalize this definition. In other words, researchers must choose what conditions will and will not be included, quantify the point at which an individual is at increased risk for one of the selected conditions, and set the point at which the needed services are beyond those required by children in general. Furthermore, researchers must have the appropriate data available to determine who does and who does not fit in their study’s definition.

The second challenge concerns issues related to **multiple financing systems**. Szilagyi in 2003 noted: “the variety of public programs and delivery systems for children with special health care needs poses a difficult challenge in evaluating the overall care of this population.” Not only are there several publicly funded programs as well as a variety of private insurance options, but these programs use different funding mechanisms, including fee for service, managed care, and a variety of models that blend financial systems.

Third, there are **multiple providers and products** that children with special health care needs may utilize. Within medicine, there are primary care providers and specialty providers, pediatric sub-specialists and surgical specialists, as well as a numerous array of other service providers: nurses, occupational therapists, physical therapists, speech and language pathologists, home health care providers, mental health providers, and case managers. There are also a variety of products to consider, including durable medical equipment, assistive devices, supplies, and prescription medications.

The fourth challenge is **developing instruments or identifying available data that are reliable and valid measures of access**. Different studies have used different indicators of access, including coverage, utilization, cost, access problems or hassles, satisfaction with services, and unmet needs.

These four challenges need to be addressed before questions around access to pediatric and rehabilitation services for children with special health care needs can be adequately studied.

**Approaching Research on Access:
A Review of Four Studies**

In order to understand the different ways in which researchers have met these challenges, four recent studies were reviewed and compared across four dimensions: (1) data, (2) sample, (3) financing systems, and (4) outcomes (Table 1).

All of these studies used some type of population-based data set in order to approximate a representative, random sample of children with special health care needs (CSHCN). The data sets used ranged from the National Health Interview Survey—Disability Supplement (NHIS-D), to enrollment, claims, and encounter databases from providers and payers, to lists of members enrolled in programs serving CSHCN. The methods devised to identify CSHCN varied across studies in terms of the instruments and data used, but all tried to use the information available to them to approximate at least some of the criteria in the Maternal and Child Health definition (McPherson, et al., 1998). Some studies used samples for comparing studies across different financing systems. Only one study focused on a single financing system. Finally, two different sets of outcomes were analyzed. Two of the studies looked at utilization while the other two gathered data on a wider variety of measures including service needs, access problems, satisfaction ratings, and unmet needs.

This analysis highlights an interesting challenge for future research in this area. The two studies that used somewhat better sampling techniques (Weller, et al., 2003 and Shenkman, et al., 2003), were only able to look at utilization as an outcome. In contrast, the Family Partners Study (Krauss et al., 2000) gathered data via comprehensive mailed surveys and thus was able to look at a broader array of access measures. Reliance on mailed surveys to families on membership lists of organizations serving CSHCN, however, resulted in a less representative sample. The study currently under way at Brandeis University, *Caring for Our Children with Special Needs*, was an attempt to bring together the best techniques for sampling by accessing a statewide data base and for outcomes by asking parents, via a mailed survey, to answer a variety of questions about their experiences getting health care and related services for their child with special needs. Unfortunately, however, the response rate for this survey has been extremely low.

**Opportunities for Studying Access Issues
in the Future**

A database is now available that combines the best in sampling techniques, strategies for identifying CSHCN who receive services that are paid for by a variety of financing mechanisms, and outcome measurement. The National Survey of Children with

TABLE 1—REVIEW OF SELECT RECENT STUDIES ON ACCESS-TO-CARE ISSUES

| STUDY | DATA | CSHCN | FINANCING SYSTEMS | OUTCOMES |
|--|--|-------------------------------|---|---|
| Weller, et al. | NHIS-D ¹ | Proxy QuICCC ² | Public, private, both, none | Utilization |
| Shenkman, et al. | Florida’s SCHIP MCO’s ³ | ICD-9 ⁴ and QuICCC | SCHIP | Utilization |
| Family Partners | Member lists from Family Voices and Title V programs | Proxy MCHB criteria | Public, private, private 1st and public 2nd | Need, access problems, ratings |
| Caring for Our Children with Special Needs | GIC ⁵ enrollment and claims data bases | ICD-9 codes | Private only, private and public | Utilization, costs, satisfaction, unmet needs |

¹ National Health Interview Study—Disability Supplement

² Questionnaire for Identifying Children with Chronic Conditions

³ Managed Care Organization

⁴ International Classification of Diseases (9th edition).

⁵ Commonwealth of Massachusetts Group Insurance Commission

Special Health Care Needs collects a comprehensive set of information on a representative sample of households in 50 states and the District of Columbia (van Dyck, et al., 2002). Children are identified as having a special need based on the CSHCN Screener. The parent or guardian who knows the most about the health and health care of the children in the household serves as the respondent for the interview. The interview covers ten domains that were chosen to address issues of epidemiological and policy importance. Selected questions from the Family Partners survey were used in the development of the national survey. The domains covered are (1) demographics, (2) health and functional status, (3) health insurance coverage, (4) adequacy of health insurance coverage, (5) public program participation, (6) access to health care, (7) health care utilization, (8) care coordination, (9) satisfaction with services, and (10) impact on the family. Therefore, it includes a wealth of information on a large sample of children, making it an incredible resource for addressing a great variety of questions about access to pediatric and rehabilitation services for children with special health care needs.

Children with disabilities and special health care needs present with a variety of complex considerations. In order to best serve the needs of their child, families are often required to search out limited services from providers who may not have

pediatric expertise or who may not provide services within a family-centered system of care. Policy related to financing care and designing delivery systems must take these factors into account. Information on both the quantity of services available and the quality of those services is necessary to formulate policy oriented to improving access to quality care for children with disabilities.

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Transition from Pediatric to Adult Health Care Systems

Bridging the Gap: Transition to Adulthood for Young People with Disabilities and Special Health Care Needs

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“Who are you?” said the caterpillar. “I...I hardly know, sir, just at present,” said Alice rather shyly. “At least I know who I was when I got up this morning, but I think I must have changed several times since then.”

Alice's Adventure in Wonderland, Lewis Carroll

This quote by Lewis Carroll aptly describes the near-constant changes seen in teenagers. As we think about these young people, it is important to be aware of all the changes—both internal and external—that are going on in the lives of youth with disabilities during the time of their transition from pediatric to adult health care systems. The objectives of this presentation are to: describe the population of youth with special health care needs, identify the components of transition and the hurdles to doing it successfully, discuss what is most important to young adults as they move into the adult world, and provide suggestions for improving the transition process.

A *USA Today* survey in 2000 asked adults what age they would like to remain. Overwhelmingly, both men and women chose the ages between 15 and 25. It would appear that many people look at these years, the transition years, as the best time of their lives. This is a very important period, and we certainly want to make it be a positive time as well for teenagers that have special health care needs.

Using the Maternal and Child Health Bureau's definition of disability¹, it is estimated that 20-30 percent of children and youth are considered to have a special health care need. Currently 90 percent of all children with a special health care need (SHCN) are living into adulthood. Thus, there is a growing number of young adults with SHCNs who wish to become productive citizens, participating to the fullest extent possible in their communities. This transition to adulthood can be difficult and challenging for all young adults, but especially for those with disabilities and SHCNs.

¹Children with special health care needs are those who have or are at risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type and amount beyond that required by children generally. McPherson, et al., 1998.

Transition Components and Hurdles

Throughout life, we move through a variety of transitions. Most of us gradually take control of those transitions, and by the time we are young adults we are making our own decisions regarding them. Children and youth with SHCN must also go through these transitions, however all too often many of the decisions related to those transition times continue to be made by parents, school personnel, or pediatric health care providers even when these young people become young adults.

Like all children preparing for life, preparing for transitions must begin early in life. For children with a disability and special health care needs, the gradual transition from pediatric health care services to the adult health care delivery system should begin the day a child is diagnosed. Plans for transition must be individualized, developmentally appropriate, and coordinated, thus early planning is crucial for all areas of transition.

Because of the advances in medicine over the last 30 years, children with SHCNs are living well into adulthood. Yet young adults with SHCNs are not as successful as their healthy peers in becoming adults who participate independently and fully in community life. For example, only 65 percent of youth with SHCNs have a driver's license, compared with 90 percent for non-disabled young adults. Youth with SHCNs also have higher rates of unemployment, are less likely to finish high school, and are three times more likely to live in a household with an income of less than \$15,000 a year. Also, all young adults between the ages of 18 and 30 are least likely to have health insurance. This is a particularly significant problem if you have a SHCN and an ongoing need for health care.

In 2002, the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians ratified a consensus statement to ensure that all young people with SHCNs have affordable, continuous health insurance coverage, a medical home, and health care providers who:

- ◆ Attend to the unique needs of the youth during transition,

- ◆ Have core knowledge and skills related to disabilities,
- ◆ Use comprehensive guidelines for primary care,
- ◆ Have been trained in the process of transition,
- ◆ Will develop a written health care transition plan by the child's age of 14, and
- ◆ Maintain a current medical summary.

Priorities of CSHCN

The driving force during adolescence is becoming competent. All youth, including those with disabilities, want to feel competent. A Parent Advocacy Coalition for Educational Rights (Wright, 1996) study showed that youth with disabilities identify six priorities for adulthood: career development, independent living skills, finding and paying for health care, exercising their rights under the Americans with Disabilities Act (ADA), protecting themselves from crime, and obtaining financing for school. Like youth throughout the country, youth with SHCNs want to get whatever support it is that helps them to become an independent adult. It is crucial that service providers recognize these goals of youth.

In an attempt to assist young people with disabilities during transitions, some time ago I started a medical transition program in a pediatric institution—and nobody came. Then I started a pre-vocational program in a pediatric hospital, and I'm now turning away 10 youth a week. You've got to give them what they want, which is to "make it" on their own in the adult world. If you can get them engaged and feeling competent in something, everything else follows.

Not working and being without health insurance is the truest definition of what it means to be disabled in America. If you don't have a job or insurance, and then on top of that you have special health care needs, you really are fighting an uphill battle. Maintaining employment is crucial to maintaining health insurance. Eighty percent of Americans get their health care coverage through a work or employment-related plan. We've talked a lot about Medicaid and lots of public programs, but in the end employment is where most health care coverage comes from. So we need to get young adults successfully into the job market—hence the

importance of pre-vocational programs and other transition initiatives that provide real skills.

The future job market has a number of challenges. To attain and maintain employment you need an education, on-going continuing education, and flexibility. For most positions, a college degree is needed. You also have to keep retraining and be flexible. These are hard things for all of us to do. You also need to expect to change careers—not just jobs—three or four times.

Employers rank prior work experience, attitude, and communication skills most important in making hiring decisions. Forty percent of seventh and eighth graders are doing some kind of part-time work, and 80 percent of high school students are working. If a youth with a SHCN who does not have work experience is competing for a job with somebody who has some experience and doesn't have a SHCN, the youth with SHCN is not going to get the job not because of his disability but because of his lack of experience. Educational level attained relates to survival; it affects one's future income level and the probability of participating in the labor force. That's true whether you have a disability or not.

We know part-time work is extremely important; it helps get people ready and thinking about ways to incorporate themselves into the workplace. Minority, poor, and disabled youth have less work experience by far than their peers from a majority population who come from more affluent backgrounds, but when the first group of young people get work experience, they make the same wages. Thus, work experience can be a leveler.

The Social Security Administration has done a study that looks at youth in the District of Columbia who are on Medicaid and receive benefits from the Supplemental Security Income Program. These young people between the ages of 12 and 18 were asked if they would like to participate in a pre-vocational program. They also completed multiple questionnaires. Two hundred of the 800 youth who were surveyed agreed to participate. Even with the uncertainty of their future given their health and economic status, when asked about future employment,

they overwhelmingly replied that they were interested in getting a job. This was true if the young adult had HIV, diabetes, spina bifida, or any of the other health conditions that were included in the study.

Of all the age groups surveyed, 13 and 14 year olds with disabilities were most interested in career readiness programs, even though their life-skills mastery was lower than that of young people without disabilities. Seventh graders with SHCNs actually had *higher* scores for positive attitude, interest, and competency towards work than those without disabilities. However, as the young people surveyed aged, this difference became smaller, and ultimately the scores of youth with disabilities ended up lower than those of youth without disabilities. The conclusion is that over time they have come to have a lower self-image. As they get older, their health quality of life also decreases.

A conclusion from this study is that the transition process should be started when youth with SHCNs are most interested, around the age of 13. Don't wait for the downward spiral to start. At this age, the gap between them and their non-disabled age mates is least. We must tailor service to keep these young people from falling behind their healthy peers.

Suggestions for Improving the Process of Transition

The following are some suggestions for future inquiry and action:

- ◆ Know the services that are available to support transition and coordinate these services.
- ◆ Increase the expectations of young people with SHCNs, capitalizing on their positive attitudes about their future lives during the early teen years.
- ◆ Protect young people's access to health care.
- ◆ Understand which issues support and impede the completion of high school for young people with SHCNs.
- ◆ Study the effects of the federal No Child Left Behind legislation and the high-stakes testing involved in its implementation.
- ◆ Keep youth on track by helping those with SHCN identify and reach milestones related to work preparedness.

- ◆ Understand why youth with certain disabilities do better in the work world; use the lessons learned from these young people to support and encourage youth with other kinds of disabilities.
- ◆ Begin long-term, follow-up studies focused on understanding factors that promote—and hinder—successful transitions into the adult working world of young people with disabilities.

To conclude, I want to share two quotes. The first is from Franklin Roosevelt:

“The ablest ‘person’ I’ve ever met is the person you think you are.”

The second one is from Ralph Waldo Emerson:

“Not in his/her goals, but in his/her transition is man/woman great.”

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Promising Practices in Health Care Transition

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Health care transition is a major problem area in health care policy. More importantly, it is a challenging life event for young people, for families, and for the pediatric and adult health care providers who work with young people who have special health care needs.

This presentation will address some of these challenges by 1) presenting a definition of health care transition, 2) describing findings from our recently completed study on health care transition experiences, and 3) presenting a number of practices that appear to promote more successful transitions from pediatric to adult care.

What is Health Care Transition?

The beginning of the national discussion of health care transition came in 1989 at the “Growing Up and Getting Medical Care Conference,” a meeting convened by then Surgeon General Dr. C. Everett Koop (Magrab & Miller, 1989). While the participants at this meeting did an excellent job of identifying the important health care transition issues and developing a plan of action, our nation has not made much progress since then. The problems that were identified 15 years ago are still with us today.

Currently, more young adults with special health needs are aging out of pediatric care. Unfortunately, adult-oriented health care providers are, as a rule, not prepared to provide the high quality, coordinated, continuous, individually oriented care these young people need. The medical community, however, is now becoming more aware of the issues related to health care transition. Developed in 2001, *The Consensus Statement on Health Care Transition for Young Adults with Special Health Care*

Needs (2002) has now been endorsed by the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians. This consensus statement clearly presents the goal of health care transition as being “to maximize lifelong functioning and potential through the provision of high quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood.” Health care transition is also included as one of the federal Maternal and Child Health Bureau’s National Goals for Children with Special Health Care Needs, and it is the focus of a Title V Maternal and Child Health Block Grant Performance Measure.

The National Survey of Children with Special Health Care Needs (van Dyck, 2002) gives us an idea of how well health care transition is being addressed. The results of this survey indicate that only six percent of teens with special health needs were given guidance and support as they transitioned to adult health care, vocational and career training, and preparation for adult employment. In total, however, approximately 600,000 adolescents with special health care needs turn 18 every year. Because of medical advances, young people with disabilities and special health care needs are thriving well into adulthood. They will require appropriate adult-oriented health care if they are to continue to be healthy and contribute to our society.

Experiences/Findings in Health Care Transition

Since 2000, my colleagues Robert W. Gibson, Leslie Walker, and I conducted 34 focus groups and interviews with young adults, family members, and physicians and nurses to better understand the experience of health care transition as it is lived.

Participants in the study described successful health care transition as a developmental process, identified numerous barriers that exist to accessing the adult health care system, and underscored the central role that interpersonal relationships play in obtaining successful health care (Reiss & Gibson, 2002, Reiss, Gibson, & Walker, 2005).

Based on the information shared with us by families, we have concluded that health care transition, as a developmental process, has three major stages: (1) Envisioning the Future, (2) the Age of Responsibility, and (3) the Age of Transition.

Families indicated that the process of **Envisioning the Future** for their child often began when their physician asked them what they thought their child's life would be like when he or she reached adulthood. Where would they live? Would they have a family of their own? What would they do for a living?

During the **Age of Responsibility** stage, the child learns how to take responsibility for his or her own care; the development of these medical and personal self-care skills serves as the foundation for their future independence. Examples included doing household chores, making sure that medical equipment is clean and functioning, learning about medications, becoming good informants about their own medical condition, independently interacting with health care providers, and becoming involved in medical decision-making by participating in and giving assent to their own plan of care.

The **Age of Transition** focuses on future expectations and builds on the independence-related skills that are developed in the two previous stages. It is during this time that responsibility for self-care is increasingly transferred to the young adult and specific arrangements are made for his or her transition to adult-oriented providers.

While we based this three-stage developmental model on the information we gathered through our interviews, we did not find many youth whose transition experience conformed to this "ideal" transition process. Most participants faced a number

of barriers and difficulties. One common barrier was the low level of information, training, and support provided to young adults and families to prepare them for transition. Transition often was prompted by age or behavior, rather than by the young person's readiness to negotiate the adult health care system. Another barrier was difficulty in finding adult-oriented providers who had knowledge and experience with chronic health conditions and disabilities, and who also were willing to provide care to the young adult with these needs.

Because of the way medical training is organized, many adult-oriented providers do not have experience with the childhood-onset chronic conditions that are regularly treated in pediatrics. Another significant problem is maintaining or finding health insurance for young adults as they age out of their parents' coverage or out of public insurance programs for children. These problems can be seen as differences between the pediatric and adult health care systems. Many participants observed how difficult it was to learn a new system of care that was significantly different from the care that they were used to and were satisfied with.

Participants in our study told us that relationships among families, young adults, and providers were an important aspect of pediatric care. Many times these relationships had developed and were strengthened over a number of years. As a result, the process of saying goodbye in a positive manner is an important aspect of transition, and requires specific attention. We believe that in order to terminate a health care relationship therapeutically, it is necessary for providers, families, and youth to acknowledge their feelings about each other and the upcoming changes, and to negotiate how they will relate to each other after the transfer is made to adult care. Unfortunately, most pediatric providers do not receive training in this area. Without good closure of these relationships, adult-oriented providers are often confronted with interpersonal as well as medical challenges.

Practices that Promote Successful Transitions

In our study, families also identified activities, attitudes, beliefs, and behaviors that help make

their health care transition successful. We call these “Promising Transition Practices.” Presented here are a number of these promising practices.

Have a Life. Many young adults stressed the importance of “having a life.” This is an important message. Medical interventions are designed to support survival. But having a full and productive life involves learning, having fun, making and being with friends, and being involved with activities in the community as well as in the world at large. Therefore, youth and families stress the importance of living as normal a life as possible, and accommodating medical interventions in that life (rather than planning one’s life around needed medical care).

Start Early. Begin preparations for transition as early as possible so that self-responsibility and self-care become a habit even before a child reaches the “rebellious” teenage years.

Speak Up and Ask. If pediatric providers don’t initiate discussion about health care transition, then families should raise the issue.

Build Pediatric-Adult Networks. Pediatric providers should work to develop connections with the adult provider community in order to help make transition referrals smoother.

Health Journal. Developing and keeping a medical journal and health summary can be one important way to lay the foundation for young adults to take charge of their health care and also to make it easier to communicate with new adult-oriented providers about health needs.

Guardianship and Health Surrogates. For young adults with limited cognitive or decision-making capacity, it is important for parents to begin the legal process of guardianship before the age of 18. It is also important to identify siblings and family friends who can serve as health care surrogates and can assist in decision-making when parents are no longer able to carry out these responsibilities.

Our research tells us that the process of change regarding health care transition, at least initially, is

in the hands of families and also in the hands of young people themselves. Over the last 30 years, families have helped reshape pediatric practice so that it is more family centered and user friendly. As more and more young adults and their families access adult-oriented care, these same pressures will be brought to bear on the adult-oriented health care system. We need to do a better job of enabling youth to move those systems forward. We also need to do a better job of training both pediatric and adult-oriented providers in terms of their medical knowledge base, interpersonal skills, and ability to work collaboratively with school-based personnel and school-based transition programs.

Providers of services to children and youth with disabilities and special health care needs have a long-term commitment to children with special health care needs that continues into their young adult years. Future research needs to focus on children as they become young adults: their health status, quality of life, productivity, role in the community, and role as change agents in the adult health care system. From a policy perspective as well, we need to make sure that there is a coordinated and coherent approach to transition across the many elements of our health care system.

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Assistive Technology for Children and Youth with Disabilities and Special Health Care Needs

Assistive and Therapeutic Technologies for Children and Adolescents: Images and Reflections

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The field of assistive technology has grown significantly over the past three decades. Once it seemed like science fiction when you had a computer that filled a room. It is now commonplace to hold an even more powerful computer in your palm.

The purpose of this presentation is to review the types of technology available in the rehabilitation field and to pose salient questions as we move into the next phase of large-scale implementation of technology.

Virtual Reality as a Therapeutic Tool

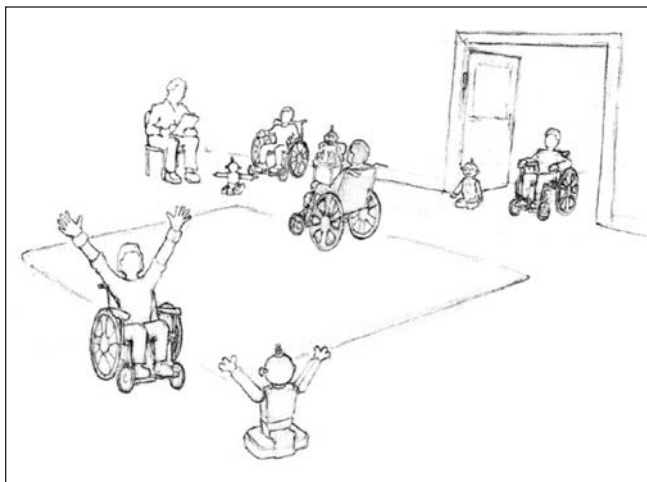
Most of us have had the experience of using virtual reality (VR) as an entertainment medium. Cheryl Trepagnier and Marc Sebrechts of Catholic University, however, have been using this technology with children who have autism as a way of helping the children develop positive social behaviors. Through the use of a virtual reality system, a child is placed in a space filled with social challenges and the child must choose the most appropriate behavior, depending on the context.

Dr. Trepangier, in collaboration with Corinne Lathan, Ph.D., of AnthroTronix Industries, is also using VR to increase eye contact in children with autism. The VR Buddy provides vestibular, visual, and auditory stimulation contingent upon eye contact. Through virtual reality, the vestibular reward takes the child through space on the back of a rocket.



Robotics as Therapeutic Aides

Cori Lathan and her team at AnthroTronix have also developed a line of products aimed at enhancing the therapeutic experience. CosmoBot is a robot that is wirelessly connected to a child. CosmoBot moves in imitation of the child, correctly moving, dancing around, and singing songs. CosmoBot can be programmed to respond to increasingly complex and difficult movements.



Another use of robotics is as assistance to therapy. “Boing” provides resistance to movement while at the same time providing a visual stimulation in response to the “correct” movement, thus providing convergence of exercise with virtual reality. As an extension of Boing, John Noiseux at the National Rehabilitation Hospital has created “Ani-Mate gameware” to be used with Boing. This gameware, be it basketball, football, or bubble popping, motivates the child. It can be programmed to



respond to the individual needs of each child. Additionally, the gameware can be easily changed and enhanced to meet the individual interests of the child as seen by a teacher, a therapist, or a parent.

The Lokomat Robotic Gait Training System is a bilateral device that assists a person in walking in a partial weight-bearing harness by having a robot move each leg. The system is effective for individuals with spinal cord injury, cerebral palsy, stroke, or brain injury.

The Manus is another therapeutic aide that nudges a limb in synchrony with visual exercises on a screen. The therapist can program the device to provide either assistance or resistance; the individual can perform the exercise either isometrically or isotonicly.

Robotics as Assistive Technology

Robotics are also used as assistive technology, helping an individual perform functional tasks. The Segway from Dean Kamen is the newest of these devices. This device is quite popular and can be seen on streets everywhere. The Segway is a compact device that allows the individual complete freedom of movement. This is a similar technology to the iBot (a wheelchair that allows a person to change heights and move up and down steps). Prostheses that are controlled through a remote switch, electromechanical design, or through EMG technology also are all currently available.

Telepractice (Telehealth)

Telepractice is a service-delivery methodology. Providers deliver therapeutic, surgical, and consulting services remotely through information technology and phone lines. Rehabilitation, educational, or medical services and supports for independent living are provided at a distance through information and telecommunication technologies.

The National Rehabilitation Hospital, in collaboration with the Sister Kinney Institute in Minnesota, uses telepractice to deliver rehab services to children in American Samoa. The least expensive way of doing this is through the videophone. Web-cam technology through the Internet is another

common tele-methodology. The bandwidth of your computer will dictate how clear the pictures are. The quality of the pictures can be quite good with DSL, cable modem, or a broadband line.

Simple yet sophisticated videoconferencing has a variety of uses, for example, to provide follow-up services in schools, community settings, and homes. A practitioner at some distance can provide consultation, follow-up, instructional services, etc. to a child, family member, or colleague through videoconferencing. This type of technology has enhanced access to specialty providers for many people, especially those in remote settings.

A more sophisticated telepractice application is now in controlled trials at the National Rehabilitation Hospital. It is called RESPECT (REmote SPEech-language and Cognitive Therapy). In RESPECT, a touchscreen interface is used for cognitive, perceptual, and linguistic assessment. Thus, a therapist at one location is able to converse with a client at another. They are able to see one another, hear one another, perform tasks, and collect data automatically.

Adapting telepractice applications for physical therapists and occupational therapists who rely on physical movement of the client has been a challenge. This challenge is being worked on in two areas: sensory substitution and haptics. *Sensory substitution* has been used with individuals who are blind in that sound or tactile sensation has been substituted for vision. *Haptics* involves a system that mechanically substitutes for the therapist's hands. For example, applying resistance to the forearm through



a sleeve that is controlled off site, the therapist can modify the movement pattern or the resistance.

The World Wide Web as a Community

As the World Wide Web expands, the concept of a community emerges. The Web can be used as an electronic health site that incorporates vetted health information and peer-to-peer interaction.

An extension of the Web is teleplay. Through the Web, a child-child dyad or child-therapist dyad can play a game with one another, or the child can play against an opponent built into the computer. The play requires the child to pay attention, engage cognitively, and plan ahead. Meanwhile, the therapist, teacher, or counselor is able through the Internet to track how the child is doing and to download changes to the game, making it more challenging and interesting or even to introduce new or different concepts. AnthroTronix has created a software version of CosmoBot called CosmoWeb. In this version, the robot engages in a game with a child player.

Commercial Products as Assistive and Therapeutic Technology

Commercially available products can be used as therapeutic technology and assistive technology (AT). Global Positioning Systems can be used to monitor and track individuals who wander. Speech recognition was cutting edge technology 12 years ago and now it has become ordinary assistive technology. Camera watches and cell phones can be used to connect hospitalized individuals with family members, classmates, or colleagues. Microsoft Portrait is a research prototype for mobile video communication that connects to cell phones or to pocket/handheld PCs. Haptic controls for PCs or gaming systems are now available for under \$100.

Summary

The world of technology is ever expanding and becoming universal. Universal technology is assistive technology. Computing, smart homes, wireless gadgets of all types, and car-tracking satellite systems are all meant to make life easier for all of us, and are examples of universal technology. All useful technology is assistive. It is part and parcel of all the technology that we use.

But there are challenges that researchers must address. Following are five recommendations that can make universal technology a reality.

- ◆ Train providers to understand that technology can be a functional assist or a compensation for individuals with disabilities, and not a failure of intervention.
- ◆ Recommend assistive technology based on sound, systematic evidence of its benefits, not based solely on the recommendation of sales persons.
- ◆ Recognize that not all technology is beneficial, functional, or wise.
- ◆ Ensure that AT services are in place to support AT, especially when complex, highly sophisticated technology is being used.
- ◆ Create rational, sufficient, and appropriate reimbursement for AT and AT services.

Creating a System of Care for Children and Youth with Disabilities and Special Health Care Needs: The Promise of Technology

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Children and youth with disabilities have complex habilitative and health care needs that often require a complex array of services throughout their lives. Rehabilitative services and early intervention are increasingly available to children with disabilities; assistive technology is a critical component of this service array.

In order to provide the most efficient and comprehensive service to children, youth, and their families, a system of care is the preferred service delivery model. Technology in the form of assistive technology, assistive technology services, and telehealth practice hold promise in helping providers and communities create a system of care that is comprehensive and flexible in order to meet the individual service needs of children and families. I am interested in showing how our work in assistive technology and telehealth fit within the framework of creating a system of care for children with special health care needs and disabilities.

The purpose of this presentation is to describe the framework of a system of care for children and youth with disabilities and special health care needs and to integrate into that framework the findings of two studies focused on the training needs of providers of assistive technology.

Assistive Technology and Assistive Technology Services

Assistive Technology is any product that is used to increase, maintain, or improve the functional

capabilities of individuals with disabilities. Examples range from items as simple as a suction-cup rattle to sophisticated computerized communication devices. Assistive Technology Services include the services and supports necessary to figure out which is the technology that is appropriate to meet an individual's needs. Continual advances in technology increase the likelihood that more and more children with disabilities can benefit from assistive devices.

BOX 1

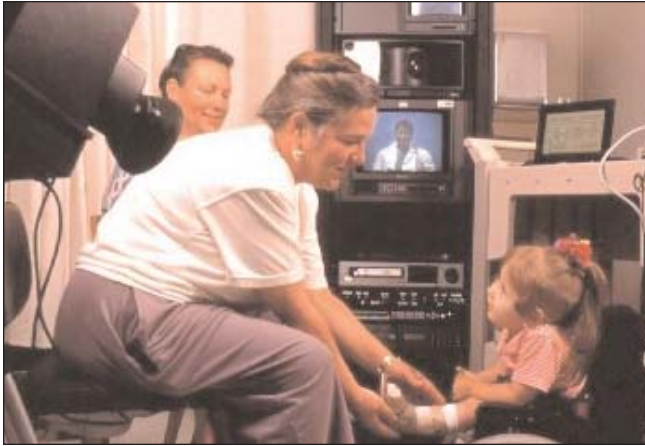
Definition of Assistive Technology and Assistive Technology Services (AT/AT Services)

Assistive Technology: Any item, piece of equipment, or product, whether acquired commercially, off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities.

Assistive Technology Services: The evaluation of the needs of the child; purchasing, leasing, or otherwise acquiring a specific device; selecting, designing, fitting, customizing, adapting, applying, maintaining, repairing, or replacing specific devices; coordinating and using other services such as therapy, education, rehabilitation, and vocational training or technical assistance for the child, family, or caregivers in the use of specific devices; and technical assistance or training for professionals or others who provide services to the child.

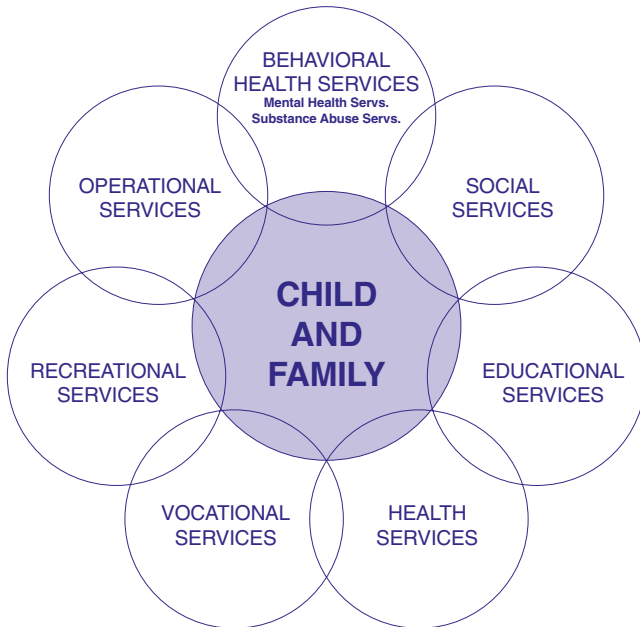
Telehealth

Telehealth is a service delivery system that brings people who are in remote locations together through the use of communication devices.



Systems of Care

Systems of care are inter-connected networks of services for children and youth with disabilities that are comprehensive, coordinated, family-centered, culturally competent, and community based.



A system of care helps us identify in an organized fashion the array of services that children and youth with disabilities need. Clarifying and organizing this array helps us build partnerships among and within disciplines and providers.

Connection Between Technology and Systems of Care

Technology can enhance the capacity of communities to provide services and supports to children, youth, and their families so that the children can be full participants in the communities in which they live.

Technology can:

- ◆ Improve access to care
- ◆ Enhance the independence of an individual
- ◆ Increase the affordability of care
- ◆ Increase the efficiency of service delivery
- ◆ Empower families and individuals to get the care they need.

In current practice, however, assistive technology, and assistive technology services, are underutilized and providers are reluctant to establish telehealth linkages because:

- ◆ Very often the technology gets abandoned.
- ◆ Technology is expensive:
 - ◆ The services needed to support the use of the technology are rarely adequate to help individuals make the best use of it.
 - ◆ Telehealth systems are considered expensive both from a technological standpoint and from a provider standpoint.
 - ◆ Reimbursement for telehealth systems often is neither adequate nor available.

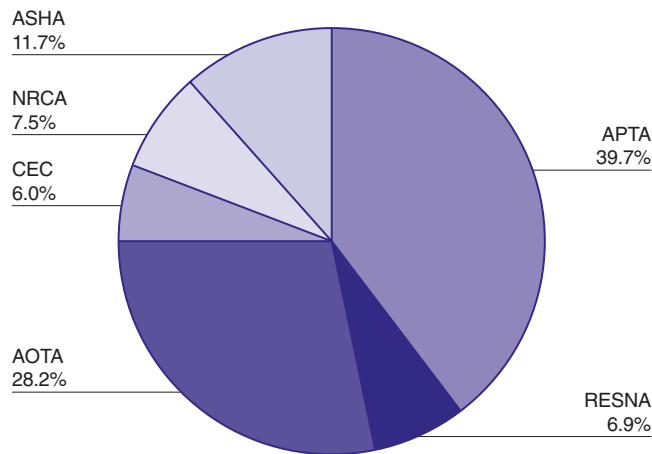
Evidence-Based Changes to Current Practice: The Training Needs of Interdisciplinary Team Members in Assistive Technology

I'm going to share the findings of two studies focused on training service providers in how assistive technology can be used as a tool to assess, treat, and support children and youth with disabilities, thereby empowering them as individuals and allowing them to become vital parts of their communities.

The purposes of our study were to determine the current status of training for service providers in the area of assistive technology, and to identify the specific training needs providers have.

One thousand thirty-one interdisciplinary team members who are in positions to recommend, order, design, monitor, and evaluate individuals for assistive technology and AT services responded to a survey sent to over 3,000 members of six professional associations: the American Physical Therapy Association (APTA); the American Occupational Therapy Association (AOTA); the American Speech, Hearing, and Language Association (ASHA); the Council for Exceptional Children (CEC); the Rehabilitation Engineering Society of North America (RESNA); and the National Rehabilitation Counselors Association (NRCA).

The respondents were primarily from the three primary rehabilitation professions: physical therapy, occupational therapy, and speech and language pathology.



The survey consisted of 19 closed, multipart, and open-ended questions in three areas:

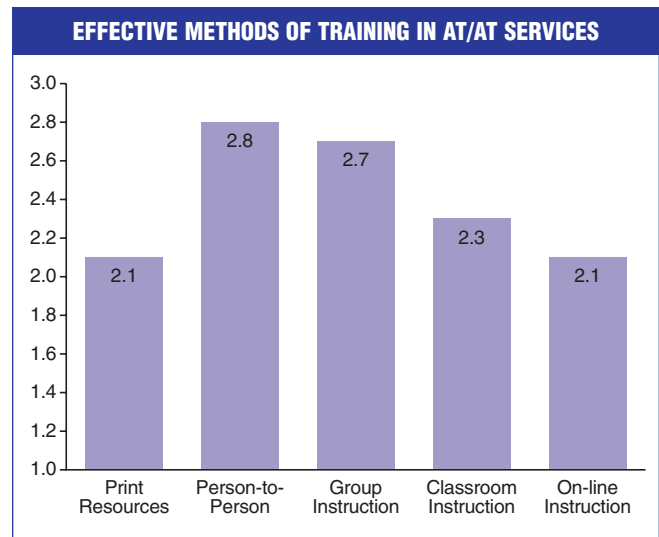
1. Adequacy of Training in AT/AT Services to Children with Disabilities
2. Access to Information about AT and AT Services
3. Confidence in Providing AT/AT Services

Findings

Generally, the respondents to our study reported that they have had adequate training in the areas of disability and collaboration, but less than adequate training in three areas: service delivery, working with families, and legislation concerning children

with disabilities in relation to providing AT and AT services to children with disabilities and special health care needs. Members of RESNA, who are primarily assistive technology specialists, were more likely to report adequate training in all areas. They also reported having more job responsibilities related to AT/AT services.

The respondents also were found to be relatively traditional in reporting their view of the effectiveness of the training methods used—they preferred person-to-person training such as consultation, mentoring, supervision or group instruction in the form of in-services, workshops, and continuing education.



Although most of the respondents indicated that they did not feel adequately trained in AT/AT Services, they are in positions where AT recommendations and AT services are expected of them. Because of this, we asked how confident they felt in providing these services. The respondents reported that they felt confident in recognizing the benefits of assistive technology and in the use of low-tech devices such as pencil grips or manual wheelchairs, but they had little or no confidence in knowing about funding sources, high tech devices, or identifying suppliers in their community. In sum, although providers may feel that a piece of equipment or a device may benefit their client, they have little knowledge about where to go to obtain the device or where to go to get funding for the

device. Generally, the respondents felt somewhat confident in non-AT areas, more indicative of what they do on a regular basis: assessing and evaluating outcomes and creating intervention menus.

| CONFIDENCE IN PROVIDING AT/AT SERVICES | | |
|--|---------------------|-----------------|
| NO CONFIDENCE | SOMEWHAT CONFIDENT | CONFIDENT |
| Funding | Assessment | Benefits of AT |
| Hi-Tech Devices | Evaluating Outcomes | Lo-Tech Devices |
| Identifying Suppliers | Creating Menus | |
| | Matching Devices | |
| | Providing Training | |
| | Cultural Diversity | |

The Use of Telehealth for Children with Disabilities and Special Health Care Needs Living in Remote Settings

Working with the Consortium and additional partners (the University of Missouri, the University of Washington, and Twyla Bohl from South Dakota), we conducted in-depth interviews with families and providers who have been involved in a telehealth event. The Consortium was interested in determining what the added value (beyond satisfaction) was to families and providers in participating in a telehealth activity. Through analysis of these interviews, we determined that telehealth could lead to three categories of outcomes:

Immediate outcomes:

- ◆ Enhanced access to specialty care providers (ease of access, timeliness, and frequency of access)
- ◆ Family and provider acceptability and satisfaction of telehealth
- ◆ Effectiveness in achieving the intended purpose because of improved access to care
- ◆ Time and cost savings

Intermediate outcomes:

- ◆ Enhanced communication and collaboration. *“You can see that person (via videoconferencing), you*

know who they are, and that’s really a relationship.”—Public Health Nurse

- ◆ Timely implementation of care plans. *“It (the care plan) could have been created without videoconferencing, but I think it would have been much more difficult to pull off because of the distance.”*—Physician
- ◆ Enhanced range of treatment options because of access to a variety of health care possibilities
- ◆ Increased family and provider confidence due to ease of communication and relationship building

Long-term outcomes/impact:

- ◆ Enhanced local capacity (improvement in quality of community-based care; reduced reliance on tertiary care facility). *“Before the videoconference I had no confidence. I didn’t trust the schools or the teachers. After telemedicine, we talk more. That gave me the confidence to let him go to school.”*—Mother
- ◆ Enhanced integration/coordination of services (system of care) *“What happened as a result of telemedicine is that they (school/public health providers) probably had a more cohesive decision-making capability regarding the child because more of them were involved in gaining information together.”*—Physician
- ◆ Integration of telehealth into the overall service delivery system
- ◆ Reduction in family burden of care
- ◆ Increased access to community participation (e.g., school)

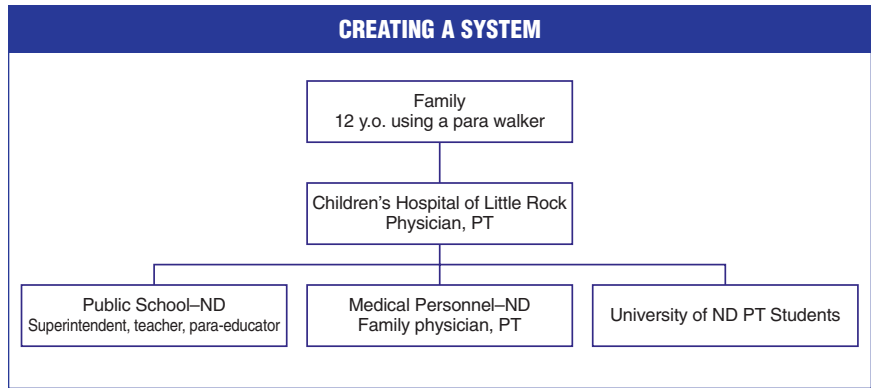
Fulfilling the Promise: Creating a System

A system of care requires:

- ◆ A variety of interconnected service delivery systems
- ◆ Flexibility in providing services
- ◆ Collaboration across disciplines, professionals, and systems
- ◆ Knowledgeable, confident providers
- ◆ Providers responsive to the individual differences of the populations served
- ◆ Active participation of providers, family members, and the child/youth with special needs

Technology enhances the capacity of communities by providing to all citizens in the community access to naturally occurring services and supports. In order for assistive technology, assistive technology services, and/or telehealth to be incorporated into a community, there has to be training and this training needs to include information on the values inherent in and the processes involved in building a system of care. It is not enough to teach an individual how to use a particular AT device. Training needs to help providers understand that technology can help the individual be more a part of their community. With that type of training, policy initiatives and an infrastructure in funding streams can be established.

In closing, I would like to tell you a story about how one family created a system of care for themselves using a combination of assistive technology for their son and telehealth. This is a story about a family in rural North Dakota with a 12-year-old son who has spina bifida. His family had heard of something called a ParaWalker and they wanted him to try and use it. His school personnel had never heard of a ParaWalker. His local physician and physical therapist in the community also had never worked with a ParaWalker, so of course the parent was a little bit apprehensive about bringing it into the community. But following a conference that the mother went to where she heard some information about telemedicine, she was able to develop a way to introduce the parawalker into her community. She contacted the physicians in the Little Rock Children’s Hospital in Arkansas who were willing to provide the child with the parawalker. Between the hospital in Arkansas and the University of North Dakota she was able to create a telehealth event for the community-based providers, her family, and the specialists in Little Rock.



She brought together the public school personnel, including the superintendent, the child’s teacher, and the para-educator who worked with the child, plus the child’s community-based medical personnel (his physician and physical therapist). And because the mother did this at the University of North Dakota, the physical therapy students in the physical therapy program were involved in the event itself.

Because of this one-time event in which the physicians and the therapists in Arkansas were able to discuss with the providers in North Dakota what a ParaWalker was and what it could do for the child, the child was able to use his ParaWalker in school, the school personnel felt very comfortable with it, and it became an integral part of his educational plan. More importantly, using this telehealth approach created a collaborative relationship between a team in Arkansas and a team in North Dakota. And that collaborative relationship built the capacity of the local school system and local medical personnel to use a new piece of technology. It enhanced the community’s capacity to embrace new technology and thereby to allow full participation by this child in his school and in his community.

“ I wanted collaboration between my son’s school (because he would be using the equipment there) and the medical personnel working with him.”

Using Performance Management to Plan for Outcomes and Demonstrate Results

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Thank you for that generous welcome and for allowing me to come here to focus on a very important issue for NIDRR: access to rehabilitation for children and youth with disabilities and special health care needs.

This morning I am going to focus on the concept of accountability from NIDRR's perspective. I really want you to understand this concept in order to be able to use it in a meaningful way.

I'm going to talk about four things:

- ◆ Why are we undertaking this accountability shift?
- ◆ What are the key components of our new language?
- ◆ What are the tools you can use to account for your time and effort?
- ◆ What are the challenges and benefits of working with people who are moving from an activity-based mindset to a results-oriented mindset?

A Shift in Accountability

What is this accountability shift and why has NIDRR decided that we must do it?

- ◆ This shift, in fact, will help all of us get to the bottom line to see what the results are of doing the work we do—the concrete products and effects of our research, training, writing, and all of our activities.
- ◆ This new process of accountability will change all of us from documenting activities to documenting impact.

- ◆ This shift will allow us to see what changes as a result of our work.

What does accountability for results mean? Essentially, it's looking at what difference your program is going to make. Within NIDRR we're talking about *results*. And we use a special language to talk about results:

- ◆ **Outputs:** are things that are tangible—like products, specific services, and publications.
- ◆ **Short-term outcomes:** are changes and improvements in the learning and knowledge system.
- ◆ **Intermediate outcomes:** are identifiable and sustained changes and improvements in policy, practice and behavior and occur within specific systems and services.
- ◆ **Long-term outcomes:** are changes in overall societal conditions. They usually refer to rates, i.e., reduction in the incidence rate of x.

This new terminology and accountability process comes from implementing the 1993 Government for Performance Results Act (GIPRA) requirements. Although GIPRA has been around for over ten years, the Office of Management and Budget (OMB) has only recently implemented it. The OMB focuses on impacts. Impact/results are what agencies like NIDRR must report on, and thus the projects we fund must give us that type of information.

All of the Department of Education's programs go through a process of answering a 25-question

instrument. This questionnaire includes items such as: Does the program have a clear purpose? Are the goals clear? Do you have long-term and measurable goals? Do you have performance indicators? Because of this, NIDRR is working to realign and focus our attention on the results of our research. It's a mind shift, a mindset change. It's a change from what research we're doing to what the *results* are of this research.

Logic Modeling: Key Concepts, Managing Results, and Outcome Planning

How do we approach managing for results? We do it by creating a logic model. But before we discuss the NIDRR logic model we must first answer the question: What is the purpose of outcomes planning? Outcomes planning helps us to identify a limited number of high priority, problem-focused, reasonably ambitious and measurable outcome-oriented performance goals. This forces us to think about **why** we're doing **what** we're doing. What changes are you trying to bring about? The reason you have to do this is that you must now respond to NIDRR's priorities, its requirements, and GPRA's performance indicators.

Now here's the tricky part and here's where we are in the middle of the sea. What's happened at NIDRR is that for a long time all of our priorities had been activity based. This grantee, for example, will investigate the prevalence of learning disabilities among school children while this other grantee will conduct a certain interventions trial. And a third grantee will identify the demographic barriers and trends in the population of people with disabilities. All of those tasks are activity based.

Activity-based priorities are still okay, but now you have to go at least one step further. You now have to ask: What changes or improvement, outcomes, and outputs/results do you want/expect from the activities you are doing? This is a total shift because the grantees have been conditioned to report on activities and not on the consequences of those activities. You've focused on conducting this survey, collecting this data, analyzing the data, preparing a report, and even conducting this State of the Science Conference.

The next question you need to ask is: What's going to change as a result of all this activity, and for whom? NIDRR needs you to capture the anticipated effects and benefits of project activities and outputs for identified subgroups of large populations. You also need to identify why is something going to change and how do you know it's going to change.


What does managing for results mean? We all know that you can't make the changes if you don't produce your output. Managing for results requires a change in mindset. What are you hoping to *accomplish* with this publication, this journal article? What is the end goal? It could be something like: to increase knowledge and learning and awareness about a salient issue in service delivery. Your responsibility is to make that connection clear.

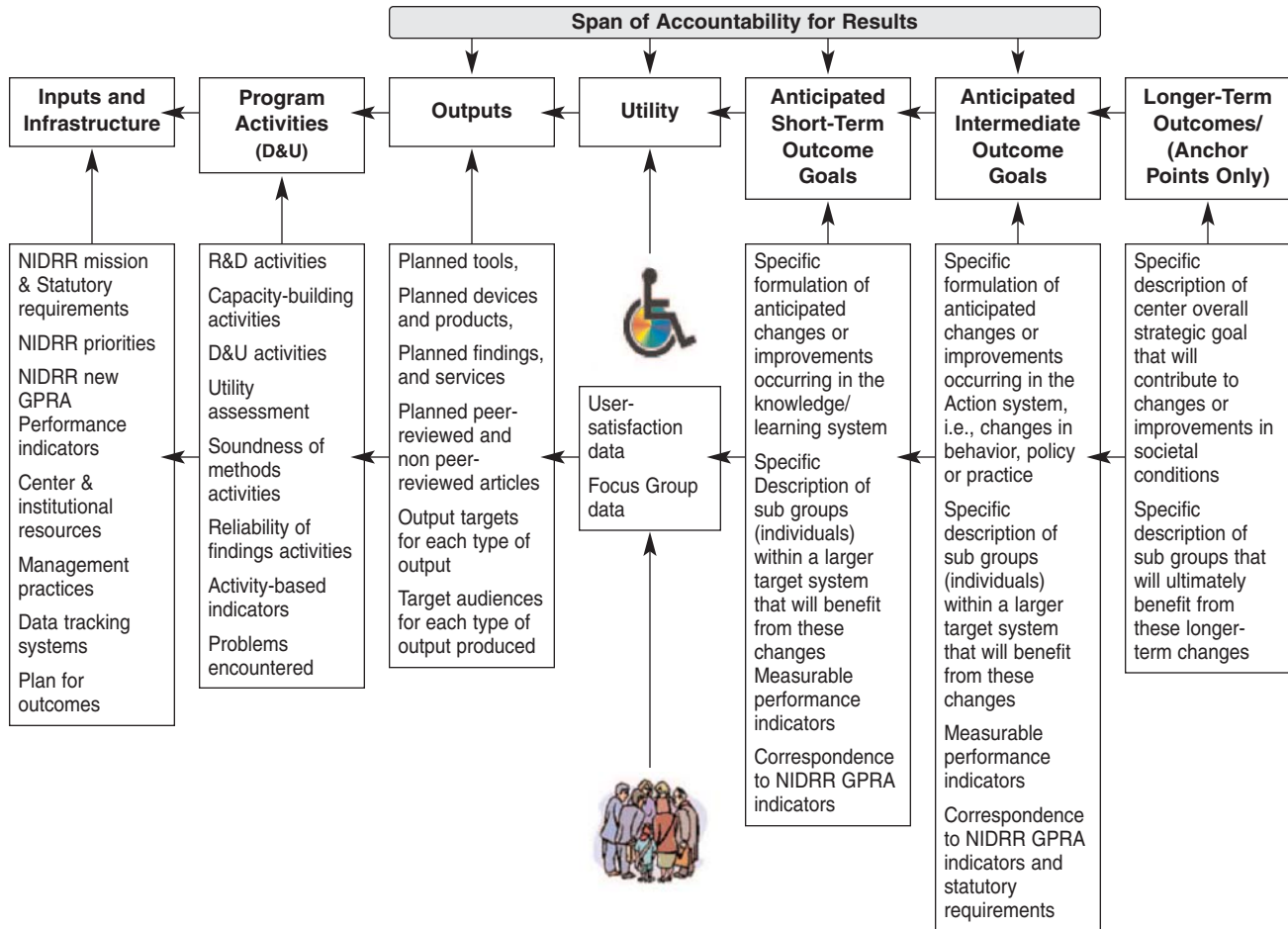
There is inherent logic in this. It's kind of like driving. Normally do you get into a car and just drive? Not around the Beltway you don't! You usually get in the car knowing where you want to end up. Now, that's where you must *start*—with a clear identification of where you want to end up.

Conducting activities is great, but NIDRR is now asking you to re-express your program goals and objectives in the language of planned outputs and anticipated outcomes. So how do you do this? What are the tools? Logic modeling is the tool or vehicle for dialogue, planning programs, getting information, making improvements, and doing evaluation. It's a picture of how everything links up. It's a graphic representation or blueprint of the key elements of a program or project and how it will work to resolve an issue, identify a barrier, and support a change. Draw me a picture of your program and tell me how it works. Tell me how the pieces fit together. Tell me what you're going to change. I'm happy that you've got significant p values. I might not know what they are, but I'm happy that you've got them, but even more I want to know what they are going to change—and how. A logic model is a helpful tool for identifying outcomes and depicting the chain of events. The model links inputs and activities to outputs and outcome. It's a logical way of describing a program.

REQUIRED DATA ELEMENTS FOR OUTCOMES PLANNING AND CONSTRUCTING A LOGIC MODEL OF PERFORMANCE FOR YOUR PROGRAM

Prepared by the NIDRR PPB&E Division¹

 **Important Tip: When Planning for outcomes, begin with the end in mind.**



¹Source: Adapted from McLaughlin, J. A. & Jordan, G. B. (In Press/2003). Logic models: a tool for describing program theory and performance, in Wholey, et al.: Handbook of Practical Evaluation. Jossey-Bass. the lead author may be contacted by email at: macgroupx@aol.com

Note: The above logic model does not include the standards by which the quality, relevance, and productivity of performance will be measured and evaluated across the spectrum. For NIDRR centers and model systems this is provided by the "centers of excellence" (CoE) criteria.

Created: March 18, 2004

I'm going to go through each component of this model from left to right and give you the definitions of each term.

◆ **Inputs and infrastructure.** This is what you bring to the table at the time you start: your expertise, your faculty, your staff, your resources, your agency's priorities, the institutional support you have available, the partnerships you have in place, and your previous accomplishments.

◆ **Program activities** are the action steps. These are the procedures performed and services delivered in implementing your plan, program, research and development work, capacity building and training with technical assistance, dissemination, and utilization. Examples: When conducting research and recruiting samples, it's the steps you go through to get the information you want to determine what and how you can provide information, services, or whatever it is

that will make a concrete impact. *In GPRA speak, the steps you follow are the activities; the research paper is the output.* A short-term outcome would be the documentation that someone read your information (reading is the ACTIVITY but what was read is the OUTPUT) or went through a training program (OUTPUT) you conducted, and, due to this *activity* they have increased their understanding or gained new knowledge of x (SHORT-TERM OUTCOME).

- ◆ **Outputs** are the direct results of program activities. These include research findings, publications, product devices, training manuals and specific services provided to external audiences.
- ◆ **UTILITY:** documentation that shows potential or actual user satisfaction or a perceived usefulness of produced outputs by users.

So far the model is telling us about the inputs/infrastructure of the program, its activities, UTILITY and its outputs. But the model also tells us that to document this information effectively we must have corresponding output measures. And NIDRR has examples of these output measures. For example, 1) the number of new discoveries made or 2) the number of manuscripts published are examples of output measures.

We need to have output measures that link to outcomes. We need to have a performance goal. As specifically as possible, we need to know who that performance goal is targeting. There's not necessarily a one-to-one correspondence between output and outcome. In other words, for every output that you produce, you're not going to necessarily have a separate outcome; you may have multiple outputs that contribute to making progress toward achieving that outcome.

- ◆ **Outcomes** are changes or improvements in knowledge, learning or awareness as well as changes in policy, practice, or behavior, or in whatever you are aiming to achieve. It's the effects. For example, as a result of me doing a presentation (activity) with the use of a PowerPoint presentation (output), an audience member works very hard and learns new knowledge (short-term outcome). Short-term outcomes are what people take away

immediately from your work; they increase their knowledge or awareness about a topic.

Intermediate outcomes build on short-term outcomes. Your short-term outcomes are designed to increase awareness or learning or understanding. Intermediate outcomes *apply* new knowledge and usually reflect the use or adoption of this new knowledge to change policy, practice, or behavior.

Longer-term outcomes are your strategic goal(s)—something that affects societal conditions. That's your anchoring point. For example, if you are an engineering RRTC, your longer-term outcome might be to increase the safety and ability of mass transit systems to transport people with disabilities while seated. NIDRR realizes that in five years most of the research, most of the effort, is going to be on increasing knowledge, increasing awareness, and increasing understanding.

This, then, is the basic jigsaw puzzle. You start from the end and work backwards. Just like when you get into your car you start driving with your end in mind, your destination, your long-term outcome, and then you work backwards. The longer-term outcomes piece is the anchor point. It's the strategic goal for the whole plan. Longer-term outcomes say a lot about what you are doing—about the social conditions you are trying to change. For example, you want people in wheelchairs to be more independent in getting around town through the use of public transportation. Well, what do you have to change? You have to get the manufacturer of wheelchair-restraint seating systems to adopt new safety standards. You have to develop the new standards, and you have to increase people's knowledge about those standards.

Another example would be if people are using a new drug to treat individuals who have sustained a brain injury. One indicator of an intermediate outcome could be the number of new prescriptions that are written by doctors for this new drug. Working backwards (from right to left in the logic model) the number of new prescriptions written by doctors would be an intermediate outcome because the doctors have changed their practice, i.e., changed what they

prescribed to treat x condition of TBI survivors. But before the medication is adopted or in use as evidenced by the number of new prescriptions, treating physicians need to increase their awareness and knowledge about the effects of this drug (short-term outcome), so you therefore put out a curriculum on drug use which is an output that must be available to doctors to read before their knowledge increases.

In the middle is **utility assessment**, the usefulness or the perceived usefulness of your output. Utility assessments provide information on how useful the consumer finds the output. Outcomes do not happen just because they're there. They happen due to the interplay of the capacity building and training efforts. They happen due to the dissemination and utilization efforts. And so you need to identify what activities each of those programs or areas are doing to promote the actual achievement of the overall short-term and intermediate outcomes that you're all about.

So when you write outcomes, you want to have a limited number of problem-focused outcomes. Under GPRA regulations, for example, NIDRR for all of its programs in R&D, is allowed only three outcomes!

Challenges and Benefits of the Logic Model

This process is tough. I predict that when you break out into your work groups, you're going to have a hard time trying to use this approach and vocabulary within your three topic areas. One major challenge is the tendency for teams to develop more outcomes than necessary. What's the first problem? It's lack of specificity in what is changing or improving as a result of activities and outputs. You need to ask: "What is the change we want to bring about?" You're going to try to bring about two changes, either an improvement in the knowledge or learning or you're going to bring about changes in behavior, policy, or practice. And you can't really adopt new policy and new practices if you don't have the new knowledge upon which those changes are built. The short-term outcome may be an advancement in existing theory, an advancement in

knowledge, whereas the intermediate outcome is the application of the new knowledge that changes the way you do things.

In addition to specifying *what* is changing, you also have to specify *for whom* and *where*. To do that, you're going to need to identify a specific subgroup within the larger group or service network. Members of this specific sub-group are the targets whose level of knowledge or awareness you expect to change and later whom you might expect will adopt or use this new knowledge to change policy, practice or behavior. It is important to be as specific and as focused as possible when identifying your targeted systems or groups

Think of a quilt to illustrate the logical connections between all of the components of performance measurement. Each component of performance measurement (inputs, activities, outputs, etc.) is a separate but important patch that will contribute to the making of the entire quilt. The thread that connects all the patches is the logic model which shows how each piece is dependent on the other to form a logical interconnected whole. The achievement of intermediate outcomes—or changes in policy, practice, or behavior—is dependent on the use or adoption of new knowledge, learning, or awareness, i.e., the achievement of short-term outcomes. The achievement of a short-term outcome is in turn dependent upon the production of outputs, which we hope will be perceived as useful by those who access them (utility). The production of outputs is in turn dependent on the conduct of activities or processes and the quality of these activities or processes is in turn dependent upon the inputs and infrastructure that you start out with. Because achieving intermediate and short-term outcomes takes time, and is usually incremental in nature, it is best to err on the side of specifying fewer outcomes than more. Perhaps one or two short-term outcomes and one intermediate outcome for your whole center may be appropriate given your scope of work.

There can be confusion between activities and outcomes. Activities are "ing" words like recruiting participants, collecting and analyzing data,

conducting workshops. The outcome is what will change after I do something, or the effect of my work. Getting a handle on outcomes requires individuals to think about the following compound question: as a result of doing x activity, what do I expect will change and why and for whom? Once you answer the preceding question, you need to now ask yourself, “how do I measure and track progress towards that outcome?”

Developing a logic model will help you design a comprehensive program whose components are clearly linked. It integrates your efforts. It gives you objective measurements of your progress towards specified goals. It facilitates program monitoring and

improvement. It improves program accountability and documents results. And it gives you a vehicle for telling people your success stories. What gets measured gets done. If you don’t measure results, you can’t tell success from failure.

Accountability for results involves a partnership between NIDRR grantees, programs, and NIDRR. A key assumption for NIDRR is that all grantees have accomplishments. What’s missing is the performance goals and the outcomes data. For you, a key axiom to remember is “if you can demonstrate results, you can win public support.”

Thank you very much.

Work Group Session Reports

Following the presentations that laid out the state of the science in the three topical areas addressed by the Consortium, work groups developed recommendations building on work being done in those three fields. Each work group included a facilitator, a recorder, and a variety of experts including researchers, policymakers, consumers, and service providers as well as representatives of the Consortium. The discussion that took place during the work group sessions is summarized below.

TOPIC 1: Availability and Financing of Health Care Services for Children and Youth with Disabilities

This work group recommended that action be taken in three areas:

- 1. Increase the Use of Telehealth:** Recruit additional financing for telehealth. Find ways to improve how and how often it is used within national and local health care systems by children and youth with disabilities and their families. Urge collaboration among researchers and practitioners to develop improved telehealth technology.
- 2. Encourage School and Health Care Systems to Coordinate their Services:** For the benefit of families and providers, clear up confusions that exist over the various points where school and health care systems intersect. Explore the following questions: Which services are available within each of these two systems? At what locations? How can these systems be better linked?
- 3. Clarify Funding Sources for Services to Families of Children and Youth with Disabilities:** Determine the total out-of-pocket costs families incur when obtaining services for their children with special needs. Determine the impact of financing issues on families by pinpointing where those costs come from and how they relate to a family's income. Use a case study methodology to identify those families that have been successful in managing access to and finding financing for services as a way of clarifying the access and funding barriers families face.

This work group recommended that in each of the above action areas cost and access issues should be broken down by important subgroups both in terms of the array of disabilities and culture and ethnicity.

TOPIC 2: Transition from Pediatric to Adult Health Care Systems

This work group defined the long-term goal in the area of transition as:

Having young people with disabilities, their families, medical and other professionals, agencies, and employers know what is needed to bring about a successful transition of young people with special needs into the adult health care system.

Part of this goal would be that the various people involved with transitions would become clear about each of their roles in that transition.

The group first identified 15 elements that they felt are key to bringing about a good transition. They then determined that four of these should be considered primary.

Elements Critical to Ensuring Successful Transitions:

- 1. Advocacy:** Make sure that all agencies and stakeholders have a common understanding about transition: what it is, how important it is, how to do it.
- 2. Training (Knowledge and Skills):** Mandate that professional education programs address transition issues. This would include schools of medicine,

social work, education, and any training place for people who will provide services to children and youth with disabilities and to their families.

3. **Policy:** Lack of affordable health insurance for young adults with disabilities and special health care needs is a major problem. Ways need to be found to guarantee funding, very possibly through insurance programs, for transition planning and services.
4. **Guidelines:** Develop guidelines for handling transitions.

Transition-Related Research Questions:

Making these four key elements become a reality, the group said, will require addressing a broad range of research questions. These questions include:

- ◆ Can we agree on a definition of “transition”?
- ◆ Who needs transition planning and services?
- ◆ What do people already know about the various aspects of transition?
- ◆ Why has previous transition work not moved the field forward?
- ◆ What constitutes a successful transition?
 - ◆ Can we measure it?
 - ◆ How do we measure it?
 - ◆ Is transition a formative or summative process?
 - ◆ How can we achieve consensus on what a successful transition is?
- ◆ What are the evidence-based guidelines or steps that go into a successful transition?
- ◆ What guidelines already exist? Can existing guidelines, if any, be distilled into a set of common guidelines?
- ◆ What incentives are needed to encourage all involved parties to participate positively in the transition process?

TOPIC 3: Assistive Technology for Children and Youth with Disabilities and Special Health Care Needs

The participants in this work group based their discussions on the philosophy that children with special health care needs should be an integral part of their family and communities. Using the World Health Organization’s (WHO) international classification of function terminology, this is called “social participation.” The WHO classification system served as the anchor point of this group’s discussion.

In order to achieve the goal of social participation, this group recommended that work be done to help children and families gain better access to appropriate, high-quality services and supports that are disability, culturally, and linguistically “competent” as well as family driven within the young people’s home communities. Technology plays a unique role, acting as a bridge to learning, to skills, and to functional independence. Thus, it is a key service that needs to be available and offered.

The work group recommended the following goals and activities related to assistive technology:

- ◆ **Change attitudes:** Change the view of insurance companies as to the importance of
 - ◆ telehealth, especially as it makes possible comparatively low-cost face-to-face consultations with specialist providers.
 - ◆ Assistive technology as it promotes participation in existing community based programs and activities.
- ◆ **Educate providers:** Educate the broad range of providers about the value of telehealth, including occupational therapists, physical therapists and speech-language pathologists. Telehealth can be a crucial bridge to get information about products and approaches to service providers in an effective way; *if* you can convince providers that learning doesn’t always have to be face to face.
- ◆ **Increase awareness of insurance companies about the importance of families:** Help insurance companies recognize that family time is a positive commodity that can’t be discounted. It should be built into part of the cost equation.

- ◆ **Increase** funding for training individuals (professionals, youth themselves, and family members) to use assistive technology devices.
- ◆ **Create education mechanisms** that address the knowledge gap around technology and assistive technology. This kind of technology is not new, but it's not yet an integrated part of people's thinking in terms of what it can do and what it allows service providers to bring to the table.
- ◆ **Take the fear out of using technology:** Service providers often don't recommend an assistive device or strategy because they fear their lack of technological knowledge or competency will do more harm than good. Overcoming this fear requires collaborative problem-solving among the partners within the system of care of the child or youth to learn how technology can augment the services available to build skills that promote independence in children and youth with special health care needs.
- ◆ **Develop policy that promotes the sharing of telehealth costs.**
- ◆ **Help families get the right equipment for their child at the right time.**

This work group ended its report by reminding conference participants that technology is not the end game—it's just the tool (albeit a really good one) to improve access to services, to education, to skill development, and to independence for children and youth with disabilities.

Panel Discussion

A rich discussion among panel participants and the audience took place following the formal presentations. Collaboration among a variety of professionals, family members, and consumers is the hallmark of the Consortium. Panel participants reflected that broad collaboration and gave voice to the various perspectives of people who work with children and youth with disabilities and special health care needs.

Panel Participants:

- ◆ **Larke Huang** is the Director of Research at Georgetown University's Center for Child Health and Human Development as well as at its National Technical Assistance Center for Children's Mental Health.
- ◆ **Bonnie Gracer**, NIDRR Project Officer for this grant, is a social worker with experience providing services to children and adults with disabilities. Prior to coming to NIDRR, she worked at the Department of Justice writing a guide to disability rights law.
- ◆ **Rebecca Goniwich**, a member of Family Voices, is a parent of three children, all of whom have special needs. She has been awarded a fellowship to participate in policy activities at the state level. She also teaches workshops in positive behavioral support and is a special education advocate in Massachusetts.
- ◆ **Jean Minkel** is the founder of an independent consulting firm that specializes in assistive technology. She is involved in research and clinical practice, particularly in adaptive seating and mobility.
- ◆ **Julia Socha** is a program analyst at the Institute on Community Integration, a University Center for Excellence in Developmental Disabilities at the University of Minnesota.
- ◆ **Don Lollar** is a policy analyst from HHS' Centers for Disease Control.
- ◆ **Liz Waetzig** from Georgetown University moderated the panel.

Julia Socha initiated the panel discussion sharing her first-hand experience of growing up with a disability.

I'm 29 years old and both my husband and I were born with spina bifida and hydrocephalus. At the Institute on Community Integration in Minnesota I work on youth leadership issues as well as on developing work and life opportunities for individuals with and without disabilities.

One of the nice things that I've seen throughout this conference is the focus on transition in health care services and how important it is to create a support network around health issues for an individual. Unfortunately, the transition planning process of my own Individualized Education Plan (IEPs) did not address my health issues. Access issues such as physical barriers were addressed, but not the question of how my health impacts all the different areas of my life.

Fortunately, my mother stressed the importance of starting early on transition planning. When I was about 16, I began going to my medical appointments on my own. And even before then my mother helped me be my own spokesperson. For example, when I was about 13 I remember my mother being called out of the room to talk with the health care provider about my weight management. Mom's response was, "Well, I don't feed Julia. She eats for herself. She can manipulate a spoon and a fork. If you have issues you need to discuss with her, take them up with her directly." From then on, although my mom was still at my appointments, the focus was turned to me.

I also found out early on that I had to know a great deal about my own health condition. I found out, for example, that I had been explaining my level of spina bifida incorrectly. I also had to learn about my medications and how they would affect different aspects of my life. This will be a lifelong process. So I'm really impressed to find out that there are

others out there who are agreeing with me that planning for transition is critical.

Transition planning is also cost effective. Starting transition planning early can reduce costs. Research issues that need to be examined are: What are the outcomes of transition planning? How effective is it? How does good planning relate to saving money?

It's really important to get individuals who have gone through and learned about their own health care transition to help those that are younger coming along in the process. There are different models "out there" for health care transition, including life-span issues. In Minnesota, we have a program called the Lifetime Specialty Care Clinic. This program has a satellite space devoted to life span issues of people with disabilities, especially spina bifida and cerebral palsy. The professionals at the clinic have taken time to be respectful of individuals with chronic/long-term health and specialized health conditions. They respect and value us.

One thing that is very important to me is that I need to work. To do that, I need to have my time valued. This translates to needing to have a coordinated health care system so that I'm not going to multiple medical appointments on multiple days, forcing me to take a lot of time off work. My time is just as valuable as the time of the health care professionals.

Another issue is having affordable services and technology. Many assistive technology products cost a great deal. The clinic that I go to sees that my hesitation is not necessarily an unwillingness to look at an innovative product, but sometimes it's a financial issue that slows me down.

A person with a disability faces multiple transitions that are affected by a variety of factors such as costs of care, access to care, availability of providers, and service options. All of these factors need to be considered when creating appropriate, meaningful transition plans.

Julia's story captured the essence of a number of topics that were then addressed by panel members

and sessions participants. In their own voices, these topics included:

Respecting and valuing an individual and their family:

"Being known is the centerpiece of the medical home initiative. It's about young folk feeling that somebody knows them. There's something about being known that's crucial. Parents need to feel that their family is known and that their young person is known. It's the knowing and being known that is important."—*Policy analyst*

"I've learned that parents don't care how much you know until they know how much you care. You could be the best researcher in the business, but if they don't know that you care and are willing to go to bat for them and their child, it's a waste of time."—*Policy analyst*

"When we talk about family-driven care and family-driven systems, we need to think about what are the types of services that families want. When we're talking about family driven, we're also talking about choice. That means families having choices about the different kinds of services they want for their child and having a choice of providers as well. This makes our picture much more complex. But I think that if we're really talking about system change, we are talking about different levels of choice."—*Researcher*

"Families may have a very different understanding of 'impact' from an insurance company or a provider agency."—*Researcher*

Cost issues in all aspects of service:

"Although my physician has identified that my children are missing certain nutrients, the supplements they require and benefit from are not covered by insurance. There are so many different things in our lives that can help us function, but that cost so much money we can't put them to work."—*Parent*

"We know from the developmental disabilities literature that if families are given choices and the supports and the resources needed to actually implement and act on these choices, they have better outcomes for their children."—*Researcher*

Access to care:

“I think we’re really talking about working on multiple levels: infrastructure levels, system levels, the provider level, the training level, and the financing level. Also within each one of those levels, how do we change the cognitive sets or frames around individual thinking? How do we combine multiple methods? The real measure of a successful company is what’s the bottom line? Are the shareholders happy?”—*Service provider*

“I have three children, all of whom have special needs. My family is affected in every one of the categories discussed at this conference. So I can walk the walk with everyone. What I’ve learned here is that I need to go home and change my pediatrician and personal doctor because I’ve never received the kind of care that everyone here is talking about.”—*Parent*

“A key issue is how do we really get access to information [about services]. How do we study the pathways to information for different recipients? It seems clear to me that we are in our own kind of choir. Beyond the choir, how do you speak a different language to a different audience so that you can have an impact? This is a very, very difficult and daunting task.”—*Researcher*

“We need to think how do we start to share languages and learn lessons across service systems because our kids don’t have needs in any one particular system, but rather in many.”—*Researcher*

Transition and life-span issues:

“The World Health Organization classification of functional disability and health, which includes environmental factors, personal limitations, and social participation, is the conceptual framework and the classification framework and the coding framework that can be the basis for solid research throughout the life span.”—*Researcher*

“It’s all about transition. Being aware of developmental phases is critical if we are trying to get something positive to happen for young people with disabilities. This is especially important for health care professionals.”—*Policy analyst*

Technology:

“...but the bottom line is how do we get information out there into the Wal-Marts so people (therapists, physicians, providers, and family members) can buy and use it? Telehealth is a perfect example. [Some years ago] there wasn’t good technology for people to have face-to-face and voice communication. Well there is now. So maybe we should now focus on training people how to use commercially available technology expressly for the purpose of helping rehab professionals communicate with each other.”—*Policy analyst*

“I am absolutely clear about the need for telemedicine, but I’m also clear that you cannot, with all your technology, lose a personal relationship and touch.”—*Parent*

Conclusions and Recommendations

The Importance of Building Systems of Care for Children and Youth

There have been tremendous shifts in policy and service delivery for children and their families over the past two decades. This shift has been based on a consensus among policymakers, providers, advocates, researchers, and families that:

1. Children with special health care needs require a range of services and supports that are best delivered within their families and communities, and
2. These services are more effective and efficient when service systems and agencies are coordinated and organized to provide a system of care that is culturally competent and family centered.

Supporting these assumptions, the Consortium's research identifies a variety of factors that can be barriers or facilitators to service delivery. Overall, the Consortium promotes a system-of-care approach to the delivery of services to children and youth with disabilities and special health care needs. Based on the research of the Consortium, much of which was presented during the State of the Science conference, we conclude that:

A system of care for children and youth with disabilities and special health care needs and their families is created when the following elements are present:

- ◆ A variety of interconnected service delivery systems
- ◆ Collaboration across disciplines, professionals, and systems
- ◆ Knowledgeable, confident providers
- ◆ Providers who are responsive to the individual differences of the populations served, including cultural differences

- ◆ Active participation of and collaboration among providers, the child or youth in question, and their families
- ◆ Flexibility in providing services and in finding ways to pay for them

Research related to building systems of care shows that:

- ◆ Most children and youth with disabilities need multiple services. Families have to learn to access care and negotiate a variety of service systems, which can be both confusing and unproductive.
- ◆ Access problems vary by service area, but the most common difficulties families encounter in accessing care for their children are:
 - ◆ Getting the number of provider visits needed to successfully address a disability problem or problems
 - ◆ Finding providers with the specific (and variety of) skills necessary to constructively address disability and development issues
- ◆ Problems related to accessing care are particularly difficult when:
 - ◆ The child has health care needs that keep changing
 - ◆ The disability or disabilities are severe
 - ◆ There is a behavioral health condition
 - ◆ The family has no secondary health plan
- ◆ Case managers help families identify services and coordinate care, but only one-half of the children with disabilities have a case manager.
- ◆ Families are for the most part satisfied with the provider benefits offered by their health care plans, but are less satisfied with the support and information provided by the plan as it relates to their child's disability or to ways they need to negotiate the system.

- ◆ There are major differences between pediatric and adult medicine and health care systems, creating barriers to a smooth transition from one service delivery model to another.
- ◆ Adult-oriented medical providers often are not properly prepared to deal with young adults entering their practice because they frequently lack knowledge about childhood onset chronic conditions, developmental disabilities, and the potential of young people with special health care needs
- ◆ Families often are not aware of or knowledgeable about health care transition issues and how to be prepared for these major changes.
- ◆ Young people with disabilities themselves are not properly prepared for the various transitions they will have to navigate.
- ◆ The transition between pediatric and adult health care services often is triggered by the young person's age or behavior rather than by that individual's readiness to move into an adult health care system.
- ◆ The three phases of the transition process, *Envisioning a Future*, *Age of Responsibility*, *Age of Transition* require specific planning among the providers, family, and youth.
- ◆ Service providers require on-going training in evolving areas of practice, especially technology, to offer children and youth with disabilities and special health care needs comprehensive intervention options and service delivery mechanisms.
- ◆ Most service providers would benefit from training in collaboration among providers and systems, financing and funding of services, and systems and regulatory mechanisms.

To build a system of care...

Training needs to be provided:

- ◆ To providers involved in access to services and funding of services so that they can advocate for appropriate and adequate services as well as for the funding of these services.

- ◆ To all (professionals and families) involved in transition issues in order to develop seamless systems of health care transition that bridge pediatric to adult health care systems.
- ◆ To policy makers and providers alike about the importance of technology as a functional form of assistance to children and youth with disabilities and about the importance of offering assistive technologies as options as early as possible in a child's life in order to promote development and functional skills.

Research needs to be done:

- ◆ To determine barriers and identify the supports needed to build, maintain, and sustain a responsive health care system across the life span of children and adults, taking into consideration:
 - ◆ Long-term health status
 - ◆ The quality of their lives over time
 - ◆ The family of the child with disabilities as a unit of analysis
 - ◆ Promising practices and programs
 - ◆ Model relationships among pediatric and adult providers, facilities, and organizations.
 - ◆ The financing and delivery of care over the life span of children and adults.
- ◆ To identify improved ways of navigating complex Social Security Income provisions and programs that may hinder the transition process.
- ◆ To increase knowledge about and expectations of youth, family, and community members and providers related to the various transition points in the life a child and youth with disabilities and special health care needs.
- ◆ To chronicle the methods used to successfully make a transition.
- ◆ To show that interventions, including AT and AT services, telehealth, and other service delivery systems show a return on the investment made by providers, funders, and service delivery systems
- ◆ To determine the impact of the Olmstead Decision and the New Freedom Initiative on children and youth with disabilities and special health care needs over the life span.

Policies need to be developed:

- ◆ Which provide incentives to young adults with disabilities to become employed through waivers, SSI eligibility, and vocational rehabilitation.
- ◆ To expand Medicaid coverage and improve reimbursement rates to children and youth with disabilities and their families.
- ◆ That ensure that AT services are in place to support AT, especially when the technology is complex and highly sophisticated.
- ◆ That support adequate and appropriate reimbursement for AT and AT services and other technological supports.

A theme throughout this conference and throughout the work of the Consortium and its members over several decades is the importance of relationships among service providers, families, children and youth with disabilities and special health care needs, and service systems. Building these relationships can and will be an ongoing focus of the Consortium and its affiliates, even as those of us involved recognize that these relationships are a challenge to create and sustain because they:

- ◆ Develop and change over time,
- ◆ Are built through unique “shared experiences,”
- ◆ Often include conflicts and crisis,
- ◆ Must be based on mutual respect and trust, and
- ◆ Involve defining and redefining roles, responsibilities, limits, and expectations.

Since 2000, the members of the Consortium have been able through shared research and collaborative efforts to build strong, lasting relationships with each other and with our partners at NIDRR. This State of the Science conference has given us the chance to broaden our connections to an even larger group of colleagues.

We thank you for joining us for these two days to address together the important issues of accessing and financing care for children and youth with disabilities and special health care needs; of constructive, intentional transition from child to adult health and service systems; and of the key role technology can play in building strong and independent lives. We count on all of your help as we work together to create systems of care for young people with disabilities and their families in communities across this country.

Appendix A: Agenda

Accessing Care: Building Capacity of Service Delivery Systems for Children and Youth with Disabilities and Special Health Care Needs

March 18-19, 2004 • Hyatt Regency Bethesda

March 18, 2004

| | | |
|--------------|--|-------------------|
| 12:45 PM | Registration <i>Tammy Edwards, Dan Callaghan, Vernice Thompson</i> | CABINET/JUDICIARY |
| 1:00 PM | Welcome <i>Phyllis Magrab, PhD, Director, The Consortium</i> | CABINET/JUDICIARY |
| | Opening Address <i>Steven Tingus, PhC, Director, NIDRR</i> | |
| 1:30 PM | Keynote Address <i>Stephen Gulley, MSW, PhD Cand., The Consortium</i> <i>Analyst and Lecturer, The Nathan and Toby Starr Center for Mental Retardation, Brandeis University</i> | |
| 2:00–3:00 PM | Availability and Financing of Care <i>Stephanie Limb, MA and Marji Erickson Warfield, PhD</i> | |
| | Health Care Transition <i>Patience White, MD and John Reiss, PhD</i> | |
| 3:00 PM | Break | |
| 3:15 PM | Technology <i>Michael Rosen, PhD and Toby Long, PhD, PT</i> | |
| 5:15–7:00 PM | Reception | FELLINI'S |

March 19, 2004

| | | |
|----------|--|---------------------------------------|
| 8:00 AM | Continental Breakfast | CABINET/JUDICIARY |
| 8:45 AM | Welcome <i>Toby Long, PhD, PT</i> | |
| | Plenary Speaker <i>Bill Shultz, Ph.D., NIDRR</i> | |
| 10:00 AM | Work Groups | CABINET/JUDICIARY, EMBASSY & PATUXENT |
| 12:00 PM | Lunch | FELLINI'S |
| 1:00 PM | Reports from Work Groups | EMBASSY/PATUXENT |
| 1:45 PM | Break | |
| 2:00 PM | Discussion Panel <i>Larke Huang, Bonnie Gracer, Rebecca Goniwich, Jean Minkel, Julia Socha, Don Lollar</i> | |
| 3:15 PM | Conference Closing <i>Phyllis Magrab, PhD</i> | |

Appendix B: Speaker Biographies

Rebecca Goniwich

Rebecca Goniwich is the mother of three children, all of who have special health care needs, including severe autism and attention deficit hyperactivity disorder. She was the recipient of the 2003 Barbara Gopen Memorial Fellowship and currently teaches workshops on Positive Behavior Support Plans. Rebecca also volunteers as a Special Education Advocate and has spent six years as the co-chair of the Sudbury Special Needs Advisory Council in Sudbury, MA.

Bonnie Gracer

Ms Gracer is the NIDRR Project Officer for the Consortium. She holds a Master of Social Work degree from Catholic University and a Master of Art degree from Baltimore Hebrew University. Ms Gracer has provided clinical services to children with disabilities at Children's Hospital National Medical Center and to adults with complex language and psychiatric needs at St. Elizabeth's Hospital. Prior to coming to NIDRR, Ms Gracer was a staff member for Senator Tom Harkin and at the Department of Justice. She is the author of the Department of Justice's *Guide to Disability Rights Law*.

Stephen Gulley

Stephen Gulley holds an MSW from Boston University and is a doctoral candidate at the Heller School for Social Policy and Management at Brandeis University. A wheelchair user for over twenty years, he has served individuals with disabilities and their families as both a peer counselor and as a medical social worker. He has been a part of the Consortium for Children and Youth with Disabilities and Special Health Care Needs since its inception. His focus in the consortium is on access problems among families with children needing specialty medical and rehabilitative services. He has co-authored articles in the Journals *Mental Retardation* and *Children's Services: Social Policy, Research, and Practice* as well as a series of fact sheets published by the

Consortium. In addition to this work, Mr. Gulley has a breadth of interests concerning people with disabilities, health care and the field of disability studies. His dissertation examines gaps in insurance coverage among working age people with disabilities, using data from the Medical Expenditure Panel Survey. He also teaches a course in the sociology of disability for undergraduates at Brandeis.

Larke Nahme Huang

Larke Nahme Huang, PhD is the Director of Research at the Center for Child and Human Development at Georgetown University Medical Center, and a Senior Policy Associate at the National Technical Assistance Center for Children's Mental Health. She has worked in the field of mental health for over 20 years with a primary focus on mental health services for children and families and underserved, culturally diverse populations, and research/evaluation of mental health and education services for youth. She is co-author of two recent books, *Children of Color: Psychological Interventions with Culturally Diverse Youth* and *Using Evaluation Data to Manage, Improve, Market and Sustain Children's Services* and a recent evaluation newsletter, *Data Matters: To Be or Not To Be...Evidence-Based*. She is a member of the Mental Health Task Force of the Carter Center, the American Psychological Association's (APA) Children, Youth and Families Committee, the Advisory Committee of the APA Minority Fellowship Program, and is a founding board member of the National Asian American Pacific Islander Mental Health Association. In April 2002, she was appointed to the President's "New Freedom" Commission on Mental Health where she co-chaired the Committee on Children and Families and served on multiple subcommittees, including cultural competence, Medicaid, consumers rights, and evidence-based practice. Dr. Huang received her doctorate in clinical/community psychology from Yale University.

Marty Wyngaarden Krauss

Marty W. Krauss, PhD is Provost and Senior Vice President for Academic Affairs and John Stein Professor of Disability Research at the Heller School for Social Policy and Management, Brandeis University. Prior to assuming the position of Provost, she was the Associate Dean for Faculty at The Heller School. She is also the Director of the Starr Center for Mental Retardation at The Heller School. Professor Krauss has served on numerous federal advisory panels, including panels of the National Research Council and the National Institutes of Health. She was Chairperson of the Governor's Commission on Mental Retardation in Massachusetts from 1993-1999. Her research focuses on the lifelong impacts on families of having a member with developmental disabilities, the development of community-based systems of care for persons with disabilities, and the special health care needs of children with disabilities. She teaches courses on research methods and on disability policy issues. She received her PhD in 1981 from Brandeis University. Professor Krauss is the co-author of five books and the author of scores of articles in scholarly journals. She is the recipient of many awards and honors, including the Joseph P. Kennedy, Jr. Foundation International Award for Leadership, the Christian Pueschel Memorial Research Award of the National Down Syndrome Congress and the Distinguished Research Award of the Association for Retarded Citizens of the United States.

Stephanie J. Limb

Stephanie Limb is a senior health policy analyst with the Maternal and Child Health Policy Research Center. She has extensive experience managing projects related to public and private financing, service delivery, and reimbursement issues affecting access to care by children, particularly those with special health care needs. A major focus of her research is public program coverage for children. She has managed projects examining Medicaid managed care arrangements for children with chronic or disabling conditions, the impact of Medicaid demonstration waiver programs on children with special needs, program changes as a result of budget shortfalls, SCHIP benefit packages and cost-sharing policies, and contractual safeguards

for children with special health care needs. Before joining the Maternal and Child Health Policy Research Center, Ms Limb was the associate editor of Healthcare Trends Report. Ms Limb holds a bachelor's degree in philosophy from Yale University and a master's degree in philosophy and public policy from George Washington University.

Don Lollar

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Toby Long

Dr. Long is the Associate Director for Training at the Georgetown University Center for Child and Human Development, the Director, Division of Physical Therapy of the Georgetown University Center for Child and Human Development and Associate Professor in the Department of Pediatrics, Georgetown University. She is also an adjunct faculty member of the Krannert Graduate School of Physical Therapy at the University of Indianapolis and Rocky Mountain University of Health Professions. She received her degree in physical therapy from Boston University, a master's degree in special education from George Washington University and her doctoral degree in human development from the University of Maryland. She is internationally recognized as a leader in the field

of early intervention, service delivery to children with disabilities and their families, and the training of professionals, especially physical therapists and occupational therapists in state of the art service delivery. Dr. Long has taught at the university level and for continuing professional education on issues related to the delivery of service to children and their families. She is the Past President of the Section on Pediatrics of the American Physical Therapy Association. Dr. Long has published extensively in the area of early intervention. The second edition of her book *Handbook of Pediatric Physical Therapy* is available.

Phyllis R. Magrab

Dr. Phyllis R. Magrab, Professor of Pediatrics, has been Director of the Center for Child and Human Development, since 1975 and also has been Chief of Pediatric Psychology since 1969. Dr. Magrab has written/edited ten major books as well as written numerous articles and chapters that reflect her personal commitment and philosophy of caring. She was one of the founders of the field of pediatric psychology and her text, *Psychological Management of Pediatric Problems*, represents one of the first works in the field that established its academic presence. She received the Distinguished Contributions Award from the American Psychological Association, Society of Pediatric Psychology for her efforts in 1985. She has also received the Distinguished Service Award from the Division of Clinical Psychology of the American Psychological Association, the Estelle Ramey Medical Women Faculty Award from the Georgetown University Women's Medical Society, the Surgeon General's Award for Distinguished Service, and the John C. Mac Queen Award of the Association of Maternal and Child Health. Currently, Dr. Magrab is actively involved in global issues related to social exclusion. She is working with UNESCO on their agenda of Education For All and with the OECD on policies for serving at-risk children in their communities.

Jean Minkel

Ms Minkel is the founder of an independent consulting firm that specializes in the area of assistive technology. She provides consulting

services to service delivery programs, corporations, organizations, and educational institutions. She has been involved in coordinating a quality assurance program in assistive technology service delivery for the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA). Prior to her consulting practice, Ms Minkel was Director of the Seating and Mobility Program of the Center for Rehabilitation Technology at Helen Hayes Hospital (Haverstraw, NY). She was responsible for administering a program that addressed the seating, mobility, and adaptive equipment needs of people with disabilities. In addition she determined clinically relevant research topics and participated in ongoing clinical research related to seating and mobility. Ms Minkel has also been actively involved in the development of ANSI/RESNA wheelchair standards and has recently been appointed to Chair the new Subcommittee on Wheelchair Seating Standards.

John Reiss

John Reiss, PhD, is the Chief, Division of Policy and Program Affairs, Institute for Child Health Policy; and Associate Professor of Pediatrics and of Health Policy and Epidemiology at the University of Florida, Gainesville, Florida. Over the last 15 years, Dr. Reiss' work has focused on facilitating collaborative action among public and private sector organizations at the federal, regional, and state levels and between families and professionals to improve the organization, financing and delivery of health care for children and youth with special health care needs; and to promote full partnership with families. From 1993-2003 he directed a series of Maternal and Child Health Bureau (MCHB)-funded projects providing training and technical assistance to Title V CSHCN Program staff and other key stakeholders. Dr. Reiss began his work on the issue of health care transition as part of the federally funded Center for Policy and Program Partnerships. In addition to his work with the Consortium, Dr. Reiss is developing, for the Florida Children's Medical Services Program, a Web-based Health Care Transition training curriculum for CMS nurses and web-based HCT training materials for families and youth through the Florida Department of Developmental Disabilities. Through the NIDRR

grant, Dr. Reiss also moderates a special interest e-mail discussion group, which has more than 2000 members, internationally.

Michael Rosen

Dr. Rosen is Director of the Rehabilitation Engineering Service at the National Rehabilitation Hospital, Director of the NIDRR-funded Telerehabilitation Engineering Research Center, and Director of the Department of Defense funded Assistive Technology and Neuroscience Research Center. Prior to coming to NRH, Dr. Rosen was Director of the Rehabilitation Engineering Program and Associate Professor in the Biomedical Engineering Department at the University of Tennessee Memphis. Before that he served for eighteen years as Principal Research Scientist and Lecturer in the Newman Lab for Biomechanics and Human Rehabilitation in the Mechanical Engineering Department at MIT. He has graduate degrees in Electrical/Biomedical Engineering from Northwestern University; two and a half decades of experience teaching and conducting rehabilitation engineering research and development in biomedical, rehabilitation and design engineering in academic engineering departments; and seven years as director of clinical rehabilitation engineering programs. His interests include product design for people with disabilities, telehealth techniques applied to rehabilitation service delivery, and assessment and amelioration of motor disorders. He has received the Distinguished Service Award from the Rehabilitation Engineering Society of North America three times.

William Schutz

Dr. Schutz is with the National Institute on Disability and Rehabilitation Research's Planning Budget and Evaluation Division. In this division, his major assignment is the operation of NIDRR's program review process. Dr. Schutz received a doctorate in social policy and applied research methods with a concentration in disability issues and a Master's in Public Health from the University of Pittsburgh. His major research interests include disability program implementation and evaluation, computer usage in the human services, electronic information dissemination, participatory action

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Julia Socha

Ms Socha is Community Program Associate at the Center for Community Integration at the University of Minnesota. Ms Socha has been an activist for over ten years in many state and national organizations and is an active leader and spokesperson with the Spina Bifida Association of Minnesota. She has also been a member of the Minnesota Transition Team for nine years. Ms Socha was born with spina bifida and hydrocephalus, has a learning disability, and uses a wheelchair for mobility. As a young woman, she actively participated in the federally mandated process of transition planning under IDEA and has been a leader in the area of transition planning in the state of Minnesota since high school. She was recently the recipient of the Rose and J. Blumenthal Award through Courage Center for her ongoing success.

Steven James Tingus

Steven James Tingus is the Director of the National Institute on Disability and Rehabilitation Research (NIDRR). Mr. Tingus chairs the Interagency Committee on Disability Research (ICDR), the Department of Education's New Freedom Initiative (NFI) efforts including the New Freedom Initiative Workgroup. Prior to his appointment to NIDRR, Mr. Tingus was the Director of Resource Development and Public Policy for the California Foundation for Independent Living Centers, Inc. (CFILC) and its non-profit project, the Assistive Technology "AT" Network. Prior to joining CFILC he served Governor Pete Wilson as Health Care Policy Analyst for the California Department of Health Services (DHS). Tingus previously worked as a Postgraduate Researcher at the University of California, Davis, where he studied muscular dystrophy and the effect of anabolic steroids on skeletal muscle regeneration. He earned a Bachelor of Science degree in 1985 from the University of California, Davis in Biological Sciences, and also earned a Master of Science

degree in 1990 and a Candidate in Philosophy degree (PhD ABD) in Physiology. Mr. Tingus has received the “Best New Freedom Individual” Award from the Jim Mullen Foundation and the National Spinal Cord Injury Association’s Gil Moss Award. Tingus was also nominated for the Gold Key Award from the American Congress of Rehabilitation Medicine.

Elizabeth Z. Waetzig

Elizabeth Z. Waetzig, JD is Director of Collaborative Systems Design at the Georgetown University Center for Child and Human Development, a component of the Department of Pediatrics. Within this capacity, Ms. Waetzig has created and implemented training programs in different collaborative processes including negotiation, mediation and facilitation. In addition, Ms. Waetzig is an experienced mediator and facilitator in health care and mental health child serving systems. Prior to serving on the faculty at Georgetown, Ms Waetzig practiced law as a litigator and mediator in a variety of contexts. Ms Waetzig is a graduate of the Duke University School of Law and Whitworth College.

Marji Erickson Warfield

Marji Erickson Warfield, PhD, is a scientist in the Starr Center for Mental Retardation at Brandeis University. Dr. Erickson Warfield is the principal investigator of the Brandeis component of the Consortium and is directing a statewide survey in Massachusetts examining the delivery of pediatric and rehabilitation services to children and youth with disabilities and special health care needs. In addition, she is the principal investigator of an NIH-funded study on balancing work and family among parents of young children with disabilities. She is also co-principal investigator of the Early Intervention Collaborative Study (EICS), an investigation of the development of children with disabilities and the well being of their parents, extending from infancy through early adulthood. She is the author of many journal articles and several book chapters focused on children with disabilities and their families. She is an Associate Editor for the journal *Mental Retardation*. She received her PhD from Brandeis University in 1991.

Eleanora Wells

Eleanora Wells, MS, is the Director of the Family Voices Family Survey in California, Family Voices Partners Project, National Coordinator for Family Voices and a consultant with NEC*TAS. Ms Wells, a parent of a child with a disability, has contributed significantly to the field in the area of quality indicators of care for CSHCN and provides training and technical assistance on accessing care for CSHCN. Ms Wells serves the Consortium as a Family Consultant.

Patience White

Patience White, MD is an internist and pediatric rheumatologist who has for the past 20 years been involved in the care of children with disabilities. In 1984 she created the Employment Readiness Center (AERC) at Children’s National Medical Center in Washington, DC to assist youth with disabilities to transition into the work force. She has won numerous awards such as the National CBS/Newsweek American Achievement Award and the Distinguished Service Award from George Washington University for her dedication to children and young adults with disabilities. She is an internationally recognized expert in the field and has written numerous articles. Dr. White has been invited to England, Australia, Canada, Sweden and Israel to consult on issues of transition for young people with disabilities. Dr. White is Associate Dean for Faculty Affairs as well as Professor of Medicine and of Pediatrics at George Washington University School of Medicine and Health Sciences and Chair, Section of Pediatric Rheumatology at Children’s National Medical Center.

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Appendix D: Products and Publications

The Consortium Briefs

1. Children with Special Health Care Needs and Access to Health and Rehabilitative Services: A Fact Sheet on Findings
2. Children with Special Health Care Needs and Access to Specialty Care from Physicians: A Fact Sheet on Findings
3. Children with Special Health Care Needs and Access to Home Health Services: A Fact Sheet on Findings
4. Children with Special Health Care Needs and Access to Mental Health Services: A Fact Sheet on Findings
5. Children with Special Health Care Needs and Access to Physical Therapy Services: A Fact Sheet on Findings
6. Children with Special Health Care Needs and Access to Occupational Therapy Services: A Fact Sheet on Findings
7. Children with Special Health Care Needs and Access to Speech Therapy Services: A Fact Sheet on Findings
8. Children with Disabilities and Private Insurance Coverage of Medical Services: A Fact Sheet on Findings
9. Promising Practices in Health Care Transition: A Project Brief
10. Education for All and Children with Disabilities: International Policy and Practice
11. Inclusive Education in Secondary Schools: A Global Perspective
12. Assistive Technology for Children with Disabilities and Special Health Care Needs: Introducing the Consortium's Annotated Bibliography of Audiovisual Resources
13. Promoting Assistive Technology in an Outcome-Driven Model of Service Delivery
14. Evaluation and Assessment Models for Assistive Technology: A Fact Sheet for Service Providers
15. The Benefits and Challenges of Research Partnerships: Families and University Researchers Working Together

The Consortium Consumer Briefs

1. Promising Practices in Health Care Transition: A Research Fact Sheet for Consumers
2. Secondary Health Coverage For Children With Special Health Care Needs: A Fact Sheet For Families
3. Funding Sources and Reimbursement for Assistive Technology: An Issue Brief for Families
4. Wheeled Mobility: An Issue Brief for Consumers

Consortium Briefs In Process

1. Understanding Funding Sources and Reimbursement for Services Provided Using Telehealth: An Issue Brief for Families

Peer-Reviewed Publications

1. Leiter, V. (in press). The division of labor between systems of therapeutic care for children with disabilities. *The Journal of Disability Policy Studies*.
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