



Beach Center on Disability

BEACH CENTER NEWSLETTER

**VOLUME 7: SUMMER 2006
FAMILY SUPPORT EVERYDAY AND IN TIMES OF CRISIS**

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REAL STORY

Pyramid Parents and Hurricane Katrina: When a Crisis Hits

"There was chaos in New Orleans BEFORE the storm."

These are the words of Ursula Markey, co-director of a center in New Orleans that provided training and family support to underserved groups of parents of children with disabilities. Since 1998, Ursula and her husband, D.J., had guided the Pyramid Parent Training Community Resource Center and its mission to educate and empower families facing the multiple challenges of disability, racism, and poverty. Hurricane Katrina proved to be the biggest threat to family support in the 9th ward and surrounding neighborhoods although adversity was a fact of life for many Pyramid families long before disaster struck.

"We had enjoyed great success with our parents in educating them about their rights and in lifting their expectations. Unfortunately, their expectations were seldom met. It was getting very frustrating. Right before the storm, everyone had become so discouraged."

Support to Address Compelling Family Needs

Pyramid Parent Training was created in 1998 as a result of Ursula and D.J.'s experiences with their son, Duane, who was born with autism in 1972. "We had to search for any information about both his disability and his rights. As we began to negotiate the system, we found that there were other families who didn't have any information about Autism or other disabilities or what their rights under IDEA were because the law was so new. As we set about looking for a quality education for our child, we met others and we began to share what we knew with them. So we were doing our own little family support work back then."

"We achieved a lot of success for our son, our friends, and families. Family support meant the same thing then as it does now: somebody who really cares not just about the child with the disability but how that whole family needs to function in order to preserve itself and go forward."

Family support through Pyramid addressed the compelling and often desperate needs of undeserved New Orleans parents and children. Pyramid families dealt with not only disability issues but racism, poverty, abuse, unemployment, poor-performing public schools, and limited access to medical care. In fact, the juvenile justice and education systems in New Orleans were seen as among the country's worst.

Disability Rights and Civil Rights

Ursula and D.J. saw no distinction between disability rights and civil rights. Family support through Pyramid embraced the added elements of cultural mediation and leadership development to empower families of children with disabilities as outspoken advocates for justice and quality of life.

"Pyramid had been so very active in every aspect of disability in New Orleans, from housing to juvenile justice to early intervention services and positive behavior support," Ursula recalls. "We were just trying to get equity and excellence in our education system. We wanted to ensure that all kids would have access to best practices in education. We weren't getting very far because our school district was so embattled fighting for their lives. They were facing a state takeover which has, in fact, happened."

REAL STORY Cont.

In the year preceding Katrina, Pyramid struggled to implement positive support in the public schools so police weren't routinely called for student behavior infractions. They fought the

creation of an alternative elementary school, which Ursula called "a real trajectory toward the juvenile system for our children." And, Pyramid hosted a series of community breakfasts to bring together parents of children in high-performing and low-performing public schools. "We didn't have much success there although we really worked hard to bring about some understanding and to facilitate a dialogue. So we were quite discouraged." Then came August 29, 2005.

No Way to Leave

With Hurricane Katrina looming off shore, New Orleans Mayor Ray Nagin ordered the mandatory evacuation of New Orleans. Ursula estimates as many as 40 percent of the New Orleans population lacked the means to leave the city. The Louisiana Superdome became one of several so-called "refuges of last resort," an emergency shelter ultimately housing an estimated 26,000 people.

"For our families with kids with disabilities, the stories are horrific. As we were preparing to leave the city, one parent called me and said she didn't know what she was going to do. Her elderly mother, who was an amputee, lived with her and her son with Autism. She had nowhere to go. I advised her to call the hospital to see if there was a place for her mother. But the hospital informed her that they didn't do that sort of thing. Her church was filled to capacity. I finally advised her to go to the dome. I thought I was giving her good advice only to find out otherwise. I'm happy to say they did survive."

Another Pyramid family had a child with Autism who had undergone surgery three weeks before the storm. "They wound up in the dome where they had to spend hours in line," Ursula said. "This is a teenager who is not capable of self care. When they finally got in, they couldn't go to the section reserved for people with disabilities because he could walk. People had to be in wheelchairs – forget it if you had any other kind of disabilities or mental distress."

And there was plenty of distress. "Kids were off their medications and climbing the walls. They were in shelters with thousands of other people. There was little food available, and some of these children have special diets. Everybody was scavenging for food, for clothes."

The Stress Continues

The Markeys ended up in Canton, Miss., where they stayed for eight months. The families they had supported for so long were scattered over six states. As far as the damage caused by Katrina, Ursula says, "It continues."

"Our families have problems with other states honoring their requests for medication without records. People flown across the Gulf Coast have been notified that their benefits in Louisiana have expired. The only way those benefits can continue is if they return to Louisiana. The problem is, there's no way to return because there's no place to live. They have to start all over again."

While schools in neighboring states were welcoming at first, Ursula said "it's beginning to wear thin. Children have their own turf, and there are problems surfacing." Worst of all, when people fled New Orleans they left their children's IEPs behind. "Parents have no documentation of their child's prescriptive plan. At a time when they have already been traumatized, they have to reconstruct and participate in a plan for their child."

REAL STORY Cont.

Family Support Continues from Afar

Ursula, D.J., and the Pyramid staff have continued to help families long distance by participating in IEP meetings via telephone. A Pyramid social worker also is working to address trauma and grief among its families.

Pyramid sent out a questionnaire through a recent newsletter asking how families were adjusting. For whatever reason, of the nearly 1,000 families in the Pyramid data base, only 75 have responded. Of those 75, all but one hope to return to New Orleans.

As a result of those questionnaires and the Markey's personal experience in Katrina, Ursula has several tips for families with children with a disability trying to cope with a disaster, including the importance of having a communication device. She said the number one lesson that families learned from Pyramid is to never give up. Those who responded to the survey also cited the importance of religious faith. "It wasn't about PBS. It was about a higher power. You go to the place where you think you are valued and ask God for help."

Recovery Trust Fund Gets to Work

Right after the storm, Beach Center co-directors Ann and Rud Turnbull established the Pyramid Parents Recovery Trust Fund to help Ursula and D.J. continue to serve Pyramid families, displaced across Alabama, Florida, Louisiana, Mississippi, Tennessee, and Texas. Donors contributed nearly \$30,000 to the fund, monies that have already been distributed to Pyramid to help families.

Pyramid has opened a small office provided by the Juvenile Justice Project of Louisiana. Thanks to the recovery fund, Pyramid has helped some families move out of shelters and into hotels and apartments. "There's a very great need, and we hope to in some small way to help out with a few things with families," Ursula said. "Especially as FEMA support withdraws, Pyramid families will need emergency funds for housing."

The trust fund also will be used to help families obtain some kind of communication device. Ursula said the lack of a phone was devastating for many people stranded for days on rooftops after Katrina.

More than Words

The day Ursula was interviewed for this story, she and D.J. were living in the top floor of their home, which, during the flood, had 9 1/2 feet of water. "You can't feel sorry for yourself when all of your family and friends around you have lost everything. I just think that it's going to be a long time, a very long time, before people will feel whole again."

"Even those who don't particularly care for the government to be that involved in their lives have found out there is a role for government to play at times of disaster. Family support can't exist in a vacuum. Family support has to show that all citizens are valued. It's more than just some words on a piece of paper."



ARTICLE

After a Complex History, Family Support Stands at the Crossroads

The famous English jurist Lord Coke once remarked: If the reason for the law ceases to exist, then the law itself should cease to exist. If we turn Lord Coke's axiom around, we hear him say: If the reason for the law still exists, the law itself should continue to exist.

That is how it is with family support. The reasons for a federal law on family support exist, and there is a family-support law. To know those reasons and to understand the law, it is necessary to review some recent history. Among other lessons that our review of history will teach us is this: No matter what the law says, there is almost always a slip between the cup (the law) and the lip (its utility). So, let us review some history about family support and determine where and how large those slips are.

Defined by Its Purposes and Services

We should begin by defining family support. That is easier said than done. Under the laws that we will review below, family support is defined by its purposes, which are, essentially, to ensure the family's integrity and unity. These laws also define family support by the services that the laws authorize. Basically, these are cash transfers, vouchers for services, or services themselves. In addition to these two definitions, family support is defined by the research community as it gathers demographic and fiscal data related to the families, their members with disabilities, and the federal and state funds allocated to the families and their members. Finally, family support is defined by the families themselves, but those definitions are unique to each family and hard to generalize.

Having four definitions is a problem. To compound the matter, however, the term "family" poses some definitional problems. Strangely, "family" in family support rarely is defined by federal or state law. Indeed, the term itself has various definitions, including the ones used by the U.S. Bureau of the Census (essentially, blood, legal relationship, and in-household) and, by way of contrast, by the Beach Center (essentially, two or more individuals who perform the functions that families perform and who think of themselves as family). Similarly, "support" in family support rarely is defined in federal or state law except by reference to the services authorized under "family support."

Beyond these matters of definition, however, lies clarity. There is little doubt about the core concepts of disability policy that justify federal and state family support programs. These core concepts are:

1. Family integrity and unity, namely, keeping the family intact;
2. Family autonomy, namely, preserving to the family the right to choose how to conduct its personal business and raise its children, including by seeking or not seeking services from or consenting or not consenting to services from federal and state funded programs;
3. Empowerment and participatory decision-making, namely, having a say about how providers deliver services to the family;

ARTICLE Cont.

4. Cultural responsiveness, namely, providing for flexibility in federal and state funded programs so as to make them consistent with the cultural, ethnic, and linguistic traits of the family; and
5. Family-centeredness, namely, providing services to the family because a disability in one member of the family affects all members of the family.

Launched First by the States

Having addressed the issues about definitions and core concepts, let's now undertake that history lesson that we promised earlier. We begin with the states' initiatives and then go to the federal government's initiatives.

State governments launched the first modern family support programs in the 1970s and expanded them in the 1980s. Today, more than 30 state legislatures have enacted family support laws. All states, either under these family support statutes or under other laws, sponsor family support programs. These state programs originally benefited families who have children with disabilities who are younger than 18 years of age. Today, however, many state programs benefit these families as well as families who have adult members with disabilities living in the family home.

As we noted when discussing the second approach to defining family support, these programs provide cash assistance ("cash transfers"), services or vouchers for services, or both.

Building on the states' family support initiatives and in response to family advocates who wanted to see more family support services at the state level, Congress enacted the Families of Children with Disabilities Supports Act of 1994 (codified as Part I [as in "eye"] of Individuals with Disabilities Education Act). Congress then repealed Part I in 1998.

There are at least two reasons why Congress repealed Part I. First, Congress had authorized services under Part I but had not funded them to any significant degree; the federal initiative was "on the books" but not a strong program because of scant funding. Second, IDEA itself was not the proper vehicle for federal family support programs. IDEA deals with early intervention and special education, and those are different activities than family support.

Family Support and the DD Act

The "sun setting" of Part I, however, did not put an end to federal family support initiatives. Those family advocates who persuaded Congress to enact Part I in 1994 simply would not abandon their cause. They were successful in persuading Congress to amend the Developmental Disabilities Assistance and Bill of Rights Act in 2000 by adding a new title, Title II, Family Support. Today, Title II is the only federal law that explicitly sponsors family support programs. It authorizes states to create or expand state family support programs, and it also authorizes the federal government to sponsor its own family support programs. Before we get to the details about those authorizations, however, let's discover why Congress acted. We'll review the "findings" of fact that Congress used to justify its action. Then we'll discuss the "purposes" that Congress seeks.

Title II sets out Congress' "findings" about families and family support. Two findings are particularly important. The first is that "It is in the best interest of our Nation to preserve, strengthen, and maintain the family." The second is that "The goals of the Nation properly include the goal of providing to families of children with disabilities the family support services

ARTICLE Cont.

necessary” to “support the family,” “enable families of children with disabilities to nurture and enjoy their children at home,” enable the families to “make informed choices and decisions regarding the nature of supports, resources, services, and other assistance made available to such families,” and “support family caregivers of adults with disabilities.”

Title II also contains several purposes. One is to “promote and strengthen the implementation of comprehensive State systems of family support services” that are “family-centered and family-directed and that provide families with the greatest possible decision-making authority and control regarding the nature and use of services and supports.” Others are to promote family leadership in planning, implementing, and evaluating family support systems; promote inter-agency coordination and collaboration; and increase the availability and funding of family support services.

To implement Title II, the Administration on Developmental Disabilities has funded various projects of national significance to conduct family-related research, help families organize around family support policies and practices, and educate policy makers about families’ needs for support. State developmental disabilities planning councils have sponsored family-support projects to demonstrate innovative service-delivery models, improve the cultural competence of state and local agencies, and expand services to ever-increasing numbers of families. Currently, the Administration sponsors pilot projects called “Family Support 360” initiatives; these assist families to access all the services they need, including those under the 1996 welfare-law (Temporary Assistance to Needy Families, Personal Responsibility and Work Opportunity Reform Act).

Other Laws Provide Services, Too

As we noted above, Title II is the only explicit federal family support law. That does not mean, however, that Title II is the only law that provides cash transfers or services to families for the same or comparable purposes as Title II.

Congress has authorized services to families under the Individuals with Disabilities Education Act, Title V of the Social Security Act (Maternal and Child Health Block Grants), and Children’s Mental Health Act. Most of these services, however, have the purpose of supporting the family in order to benefit the child who has a disability. These laws regard families as the means for the child’s development; thus, the ultimate beneficiary of these laws is the child, and the family is a secondary or incidental beneficiary.

In addition, Congress has authorized cash assistance to needy families who have children with severe disabilities under Title XVI of the Social Security Act, the Supplemental Security Income (SSI) program. Further, Congress has authorized reimbursement of community-based medical assistance and the provision of early periodic screening, detection, and treatment programs under Title XIX of the Social Security Act, Medicaid.

Family Support Research: Show Us the Money

Altogether, federal and state family support expenditures for family support amount to \$1.981 billion, out of approximately \$38 billion in all federal and state expenditures on disability services (Braddock, et al., 2005). We said earlier that the research community is one source of the definition of family support. Most research about family support focuses on how much money the federal and state governments jointly expend on family support (Braddock, et al., 2005). These researchers face some problems, not of their own making. Federal and state data

ARTICLE Cont.

suffer from a lack of a uniform set of standard measures to track the status of publicly financed family support on a nationwide basis.

Moreover, existing federal and state data sets do not provide the level of information needed by policy makers to distinguish the resources and supports furnished to family from those provided to adults with disabilities who live in their families' homes. Specifically, information is not available about adults who are living in the home of a family member and who are self-directing their services, being supported by a family member, receiving services from a traditional provider agency, or receiving some combination of each of those three types of supports. Nowadays, when federal budget deficits are ever-increasing and state revenues also are restricted, and when entitlements such as Medicaid are under siege, the lack of clear, uniform definitions and measures impedes the development of more effective and appropriate funding levels for federal and state family support programs.

Today, Asking the Hard Questions

Family support itself raises a profoundly difficult question of political philosophy. The question is this: What duty does any government (federal or state) owe to families who have members with disabilities? What is the nature of the social contract, the culturally implicit or legally explicit agreement, between governments and the governed? Is it to support families or, by not supporting them or supporting them only minimally, to have them be self-reliant? Is social and collective responsibility the dominant approach, or is personal responsibility the dominant one? We cannot fully answer those questions here, but we can suggest a few responses by returning to the English jurist we cited at the beginning of this article.

Let us return to Lord Coke and his maxim, turning it around and asking a question: Are the reasons for family support still valid? Increasingly, the answer seems to be, "Yes." Waiting lists confront families in all states; the effects of the nation's fiscal and tax policies increase the gap between families who can afford the services they need and those who cannot. The number of children who have disabilities seems to increase every year, but without comparable increases in family support services. Reductions in Medicaid-funded services seem inevitable and limitations on Medicaid eligibility do, too, under the Deficit Reduction Act of 2005, which also allows states to establish waiting lists.

As Congress, in 2007, considers whether to reauthorize the DD Act and, if so, whether and how to strengthen its family support provisions, families will find themselves caught in a familiar bind. It is the "wealth-and-poverty" bind. On the one hand, \$1.981 billion seems to be a large amount of family support money. On the other hand and especially in light of the many factors noted above, it is clearly not sufficient to make it possible for families to support themselves, much less "nurture and enjoy their children at home."

What the law declares, that is, "policy on the books," and what happens, that is, "policy on the streets," are two entirely different matters. Yet the DD Act can guide Congress and seems worth preserving.

Real Benefit or Just Rhetoric?

These are the issues, in a nutshell: Is the reason for the law ("to preserve, strengthen, and maintain the family") still valid? If "yes," then will the reason produce funding at a level that really does benefit families, under the premise that the family is the core unit of society and that supporting it is a way of blunting the effects of disability on the person, family, and eventually

ARTICLE Cont.

the nation? Or is the reason simply an expression of high-minded rhetoric that is more honored in the breach than the observance?

If the latter, then Lord Coke would advise: repeal the law! If the former, then the Consensus Statement that accompanies this newsletter could be a good guide for Congress and policy leaders, advocates, and disability organizations to use as a foundation as Congress prepares to reauthorize the DD Act..

References

Braddock, D., Hemp, R., Rizzolo, M.C., Coulter, D., Haffer, L., & Thompson, M. (2005). *The state of the states in developmental disabilities*. Boulder, CO: The Coleman Institute for Cognitive Disabilities and Department of Psychiatry, University of Colorado.

**INTERVIEW****Families Face Challenges Every Day, Not Just During Disasters**

It doesn't take a catastrophe the scope of Hurricane Katrina for a family to feel battered by a crisis.

According to John Agosta, vice president of the Human Research Institute in Portland, OR., any unexpected event in a person's life can become a crisis, especially if that person has a disability. That's why family support is so important.

"Families can face extraordinary challenges every day when they have a child with a developmental disability. The needs of the child have an impact on the whole family. The child needs to get dressed and get to and from school. The parents have to work and pay bills. Ideally family support addresses the whole range of challenges facing families who have a member with a disability."

Twenty years ago when the first family support programs were taking shape, the public agencies that funded these programs often embraced a "whatever it takes" attitude. Agosta said. "Support was family-driven, designed to do almost anything to support the family in the community. Programs took into account that a parent often needed to stay home and care for a child while the other needed to keep a job, or that there were many stressed single many households had. As a result, programs sought to offer a great range of support."

"Today, given budget shortfalls in so many states, public agencies have a more narrowed view of what they will or will not pay for. This is especially so if states use Medicaid to fund services because this source of money is more focused on the health and well-being of the person with a disability and less on overall family quality of life," Agosta said. "More people are looking for services, and people are living longer. There are wait lists. The states can't keep up the pace."

As a result, state programs are specifying what things they will and won't pay for. "So, the state will help pay for a device to help Susie get out of bed or to repair that device. But, the state will likely not pay for physical therapy for Susie's mother who injures her back while lifting Susie."

INTERVIEW Cont.

Given the realities of current state and federal funding, Agosta described a three-legged approach to keep family support programs alive and well.

1. Identify what the government can do.
2. Organize networks of peer support to systematize ways that families can help one another.
3. Conduct "community asset mapping," which identifies community resources and assets and establishes connections between individuals and organizations.

Agosta praised the work of Pyramid Parent Training in New Orleans for knowing instinctively how to approach family support. "What the Pyramid folks are doing is perfect. Before Katrina, they were reaching out to the schools and trying to partner with other groups. They're awesome. But the government needs to get them some dollars.

"Family Support is the only thing that helps families keep their sanity on a day-to-day basis," Agosta said. "Life is a lot bigger than what Medicaid considers family support. Dads get cancer, moms fall down, and people lose their jobs. There is real concern that government is changing its promise to families. We're in a tough place as a nation."



RELATED RESEARCH ON FAMILY SUPPORT

From the old to the new paradigm of disability and families: Research to enhance family quality of life outcomes (2002)

Turnbull, A.P. & Turnbull, H.R. Abex Publishing, 83-119

Research needs to investigate natural environments where events occur. We take as a fact that one of the natural environments affecting individuals with disabilities is their family. A person with a disability affects and is affected by the person's family. Furthermore, families are systems. There are systems in which an event that affects primarily one person (e.g., a child with a disability) also affects all other members. The converse is true; whatever happens to the family affects the child as well.

OPTIONS:

a. Read more about [this article](#) or more about the Beach at:

(<http://www.beachcenter.org/research/default.asp?intResourceID=1348&Type=General%20Topic&act=detail&id=4>)

b. Read more about the Beach Center's [Family Quality of Life](#) research in general at:

(<http://www.beachcenter.org/default.asp?act=view&strResource=all&submitFlag=true&type=General%20Topic&id=4>)

**BOOK****Families, Professionals, and Exceptionality: Positive Outcomes Through Partnerships and Trust (5th edition)**

Author(s): Ann Turnbull, Rud Turnbull, Elizabeth J. Erwin, Leslie C. Soodak

Publisher: Merrill/Prentice Hall

Overview: This textbook provides an in-depth look at family systems, traces the historical role of families and school reform, discusses the essential elements of effective partnerships, and outlines specific steps to implement partnerships. The book also includes extensive profiles of four real families dealing with the joys and challenges of raising a child with an exceptionality.

**GROUP****GRASSROOTS CONSORTIUM**

OVERVIEW: The Grassroots Consortium is a national group formed to advocate and assist families of children with disabilities. The Consortium was created to encourage and augment (but not replace) the services of individual community parent resource centers. The mission of the Grassroots Consortium is to enhance and strengthen local community parent resource centers through leadership, advocacy, and training programs.

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**TIPS****How can Families of Individuals with Disabilities Survive Disaster?**

The following tips were contributed by Ursula Markey, co-director of Pyramid Parent Training in New Orleans, and Patricia McGill Smith, a national leader in the parent movement and now a consultant.

How can families with a member who has a disability prepare for a natural disaster? If one strikes, what are some strategies for coping with a catastrophe?

TIPS Cont.

1. Have a working communication device at all times. This term in the Special Education field usually means assistive technology for someone who is nonverbal.
2. Keep important personal records in some kind of transportable format, such as on a CD. This would include medical history, medications, even IEP information. The CD should be part of an emergency kit that can be easily carried and kept in a convenient, accessible place.
3. Keep a log book or a folder (if you don't have access to a CD) tracking medications, treatment plans, phone numbers, account numbers, and other important papers for your child.
4. Include simple things in the emergency kit, such as aspirin, band aids, stool softeners, stomach soothers, Tylenol, lotion, and any items you or your children need to get by.
5. Maintain a schedule for your family that is as predictable and regular as possible if you find yourself living in temporary housing, such as a shelter.
6. Create "your own space" in the shelter, a place where family members feel they belong even if it's only temporary.
7. Acknowledge every good act that a family member with a disability does, whether carrying a bundle of clothes or helping with a baby.
8. Call upon your religious faith for strength.
9. Try to stay as calm and collected as possible. Children follow their parent's lead in difficult times. A positive attitude will spread to those around you.
10. Never give up.

**Consensus Statement**

The Beach Center on Disability (along with several national partners) has developed a Consensus Statement on Family Support. The purpose of this statement is to identify a common understanding regarding the definition, components of, and need for Family Support for service providers, family organizations, and policy makers.

Please take a look at the Consensus Statement and endorse to show your support (<http://www.beachcenter.org/default.asp?act=consensus>).

Statement Cont.

Support to Control of One's Life: a Consensus Statement on Family Support

WHEREAS

Families are the core unit of society and advancing their quality of life and power to control their destinies is consistent with long-established constitutional principles of family autonomy and personal liberty.

Families who have relatives with developmental disabilities living at home face extraordinary challenges related to the individual's disability and the family's capacity to provide support.

"Family support" consists of a variety of including cash assistance, professionally provided services, in-kind support from other individuals or entities, goods or products, or any combination that are provided to families who have minor or adult members with disabilities living in the family's home.

"Family support" enables families to provide needed support at home, and assists them to stay intact, enhance their quality of life, be included in their communities, and guide their member with a disability toward achievement of the nation's goals for people with disabilities.

Family support policies and practices are more effective when the family and the individual each have the right and opportunity to control the use of funds and determine what and how they are served.

Autonomous, empowered, self-determined individuals come from families who are also autonomous, empowered, and self-determined.

Family support effectively improves the lives of people developmental disabilities and their families.

Families' needs for support services are increasing, but the public resources have remained stable or in some cases have been reduced.

NOW, THEREFORE, WE CALL ON

The Congress of the United States, the Commissioner of the federal Administration on Developmental Disabilities, other appropriate federal agencies, and other national policy leaders;

State Legislatures, State Directors of Developmental Disabilities Services, and other state policy leaders,

The National Governors' Association, the National Council of State Legislatures, and other relevant members of disabilities services networks

Statement Cont.

TO TAKE THE ACTION THAT EACH CAN TAKE

To advance, establish, and sufficiently finance family support policies and practices that are designed to achieve the goals of family support, and enable families and individuals to control their lives and the supports they receive.



BUZZ AT THE BEACH

Ann Turnbull Participates in Historic Qatar Conference

Beach Center Co-Director **Ann Turnbull** was among the speakers invited to an international forum held May 7-9 in Doha, Qatar, to celebrate the opening of a new center for children and young adults with developmental disabilities.

The First Annual Forum for Children with Special Needs brought experts from around the world to the Shafallah Center, a non-profit facility that will serve 1,000 children, adolescents, and young adults. The center includes three schools, swimming and therapy pools, a sports hall, libraries, and research facilities.

Turnbull joined a panel discussion on parent, family, and community issues. In her presentation, she discussed the perspective of families and family organizations in the U.S. and their role in the six goals outlined in the 2003 National Goals conference.

Speakers also included Cherie Booth, wife of Prime Minister Tony Blair and president of the largest children's charity in the United Kingdom. Moderator was Christopher Dickey, *Newsweek's* editor for the Middle East.

An independent, sovereign state, Qatar is on the Arabian Gulf. The name of the center – Shafallah – is the Arabic name for a flowering caper plant. For more information visit <http://www.shafallah.org.qa/home.htm>

International Visitors Collaborate with Beach Researchers

Two international researchers visited the Beach Center in March to explore possible collaboration on family research projects.

Consulting over a three-day period were Richard Hastings, professor and acting head of the School of Psychology at the University of Wales-Bangor, and Climent Gine, professor and dean of the faculty of Psychology, Education, and Sports Sciences at Ramon Llull University in Barcelona.

Hastings hopes to collaborate on Family Quality of Life research and positive perceptions of disabilities within families. Several family organizations in the United Kingdom are already participating in quantitative studies conducted by Hastings and his research team.

BUZZ Cont.

Gine intends to develop an adult version of the Beach Center Family Quality of Life Scale and to adapt it in Catalan. He will launch focus groups in which individuals with disabilities, siblings, and parents react to the child version of the FQOL scale to determine what domains and items apply to adulthood. His goal is to help professionals in Spain improve their practices in order to promote quality of life for individuals with disabilities and their families.

CEC Conference Honors Beach Researchers

Four researchers and one doctoral student at the Beach Center received special recognition at the annual Council for Exceptional Children (CEC) conference held April 5-9 in Salt Lake City. Beach Center co-directors **Ann** and **Rud Turnbull** received the 2006 Burton Blatt Humanitarian Award. Associate Director **Michael Wehmeyer** and **Susan Palmer**, associate research professor, received the 2006 Research Award from the Division on Developmental Disabilities. Doctoral student **Suk-Hyang Lee** received the 2006 Herbert J. Prehm Student Presentation Award.

Field Research in North Carolina Launched

Rud Turnbull, **Martha Blue-Banning**, research associate, and **Denise Poston**, associate research professor, traveled to North Carolina in the spring to conduct field research on the effects of Medicaid policy on families in that state. The three researchers also are currently preparing a proposal with the Kansas Department of State Rehabilitative Services for a "systems change" grant from the Centers on Medicare and Medicaid Services of the U.S. Department of Health and Human Services.

Books on Special Education, IDEA Now Available

Ann Turnbull, **Rud Turnbull**, and **Michael Wehmeyer** co-authored a new edition of the special education textbook *Exceptional Lives: Special Education in Today's Schools*. Contributing chapters were KU colleagues Jane Wegner, director of the Speech-Language-Hearing Clinic, and Sally Roberts, associate professor of Special Education. The book is published by Merrill/ Prentice Hall. For more information see <http://vig.prenhall.com/catalog/academic/product/0,1144,0131708694,00.html>

A new edition of a book on the Individuals with Disabilities Education Act, written by **Rud Turnbull**, **Matt Stowe**, and Nancy Huerta, will be available in late spring. *Free Appropriate Public Education*, published by Love Publishing, details the six principles of IDEA and provides an overview of the American legal system and anti-discrimination laws. Stowe is an assistant research professor at the Beach Center and Huerta is an attorney who owns a consulting firm in Shawnee, KS.

Student News: Beach Student Invited to National Roundtable

Beach Center doctoral student **Nina Zuna** was among a select group of national disability officials and advocates invited to a roundtable on economic freedom for people with intellectual disabilities held March 22 in Washington, D.C.

The roundtable was sponsored by the President's Committee for People with Intellectual Disabilities, in cooperation with the Office of Community Services and the Assistant Secretary for Planning and Evaluation from the Department of Health and Human Services. It was entitled "Personal and Economic Freedom for People with Intellectual Disabilities: An Exploration of Asset Development." Zuna was one of only 28 participants, a group that included federal

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commissioners and deputy commissioners along with directors of several national advocacy organizations.

Shogren Named First Recipient of Award in KU School of Ed

Beach Center doctoral student *Karrie Shogren* was named the first recipient of the Judy Tate Outstanding Doctoral Student award by the KU School of Education in April. The award honors a long-time Special Education staff member who died in 2004. Shogren co-founded the University of Kansas Professionals for Disability and delivered the graduate student remarks at the School of Education Convocation on May 20.

Sayles Wallace Wins Research Award

Beach Center doctoral student *Luchara Sayles Wallace* was one of two graduate students at the University of Kansas who won research awards at a Graduate Student Research Summit held March 8 at the state capitol in Topeka.

Wallace won a \$500 scholarship from Kansas Bio, a consortium of Kansas biosciences companies and organizations that includes the Kansas City Area Life Sciences Institute. Her award-winning qualitative research project studied how support brokers can get the most out of the self-determination approach for individuals with disabilities who choose the HCBS Medicaid fund option. She was one of nine KU graduate students who were chosen to present their research at the Summit.

Hall Receives Black Faculty and Staff Award

Tonya Hall, project coordinator for Positive Behavior Support, received the University of Kansas Black Faculty and Staff Award in April. The award honors high academic achievement by undergraduate and graduate students who are African American.

Students Complete Major Milestones

Four students at the Beach Center completed their doctoral degrees at KU in May. They are: *Stelios Gragoudas*, doctor of Education/Special Education; *Tonya Hall*, doctor of Philosophy, Developmental/Child Psychology; *Suk-Hyang Lee*, doctor of Philosophy, Education; *Karrie Shogren*, doctor of philosophy, Education/Special Education.

In addition, doctoral student *Hoon Choi* passed his written comprehensive exams in May with honors.

Beach Center Staff News

Beach Center researcher *Susan Palmer* has been promoted to research associate professor at the University of Kansas. She works with Michael Wehmeyer on self-determination and access to the general curriculum. She also holds a courtesy appointment in the Department of Special Education where she provides support for graduate students.

Samara Klein has joined the Beach Center staff as a part-time research associate with the Human Genome Project. She holds a law degree from KU and was most recently executive director of the Kansas City-based non-profit organization REACH for Kids.

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Joan Houghton has been named the Director of the Kansas Project for Children and Young Adults Who Are Deaf-Blind, Student Support Services Division, Kansas State Department of Education. She had been an assistant research professor at the Beach Center since 2002.

George Gotto, a research assistant at the Beach Center and doctoral student in Anthropology, has been selected for the Preparing Future Faculty program at KU. The year-long fellowship is designed to familiarize KU doctoral students with the academic life at colleges and universities with diverse missions and to enhance their placement at such institutions upon completion of graduate school.

Third PAR Meeting Set for Human Genome Project

Matt Stowe and his team of researchers on the Human Genome Policy Project – **Samara Klein, Jennifer Rack, Suzanne Schrandt, and Ann and Rud Turnbull** – will convene their third Participatory Action Research Team June 23 in Lawrence, KS. PAR members include parents of children with disabilities, biologists, psychologists and policy analysts.

Researchers Present Several Sessions at Montreal Summit

Several Beach Center researchers and doctoral students presented at the 2006 annual meeting of the American Association on Mental Retardation held May 3-4 in conjunction with the Internal Summit for the Alliance on Social Inclusion in Montreal. Beach Center researchers are noted in boldface and italics below:

Misenheimer, A., Tassé, M., & **Poston, D.** *New horizons: Self-direction in a managed care environment.*

Palmer, S. B., & Wehmeyer, M.L. *Technology use for people with intellectual disabilities results of two U.S. surveys.*

Summers, J., Gotto, G., & Zuna, N. *Effective administration for effective practice: Identifying administrative structures that are related to implementing best practices.*

Summers, J., Zuna, N., Patrick, R., & Stuber, G. *No family left behind: Relationships of preschool experiences to school readiness and family quality of life.*

Turnbull, A., & Poston, D. *What do we really mean by self-determination or individual control of funding? The results of a national discussion on the defining characteristics of individual/family control of family.*

Turnbull, A., Poston, D., Blue-Banning, M., & Wallace, L. *What does it mean to really have choice and control over Medicaid HCBS funds?*

Zuna, N. *Social role valorization: Implications for and application to self-determination, school inclusion, and community integration.*

Bashinski Provides Training Throughout Kansas

Susan M. Bashinski, research assistant professor, provided several training sessions and mini-courses throughout the spring for various groups of students and professionals.

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Bashinski and Deb McVey, psychologist for the Lawrence public schools, co-presented four sessions March 16-22 for the Kansas State Department of Education to train professionals in scoring procedures for the Kansas Alternate Assessment. The sessions were broadcast over the state's Kan-Ed network to 30 local sites.

Bashinski presented a session April 12 on augmentation strategies for teaching functional nonsymbolic communication as a part of the Kansas Instructional Support Network's autism mini-team training series for the Kansas State Department of Education. The session was broadcast to remote sites throughout the State of Kansas.

Also, Bashinski presented a session on maximizing the communication potential of all learners for staff in two Kansas school districts on April 14 as a part of a project called Preparing Educator Paraprofessionals (PEP).

Sailor Keynotes New York Conference

Beach Center Associate Director **Wayne Sailor** served as keynote speaker for the New York Education Administrators Council Conference held March 16 in Albany, NY. Sailor discussed the Schoolwide Applications Model in Positive Behavior Support.

Other Presentations

Bashinski, S.M., Zody, A., Hauptman, M., Wilson, S., & Guthrie, N. (2006, April). *Inclusive Network of Kansas (INKS) field-based technical assistance and professional development: Case examples*. Kansas State Department of Education Annual Conference, Wichita, KS.

Blue-Banning, M. (2006, April). *Creative employment options for adults with developmental disabilities*. Presentation at KansTrans Transition Summit 2006, Wichita, KS.

Blue-Banning, M., & Poston, D. (2006, February). *Making visions a reality for transition-age students and young adults*. Presentation at Families Together, Inc. Conference: Together We Can Learn, Topeka, KS.

Brady, N., **Bashinski, S.M., & Houghton, J.** (2006, March). *Teaching communicative gestures to young children who are deaf-blind through an Adaptive Prelinguistic Milieu Teaching (PMT) approach*. Presentation at the Kansas Division of Early Childhood Education (KDEC) Conference, Overland Park, KS.

Murphy-Herd, M., Stuckey, D., **Bashinski, S.M.**, & Dunbar, M. (2006, April). *IntelliFeature this*. Presentation at the 2006 Assistive Technology National Topical Conference, National Technical Assistance Consortium for Children and Youth Who Are Deaf-Blind (NTAC), St. Louis, MO.

Palmer, S.B., Garner, N., Geiger, D., Johnstone, R., Withers, A., & Williams, P. (2006, March). *Self-determination and transition – What's the big deal?* Presentation at the Vocational Education for Special Populations Statewide Conference, College Station, TX.

Palmer, S.B., Garner, N., Geiger, D., Johnstone, R., Withers, A., & Williams, P. (2006, March). *Practical ideas for self-determination and transition*. Vocational Education for Special Populations Statewide Conference, College Station, TX.

Palmer, S.B. (2006, April). *Fundamentals of self-determination*. Arkansas Transition Summit, Little Rock, AR.

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Palmer, S.B., & Walker, C. (2006, April). *Self-determination for the future*. KansTrans: Transition Summit 2006. Wichita, KS.

Sailor, W. (2006, March). *Linking schoolwide Positive Behavior Support to structural school reform: The Schoolwide Applications Model (SAM)*. Presentation at the 3rd International Conference on Positive Behavior Support, Reno, NV

Sailor, W. (2006, May). *Response to intervention logic model for all students: The Schoolwide Applications Model (SAM)*. Presentation at Louisiana State University Health Sciences Center and Human Development Center, New Orleans, LA.

Stowe, M. (2006, April). *Genetic research: What it means for persons with disabilities and their families*. Paper presented at Environmental and Genetic Effects on Disability, Kansas Chapter of the American Association on Mental Retardation, Lawrence, KS.

Stowe, M. (2006, May). *LRE and due process: Implications of IDEA as related to preschool age children and their families*. Seminar for State Education Resource Center, Middletown, CT.

Recent Publications by Beach Center Researchers

Agran, M., & **Wehmeyer, M.** (2006). Child self-regulation. In M. Hersen (Ed.), *Clinician's Handbook of Child Behavioral Assessment* (pp. 181-199). Mahwah, NJ: Lawrence Erlbaum and Associates.

Lee, S., Palmer, S., Turnbull, A., & **Wehmeyer, M.** (2006). A model for parent-teacher collaboration to promote self-determination in young children with disabilities. *Teaching Exceptional Children, 38*(3), 36-41.

Stock, S., Davies, D.K., & **Wehmeyer, M.L.** (2006). Evaluation of an application for making palmtop computers accessible to individuals with intellectual disabilities. *Journal of Intellectual and Developmental Disabilities, 31*, 39-46.

Stowe, M., Turnbull, R., & Sublet, C. (2006) The Supreme Court, "Our Town," and disability policy: Boardrooms and bedrooms, courtrooms and cloakrooms. *Mental Retardation, 44*, (2), 83-99.

Turnbull, H. R. (2005). Individuals with Disabilities Education Act reauthorization: Accountability and personal responsibility. *Remedial and Special Education, 26*(6), 320-326.

Turnbull, H.R. (2005). Theological, personal, and universal: Responses to Iozzio, M.J. The writing on the wall: Alzheimer's disease. *Journal of Disability, Religion and Health, 9*(6), 75-78.

Turnbull, H.R. (2005). What should we do for Jay? The edges of life and cognitive disability. *Journal of Religion, Disability, and Health, 9*(2), 1-26.

Turnbull, H.R. (2006). The legacy of our journey. *TASH Connections*, Jan./Feb., 40-41.

Wehmeyer, M.L. (2006). L'autodeterminazione: Il nuovo paradigma per la disabilità. [Self-determination: The new paradigm for the disability movement]. *Giornale Italiano delle Disabilità* [Italian Journal on Disability], 6(1), 3-13.

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Wehmeyer, M.L. (2006). Self-determination and individuals with severe disabilities: Reexamining meanings and misinterpretations. *Research and Practice in Severe Disabilities, 30*, 113-120.

Wehmeyer, M., & Agran, M. (2006). Promoting access to the general curriculum for students with significant cognitive disabilities. In D. Browder & F. Spooner (Eds.), *Teaching language arts, math, and science to students with significant cognitive disabilities* (pp. 15-37). Baltimore: Paul H. Brookes.

Wehmeyer, M.L., & Smith, J.D. (2006). Leaving the garden: Henry Herbert Goddard's exodus from the Vineland Training School. *Mental Retardation, 44*, 150-155.