

The Institute on Disability and Human Development, Summer 2006

Alert!

In this issue:

Hot Topic: Families

The Chicago Festival of Disability

Arts & Culture

International Perspectives: Disability in Spain



UIC Department of Disability
UNIVERSITY OF ILLINOIS and Human Development
AT CHICAGO COLLEGE OF APPLIED HEALTH SCIENCES



Alert Editors:

Vladimir Cuk (Associate Editor)
Kristen Ball
Katie Keiling
Mary Kay Rizzolo

Special Thanks to:

Claudia Diaz
Carlos Drazen
Alan Factor
Darlene FASTER
Glenn T. Fujiura
Glenn Hedman
Joan Ingram
Sarah Rothberger
William J. Schiller
Sharon Snyder
Larry Voss

Feedback

We welcome your feedback on our newsletter and activities. Please send your comments and suggestions to Vladimir Cuk. Contact Vladimir if you would like to be added to our mailing list or would prefer to receive the newsletter electronically:

Vladimir Cuk
Institute on Disability and Human
Development M/C 626
1640 W. Roosevelt Road
Chicago, IL 60608-6904
Phone: 312.413.1535
Email: vcuk2@uic.edu

Cover Photo:

Geoffrey Mikol with his mother Ann
Cameron Caldwell, Ph.D.

Welcome from the Director

This issue focuses on families and their roles in the lives of people with disabilities. We report on a number of research projects that look at families from multiple perspectives, that of the parents, the siblings, and persons with disabilities. These studies address such varied questions as:

- What do people with disabilities want from their families?
- What are the benefits of consumer-directed family supports?
- What are sibling concerns regarding the future of their sibling with developmental disabilities?



Nearly all the literature on families of people with disabilities includes the perspectives of non-disabled members. Carol Gill and Renee Taylor's study is unique in its focus on the views of the disabled member. Many of the persons interviewed very much valued family contact; yet they also encountered considerable negative attitudes towards their disability.

Earlier research that I conducted on the Illinois' Home Based Support Services Program showed many benefits to its participants. More recent research conducted by Joe Caldwell highlights the economic, health, and social benefits for family caregivers. This study provides compelling evidence for expanding consumer-directed programs for families of persons with developmental disabilities.

A new IDHD research brief "Involvement of Adult Siblings of Individual with Developmental Disabilities in Future Planning" describes siblings' concerns about the future and their needs for support regarding their sibling with disabilities.

A major part of the IDHD's mission is to serve its community and its families. We highlight two family-centered programs. The Family Support 360 program is an example of how a group of committed families, a supportive community agency, a university, and other partners can come together to obtain funding and develop a plan for a family-centered one-stop center serving the primarily Latino families in the Berwyn and Cicero neighborhoods.

In response to the growing number of individuals with autism spectrum disorders, the IDHD Family Clinic has expanded its services for this population. We helped start and continue to foster a support group for Hispanic families of children with autism that has grown to over 150 families who attend regularly. With the scarcity in clinical programs for adults with autism, we have further developed our adult autism clinic to provide a more comprehensive array of services.

I encourage you to visit our newly revamped Department on Disability and Human Development website (www.ahs.uic.edu/dhd) for more about our programs.

Sincerely,

Tamar Heller, PhD

Table of Contents:

Welcome from the Director 2

Hot Topic: Families

A Community Comes Together to Support Latino Families:

The Family Support 360 Project 4

Families Benefit from Autism Services at the IDHD Family Clinic 6

New Research Highlights Benefits of Consumer-Directed Supports on Families 8

How do People with Disabilities View their Families? 9

Fighting Obesity through Family Fitness 10

International Perspectives: Disability in Spain 11

Awards, News, Events 12

Disability and the Media

Bodies of Work — the Chicago Festival of Disability Arts and Culture 13

DHD Alumni: Cathy Ficker-Terrill 14

Department of Disability and Human Development Launches their NEW Web Site 15





community leaders, state officials, and representatives of local civic, religious and non-profit organizations. Family members who live in these towns are also part of the project staff. Four focus groups (composed of 37 families) helped identify community needs and the desired characteristics of the center. Another source of information for the plan was data obtained through the Illinois' Statewide Disability Needs Assessment, the Prioritization of Urgency of Need for Services (PUNS).

A Community Comes Together to Support Latino Families: The Family Support 360 Project

Family Support 360 is a unique project designed to meet the needs of un-served and underserved families of persons with developmental disabilities (DD). Beth Lacey, Executive Director of Community Support Services, Inc. (CSS), an agency that serves nearly 600 persons with DD and their families each month in Chicago's western suburbs, recognized the need for such a program in Berwyn and Cicero. These communities have recently experienced a dramatic growth in their Latino population. CSS partnered with the Institute on Disability and Human Development (IDHD), with funding from the Administration on Developmental Disabilities (ADD) of the U.S. Department of Health and Human Services, to develop a plan for a one-stop center to meet the needs of these families. Once the plan is completed, additional funds will be sought from ADD and other sources to implement it.

Family input is a vital component. The Advisory Committee involved in creating the plan is composed of families who live in Berwyn and Cicero as well as

Family Representative Anna Valdovinos, an Advisory Committee Member, reported that *she is proud to be part of a committee that values and appreciates her contributions.*

Another family representative and Advisory Committee member, Isela Marquez, realized that *she knew enough to make a difference.* She takes pride in knowing that she is part of a project that will "*open the doors for others in the future.*" Her vision for the center is that of a warm and inviting place where families can go and not feel alone; a place where families who share the same needs can meet, feel safe, and find everything they need in one location. "Thank you for getting our people here. It is a beautiful thing to know that we are not forgotten," Isela Marquez.

"Thank you for getting our people here. It is a beautiful thing to know that we are not forgotten," Isela Marquez.

Senator Martin Sandoval of the 12th District that includes Berwyn and Cicero, also a member of the Advisory Committee, has been an early supporter and strong advocate of this program. "I am very happy to see a project like this come to the 12th Legislative District. Families of children with developmental disabilities need to have somewhere to go that will provide them all the services in one place without them having to search or travel away from their community," Sandoval said. (Source: The Illinois State Senate Democrats website: www.senatedem.state.il.us/sandoval/news-h.shtml). Sandoval along with State Representative "Skip" Saviano, played a key role in gaining the support of

the Illinois Legislative Latino Caucus, which led to a \$500,000 capital grant in FY 2006 and an operating grant of \$250,000 in FY 2007.

One exciting event sponsored by the project was a Family Advocacy Training Series led by Charlotte Cronin and Dorelia Rivera-Martinez of the Family Support Network, a grassroots advocacy organization of families and individuals with disabilities in Illinois that has successfully advocated for consumer-directed family support policies. The training series helped families identify and prioritize their needs and learn how to improve services for their relatives with developmental disabilities. As part of the training series, families learned how to talk to their legislators and were provided with the opportunity to meet personally with Senator Martin Sandoval and directly express their needs to him. The training series concluded with a trip to the state capitol that included nearly 40 people, the majority of whom were Latino family members, advocating for funding for the center, personal assistance, and a children's Medicaid waiver. The trip to the Capitol included a private meeting with Senator Martin Sandoval, meetings with 27 legislators (several from the Latino

Caucus), a tour of the building, and observations of the House and Senate in session.

To date, the project has been a success and is the result of the efforts and valuable contributions of the people involved. Beth Lacey stated, "Community Support Services has been delighted to partner with UIC's Institute on Disability and Human Development on this important project. Through our strong and successful collaboration, we are building a community-based center based on what people need and want. As the project matures, it will bring positive change in the lives of persons with disabilities and strengthen their families and their communities."

I feel privileged of being able to participate in the trip to Springfield. It was truly exciting, rewarding and feel very proud as a mother to go out and truly advocate on behalf of my son and other individuals with disabilities ... I truly believe now that when individuals unite and advocate for the same cause we can truly make a difference.

- ARMANDO'S MOM, Ana Valdovinos

Principal Investigator: Tamar Heller, PhD
Contact: Kristen Ball
Email: kball2@uic.edu
Phone: 312.413.3027





resources, and support in advocating for their children. They also have the opportunity to network with other families who have a member with ASD. With its family-centered practices, the clinic staff emphasize the value of family, resources within the community, and the importance of a multi-disciplinary life-span approach.

In addition, the IDHD Family Clinic has a full team of

Families benefit from Autism Services at the IDHD Family Clinic

The IDHD Family Clinic is serving a growing number of children and adults with autism spectrum disorder (ASD)¹ and their families. ASD is a common neurodevelopmental disorder characterized by impairment in reasoning, social interaction, and communication. It has been estimated that between 221,000 and 483,000 children under the age of 20 years in the United States have ASD, and that between 53,000 and 114,000 children under the age of five have ASD (Fombonne, 2003).

Autism is now a national health crisis (Newschaffer, & Curran, 2003). It has surpassed all other childhood disorders as the fastest growing epidemic in the United States. From accurate and comprehensive diagnoses to family interventions, the IDHD Family Clinic offers an array of services to help families improve the lives of children with ASD.

Families who come to the IDHD Family Clinic receive a tremendous amount of information,

bilingual professionals (Spanish speaking) who serve the needs of the Hispanic/Latino communities. They sponsor a support group for Hispanic families who have children with ASD. Grupo SALTO meets monthly and offers educational sessions for parents, day care for their children, and a support group for siblings. Grupo SALTO is the largest support group for parents at children with ASD in the Chicago area, with over 150 active members.

In a joint effort with the UIC Department of Psychiatry, the Family Clinic provides training and support for minority families of children with ASD (TAP project). Over 30 families have received intensive short-term cutting edge strategies to help children with ASD. Topics and approaches introduced include PECS (Picture Exchange Communication System), ABA (Applied Behavioral Analysis), and TEACCH (structured teaching, and positive behavioral support methods).

Services addressing the needs of adults with autism are scarce and greatly needed. To this end, the IDHD Family Clinic provides an array of services including diagnosis, treatment, family support, advocacy, and consultations for adult individuals who have ASD and their families. These services are provided both in English and Spanish.

We also provide one-on-one intervention for low-income families using the DIR/Floortime model

city and are very successful in helping children with ASD improve social and emotional development.

Areas of specialty include:

- Diagnosis
 - Parent training
 - Consultations to address behavioral concerns
 - Transition planning
 - Treatment for adults with ASD (both individual and group therapy)
 - Social skills training
 - Dual diagnosis of autism and mental health issues
 - Assistance to family members with adult programs and services
 - Guardianship issues
 - Consultation for medication management
 - Relationship development interventions
-

(Developmental Individual-Difference Relationship-Based model), as well as RDI (Relationship Development Intervention). Both services are extremely scarce on the south and west sides of the

For information about the Family Clinic call
(312) 413-1871 (Voice)
(312) 413-0453 (TTY)
(312) 413-1593 (Fax)

References:

Center for Disease Control: <http://www.cdc.gov>
Fombonne, E. (2003). Epidemiological Surveys of Autism and Other Pervasive Developmental Disorders: An Update. *Journal of Autism & Developmental Disorders*, 33(4), 365-382.
Newchaffer, C. & Curran, L. (2003.) Autism: An emerging public health problem. *Public Health Reports*, 118 (5), 393-399.

Footnote:

¹ Autism spectrum disorders (ASDs) is used to refer to children with Autism, Pervasive Developmental Disorder not otherwise specified or Asperger's disorder.



Sara Shields-Cole integrates “floor time” principles into speech and language therapy to help children engage and relate to and with family members.

New Research Highlights Benefits of Consumer-Directed Supports on Families

Families are the bedrock of the United States long-term care system. Throughout history, the vast majority of individuals with disabilities have lived with family. However, while over 75% of individuals with developmental disabilities (DD) reside with family, only about 5% of funding within the public developmental disabilities service system is allocated to family support (Braddock et al., 2005).

The Illinois Home Based Support Services program is a model consumer-directed program that supports adults with DD and their families. The program provides an individualized budget of about \$1,637 per month to design and purchase services. It allows individuals to hire providers, including paying family members. Since the program originated, research conducted within IDHD has demonstrated many positive outcomes for families. Families in the program are more satisfied with services and better able to meet their needs. The program increases the community participation and decreases placement of individuals with DD in more costly institutional placements.

The latest research on the program focused on economic, health, and social benefits for family caregivers. Families with relatives with DD spend a great deal out-of-pocket for disability services and

supports. On average, we found that families on the waiting list for the program were spending over \$5,300 annually out-of-pocket for services. The program assists families financially by reducing these expenses. In turn, the financial benefits from the program improve the ability of caregivers to access healthcare for themselves. Over a third of female caregivers on the waiting list indicated that they postponed seeing a physician, neglected vision and dental care, and went without prescription drugs because they could not afford the costs of care. These figures are staggering and worse than national averages. Furthermore, the program improves the mental health of lower-income caregivers struggling with combined stress, poverty and demands of providing care. Finally, the program contributes to improved opportunities for social and leisure participation of caregivers which are important for overall well-being. These economic, health, and

social benefits strengthen the ability of caregivers to provide care. While consumer-directed supports often focus primarily on individuals with disabilities, we continue to learn more about impacts on the family as a whole.

Consumer-Directed Supports Assist Families Financially: Lower Annual Out-of-Pocket Disability Expenses

	Consumer-Directed	
	Program	Waiting List
Transportation	\$670.80	\$863.64
Respite/Personal Assistance	\$438.36	\$1,338.60
Recreational Services	\$508.32	\$558.60
Medical and Dental	\$421.92	\$401.88
Medications/Related Supplies	\$599.40	\$728.16
Therapies	\$167.76	\$406.56
Adaptive Devices/ Home Modifications	\$194.40	\$323.16
Miscellaneous	\$475.80	\$743.04
Total	\$3,462.12	\$5,358.60

Contact: Joe Caldwell, Ph.D. and Tamar Heller, Ph.D.

Email: jcaldw3@uic.edu and theller@uic.edu

Phone: 312.996.7988 and 312.413.1647

Reference:

Braddock, Hemp, Rizzolo, Coulter, Haffer, & Thompson, M. (2005). *The state of the states in developmental disabilities*. University of Colorado.

How do People with Disabilities View their Families?

If you could have an ideal relationship with your family, what would it be like? Researchers in IDHD/DHD's Chicago Center for Disability Research have been asking individuals with disabilities to ponder this and other questions related to family and disability. Under the direction of Principal Investigator Carol J. Gill, Ph.D. (DHD) and Co-Investigator Renee Taylor (Department of Occupation Therapy, UIC) the research team has looked at family relationship issues of persons with physical disabilities and persons with chronic fatigue syndrome (CFS). The multi-year research project, funded by the National Institute on Disability and Rehabilitation Research, involves focus groups; in-depth case studies; and the development of a social-educational training to improve family understanding, communication, and support regarding the experience of disability.

Preliminary results from focus groups and interviews of individuals with disabilities in Chicago, San Francisco, and Raleigh revealed that :

- ❑ Many participants reported that their original families (mother, father, siblings) had more difficulty accepting the fact of their disabilities or talking about disability than did their created families (partners and children).
- ❑ Participants often developed their own alternate families through friendship, church, or other connections that augmented or replaced support from relatives.
- ❑ Participants commonly expressed a desire for family members both to acknowledge the disability realistically, including the limitations and difficulties associated with it, and to respect the person with a disability as whole and capable.

- ❑ Persons with chronic fatigue syndrome noted that it was particularly difficult for their families to accept their disabilities because their limitations were not readily apparent and their conditions were not well defined medically. Persons with visible physical disabilities, on the other hand, noted that some family members expressed embarrassment to be seen in public with them or perceived their need for help as burdensome.
- ❑ Resources participants sought (in addition to acknowledgment and acceptance) were support, frequent connection, open communication, working together and helping each other, understanding limitations, and positive expectations from families.
- ❑ Participants identified the following family attitudes and behaviors as barriers to positive family relations: pity, avoidance of contact, rejection of limitations, low or unrealistic expectations, preferential treatment of nondisabled family members, controlling behavior, overprotection, guilt over the disability, denial, and making comparisons between the disabled individual's achievements and those of others.
- ❑ Participants felt that exposure to people with disabilities was good for their family members, especially for children. Having multiple individuals with disabilities in one's extended family made disability more familiar and sometimes provided positive role models that helped the immediate family members acquire better attitudes.
- ❑ In general, participants very much valued family contact and tried to understand why family members might have negative attitudes toward disability. Among factors that participants thought contributed to such attitudes were cultural beliefs, personality factors, generational differences, lack of knowledge, and stressful life circumstances.

Contact: Carol J Gill, Ph.D.
Phone: 312.355.0550
Email: cg16@uic.edu

Fighting Obesity Through Family Fitness

Would you let a child smoke? Did you know that the arteries of a child who is obese look similar to those of a middle-aged smoker? The good news is that the damage can be reversed with proper diet and exercise. According to the American Heart Association, 15.3% of children age 6-11 years are overweight or obese. The overall numbers for obesity and children with disabilities, however, are somewhat elusive.



Sources suggest that adults with physical, emotional, or sensory disabilities are nearly twice as likely to be obese as the general population. Research on obesity as a secondary condition in specific disabilities such as spina bifida refers to obesity as a problem related to inactivity.

Regardless of the exact numbers, we know that obesity in children is a problem that can be addressed through fun family fitness activities and a healthy diet. Here are a few ideas to get the kids in your life active and decrease the devastating effects of obesity.

Be a positive role model. Make health a priority in your life. Demonstrate healthy lifestyle choices such as including exercise in your daily schedule, being active whenever possible, which could include using the stairs when possible or parking further away from the entrance of a store, and maintaining a balanced diet.

Teach children the positive benefits of physical activity including improved fitness and increased self-esteem and mood. Children are never too young to begin to learn that the choices that they make affect their health and that physical activity can improve their quality of life.

Leave your car at home and make walking/rolling your method of transportation. Walk to the park and play games on the way. For example, the red light/green light game could be used for a child with autism. Instead of saying stop and go, use facial expressions or non-verbal cues to represent stop and go. The entire family can play and the time spent walking to the park will not even be noticed.

Limit sedentary activities such as watching TV and recreational computer use. Children who watch more than 5 hours of TV a day were almost 5 times more likely to be obese than children who watch no TV or less than 2 hours a day. Studies have also shown that reducing TV viewing time was associated with reductions in body weight and body fat.

Assign active household chores such as vacuuming, dusting, or making the bed. Every movement counts—this purposeful movement will increase activity and teach responsibility.

Contact: Amy E. Rauworth, MS, RCEP
Associate Director, National Center on Physical Activity and Disability www.ncpad.org
Phone: 312-355-1584
Email: rauworth@uic.edu

International perspectives: Disability in Spain



The transition to democracy after Franco's dictatorship (1939-1975) has been particularly relevant to the development of social policies in Spain and thus to the policies on disability. Despite the short democratic history, recent laws and regulations regarding disability position Spain in a comparable situation to other developed countries in Europe. These laws affect approximately 3.5 million disabled people, 9% of the total population (Survey on Disabilities,

Impairments, and Health Statuses, the Spanish National Institute on Statistics, 1999).

The Social Integration of Disabled People Act (LISMI), the first comprehensive piece of legislation regarding disabled people, was passed in Spain in 1982. The LISMI was designed to promote the full social integration of disabled people in Spain and protect them against discrimination. After more than 25 years of this Act, however, serious challenges still exist to complete participation of people with disabilities in society. New laws have been enacted to meet the needs of people with disabilities such as the Equality of Opportunities, Non Discrimination and Universal Accessibility Act of 2003, the Home Ownership Protection of People with Disabilities and Civil Code Modification Act of 2003, the Public Employment of People with Disabilities of 2003, and the most recent Radio and Television Act of 2006. Following the European regulations, Spain also developed National Action Plans for Employment and Action Plans for Social Inclusion. Furthermore, the First National Accessibility Plan 2004-2012 has been

developed to consolidate universal design and its implementation in existing and new environments and technologies, and to establish accessibility as a management quality principle.

The disability movement strongly supported the development of these plans and advancement in legislation. The movement is led by influential social and political disability organizations such as the Spanish Council of Disabled Representatives (CERMI), the Spanish National Organization of the Blind (ONCE), and the Spanish Federation of Associations of People with Intellectual Disabilities (FEAPS). The CERMI, an independent political platform to protect the human rights and to achieve equality of opportunity for people with disabilities, was created in 1997 and brings together more than 2,500 associations and entities. The CERMI "is recognized as the valid interlocutor of the disability movement in Spain" and negotiates with the government on all issues concerning the disabled. The ONCE has also made an important impact on how the Spanish society views people with disabilities. The ONCE supports important work in the areas of employment, education, and accessibility with a budget coming primarily from lottery tickets sold by thousands of disabled people everyday. In the area of intellectual disabilities, FEAPS includes more than 800 associations from across the country. These three groups share the same mission: improvement of the quality of life for the people with disabilities in Spain!

A critical contribution to the improvement of quality of life of people with disabilities in Spain is being made by the Institute on Community Integration at the University of Salamanca (INICO). The INICO is the only official institute dedicated to research, education and consultancy in Spain. According to Miguel Ángel Verdugo, INICO's director, "whereas there has been an increase in disability research funding, specific infrastructure hardly exists making it difficult to plan for the development and consolidation of excellence research groups in this area."

Contact:

Eduarne Garcia-Iriarte, PhD student
Disability Studies Program at UIC
Email: egarci3@uic.edu

Awards



- ❑ Carlos Drazen, M.A., received the Ann and Edward Page-El Scholarship Award for 2006. The scholarship supports educational opportunities for graduate students, residents, or fellows interested in social or medical aspects of neurological disabilities.

- ❑ Michael Grice received the Arc of Illinois Life Achievement Award.
- ❑ Eynat Shevil, a student in the Disability Studies Program, has been awarded a University Fellowship for the upcoming academic year.
- ❑ John Kramer, PhD student in Disability Studies, received a UIC Provost's Award for 2006.
- ❑ Carol J. Gill, Ph.D., was notified of her selection for the Daring To Dream Scholarship Award, an award given by the Center for Community Inclusion and Disability Studies, University of Maine, to acknowledge exemplary scholarship in disability studies.



- ❑ Glenn T. Fujiura, Ph.D., received the Arc of Illinois' Volunteer Leadership Award at its annual conference held April 4th and 5th. Dr. Fujiura was selected as "one whose contributions have significantly impacted the lives of children and adults with developmental disabilities. His leadership efforts have inspired others and influenced positive change."

News

- ❑ An article quoting Jim Rimmer, Professor of Disability and Human Development, and Amy Rauworth, Associate Director of Operations and Exercise Physiology Research in the Department of Disability and Human Development, appeared in *The New York Times*. Jim Rimmer was also quoted in the *Chicago Tribune* in an article that focuses on accessibility issues faced by persons with disabilities who wish to use fitness training facilities.
- ❑ Elina Manghi, PsyD was appointed to the American Psychological Association Task Force on Guidelines for Assessment and Treatment of Persons with Disabilities.

Events

- ❑ Easter Seals and the IDHD Rehabilitation Research and Training Center on Aging with Developmental Disabilities organized and held the *Practical Approaches to Working with Adults Aging with Developmental Disabilities* conference on February 15th. Over 100 participants attended the conference and IDHD presenters included: Alan Factor, Joy Hammel, Tamar Heller, Matthew Janicki, Robin Jones, Beth Marks, Jasmina Sisirak, John Kramer and Joseph Caldwell.
- ❑ The Spring 2006 Lecture Series in Disability Studies presented *Claiming the Memoir: A Lecture* by Simi Linton, PhD on April 26th.
- ❑ Drs. Glenn Fujiura and Jim Rimmer presented at a U.S. Disability and Health Congressional Briefing on March 16, 2006. The Briefing which focused on health promotion and disabilities, had a standing room only audience of about 65 House staffers and advocacy group representatives.

Disability and the Media

Bodies of Work

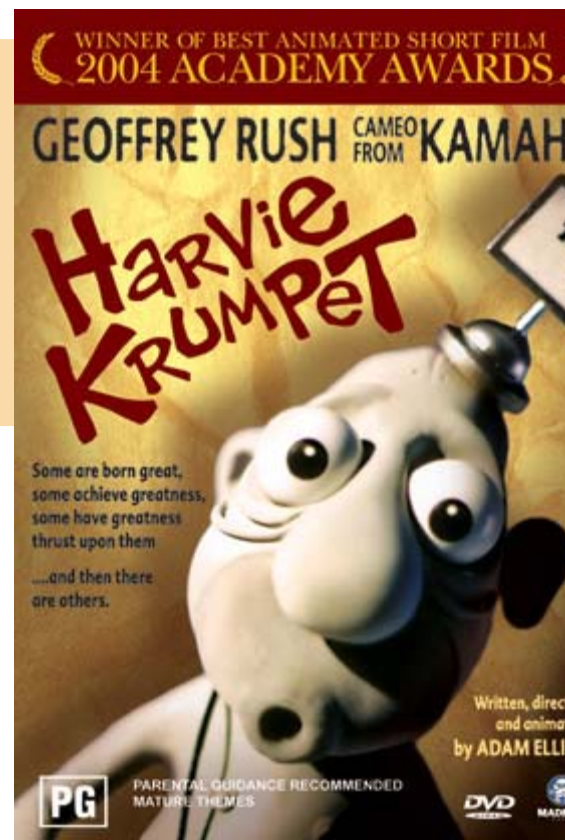
The Chicago Festival of Disability Arts & Culture was held from April 20-30, 2006. *Bodies of Work* was Chicago's first-ever festival showcasing disability arts. It explored and celebrated the contributions of artists with disabilities, the contemporary contexts of disabled lives, and works that illuminate disability experiences. IDHD/DHD and many of its units (including the Disability and Cultural Studies Unit, National Center on Physical Activity and Disability, and the Great Lakes ADA and Accessible IT Center) and the College of Applied Sciences were festival co-sponsors and several faculty and staff members participated in the festival. Especially noteworthy were the Chicago Disability History Exhibit, the International Disability and Deaf Film Festival and Crip Slam. For more information, please visit: www.bodiesofwork.org.



The Institute on Disability and Human Development sponsored a panel of Chicago leaders on disability issues entitled “In and Out of the Institution.” One of the movies screened was *Harvie Krumpet* (picture to the right).

The panel included representatives from IDHD and our two sister agencies – Equip for Equality (Barry Taylor) and the Illinois Council on Developmental Disabilities (Lester Pritchard, Chair). Representatives from IDHD included Professor Tamar Heller and alumni Andrea Dinaro.

David Mitchell, Ph.D. (Department of Disability and Human Development) was quoted in April 14th's *Chicago Tribune* in connection with the event “*Bodies of Work — the Chicago Festival of Disability Arts and Culture*.” He was also interviewed by the *Chicago Sun Times* and Cory Dogin's “Around Chicago” radio show about the Chicago Festival of Disability Arts and Culture. Sharon Snyder, Ph.D., (DHD) was also featured in a spot with Chicago Works on March 29th to promote the International Disability and Deaf Film Festival.



DHD Alumni: Cathy Ficker-Terrill



Cathy Ficker-Terrill graduated from the Masters program in Disability and Human Development at the Department of Disability and Human Development, University of Illinois at Chicago. She is President and CEO of the Ray Graham Association for People with Disabilities and past President of the American

Association on Mental Retardation. Other accolades include a leading position in the President's Committee for Persons with Intellectual Disabilities and past Executive Director of the Illinois Planning Council on Developmental Disabilities. She also serves as a member of the IDHD advisory board.

Internationally, Cathy has volunteered her time to help families in the Baltic States and Eastern Europe with the International Christian Children's Bureau. She has also helped set up early intervention, family support, and parent support groups in Poland with UNICEF, and has worked to reunite children with disabilities in Russian orphanages with their families. Cathy facilitated strategic planning in Saudi Arabia and Lithuania and has volunteered her time to expand self-advocacy in Japan and Cyprus. Most recently, Cathy volunteered with US AID to facilitate training in Kosovo with self-advocates and families.

Alert: How did you become interested in the Masters program in disability and human development?

Cathy: Education is one of the keys to empowerment. The Master's program in disability studies was the perfect solution for me. I have always had a keen interest in public policy and this degree program allowed me to focus on disability policy while also acquiring information on adaptive equipment and new technology solutions. This program allowed me to network with other professionals in the field, as well as spend time with younger professionals trying to move into key leadership positions.

Alert: How has the Masters program influenced your work/thinking as you pursue your career currently?

Cathy: The Master's program has wonderful faculty. Key national leaders provide students with current data and information about trends in the field. Professors encourage students to think outside of the box and to leverage social change through public policy, administrative modifications, research, and litigation.

The program has a focus on applied research. Students are encouraged to look at options in qualitative and quantitative research.

Alert: You run a multi-million dollar nonprofit community service agency. What are the common challenges you encounter? What is your typical day like?

Cathy: There is no such thing as a typical day. If your organization dedicates itself to continuous quality enhancement, then opportunities will always be at your door. The true leader embraces opportunities rather than focusing on barriers.

Alert: This issue of Alert is on Families. Can you please tell us how do you become an effective advocate on behalf of families?

Cathy: I started my advocacy efforts working with The Arc of Illinois. I was mentored by some of the greatest parent advocates in the early 80's. These parents taught me to listen to families, then design strategies, and then share those strategies with families before taking action. While working for The Arc I was able to travel from one end of Illinois to the other, listening to individuals with disabilities and their families. That shaped my advocacy efforts. In 1986 one of my children was born with disabilities and that too has allowed me to be a strong advocate to speak to the empowerment of individuals with disabilities.

Section of this interview also appeared in an AAMR interview. The complete interview can be found at: www.aamr.org/FYI/interview_CathyFickerTerrill.shtml

Department of Disability and Human Development launches their NEW web site

MS in Disability and Human Development

The interdisciplinary Master of Science Program in Disability and Human Development at UIC

- ❑ was featured in *The New York Times* and the *Chronicle of Higher Education*, as the **nation's first graduate degree program** focused on the interdisciplinary study of disability.
- ❑ examines the cultural, legal, programmatic, and theoretical context of disability in society.
- ❑ prepares **leaders** in community-based and governmental agencies, **advocates** in the disability-rights movement, and **disability scholars**.
- ❑ has **diverse faculty** and resources in the social sciences, health fields, and humanities.
- ❑ has **diverse students** from all over the world with backgrounds in numerous disciplines.

The curriculum examines disability and human development across the lifespan with an emphasis on promoting self-determination and community participation. Students can focus their studies and research in one of five areas, with substantial program flexibility in each:

- ❑ **Disability Ethics** considers bioethics within the framework of disability studies, critiquing and expanding current approaches in ethics practice, research, and conceptual analysis.
- ❑ **Disability Studies and Social Policy** focuses on understanding disability phenomena and policy in the context of social practices and cultural values about human differences.
- ❑ **Health Promotion** addresses the health needs of persons with disabilities by viewing health as multi-dimensional, and optimal health as a worthy goal for all persons.
- ❑ **Leadership and Organization** focuses on practical management skills relevant to the disability non-profit organization, integrated with theories of disablement, historical and contemporary disability issues, and knowledge of state and national disability programs.
- ❑ **Rehabilitation Technology** employs coursework and field experience to expose students to the spectrum of devices in the assistive technology field and methodologies to evaluate their effectiveness.

PhD in Disability Studies

The interdisciplinary PhD Program in Disability Studies at UIC

- ❑ is the **first PhD in the United States** dedicated to the burgeoning field of disability studies and is one of only a few such programs in the world.
- ❑ has been featured in *USA Today*, the *Chicago Tribune*, the *Journal of the American Medical Association*, and on *NBC Nightly News*.
- ❑ produces **disability scholars** prepared to take prominent roles in advancing and integrating the scientific and cultural study of disability.
- ❑ has **diverse faculty** and resources in the social sciences, health fields, and humanities.
- ❑ has **diverse students** from all over the world with backgrounds in numerous disciplines.

Disability studies try to answer such questions as, "What is disability, and who is disabled?" It looks beyond the conventional idea of disability as a measurable flaw inside people's bodies or minds, and it examines the complex way that society classifies and interacts with people who function differently from the "norm." Students conduct research across social, cultural, clinical, ethical, and policy perspectives.

The program also examines how addressing disability in all of its dimensions can promote the full participation, self-determination, and equal citizenship of people with disabilities in society.



www.ahs.uic.edu/dhd

Institute on Disability and Human Development (MC 626)
1640 West Roosevelt Road, Room 245
Chicago, IL 60608

Nonprofit Org.
U.S. Postage
PAID
Chicago, Illinois
Permit No. 4860

Position Announcements

Project Director Family Clinic Director

IDHD is seeking a Project Director (Family Clinic Director) to lead its Family Diagnostic and Assessment Clinic. The IDHD is a research, training and service center focused on developmental disabilities. The clinic director is responsible for providing overall leadership and direction to the Clinic through planning, management and evaluation of the Clinic. Responsible for budget, finance management and development, staff recruitment and supervision, developing and conducting research pertaining to disability, grant proposal writing and development, project management, report writing, and other duties as assigned. A graduate degree in a related discipline is required; PhD or MD is preferred. Three to five years experience in the field of developmental disabilities is required. For fullest consideration, submit resume to: Family Clinic Director Search, c/o Beverly Wellington, UIC/IDHD, 1640 W. Roosevelt Road, Rm 738C (MC626), Chicago, IL 60608-6904. We will review applications until the position is filled.

Support IDHD/DHD

Your contributions can help promote the mission of the Institute on Disability and Human Development. Opportunities for giving range from gifts to support scholarships and disability accommodations for students, to an endowment for the Institute's innovative research on technologies for improving the lives of people with disabilities, to gifts to support the Institute's physical infrastructure. For more information on making a gift to IDHD please contact:

Tamar Heller, PhD, Professor, Director / Head IDHD
Institute on Disability and Human Development (M/C 626)
University of Illinois at Chicago
1640 West Roosevelt Road, Chicago, IL 60608-6904

Phone: 312.413.1647, TTY: 312.413.0453, Email: theller@uic.edu, Internet: www.uic.edu/orgs/idhd