

The Institute on Disability and Human Development, Fall 2008

# Alert!

In this issue:  
Support Services  
Community Outreach  
Student Experience  
What's New at IDHD



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

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## Cover Photo:

Scout, Vladimir Cuk's service dog,  
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## Opposite Page:

IDHD students and staff at the  
2008 Disability Pride Parade  
in Chicago

## Welcome from the Director

*"I am very, very, very, happy!" These are the words of my sister Daphne Ron, 46 years old, who recently moved from a nursing home where she languished for over a year into a lovely home with four other women with intellectual/developmental disabilities (I/DD). At the nursing home she was left in bed for hours, and was only transferred to her wheelchair by 1-2 in the afternoon. Since moving into her new home, run by Trinity Services, she has made friends, been out to restaurants, and seen a movie for the first time this year. Critical to her success in this new setting is the quality of the behavioral and medical supports and the direct support professionals who provide the day to day care.*



*Unfortunately, as noted in this issue of the Alert focusing on support services, Illinois lags far behind other states in providing community supports to adults with I/DD. Many of these adults, like my sister in the past year, are on waiting lists for residential services or living in large public or private congregate care settings. Illinois has made some progress, and the testimonies from Dr. Mary Rizzolo from our Institute on Disability and Human Development and from that of our sister agencies (Lester Pritchard, Illinois Council on Developmental Disabilities, and Cheryl Jansen, Equip for Equality) provide recommendations for improving Illinois' community system for people with disabilities. Future issues of the Alert will continue to include columns from each of these agencies.*

*This issue examines support services from many different aspects and perspectives, including the international human rights approach and models of service delivery across countries. We look at the perspectives of not only policy makers, service providers and direct support professionals, but also that of persons with disabilities who use the services. We also examine specific types of supports such as assistive technology, personal assistance, and training in healthy sexuality. A key issue in service provision is equal access of services across populations. The Institute's Center for Capacity Building on Minorities with Disabilities Research conducts research on ways to improve services for people from ethnic minority groups and provides training and technical assistance on promoting cultural competence. This Center's work epitomizes our mission of "breaking down barriers" for people with disabilities through our research, clinical and technical assistance services, and our training of students and professionals in the field. We hope you enjoy this issue on support services.*

Sincerely,

A handwritten signature in cursive script that reads "Tamar Heller".

Tamar Heller, Ph.D

# Table of Contents:

<b>Welcome from the Director</b> .....	2
<b>Sister Agencies Advocate to Redesign Supports in Illinois</b>	
■ We Don't Have to be 51st! .....	4
■ Spending Time with Family - Just a Regular Day...Or is it? .....	6
■ Illinois' Priorities Askew! .....	7
<b>Support Services</b>	
■ International Perspectives: Disability in the Netherlands .....	8
■ Our DSPs Rock! .....	9
■ Promoting Cultural Competence .....	10
■ Personal Assistance: Empowering Independence .....	11
■ IDHD Family Clinics Promote Healthy Sexuality .....	12
■ Money Follows the Person .....	13
<b>Community Outreach</b>	
■ The Art of Ability .....	14
<b>IDHD Awarded \$4.25 Million for Aging and DD Research Center</b> .....	15
<b>Student Experience</b>	
■ Uncovering Abuse and Neglect: Interning with Equip for Equality .....	16
■ Alumni News: Where Are They Now? .....	16
<b>What's New at IDHD?</b>	
■ Martha and Robert Perske Make Generous Donation to IDHD! .....	17
■ Finding and Keeping Great DSPs .....	17
■ The 2nd Annual Meeting of The Sibling Leadership Network.....	17
■ Awards, Grants, Media, Honors .....	18



# Sister Agencies Advocate to Redesign Supports in Illinois

The three Developmental Disabilities (DD) Act sister agencies in Illinois feel that one of the critical issues in the state is the heavy reliance on the use of congregate residential settings (for 16 or more persons). Illinois ranked 43rd in community spending in 2006 and 51<sup>st</sup> (including DC) in use of residential settings for 6 or less (Braddock, Hemp, & Rizzolo, 2008).

The Illinois Council on Developmental Disabilities commissioned a study to promote systems change in Illinois. The study resulted in a report, *Blueprint for System Redesign in Illinois*, which provides recommendations to the State on how to expand funding, expand community services, improve DD service infrastructure, and promote individualized supports. The following pages contain testimony by IDHD and Equip for Equality in support of the DD Council's report as well as an editorial by the DD Council chairman.

## We Don't Have to be 51st!

The *State of the States in Developmental Disabilities* project was established by David Braddock in 1982 to investigate the determinants of public spending for DD services in the U.S. The project maintains a 30-year longitudinal record of revenue, spending, and programmatic trends in the 50 states and DC. Analysis of the rich detail of the data base reveals the impact over time of federal and state fiscal policy, and illustrates important service delivery trends in the states in community living, public and private residential institutions, family support, supported employment, supported living, Medicaid Waivers, demographics, and related areas.

The following are some highlights from the 2008 *State of the States* report and from a forthcoming report by David Braddock and Richard Hemp funded by the Illinois Council on Developmental Disabilities comparing services in Illinois to five comparison states in the Midwest.

### 1. Illinois over-relies on developmental centers and private institutions for 16+ persons



*This article is an excerpt from testimony given by Mary Rizzolo, IDHD Associate Director, to the Illinois House Disability Services Committee*

- Illinois has made some progress in the past few years in downsizing congregate care settings (for 16 or more). However, our utilization rate for state-operated institutions in 2006 is still over 60% above the U.S. rate, and three times the rate for the five Midwestern comparison states combined.
- In 2006, use of all public and private DD institutions in Illinois was 85% above the U.S. average, and 75% above that of the five comparison states combined.

### 2. Illinois allocates comparatively limited resources for community services

- In 2006, Illinois ranked LAST among all 50 states and DC in use of settings for six or fewer. Only 30% of Illinois' DD residential placements were in settings for six persons or less versus 70% nationally and from 69-90% in the comparison midwestern states.
- Illinois Intermediate Care Facility (ICF/DD) spending in 2006 was 66% greater than Home and Community Based Services (HCBS) waiver spending. This is in dramatic contrast with the U.S. and all five Great Lakes comparison states, in which the large majority of funding is associated with the Waiver. Besides Illinois, only seven states — Arkansas, Iowa, Mississippi, New Jersey,

North Carolina, North Dakota, Texas, and the District of Columbia — spend more for the ICF/MR program than for the HCBS Waiver.

- Illinois ranked 47th in federal-state Waiver spending per capita. Only Texas, Nevada, Georgia, and DC were below Illinois.

The following are a list of selected recommendations from the forthcoming Braddock and Hemp report.

**1. Continue to reduce reliance on the remaining nine state-operated institutional facilities and the large private ICFs/DD. Medicaid ICF/DD resources should be reallocated to the HCBS Waiver**

**2. Expand community services and related supports to address the state’s waiting list and aging caregivers**

- There are currently over 6,000 persons with DD on the Illinois waiting list for residential services (over 2,200 of these are designated as “emergency” needs). The need for additional Waiver services will continue to increase rapidly due to growing numbers of aging caregivers in the State.

**3. Develop a plan to significantly strengthen community services infrastructure**

- A multi-year plan should be developed to increase funding for community-based services and supports. The plan would incrementally increase Illinois spending to match the average state’s expenditure for DD community spending by 2020.

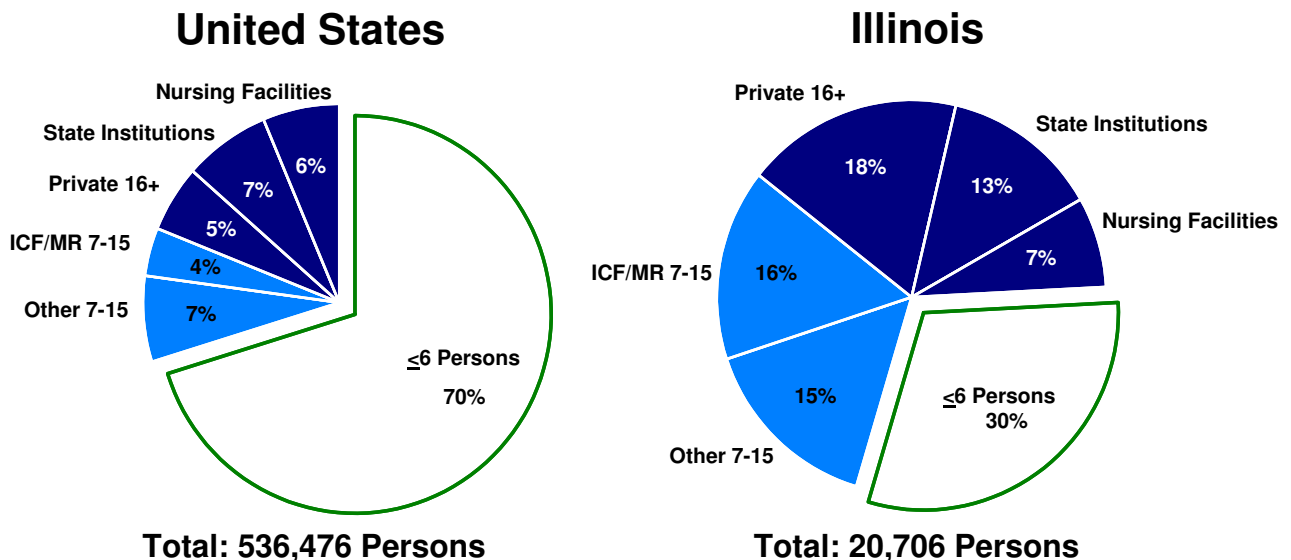
These recommendations are consistent with recommendations from the Illinois Council on Developmental Disabilities’ *Blueprint for System Redesign*. The *Blueprint* provides 16 action steps including steps to reduce reliance on large congregate settings in favor of more integrated settings and steps to build capacity in the community to support people with all levels of need.

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**With your help, we can make Illinois a better place to live for people with disabilities. We don’t have to be 51<sup>st</sup>!**

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**Persons with Intellectual and Developmental Disabilities Served by Setting in 2006**



Source: Braddock, Hemp, & Rizzolo (2008). *The State of the States in Developmental Disabilities*. Coleman Institute and Department of Psychiatry, University of Colorado.

## Spending Time with Family - Just a Regular Day...Or is it?



*Lester Pritchard,  
Chairman, Illinois Council  
on Developmental  
Disabilities*

Tim is 34 years old. Like most American men, he loves to eat. Pizza and McDonald's are his favorites. He's addicted to computer games, but also enjoys playing catch and being outdoors. He likes to play pool with his father and worships the ground his sister walks upon.

Daniel is 23 years old. He also likes to eat, and his favorite

foods include Subway, pizza and chocolate milk. Like Tim, Daniel enjoys spending time with family.

Daniel and Tim have two other things in common. They both have significant developmental disabilities, and despite their wishes and those of their families, both Daniel and Tim reside in state-supported institutions that are miles away from family and friends. On occasion, their families are able to finagle a home visit, but these occur all too infrequently.

Unfortunately, stories like these are common in Illinois. According to a report recently released by the Illinois Council on Developmental Disabilities (ICDD), our state [...] lags behind nearly every other state in its spending on community home services that would allow individuals like Tim and Daniel to live at home. The new *Blueprint* reveals that our state institutionalizes more people with DD than any other state in the nation. Rather than providing efficient, flexible and individually tailored assistance to people with DD, Illinois spends its money on outdated institutions that cost taxpayers more than twice as much per person than if quality community home services were made available to them.

[...] The *Blueprint for System Redesign in Illinois* identifies these and other key issues and offers an action plan that can be executed statewide over a seven-year period. This plan allows the State to

strengthen its community services system by adequately funding these services, expanding community home services, improving certain infrastructures and implementing budget allocation practices that focus on the actual need of individuals.

The most important steps to redesigning the current system for thousands of citizens with DD in Illinois are:

1. **Eliminate the wait list** of more than 11,000 people by 2014 and support 2,500 additional individuals annually.
2. Shift current state services to improve and **expand community home supports** so individuals have the choice either to stay at home with their families or live in the community with necessary supports. Community-based living has been shown to provide more individualized, efficient and cost-effective service and can allow Illinois to serve thousands more individuals.
3. **Allow 1,200 people living in state operated institutions to move back to their communities** by 2014. This also would enable five of the nine state-run institutions in Illinois to close. The tens of millions of taxpayer dollars the State spends annually to operate them could then be reallocated to improve and expand community home services.

The *Blueprint* gives the State a feasible and well thought out plan to update its support system for its citizens with DD. But it is more than just a report about government and mechanisms of care. It represents the way forward, toward freedom for thousands of people with developmental disabilities in Illinois like Tim and Daniel.

For more information about the ICDD, please visit [www.state.il.us/agency/icdd/](http://www.state.il.us/agency/icdd/) or call 312.814.2080

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**The Blueprint tells us how to do it. Now the question becomes – do our state's public officials have the will to implement it?**

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## Illinois' Priorities Askew!



*An excerpt from the testimony of Cheryl Jansen, Equip for Equality*

Equip for Equality (EFE), the Protection and Advocacy (P&A) agency for Illinois, commends the Illinois Council on Developmental Disabilities for undertaking a project resulting in a thoughtful and comprehensive plan to address the considerable gaps and deficiencies in Illinois' service system for people with developmental disabilities: *Blueprint for System Redesign in Illinois*.

Over the last few decades there has been a strong and consistent national movement and policy shift toward increasing community integration for people with disabilities.

However, Illinois has not kept pace with this trend on a number of fronts:

1. With only a slight increase in spending on community services, Illinois remains one of the most highly institutionalized states in the nation;
2. The amount Illinois spends on services for people with DD is consistently below the national average; and
3. A disproportionate amount of the money Illinois does spend on DD services goes to support people in larger facilities, such as state-operated developmental centers (SODCs). [...]

Simply put, Illinois has not made funding of community resources for people with developmental (and other)

disabilities a priority. Due to the inadequate funding of community supports and services, many of those who choose to live in the community have very limited residential options available to them. Most states have decreased their dependence on large congregate care facilities - even states that are less affluent than Illinois - and some have completely eliminated them [...]. Through the building, support and oversight of strong community provider networks, these states have successfully transitioned people from institutional life to community living.

In large part the success in other states is attributable to providing the services necessary to meet the unique needs of every person, utilizing a person-centered planning approach. Personalized planning addresses how each person wants to live, where and with whom to live, how each person spends his or her time, and what supports a person will need in order to have a satisfying life. Illinois has relied primarily upon a "medical model" of providing "treatment" to people with DD, rather than focusing on developing resources and supports based on individual choices and needs.

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**Simply put, Illinois has not made funding of community resources for people with developmental (and other) disabilities a priority.**

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People with DD, including those with severe disabilities, are capable of living in the community with supports and services. [...]

Because of Illinois' historic institutional bias, this can only be done if better and more community-based services are created and adequately funded with proper oversight. Once the commitment is made to serve everyone who chooses to live in the community, the system can pursue multiple strategies and focus on achieving fair and equitable supports. [...] If the funding is available, the supports can be put together – almost anywhere, anytime. But the will to make it happen is critical. [...]

For all of the foregoing reasons, Equip for Equality supports the goals and intent of the *Blueprint for System Redesign in Illinois*.

For more information about the EFE, please visit [www.equipforequality.org](http://www.equipforequality.org) or call 800.537.2632

# International Perspectives: Disability in the Netherlands



In the Netherlands, the “heart of the policy” for people with disabilities or chronic illness is the acknowledgment that they are full citizens with the same rights and obligations as all other citizens. However, in reality people with disabilities often find themselves disadvantaged in society. In the last five years, much legislation has been passed regarding disability in Dutch society. Most recently, the Dutch government signed the UN Convention on the Rights of Persons with Disabilities; however, they have not yet ratified it. Consequently, a conglomerate of advocacy organizations for people with disabilities (De Chronisch Zieken en Gehandicapten Raad Nederland) is fiercely lobbying for its ratification.

Visiting from the Netherlands, I am experiencing life in a different academic setting and society; enriching my knowledge across many domains. I received a scholarship from the Dutch VSBfonds to be able to participate in the research at the Rehabilitation Research and Training Center on Aging with Developmental Disabilities, Institute on Disability and Human Development. I am grateful for the wonderful opportunities the Institute has granted me.

I received a Master’s degree in Psychology at the Radboud University Nijmegen with a specialization in gerontology, focusing on the social relations of aging adults with intellectual and developmental disabilities (I/DD). For me the qualitative part of my thesis was especially valuable, in which the adults told me about their experiences.

Through my work as a psychologist in a center for people with I/DD, I gained valuable experience that benefited my personal and professional development. This also provided me an emic perspective of the healthcare system.

In observing differences between American and Dutch cultures, particularly concerning healthcare and welfare policy, my perspective on Dutch society has broadened and changed.

In the Netherlands people with disabilities have an enforceable right to care. Due to the aging population, changes in healthcare have been made to maintain a cost-effective system. Under the new Health Insurance Act (Zorgverzekeringswet), health insurance is obligatory and affordable for all citizens. Private companies in this sector are required by law to accept every resident. Under the Social Support Act (Wet Maatschappelijke Ondersteuning, Wmo) communities are legally obliged to provide care services for the elderly and disabled: transport, wheelchairs and special facilities in houses. Through the Exceptional Medical Expenses Act (EMEA or AWBZ) long-term care is ensured and paid for people who need it. Furthermore, clients have the choice of receiving entitlement via care through an agency or in the form of a personal care budget. Personal contribution to care is a nominal percentage of personal income dependent on the client’s age, taxable income, and domestic circumstances. The intention of these policies is to create an extramural system of long-term care and support that will allow people to continue to live independently in their own communities as long as possible.

For more information, please contact:  
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E-mail: [write2lieke@hotmail.com](mailto:write2lieke@hotmail.com)

# Our DSPs Rock!

As Alex opens the door, she smiles with anticipation. The house is quiet and she begins her work of cleaning the kitchen and doing laundry. Then, the house becomes filled with life as Sandra, Kathy, Francine and Angela arrive home from work. Alex says, "I've been supporting these women for the past two years and I really enjoy my job. It's not always easy and the pay isn't much, but I really love these ladies." In Alex's role as a direct support professional (DSP), she helps four women with developmental disabilities (DD) that live together in a community home. Alex provides assistance to the women as they make dinner, go shopping, make plans with friends and family, get ready for bed, clean their apartment, balance their

**The relationships I've developed with these women keep me motivated to continue in this line of work. These women teach me every day.**

checkbooks, and much more. She juggles the unique needs of each woman to provide support so they can be as independent as possible. Alex describes the work she does: "I help Sandra and Francine in the bathroom which has really tested me but we have developed a level of trust doing such intimate work. Sometimes the women can get upset and it is my job to calm them down. The job is not easy and the role is varied. The relationships I've developed with these women keep me motivated to continue in this line of work. These women teach me every day."

People like Alex are important to the lives of people with DD. However, there is a critical shortage of qualified DSPs in Illinois and across the nation. Illinois has been addressing these challenges over the past four years through the DSP Workforce Initiative, which began in 2004 with an investment from the Illinois Council on Developmental Disabilities. Our project partners included The Minnesota University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) and The Human Services Research Institute (HSRI).

One exciting outcome of the Initiative has been the creation of a professional association run by and for DSPs. The Illinois Direct Support Professionals (IDSP), believe:

- DSP's, consumers, and employers must work together to win changes that make sense for all those who provide and receive services.
- in the right of all consumers to receive quality long term support in their own home.
- in quality jobs for DSP's that include a living wage, benefits, training, and respectful working conditions.
- that the current long term care system is irrational, under funded, and must be changed.
- that the fulfillment of these principles will create a stable DSP workforce that is essential to providing quality services.

For more information about the IDSP, please visit [www.idspros.org](http://www.idspros.org).

**Illinois Direct Support Professional Workforce Initiative**



*A Partnership of the University of Minnesota's Institute on Community Integration, the Institute on Disability and Human Development at the University of Illinois at Chicago, and the Human Services Research Institute. Supported by the Illinois Council on Developmental Disabilities.*

# Promoting Cultural Competence

Many community-based organizations, centers for independent living and state vocational rehabilitation (VR) agencies provide supportive services to individuals with disabilities and their families. Yet, over the past several decades, research has shown that many individuals with disabilities, in particular those from ethnic minority groups, are less likely to access services and when they do, they are less likely to achieve positive outcomes. The *Center for Capacity Building on Minorities with Disabilities Research* (the Center) at IDHD uses an alternate approach, grounded in the belief that service system changes are needed to improve access to services for people with disabilities from diverse cultural backgrounds.

In the fall of 2004, the Center was funded by the National Institute on Disability and Rehabilitation Research (NIDRR) of the U.S. Department of Education. The Center supports research studies, program evaluation, training and dissemination efforts nationally—all aimed at improving services for people with disabilities from underrepresented groups.

Among other projects, the Center has a program evaluation/capacity building project that actively involves consumers and agency staff in the process of identifying service needs, selecting program goals, and implementing and evaluating change efforts to improve services. Since 2004, Center staff has partnered with over 30 organizations to evaluate their programs. The

Center trains and guides staff at each organization so that they may build evaluation into their day-to-day activities in order to improve the effectiveness of their services.

The Center also provides cultural competence training workshops to interested community-based organizations and VR offices around the country. During the trainings, organizations set goals to improve some aspect of cultural competence in their organization and Center staff provides monthly follow-along consultation to promote their attainment of organizational goals. Currently, the Center is working with the Division of Rehabilitation Services (DRS) of the Illinois Department of Human Services to train all of the rehabilitation counselors in the state of Illinois in cultural competence. Center staff is also working to create an online cultural competence training program that will be used by different state agencies in Illinois, including the Illinois Department of Human Services.

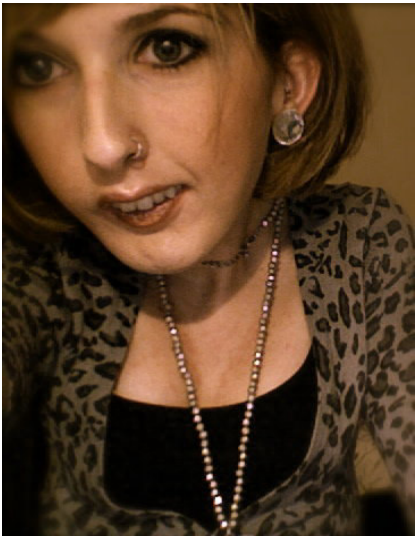
For more information please visit our website at [www.disabilityempowerment.org](http://www.disabilityempowerment.org) or call 312.413.1806 or 312.413.0453 (TDD).

Tina Taylor-Ritzler, PhD, Fabricio Balcazar, PhD, Institute on Disability and Human Development, and Yolanda Suarez-Balcazar, PhD, Department of Occupational Therapy University of Illinois at Chicago



Center for Capacity Building Team

# Personal Assistance: Empowering Independence



Until my freshman year of college I used my mother for all of my personal care, which is typical of many children with disabilities. Like all teens, by the end of my senior year of high school, I was ready to enter a new chapter of my life and become independent.

Independence has always been an ironic subject for me because in order to be independent, I depend on the help of others. I attended the University of Illinois at Urbana-Champaign (UIUC)

for my undergraduate degree, and there I was introduced to using personal assistants (PAs) for my activities of daily living. I soon learned that, for me, being independent meant I had control of who I wanted to be my PAs, and I had the ability to schedule my personal assistance to fit my own needs. Having this control was a very liberating experience for me.

I would say I was spoiled by my experience at UIUC. I lived at Beckwith Hall, a dorm for students with disabilities. I was given five hours a day for my personal care, they had meal assistants, and a 24-7 position called a Floater who was there to assist with small needs and emergency needs, for example, if your personal assistant did not show up for a shift. I felt safe at Beckwith Hall and I could have easily stayed there for graduate school, but I yearned to explore my independence and I set out to attend a school that did not have a personal assistance system like UIUC.

Following my desire to explore careers in the disability field, I chose the University of Illinois at Chicago (UIC). I was drawn to the school by its Disability and Human Development program, and, of course, the excitement

of the city. I immediately fell in love with the school, program, and city, but gaining my independence here became one of my life's biggest challenges. I was introduced to Home Services, a program run by the Illinois Department of Human Services that provides funding that enables me to pay PAs that I hire. Although I am grateful there is a program in Illinois that helps me pay for personal assistance, the program's policies have become a significant stressor in my life and could use many improvements.

One of Home Services' biggest problems is the rate of pay for PAs. A PA is only paid \$9.85 per hour. This payment becomes a barrier; it is hard to find quality people to work for this amount of money. These people are responsible for your everyday needs and

essential components of your quality of life. We need to fight for higher pay for our personal assistants. This will legitimize the job and make it easier to find quality help.

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**We need to fight for higher  
pay for our personal  
assistants.**

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Although I believe there should be many changes made to personal assistance policies, I have had many positive experiences with using personal assistance. Personal assistance is the key to independent living and improving programs for customers and employees will ensure that this service is available to everyone seeking independence. My experience has helped me be active in my own community to help bring personal assistance programs to UIC. As the Community Access Consultant at UIC's Disability Resource Center, I hope to set up a personal assistant pool for students to hire from and to train students on independent living skills. Having these programs at universities will enable students to choose among universities and empower students to seek and be successful in their independence.

Anne Hopkins, MS student, DHD

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**Personal Assistance  
is the key to independent living.**

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# IDHD Family Clinics Promote Healthy Sexuality

“I’d do it! I’d give her the \$10 and get it going!”

As group facilitators for a dating skills group, this was not the response we had hoped for when asking the group how to best handle someone offering them sex for money. We were using the time-honored group-work techniques of creating group dialogue and processing and assumed participants would give the “right” answer...if such a thing exists.

“Well...” I stammered, momentarily off-balance, my mind racing to find that perfect response, when a 19 year old female group member came to my rescue. “Prostitution is bad because it can make women feel bad about themselves and its illegal!”

“Thank you, Delilah – that is very true.”

We were on week four of our six week adventure as second year social work students facilitating a socio-sexual skills building group for individuals with developmental disabilities (DD). The topic was “resisting persuasion” and our goal was to teach skills for handling situations where members are being pressured into doing something unsafe, that would get them into trouble, or that goes against their values. We were once again confronted with the difficulty teaching socio-sexual competence without imposing our personal values. Even for two students trained in the social work principle of client self-determination, our group members’ real-life experiences often put those values to the test. There is an inherent tension between supporting a client’s right to self-determination while upholding an ideal of professional responsibility. We found our role was to provide resources in order to help group members make informed decisions and understand the potential consequences of their actions.

At the beginning of the semester, we had been initiated into the complex terrain of sexuality at a workshop on “Promoting Healthy Sexuality in Persons with Developmental Disabilities,” sponsored by IDHD and Arts of Life. The workshop had a heavy focus on the prevention of sexual abuse – a significant issue among



*Peggy Best and Eric Brooks during their UIC Jane Addams School of Social Work MSW internship at IDHD*

people with disabilities. This distressing fact was sadly brought to life for us in the shared experiences of our group members. Out of six members, four reported incidents of past sexual abuse. While helpful, a day-long seminar could only lay the groundwork for what we were to experience in the weeks to come.

Clearly, supporting our group members in making choices that help keep them safe had to be a focus of the group. Program developers of the curriculum we used – Mueser, Valenti-Hein, and Yarnold (1987), created a curriculum which balanced the need for teaching safety with respect for the rights of individuals with DD to pursue relationships. Often the need for safety is used as an excuse to deny people with DD access to information about intimacy and sex. This denies them the freedom and opportunity to explore this fundamental aspect of their humanity. One potential group-member was prevented from joining the group by her guardian – a well-meaning grandmother, who balked when she found that the group was taking an inclusive perspective on sexual education as opposed to an abstinence-only approach.

Once a person has the information they need to pursue a romantic and possible sexual relationship, the issue of access comes to the fore. There are often few

opportunities for individuals with DD to put these skills into practice. When being constantly monitored and having time managed by guardians and service providers, when and how does a person develop a relationship? This fundamental right needs to become a priority of those who support people with DD if we are to truly say we care about their quality of life. Our group members brought with them a wealth of life-experiences and were constantly teaching us and each other. While we had the manual in our hands, the group members were the true experts on their experiences.

For more information on *The Dating Skills* group, please contact:

Linda Sandman, MSW, LCSW,

Institute on Disability and Human Development

email: [lsandman@uic.edu](mailto:lsandman@uic.edu), phone: 312.413.1640

## Money Follows the Person



Beginning April 1, 2008, the Illinois Department of Healthcare and Family Services (HFS, Medicaid agency) has contracted with the Institute on Disability and Human Development (IDHD) for consultation services. Paul

Bennett (IDHD) will be assisting HFS in developing and implementing the federal *Money Follows the Person* (MFP) initiative in Illinois. Under this initiative, the following persons will be given an opportunity to transition to community residency:

- older adults with physical or cognitive disabilities,
- adults under the age of 60 with physical and/or intellectual disabilities, or
- adults with a mental illness receiving Medicaid and living in a long-term care facility for a minimum of six months.

MFP has four primary goals. These goals are:

- Increase use of home and community-based services rather than nursing home care.
- Eliminate barriers that prevent Medicaid eligible persons from receiving support in settings that they would prefer.
- Increase participant's ability to continue the appropriate level of services for those that choose to live in the community.
- Ensure that services are monitored for quality and continue to improve.

In addition to assisting participants with transitioning to community residency, many participants will be eligible for a one-time assistance grant for such things as security deposits and other expenses necessary for setting up a household. Participants will be transitioned to private homes, apartments, group living situations and supportive living environments.

IDHD previously produced a report under the federal CMS Systems Change grant with the Illinois Department on Aging. This report was used by HFS to secure Medicaid reimbursement for eligible MFP participants up to \$55 million over the next five years.

Paul H. Bennett, Senior Resource & Policy Analyst, IDHD

For more information, please email Paul Bennett at [pbennett@uic.edu](mailto:pbennett@uic.edu) or call 312.413.1294

# The Art of Ability



Gustave Caillebotte (French, 1848-1894), *Paris Street; Rainy Day*, 1877. Oil on Canvas.

Charles H. and Mary F. S.  
Worcester Collection, 1964.336.

*"...this is not about visual acuity, but how you see what you see [how you perceive things around you]"*  
- Workshop participant



Auguste Rodin (French, 1840-1917), *Adam*, model c.1881.

Bronze, dark brown patina. Gift of Robert Allerton, 1924.4.

The workshop was developed:

- to foster an environment for participants from different and unique backgrounds to enhance their creative thinking and self-exploration through art, and
- for individuals to learn from others and to learn about and re-evaluate their views of disability, social work, and art.

On an early Saturday morning, long before its opening and the arrival of tourists, we entered the Art Institute of Chicago. Inside the empty building, a hushed cathedral-like presence encouraged whispering and bounced our voices off the walls.

The Art-Ability workshop, using art to describe and understand disability, was now ready for a test run after weeks of planning. I stood in the lobby of the empty museum along with the IDHD and Art Institute Education teams and students from the UIC Departments of Social Work and Disability and Human Development. All were ready to learn about art and how disability can be perceived through the work of great artists. That was our purpose -- to 'see' disability through the lens of art.

Our first stop was in front of the painting "Paris Street: Rainy Day" by Gustave Caillebotte. At first glance the painting depicts a street with people walking in the rain. Sarah Alvarez of the Art Institute asked us to share what we saw. I was drawn to the building on the left side of the painting, while another participant focused on the lamppost in the middle. We were encouraged to come closer to the painting to see more detail. Sarah guided us to recognize the beauty of details such as the rain on the cobblestone. We then explored the composition of the painting and tried to make sense of what the artist was communicating to us. We saw the lamppost that cuts the scene in half with a couple on the right close and in focus and people on the left smaller and less detailed. We talked about this imbalance as a power differential and linked it to the position that disabled people are occupying in society.

In addition to paintings we explored several sculptures. One of the sculptures portrayed a male with a very fit body, perfectly defined muscles and a beautiful face, yet he held his head as if in shame. We were divided into four groups. It was interesting to note how each group interpreted and had different perspectives on the same sculpture. We discussed the contradiction of his physical look and his body language. This experience made me think of how disabled people position themselves towards the concepts of beauty, health and shame.

In the afternoon we dedicated more time to open discussion, further exploration of the morning art pieces and connected our art experiences to our understanding of disability. We acted out scenarios about disability that were created to match the relationships that we had observed in the artwork. Surprisingly, 3:30 pm came too quickly for many of us as we wanted to discuss more. One workshop participant said that he felt more comfortable working with disabled people after the experience, while another concluded "I can look at art in a new way - bridging disability perspectives with it."

Carlos Clarke Drazen, PhD student, DHD

For more information please email IDHD at [idhd@uic.edu](mailto:idhd@uic.edu) or call 312. 413.8833

# IDHD Awarded \$4.25 Million for Aging and DD Research Center

The Institute on Disability and Human Development will receive \$4.25 million from the National Institute on Disability and Rehabilitation Research to study lifespan health and functions of individuals with intellectual and developmental disabilities (I/DD).

The five-year award extends research at UIC's Rehabilitation Research and Training Center on Aging with Developmental Disabilities directed by Tamar Heller, professor and head of the Department of Disability and Human Development.

"It builds on prior accomplishments, but takes a lifespan approach, starting with early adulthood through old age," said Heller. "Health and function in later life depends on life-long health behavior and environmental influences. Most of the center's research targets adults with developmental disabilities (DD), due to the great need to develop model programs to support these individuals and their families."

Research will focus on age-related health changes among adults with neurodevelopmental conditions such as autism, spina bifida, cerebral palsy and syndromes such as Fragile X, Prader Willi, Williams and Down syndrome.

Projects will include, among others, studying the impact of behavior patterns on health and function; developing interventions to prevent falls and aide walking; and testing of various approaches to community-based health promotion. Other studies will examine ways to promote the health of family caregivers and to help individuals and families direct their own supports.

Project partners include Special Olympics International, which will provide matching funds for a longitudinal study of health behavior using extensive data collected on athletes with intellectual and developmental disabilities, and Easter Seals, which will provide sites around the nation for environmental interventions to improve health and increase community participation among adults with intellectual and developmental disabilities.

"Most people with these types of disabilities have a life-long need for support and live with their families," said Heller, "these individuals are more likely to experience poorer health and have limited access to quality health care and promotion programs. As persons with DD age, an urgent need exists for them to have access to quality supports that address their age-related health and social changes."

The 10-year-old Center's work includes providing an information clearinghouse for the public on disability issues. An interdisciplinary team of scholars and professional researchers participate in the Center's work. Key principal investigators include Beth Marks, James Rimmer, Kelly Hsieh, Glenn Fujiura, and Matthew Janicki, IDHD; Joy Hammel, Occupational Therapy, UIC, Sandra Magana, University of Wisconsin-Madison, and Phil Davidson, University of Rochester.

For more information on the Rehabilitation Research and Training Center on Aging with DD and to learn about its programs, please visit [www.rtcadd.org](http://www.rtcadd.org), or call 800.996.8845.



National Family Caregiving Awardees

The Rehabilitation Research and Training Center on Aging with DD was awarded a 2008 National Family Caregiving Award, sponsored by the National Alliance for Caregiving and MetLife Foundation. A \$5,000 seed grant was established to recognize their *The Future is Now!* curriculum, a peer support educational intervention to support aging caregivers and adults with developmental disabilities in planning for the future.

# Uncovering Abuse and Neglect: Interning with Equip for Equality



While pursuing a master's degree in Disability and Human Development (DHD) and working as a graduate assistant at the Institute on Disability and Human Development (IDHD), I was given the opportunity to participate in an internship with one of IDHD's sister agencies, Equip for Equality (EFE).

As the Protection and Advocacy (P&A) agency for Illinois, EFE offers self-advocacy assistance, legal services, and disability rights education. These services are provided through their five major programs which include the Legal Advocacy Program, Training Institute on Disability Rights, Public Policy Program, Abuse Investigation Unit, and Special Education Clinic/Helpline.

My internship at EFE was with the Abuse Investigation Unit (AIU), whose mission is to prevent abuse, neglect, and deaths of individuals with disabilities receiving services in any setting including community-based facilities and programs, nursing

homes, hospitals, and state-run mental health and developmental disability facilities. AIU carries out its mission by providing information to individuals who call in to report possible abuse or neglect, assisting them to become self-advocates. When providing self-advocacy information is not enough, EFE may step in and act in conjunction with the individual to assure their safety. In addition, AIU uses its broad federal and state statutory authority to review investigative reports and other documents prepared by state agencies and private facilities. Its authority also allows them to enter private and public facilities on an unannounced basis in order to review records, observe conditions first-hand, and conduct direct investigations on both individual and systemic issues.

My internship at Equip for Equality has been a rewarding learning experience. I have learned first hand how state P&A agencies operate, their investigatory function, and their role in disability advocacy. I have also learned a great deal about the service delivery system in Illinois. The experience, most importantly, has given me the privilege of personally assisting individuals in becoming empowered self-advocates.

Kelly Koomler, MS student, DHD

## Alumni News: Where Are They Now?

Noam Ostrander (PhD, 2006) is currently an Assistant Professor at DePaul University's Social Work program. Throughout his courses, which range from human behavior to social policy, he infuses disability perspectives to inform his students' future work in non-profit and government organizations. Since being at DePaul, Noam has developed new Disability Studies courses and is currently exploring ways to create a Disability Studies certificate program at the University.

Noam's research focus on disability, gender and sexuality builds from his dissertation work with current and former gang members who had been shot and paralyzed. Articles from this research have been published in *Disability and Society* as well as the *Child and Adolescent Social Work Journal*. His most recent project explores sexual knowledge and behaviors of youth with disabilities compared to their non-disabled peers. The results of this work should provide

awareness to members of social institutions and health care providers to include youth with disabilities in discussions about sexuality and sexual health. In addition to this research and other publications, Noam—along with fellow DHD alum, Bruce Henderson—recently edited a special double-issue of *Text and Performance Quarterly* on disability and performance.

Finally, Noam was recently elected president for the Society of Disability Studies (SDS). This organization brings together disability scholars, activists, and artists to explore and expose intersections of disability within society and culture. Noam joins a short list of individuals, including some UIC faculty, who have led SDS over the past few decades. Bruce Henderson, DHD alumni, will serve as secretary of SDS.

Noam Ostrander, PhD, LCSW

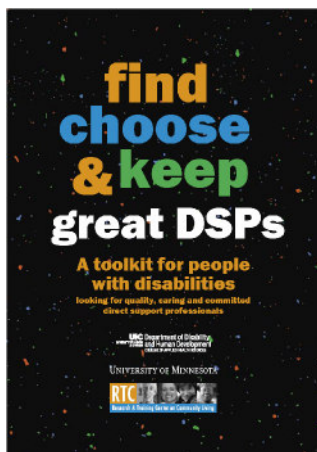
# Martha and Robert Perske Make Generous Donation to IDHD!



Drawing by Martha Perske

IDHD recently received a donation from Robert and Martha Perske of 10 beautiful signed art prints drawn by Martha that were rendered by the late Georgia O'Keefe's printmaker. They will be displayed throughout the DHD Braddock Library on Disability and the DHD student lounge. We are thrilled to be the curators of these seminal works.

## Finding and Keeping Great DSPs



The “**Find, Choose, and Keep Great DSPs: A Toolkit for people with disabilities and families**” is designed to provide easy-to-use tips and strategies to find, choose, and keep high quality direct support professionals (DSPs - also called personal assistants, home care workers, etc.). There are two versions of this toolkit (1) for people with disabilities and (2) for their family members and supporters. The Toolkits were created through the DSP Initiative by IDHD and the Institute on Community Integration in Minnesota. Development of the Toolkits incorporated people with disabilities and family members in every aspect of the process to ensure they are relevant and accessible for people with a wide range of disabilities. Customized training can also be provided along with the Toolkits. The Toolkit can be downloaded for free at [www.ildspinitiative.com](http://www.ildspinitiative.com) or a hardcopy can be ordered from Katie Keiling at 312.996.1002.

## The 2nd Annual Meeting of The Sibling Leadership Network

November 6-7, 2008 Columbus, Ohio.  
For more details visit [www.siblingsupport.org](http://www.siblingsupport.org)  
or call Katie Keiling at 312.996.1002.

Hosted by: The Nisonger Center at The Ohio State University, the Rehabilitation Research and Training Center on Aging with Developmental Disabilities: Lifespan Health and Function, Sibling Support Project, and Vanderbilt Kennedy Center for Excellence in Developmental Disabilities



## Awards

- John Kramer, PhD student, was awarded the 2007 Anne Rudigier Award by the AUCD.
- Jessica Kramer & Edurne Garcia, PhD students, were both awarded the Dean's Scholar Award in April 2007.
- Vladimir Cuk, PhD student, was awarded the 2008 Ann & Edward Page-El, M.D. Scholarship Award.
- Elizabeth Lockwood, PhD student, was awarded the Inter-American Foundation's Grassroots Development Fellowship, which will fund her dissertation research on the grassroots activism of the Deaf Uruguayan community.
- Mansha Mirza, PhD student, was awarded the UIC Provost's Award in May 2008.
- Rahnee Patrick, Access Living staff and IDHD Advisory Committee member, received the 2008 Paul G. Hearne/American Association of People with Disabilities Leadership Award.
- IDHD was awarded the Partnership Award from Community Support Services in November 2007.
- Tamar Heller was selected for the Lifetime Research Award from the Special Interest Research Group on Aging of the International Association for the Scientific Study of Intellectual Disabilities (She received her award in Capetown, South Africa in August).
- Beth Marks, Research Assistant Professor, received a grant from NorthPoint Resources to fund a Health and Wellness Capacity Building Project.
- Sheila Swann-Guerrero & Amy Rauworth, NCPAD, were awarded two grants, the Walk/Roll School Pilot Program and Inclusion of Children with Disabilities in Safe Routes To Schools, by the Illinois Department of Transportation.
- Kiyoshi Yamaki, Research Assistant Professor, was awarded a grant from the Illinois Department of Public Health for a State Implementation Project to Prevent Secondary Conditions and Promote the Health of People with Disabilities.
- James Rimmer, Professor, was awarded a grant from NIDRR for a Rehabilitation Engineering Research Center on Recreational Technologies and Exercise Physiology Benefiting Persons with Disabilities.
- Elina Manghi and Lorna Sanchez, Family Clinic, were awarded a grant from the Daniel Jordan Fiddle Foundation to fund their Grupo SALTO arts recreation program.
- Fabricio Balcazar, Professor, was funded by the Department of Human Services (DHS) to provide a web-based cultural competence training program for over 60,000 state employees from 10 state agencies.

## Grants

- IDHD received 5 more years of funding from the Administration on Developmental Disabilities (ADD) to serve as the University Center for Excellence in Developmental Disabilities for the State of Illinois.
- The National Center on Physical Activity and Disability (NCPAD) was awarded a \$3.5 million renewal grant from the Center on Disease Control and Prevention (CDC).
- Jennifer Rowland, Assistant Professor, was awarded a grant "Video Gaming Technology to Promote Health and Fitness Among Adolescents with Disabilities" by the National Institute on Disability and Rehabilitation Research (NIDRR).
- Tamar Heller, Director, was awarded a grant by Special Olympics International in June 2008 for a Research Collaboration Center.

## Media

- Mary Rizzolo, Associate Director, was interviewed in a CBS2 story "What Happened To Brian?" CBS2 exposed allegations of abuse at Kiley Developmental Center. The piece can be viewed at <http://cbs2chicago.com/local/what.happened.brian.2.741753.html> A report by Equip for Equality examines the death of Brian Kent as well as 21 individuals at Howe Developmental Center. The report is available online <http://www.equipforequality.org/news/state-operated-dev-disability-institutions.php>
- James Rimmer, Professor, was quoted in an October 2007 article appearing in *Education Week*, titled "Disabilities Seen Complicating Anti-Obesity Efforts."

- David Braddock, Professor Emeritus, and past IDHD Director, was cited in a story in the *Chicago Tribune* headlined: “‘An Incredibly Bleak Picture’ — As Developmentally Disabled Baby Boomers Live Longer, their Long-term Care Becomes a Burden for their Aging Family Members” in September 2007.
- James Rimmer, Professor, was quoted in an Associated Press article on problems people with disabilities face staying fit, carried by *the New York Times* and *Washington Post* in April 2007.
- Glenn Fujiura, Associate Professor, Director of Graduate Studies, was quoted in a *Daily Herald* article on a campaign to help people with disabilities find jobs in November 2007.
- Matthew Janicki, Associate Director for Technical Assistance, RRTC, was quoted in an April 2008 article in the *Seattle Times* on aging parent caregivers of persons with developmental disabilities.
- Ann Cutler, Clinical Assistant Professor, was appointed to the *Illinois Chapter of American Academy of Pediatrics’* executive committee.
- Robin Jones, Director, Great Lakes ADA Center, was appointed to the *Chicago 2016 Committee*, to help develop Chicago’s bid to host the 2016 Olympic and Paralympic games.
- James Rimmer, Professor was elected chair of the *American Public Health Association Disability Section*. Jennifer Rowland was re-elected Secretary of the *American Public Health Association Disability Section*.
- James Rimmer, Professor, was elected as a Fellow to the *American Academy of Kinesiology and Physical Education*.
- Tia Nelis, Self-Advocacy Specialist, was appointed Vice-President of *Self Advocates Becoming Empowered (SABE)*
- Lennard Davis, Professor, had an essay featured in the June 2008 *Chronicle of Higher Education* titled “Where Did I Put My ‘Foucault’?”
- Mansha Mirza, PhD student, co-authored an article in the Spring 2008 edition of *Disability and Society*, on participatory action research for people with psychiatric disabilities.
- Eunjung Kim, alumni, co-authored an article on disability and sexuality in the Spring 2008 *Canadian Journal of Film Studies*.

## Honors

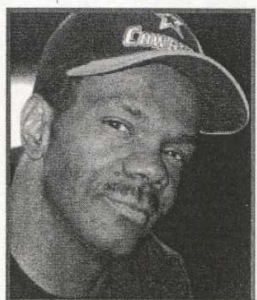
- Tamar Heller, Director, was named President-elect for the *Association of University Centers on Disability (AUCD)* in June 2008.
- In March 2008, Fabricio Balcazar, Professor, was invited to help the community of Juanacatlan (Jalisco, Mexico) to develop an agenda for community improvement.

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## IDHD welcomes two new Advisory Committee members!

- **Marty Fox** is a self advocate and member of the Self Advocacy Council of Northern IL.
- **Tara Kosieniak** is a sibling of a brother with developmental disabilities and works as an Individual Service Coordinator.

## In Memory of Our Friend David Wricks



David Wricks

“I would like to say a few words about our friend David, who was a strong leader in the self-advocacy movement. He would always come to our meetings with a smile and a kind word. He would listen and support people to speak out and people would learn from him. He was there to talk about things that were important for the group. Even when he was not feeling well, he was there for people he cared about and loved. At our meetings, he would help in any way he could. People loved hanging out with him and learning from him. David was involved in many different groups, boards, and committees. He helped people with disabilities make this world a better place. David helped so many people to grow strong and to find their voice. We will all miss him. He was not only a friend but a family member to the People First of Illinois. We loved him and we know that he will always be in our hearts. We will miss you David. Thank you for all your hard work and for making us stronger.”

Tia Nelis

**Institute on Disability and Human Development (MC 626)**

1640 West Roosevelt Road, Room 245

Chicago, IL 60608

## Support IDHD/DHD

Your contributions can help promote the mission of the Institute on Disability and Human Development. Opportunities for giving include the following examples:

- Supporting the Ann & Edward Page EI MD Scholarship Award for graduate students
- Advancing the use of computers by children with autism
- Promoting the participation of people with disabilities into their communities

**For more information on making a gift to IDHD please contact:**  
**Tamar Heller, PhD, Professor, Director / Head**  
**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](mailto:theller@uic.edu)**

**[www.idhd.org](http://www.idhd.org)**