

On Target

Informing Indiana About
Disability Issues

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About Disability Issues

On Target is a monthly publication of the Indiana Governor's Council for People with Disabilities.

We welcome your suggestions for newsletter content and ideas concerning the actions of the Council. *On Target* is made available in accessible formats upon request.

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Health care issues to dominate General Assembly and national agenda

Conference sessions discuss local, national issues

A major issue for the upcoming Indiana General Assembly and national congressional sessions is health care. This, and other local and national legislative issues, was discussed at two workshops during November's annual disability conference sponsored by the Governor's Council. Members of the workshop panels represented several organizations, including the Mental Health Association in Indiana, AARP, the Indiana Institute on Disability and Community, the American Association of People with Disabilities (AAPD), the Universal Health Care Action Network and several others.

In one of the workshops, Cathy Levine, J.D., executive director of the Universal Health Care Action Network in Ohio, shared a number of insights about fixing health care for Indiana and the United States. The presentation explained why there is a health care crisis in our country, as well as its extent. In Indiana alone, 860,000 Hoosiers are uninsured. A number of local and national initiatives are underway to address the crisis.

At the other workshop, members of the panel

stated that dramatic changes may occur in health care systems in the near future. States are trying to cover the uninsured, while health care is becoming unaffordable for even the middle class. One option for Indiana is to model the system used by Massachusetts. Their Medicaid program for the uninsured requires employers to pay into a state pool. Another option is to create a connector in private health care for people who find individual health care plans unaffordable.

This connector would allow individuals to join group health care plans, which are more affordable because of their purchasing power.

The following questions should be asked when looking at health care legislation:

- Is it affordable to individuals and society?
- Does it help control rising health care costs?
- Is there an adequate scope of coverage?
- Are the options portable/transferable if a person relocates?
- Is there access to quality care?
- Does the plan offer both preventive care and disease care?

Specific health care issues affecting people with disabilities that may be discussed during the legislature session include funding for long-term care, home- and community-based Medicaid waivers, Medicaid funding and the Hoosier Rx program. General long-term care reform may look at service needs and the limitations of adult foster care, as well as partnerships with area services for the aging.

Another health care option Levine proposed is that of a single-payer system, similar to Medicare. This system would eliminate private insurance companies from financing health care, but doesn't eliminate private providers. The

current Medicare system is a single-payer system with administrative costs between 2 and 3 percent, which is very low. Proponents of a single-payer system say the low administrative costs of a single-payer system could save \$350 billion per year in the United States, which is enough to cover all those who are uninsured.

Many states have movements for single-payer systems, including SPAN Ohio and Hoosiers for Commonsense Health Plan.

The speakers encouraged advocates to stay abreast of political issues by signing up for mailing lists for active Statehouse organizations and looking at active bills at www.in.gov/legislative.

Help shape the debate on health care in Indiana. Go to www.thepollingplace.org to take part in a health care survey. The Governor's Council, in conjunction with the Indiana Institute on Disability and Community and Indiana Protection and Advocacy Services, wants to hear from you about your experiences and opinions on the state of health care. Alternative formats are available by calling The Indiana Institute on Disability and Community at (812) 855-6508. Ask for The Center for Planning and Policy Studies.

UCP sponsors ATTITUDE essay contest

For the 12th year, United Cerebral Palsy (UCP) of Greater Indiana and the Governor's Council are sponsoring the ATTITUDE essay contest, which coincides with Disability Awareness Month in March.

Entrants are asked to do one of the following:

- Interview a child or adult with a disability and describe his or her experience with the attitudes of others.

- Read a book about people with disabilities and describe the impact of attitude on their lives.
- Write about their own observations or feelings about attitudes toward people with disabilities.

The contest has three divisions: third and fourth grades; fifth and sixth grades; and seventh and eighth grades.

Each student must submit only one entry with an entry form, and all submissions should be typed or legibly printed on 8.5" x 11" white paper and not exceed 500 words. Entries will not be returned and must be postmarked by March 2, 2007.

All entrants will receive a certificate of appreciation. First place winners will receive a certificate, an ATTITUDE bear and \$150. Second place winners will receive a certificate, an ATTITUDE bear and \$75. All winners are invited to an awards luncheon on March 30.

UCP encourages schools to participate in the essay contest and would be happy to give informational presentations on the subject. Teachers, school administrators or anyone else interested in more information can contact Donna Roberts at (317) 632-3561 (voice) or donnar@ucpaindy.org.

Adaptive sports offer recreation opportunities

Jon Minz is a marathon man. He participates in kayaking, snow skiing and sailing to help him stay in shape. The Ball State University junior who uses a wheelchair due to a spinal cord injury is also an active member of Community Health Network's adaptive sports program.

The goal of this unique program, according to Minz, is to adapt each activity for the individual, whether the person has a brain or spinal cord injury.

Five years ago, a handful of therapists from Hook Rehabilitation Services saw the need for a social organization for recreational sports. From this idea, the Community Health Network adaptive sports program was born. Community Hospitals Foundation provided a start-up grant of \$3,000 to purchase specialized equipment for paraplegic and quadriplegic athletes and to sponsor outings. As participation has grown, Community Hospitals Foundation has found more support through the Christopher Reeve Foundation and by working with local businesses.

The adaptive sports program now has a base group of about 200 people in Central Indiana. It sponsors two programs a month. One event is sports-oriented and the other is social. Sporting events range from horseback riding to hot-air ballooning, and social events include Pacers games and musical events. Both types of events are important and foster the independence and relationships the group is looking to offer.

Beth Edwards is a recreational therapist at Community Health Network and volunteers her time with the program. She describes watching the athletes fall in love with a new sport. "The first time I saw an athlete get out of his chair to snow ski brought tears to my eyes," said Edwards. "I work in this field - helping to rehabilitate patients daily - but I was blown away."

Minz participates in about four activities per year and plans to continue enjoying sports through his sports administration degree. He thinks the adaptive sports program is a great way to draw people out and get them engaged with the

activities they love.

If you are interested in participating in an adaptive sports program, please contact your local rehabilitative hospital.

Fort Wayne center receives national grant

In July, the Christopher Reeve Foundation awarded Fort Wayne's Turnstone Center for Disabled Children & Adults a \$10,000 Quality of Life Grant to be used for the center's ramp building program. For more than 15 years, the center has provided ramps at reduced cost to people with disabilities in Fort Wayne and surrounding Allen County.

After speaking in Fort Wayne, Dana Reeve, impressed with the center's generous ramp building program, urged the center to apply for a Quality of Life Grant which it received shortly after Dana passed away last March. These grants award projects seeking to better the quality of life for people living with paralysis. While Turnstone has received numerous local grants in the past, the Quality of Life grant is the first national grant the center has received.

With the help of hundreds of volunteers, the center has constructed more than 600 ramps for people with disabilities over the past 15 years. The ramps, which take a day to build and cost about \$850 each depending on income and need, are typically built by crews of 10 to 15 volunteers, and materials are organized and pre-cut ahead of time to ensure the ramp is finished in a day.

For volunteers, ramp building means allowing someone who eight hours earlier could not go outside on their own the opportunity to be free to go outside whenever they want. "It provides

them with freedom and independence," says Nancy Louraine, executive director for the Turnstone Center. "And that's what it's all about."

For more information on the Turnstone Center and their ramp-building program, call (260) 483-2100 (voice) or visit www.turnstone.org.

Healthy Hoosier Initiative results are in

The results of the Healthy Hoosier Initiative include interesting statistics on people with disabilities.

There are an estimated 877,000 people with disabilities in the state of Indiana. This represents about 19.2 percent of the total population. Of this number, about 379,000 are men and 498,000 are women.

Of people ages 18 to 44, 12.2 percent have a disability. In the age group 45 to 64, the number jumps to 24.8 percent. The highest percentage of people with disabilities is in the age group of 65 plus, which averages 31.3 percent of the population.

The health status of people with disabilities was also measured. Of those, 25.8 percent said they are in "excellent" health, 36 percent said they are in "good" health and 38.2 percent said they are in "poor" health. In terms of health coverage, 80.8 percent of people with a disability who are 18 to 44 have health care coverage, while 87.4 percent of those 45 to 64 have coverage.

To improve the health of people with disabilities, the Center for Disease Control (CDC) has developed the Healthy People program. Healthy People (HP 2010) is a 10-year plan intended to guide health programs, wellness activities and policies at the federal, state, local, private and community levels. Two major goals are to

increase quality and years of healthy life and eliminate disparities. HP 2010 goals for people with disabilities include:

- Reduce the proportion of people with disabilities who report feelings such as sadness, unhappiness or depression.
- Increase participation in social activities for people with disabilities.
- Increase the proportion of people with disabilities who report having sufficient emotional support.
- Increase access to health, wellness, and treatment programs and facilities for people with disabilities.

For more information, visit www.cdc.gov/ncbddd/dh/default.htm.

IU Art Museum offers "touch art" program

As a young girl, Indiana University Bloomington graduate student Marie Clapot rarely had the chance to visit museums due to her father's degenerative eye disease. Now, she's coordinating a new program for people who are visually impaired that will allow them to feel the artwork.

Clapot has the same genetic condition as her father and is currently partially sighted. She wanted the art to become a multisensory experience. This desire to make art more accessible for people with disabilities led her to secure an internship at the Indiana University Art Museum, where she helped design and coordinate a new program to allow visually impaired patrons to touch and feel selected objects from the museum's collection.

The program features two types of tours - a tour that includes an audio description of selected

pieces in the museum's galleries, as well as a touch component that provides people with low vision a guided, physical interaction with selected artwork. To date, the touch art tour is mostly limited to sculptures, though the museum plans to explore ways for people to touch other objects, such as paintings.

Touch tours are limited to people with low vision, while audio description tours are available to the general public. The two types of tours may be combined. All tours must be scheduled in advance by contacting the museum's Education Department at (812) 855-1045 (voice).

Technology provides independence, saves money

Thanks to a new telecare system called Rest Assured™, Hoosiers with developmental disabilities can gain independence in their homes while being safely monitored.

Introduced Sept. 6, 2006, by Indiana Family and Social Services Administration (FSSA) Secretary Mitch Roob, along with representatives from Wabash Center and ResCare, Inc., Rest Assured™ is an advanced system utilizing Internet technologies such as Web cams and interactive sensors, microphones, speakers, smoke detectors, personal emergency pendants, temperature detectors and other devices to monitor people with developmental disabilities from outside their homes.

Embraced by the FSSA Division of Disabilities and Rehabilitative Services, the division will pay for the new service as an alternative to in-home care. And because Rest Assured™ does not require costly individual, on-site assistance, the program is expected to save \$14 million per year - allowing the service to be provided to more people. In the event of an emergency or if the

participant requires assistance, friends or on-call staff members can be dispatched immediately.

Rest Assured™ was developed by the non-profit Wabash Center in conjunction with the Purdue University School of Technology. Tested in eight homes beginning February 2004, the initiative - a partnership between Wabash Center and nationwide human services provider, ResCare, Inc. - is funded via Medicaid waivers and currently boasts 72 users, a number sure to grow quickly.

For more information, visit www.in.gov/fssa/news/.

Of Note

Family Voices of Indiana offers online advocacy group

Family Voices of Indiana has established an online advocacy group that includes families of children with all types of disabilities. A Yahoo list serve has been created to allow timely dissemination of information on policy issues and opportunities for families to give input. To sign up for the list serve, visit <http://groups.yahoo.com/group/FVIndiana/>.

Registration open for advocacy conference

The ninth annual "Children . . . Our Best Investment" conference will be Monday, Feb. 5, at the Indiana Convention Center. This year's event will combine "Children . . . Our Best Investment" and the Point of Youth Legislative Day, as well as help Indiana residents learn how they can assist their state legislators in making effective decisions regarding important child and family issues. For more information, call (317) 264-2700 (voice) or visit

www.childrensrbureau.org/cobi.

Council receives Beacon Award

The Governor's Council was awarded the 2006 Beacon Award at the Nov. 30 annual meeting of the Rehabilitation Association of Indiana. The award recognized the Council for its outstanding contributions to enhance the quality of life for individuals with disabilities.

Correction

In the October/November "On Target," the information about IDEA regulation testing requirement for students with disabilities was incorrect. Please note that schools can continue to use the discrepancy model to evaluate a student for eligibility to receive special education services as a student with a learning disability. However, the state educational agency (e.g., the Indiana Department of Education) cannot require public agencies to use the discrepancy model, and it must permit the use of a "response to intervention" process.

Disability Awareness Month 2007

Materials are now available for the 2007 campaign "Room for Everyone." To place an order, visit www.in.gov/gpcpd or contact Kim Dennison at (317) 631-6499 (fax), kdennison@bjmpr.com (e-mail) or (317) 631-6400 (voice).

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SPECIAL CONFERENCE INSERT

2006 disability conference forged a successful path

This year's conference, "Seeking New Truths; Forging New Paths," struck a chord with the nearly 400 participants. The conference convened Nov. 16 and 17 in Indianapolis, offering three plenary sessions and 10 different workshops. Highlights from the keynote sessions and a number of the workshops follow. Also included are photos from several conference events.

Opening Speaker Brings Global Perspective

The opening keynote session, "The Impact of Globalization on the Disability Community," was led by Dr. Peter Blanck, J.D. A professor at Syracuse University, Blanck also chairs its Burton Blatt Institute, which brings together a global network of disability advocates to affect legislation, media coverage, the arts, etc.

An authority on the Americans with Disabilities Act (ADA), Blanck is frequently called upon to represent clients before the U.S. Supreme Court, as well as testifying before Congress. Blanck shared with attendees examples of several key cases, noting that although the ADA is having a positive impact, improvement is still needed - especially in encouraging employers to provide accessible work places for people with disabilities. To Blanck, the ADA is not only common sense, it's good for business.

Blanck stated he often chooses the cases he'll represent based on the people involved and how their issues affect them and their families. "For me, what defines how I approach my job is the stories behind the cases - and working with people like yourselves," he said. "We need to

make sure we don't take accessibility for granted."

In closing, Blanck noted that today's young generation will likely have higher expectations for accessibility and accommodations because they've never lived in a world without the ADA.

Keynote Speaker Teaches the Value of Intergenerational Communities

Dr. Nancy Henkin, founder and executive director of Temple University's Center for Intergenerational Learning, challenged the audience to expand the meaning of inclusion to encompass all ages, particularly the aging population. The second day's plenary session encouraged people with disabilities to consider the 77 million aging baby boomers as a new ally.

Henkin advocates place-based "communities of all ages" that enable people to be the best they can be at any age. The goal of these communities is to help people cope with the challenges of life. These communities offer:

- A continuum of services that supports individuals and families across the life course.
- Opportunities for lifelong civic engagement and learning.
- Diverse and affordable housing and transportation options.
- A physical environment that promotes healthy living.
- Policies, facilities and public spaces that promote sharing of resources and cross-age interaction.
- Shared values and a sense of community.

Henkin's strategies for inclusion and successful communities of all ages include:

- Moving from silos to partnerships
- Hearing and honoring all voices
- Finding common ground
- Building resilient leadership
- Strengthening social relationships

For more information about Henkin and communities for all ages, visit www.templecil.org.

WORKSHOP HIGHLIGHTS

Interactive Luncheon Session Entertaining and Informative

Thursday's luncheon presentation featured a preview of "The Wheelchair Monologues" and an interactive presentation of "Picture This."

"The Wheelchair Monologues" is a composite of real-life experiences sponsored by ArtWorks Indiana (AWI). The audience sampled a clip of the entire work, which is targeted for completion in 2007.

In "Picture This," a health promotion service sponsored by the Community Health Network, several scenarios were presented regarding attitudes about people with disabilities. The scenes were unexpectedly stopped in order for the audience to raise questions, react and have a dialogue with the actors.

For more information on "The Wheelchair Monologues," e-mail the chair of AWI, Chris Karson, at karsonracing@aol.com. In May, AWI will launch a new Web site designed to connect people with disabilities who are interested in careers in art. The site is www.artsworkindiana.org.

For more information on "Picture This," call (317) 621-9355 (voice).

Housing Futures Workshop

Sherry Seiwart, executive director of Indiana Housing and Community Development Authority (IHCDA), presented on the topic of housing for people with disabilities.

IHCDA is a state program that works to revitalize communities by taking people from homelessness to homeownership. Through participating lenders around the state, IHCDA offers people many financing opportunities: down payment assistance, homeownership counseling and the community home choice program. In addition, IHCDA offers community development programs such as owner-occupied rehab and tenant-based rental assistance.

IHCDA also offers rental housing tax credits through Section 8 mainstream vouchers and Section 8 homeownership vouchers. For more information on the loans and programs offered by IHCDA, call 1-800- 872-0371 (voice) or visit www.indianahousing.org.

The Generations Project and SEA 493

This session, led by representatives from The Generations Project, AARP and the Southern Indiana Independent Living Center, featured information on The Generations Project and SEA 493. The Generations Project was established in 2001 to call attention to Hoosiers with long-term health care needs. A collaborative effort of leading consumer-based organizations, the goal is to educate citizens, advocates and policymakers about the opportunities for Hoosiers to implement a balanced and responsible long-term care system.

SEA 493 was enacted by the Indiana General Assembly in 2003 to re-balance the state's system of long-term care. It focuses on

establishing and/or growing Medicaid home- and community-based services (HCBS) waivers for assisted living, adult foster care, home care and self-directed care.

The Generations Project is working with the Indiana Home Care Task Force to create draft legislative proposals designed to encourage implementation of SEA 493. For more information on the project, visit www.generationsproject.org.

Investing in Family Values

The presenters of this workshop began by noting that family support means different things to different families.

According to the Indiana Family Support Council, family support makes use of structured services and supports - as well as informal and natural supports from friends, neighbors, extended family or others in the community - for a person with a disability or a family member.

The main goals of family support are:

- Keep families together as long as desired
- Enhance a family's ability to meet needs
- Minimize the need and the cost of out-of-home placement
- Make a positive difference in the life of the person and family

For more information on family support, visit www.ipin.org/FamilySupportProject-details.asp.

Helping Children with Disabilities During Transitions

Two workshops featured information on the best ways to help children with disabilities during transitions.

The first workshop focused on children younger

than three who often benefit from the state's First Steps program. Led by representatives of Family to Family, attendees focused on a child's transition out of First Steps and the many program options, timelines and resources available at this stage.

The second workshop featured parents of children with disabilities who have made the transition from school-based services to adulthood. A number of resources - both organizational and Web-based - were shared with attendees, as well as personal stories about real-life experiences.

All three speakers are part of the Indiana Parent Information Network (IPIN). Marsha Cheesman, Jane Scott and Nancy Stone have all helped a child with disabilities transition to adulthood. Two of their children are currently attending Indiana colleges, and have learned how to tap into university services and request accommodations. When questions were taken from the audience, discussion centered around waivers, scholarships and government assistance available to help young adults attend school and perhaps live on their own.

For more information on Family to Family, visit www.INF2F.org or Indiana's State Transition Initiative at www.indianatransition.org. Visit www.ipin.org for more information on the Indiana Parent Information Network.

Employment First Opportunities

Becky Deetz from the Social Security Administration (SSA) and Susan Rinne from Options for Better Living discussed in this workshop a number of topics surrounding employment for people with disabilities.

SSA provides two employment support incentives. In one, help is given to individuals to

pay for services or items they need in order to work. In the other, help is given to individuals to maintain or even increase their cash benefits until they are stable in employment. Some of these include the Student Earned Income Exclusion, Impairment-Related Work Expense and Plans to Achieve Self-Support. A Work Incentive Liaison (WIL) is located at every Social Security office to answer questions about individual cases.

A report was also given on Indiana's Employment First Summit. The summit's goal was to help create a strategic plan for ensuring that competitive employment is the first outcome for all Hoosiers with disabilities. A number of possible solutions were identified, and next steps include gaining consensus among state policy members, enlisting the help of business leaders and ongoing communication with key audiences.

Estate Planning - Making Future Choices

Only 10 percent of caregivers to people with disabilities have planned sufficiently to protect their dependent's best interests once they are no longer around or able to do so themselves.

This session addressed common misconceptions about estate planning for people with special needs.

Recommendations shared included:

- Work with the appropriate professionals to set-up a special needs trust. It can allow caregivers to provide for their dependents without causing them to lose government assistance.
- Legally identify a caregiver for the individual, whether through a will, guardianship, conservatorship or other appropriate legal mechanism.

- Consider funding special needs trusts with appropriate vehicles such as survivorship life insurance to ensure a direct beneficiary doesn't risk losing government benefits.

This session was conducted by MetDESK, MetLife's Division of Estate Planning for Special Kids. For more information, call (877) 638-3375 (voice) or visit www.metlife.com/desk.

Five Awards Presented at This Year's Conference

The closing luncheon for the 2006 Conference for People with Disabilities ended with an awards presentation to five outstanding leaders.

Darcus Nimms of Indianapolis and Verna "Marty" Neidigh of Bremen were awarded the 2006 Distinguished Leadership Award for a person with a disability. Nimms founded Self Advocates in 1990 and is its current president. She encourages other self advocates to work toward their dreams and to be proud of who they are. Neidigh is a lifelong advocate for people who are hard of hearing and was elected to the first board of trustees for the National Self Help for Hard of Hearing organization and later organized a local chapter. She is currently working on plans for a new statewide group, the Hearing Loss Advocacy Group of Indiana.

The 2006 Distinguished Leadership Award for a parent of a child with a disability went to Donna Gore Olsen of Indianapolis. Olsen founded the Indiana Parent Information Network (IPIN) in 1987 and is its recently retired executive director. IPIN provides a parent-to-parent network that helps people to navigate the disability system. She is currently working on a new initiative for young adults with disabilities transitioning from pediatric to adult medical care.

Finally, the 2006 Disability Awareness Campaign Awards went to Indiana State University (ISU), Terre Haute, and United Cerebral Palsy (UCP) of Greater Indiana, Indianapolis. ISU was honored for "An Expansion of Perspectives," a series of seven major events held to celebrate Awareness Month and to involve the entire ISU campus and Terre Haute community. UCP was recognized for the positive influence that their ATTITUDE essay contest has had over the past 10 years. The contest has encouraged more than 4,700 children throughout Indiana to consider how attitude impacts the public perception of people with disabilities.

Nominations for next year's Community Spirit Awards will be open in the spring.

Exploring Unlimited Possibilities

This year's conference ended on a high note with an energizing presentation by Dr. Al Condeluci. Condeluci is CEO of United Cerebral Palsy of Pittsburgh.

Condeluci's presentation focused on how every person is an advocate and can be a "change-agent." Key points included:

- Start with the end in mind. What do people want? Jobs, housing, transportation, friends and opportunities.
- The most important thing to focus on is friendships. People who are active in the community and have built relationships have an easier time finding jobs, housing, transportation and other opportunities.
- People who have more relationships are healthier, happier and live longer.
- Currently, we are using the wrong system to integrate people with disabilities and to help them form relationships.
- Instead of focusing on the differences in

people, we should focus on building communities with a wide range of people.

- To help build inclusive communities, advocates should be prepared to do the following: plan, be present, use politics and persevere.

Condeluci brought into focus the messages heard during the conference and challenged members of the audience to stretch their imaginations as to what could be.

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