

Life “Frozen” for People with Disabilities Without New State Revenue

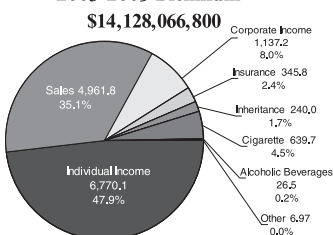
It will be up to the 2005 Indiana General Assembly to determine if people with developmental disabilities face two years frozen in place on waiting lists and at risk of losing services due to declining resources for community services and special education; or if they will finally receive services or see improvements in current programs due to new revenue sources. Legislators will have the opportunity to make a choice to continue Indiana’s strategic investment in the 317 Plan and continue to build a strong system of home and community based programs in Indiana.

The state currently relies on four major sources of revenue:

- Individual Income Taxes – 48%
- Sales Tax – 35%
- Corporate Taxes – 8%
- Inheritances – 2%
- Cigarette – 4.5%
- Alcoholic Beverages – 0.2%

The strong reliance on sales and income taxes leaves Indiana vulnerable

**Total General Fund Tax Revenue
2003-2005 Biennium**



to changes in the state and national economy.

Due to the current freeze in funding, for the first time in memory, not one student moving from special education high school programs will have access to a vocational or developmental program. No one will move off a waiting list unless his or her parents die or face an extreme crisis. The key to the future for many Hoosiers with disabilities will be whether a new revenue source will be developed dedicated to improving home and community-based services.

Some will say that the state just needs to live within its means and cut funding. We’ve done that. Just last year \$28 million was cut in funding to programs for people with disabilities. \$28 million could have provided services to over 1,500 Hoosier families in desperate situations.

Without new revenue there will be further cuts and programs for people will be in jeopardy.

The Arc of Indiana supports two avenues that could address the state’s need for revenue.

Non-nutritive Beverage Fee

A non-nutritive beverage fee would establish a small fee on syrup or powder used in the manufacture and bottling of non-nutritive beverages such as soft drinks. The cost that would be passed on to consumers would be less than a penny per can of soda.

Tea, coffee, bottled water and drinks that include more than 10% natural juices would not be subject to the fee. The fee would be dedicated to provide funding for long-term care for people with developmental disabilities and senior citizens.

- The fee would be approximately a half a cent per can of soft drink, to be collected at the point of manufacture or distribution.
- The fee will raise an estimated \$61.8 million in state dollars. The revenue would be dedicated to a Long-Term Care Continuum fund within Medicaid.
- The state dollars generated by the fee will leverage an additional \$103 million in federal Medicaid dollars.
- The administrative cost of the fee would be no more than \$100,000.
- All of the new funding will go to develop and expand home- and community-based options for seniors and persons with physical and developmental disabilities.

The Case for a Non-nutritive Beverage Fee

A sales tax is an involuntary tax. A targeted soft drink fee affects only voluntary behavior.

A targeted fee on non-nutritive beverages does not single out any socio-economic group. People of all ages and incomes drink soft drinks. A sales tax is a regressive tax. Persons with less income pay more in sales tax than the wealthy.

Soft drinks have no nutritive value. A successful model for such a targeted fee has been used in Arkansas for over a decade. Over the last 10 years, it has generated hundreds of millions of dollars for Medicaid in that state.

Internet Sales Tax

Congress is considering allowing states to include Internet sales in the collection of sales tax. By fairly including Internet sales to existing taxes, Indiana could generate up to \$400 million over the biennium. It is only fair that Internet based businesses collect and pay sales taxes that every other Indiana based business must collect. Since we depend on sales tax for a large portion of the state’s budget, it is critical that our tax policy address one of the fastest growing portions of our economy.

Congress has a moratorium on allowing states to apply sales tax to purchases made by citizens of that state via the Internet. Congress should act to allow states to apply the sales tax to these purchases, just as they are to any other purchase.

What can you do?

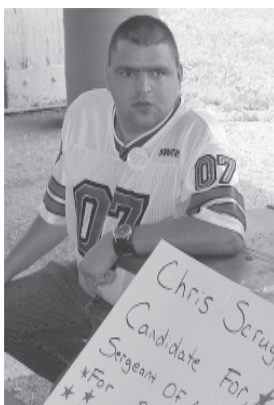
If we do not want to see families frozen in time, we must address the revenue needs of the state. You can find information on how to access The Arc of Indiana’s Legislative Action Center on page eight. You can sign up to receive Action Alerts, letting you know how and when to contact your legislators during the Indiana General Assembly. You will also find links that will let you e-mail your state legislators and your U.S. Senators and Representatives.



A non-nutritive beverage fee would cost consumers less than a penny per can of soda, but could provide nearly \$165 million in state and federal matching funds to expand home and community based services.

NON-PROFIT
ORGANIZATION
U.S. POSTAGE PAID
INDIANAPOLIS, IN
PERMIT NO. 1715

Self-Advocates of Indiana



Self-Advocates of Indiana enjoyed a picnic at Garfield Park in Indianapolis in June.

The mission of Self-Advocates of Indiana is, "To learn our rights and to speak out about our rights so that we get the respect we deserve."

Self-Advocates of Indiana works to educate people with developmental disabilities about their rights and the opportunities for them in their communities; to educate parents and supporters to calm their fears and encourage them to see the capabilities of their loved ones; to educate the public on what it means to have a developmental disability; to increase community capacity so that everyone can live independently; to develop leadership among people with developmental disabilities across the state; and to expand the principles of self-determination and self-advocacy to all regions of Indiana.

For information on Self-Advocates of Indiana, contact Maribeth Mooney, Indiana Institute on Disability and Community, 1-800-825-4733.

Photos by John Dickerson, Executive Director, The Arc of Indiana



The Right to Vote

Voter Registration

The National Voter Registration Act or "Motor Voter" law requires all public and private agencies and individuals serving people with disabilities to offer voter registration. Despite the law, a 2000 National Organization on Disability/Harris poll found that only 44 percent of people with disabilities have been offered registration services.

Count Us IN, a project of the Indiana Governor's Planning Council for People with Disabilities, is working with the Secretary of State's office, the Indiana Election Division, state agencies, not-for-profit organizations and others to ensure that all who have an obligation to offer voter registration are doing so.

Who can vote?

You have the right to vote in an Indiana election if:

- You are a U.S. Citizen
- You are a resident of Indiana
- You will be at least 18 years of age at the next general or municipal election
- You have lived in the precinct where you vote for at least 30 days before the election
- You are not currently in prison after being convicted of a crime
- You are registered to vote

Voters Needing Assistance

If you need assistance at the polls because you are disabled or cannot read or write English, you have the right to receive assistance to cast a vote in every election. The person assisting can be a poll worker or someone you choose. However, your employer or union representative cannot assist you. The person you choose must fill out an affidavit before assisting you to vote.

Accessible Polls

You have the right to a polling place that is accessible to a person with disabilities.

Traveling Voting Boards

If you are confined due to illness or disability, you have the right to vote absentee at your place of confinement before a traveling absentee voting board.

Registration Deadlines

The deadline to register to vote in the General Election is October 4, 2004.

Mail in applications must be postmarked on or before October 4 in order to be eligible to vote in the General Election.

If you are unsure of whether or not you are registered, contact the county voter registration office in your county.

Consumers' Rights

Register to Vote

Absentee Voting

A person with a disability is eligible to vote absentee at the clerk's office or by mail. First, you must complete an absentee ballot application and return it to your county election board (at the clerk's office). Applications from most voters must be received, whether submitted by mail or FAX, at least 8 days before Election Day. There may be special deadlines for certain circumstances, so please contact your county election board or county clerk early if you plan to vote absentee.

Requirements for Service Providers and Case Managers

The National Voter Registration Act or "Motor Voter" law requires all public and private agencies and individuals serving people with disabilities to offer voter registration. Service providers and case managers should make every effort to assist those persons they serve, who choose to vote, to register and vote in person or absentee.

- For voter registration forms and other information visit: www.in.gov/sos/elections/index.html
- For more information on voting and voting rights visit: <http://www.in.gov/gpcpd/vote>

Executive Director's Column



Costa N. Miller

February 2, 1940
— June 19, 2004

The Arc of Indiana celebrates the life of Costa N. Miller, who passed away after a brief illness on June 19, 2004.

Costa Miller was the founder and Executive Director of INARF, Indiana Association of Rehabilitative Facilities. He was a leader and advocate for people with developmental disabilities who can never be replaced.

Over the course of his career, Costa was awarded the Sagamore of the Wabash by four different governors for his outstanding contributions to the state of Indiana and to people with disabilities. He served as chair of the Governor's Planning Council for People with Disabilities for four years, and was vice-chair of the President's Committee on Employment of People with Disabilities. He served on numerous boards, commissions and committees throughout his career, including the Indianapolis Resource Center for Independent Living and the Council of Volunteers and Organizations for Hoosiers with Disabilities.

As the leader of an organization representing providers of services to people with developmental disabilities, The Arc of Indiana worked closely with Costa for many years. While the state of Indiana has lost an outstanding leader and advocate, the staff of The Arc of Indiana has lost a long time colleague and friend. We take comfort, however, in knowing that while Costa may be gone, he will live on through the legacy of his work on behalf of people with developmental disabilities.

Memorial contributions can be made to the Costa N. Miller Scholarship Fund through INARF, St. Mary Catholic Church in Indianapolis, St. George Greek Orthodox Church, or CASA, Court Appointed Special Advocates, in Media, PA.

Facing the brick wall. Without new state revenue, persons with developmental disabilities and their families will face a solid brick wall covered with the word *NO*.

No funds to give job training for students with disabilities leaving school. No funds to deal with a waiting list growing into the tens of thousands. No funds to deal with the growing need for direct care workers and shrinking budgets for existing programs.

All of this has an effect on our state's economy, as families consider moving, businesses consider leaving and others won't relocate here due to our failure to invest in human services.

After two years of working to tighten belts, reduce budgets and cut spending; many programs for people with disabilities are stretched thin. Last year alone, over \$28 million was cut from community programs to help offset the state deficit in revenue.

Yet it does not have to be that way.

This year the Indiana General Assembly will be considering what to do. We



John Dickerson

believe there is an alternative to this brick wall.

At the state level, The Arc, along with a number of groups representing seniors and people with disabilities, will be again proposing the Non-nutritive Beverage Fee. Targeted to support community-based services, this fee translates to less than 1 cent per can of soda pop. One penny — 4 out of 5 people won't stop to pick one up off the street. Every cash register has a container of pennies next to it where people give them away and pick them up for change. Yet one penny per can of soda could generate millions that would serve Hoosiers who are older and want to avoid a nursing home or who are developmentally disabled and need vocational or home-based support. It seems a simple choice.

Yet, tremendous opposition will

be raised by soda bottlers, retailers, restaurants and theatre owners. In fact, last year one theatre chain claimed that a 2-cent fee on a \$3.50 fountain drink would bankrupt their chain of theatres!

At the national level, Congress must let states extend existing sales taxes to Internet sales. There is no reason to exclude this business interest from the regular collection of sales taxes as it is growing rapidly and is taking money from Indiana, leaving more of a burden on local businesses which have no choice but to collect the sales tax.

It is always difficult to think of raising revenue in such difficult times. The national economy is struggling, and the impact of the war is felt throughout the land.

This is not the time to withdraw into our own private interests and only be concerned about *us*. We must continue to look for anything we can do to build a better Indiana—and begin by stepping up and raising the revenue needed to take care of its citizens.

Lifetime Achievement Award Presented to Representative William Crawford

The Arc of Indiana presented Representative William Crawford with its first *Lifetime Achievement Award* at a breakfast held in his honor on August 4, 2004.

State Representative Bill Crawford was first elected into the Indiana General Assembly in 1972, and has continued to serve his Indianapolis district for thirty-two years. In 2000, Representative Crawford became the first African-American to serve as chairman of the House Ways and Means Committee.

As the leader of the Ways and Means Committee, and throughout his legislative career, Representative Crawford has been a strong supporter of Hoosiers with mental retardation and related disabilities.

In 1994, Representative Crawford authored the law that prohibits the death penalty from being imposed on a person with mental retardation. Representative Crawford has noted that he looks on this law as one of the chief accomplishments of his legislative career. "To execute someone who lacks basic mental capacities offends not only our notions of justice but of ethical conduct of civilized people," Crawford said.

Representative Crawford was also



Lisa Kobe of Cinergy, award recipient Representative William Crawford, and Robin Winston of the Winston/Terrell Group.

instrumental in passage of legislation requiring all newborn babies to be screened for genetic disorders. This effort not only saves lives, but also prevents conditions that, if left untreated, can cause infants to become developmentally disabled.

A strong supporter of inclusion for children with disabilities in all phases of public school, Representative Crawford fights for the rights of all children with disabilities to learn in Indiana classrooms and has been a long time supporter for home and community based services for people with mental retardation and related disabilities.

U.S. Representative Julia Carson made opening remarks at the breakfast. "We have come a long way in recognizing the contributions of

human beings. I thank The Arc of Indiana for helping us all learn about these contributions. We as a society have a long way to go, but The Arc is to be commended for their work on behalf of people with developmental disabilities."

Robin Winston, a long time friend of Representative Crawford and a member of The Arc of Indiana's Development Committee, presented the Lifetime

Achievement Award to Crawford, saying, "You make a living with what you get, but you make a life with what you give. Bill Crawford reinforces every positive attribute of a public servant for what he has given."

In his acceptance of the award, Representative Crawford said, "Everyone has merit and worth, and therefore it is easy to support initiatives that raise up all people." He noted that while many of his awards are tucked away in boxes, this award will be special to him and will be proudly displayed.

The Arc of Indiana thanks sponsors of the event, Cinergy, Pacers Sports and Entertainment, and Winston/Terrell Group. Special thanks to Robin Winston, Winston/Terrell Group; and Lisa Kobe, Cinergy, for their assistance in organizing the event.

Symposium on Dual Diagnosis Scheduled for November 10

"Collaboration Across Systems: Promoting Mental Wellness in People with Developmental Disabilities"

Mark your calendars for the first Indiana Symposium on Dual Diagnosis to be held November 10, 2004, 8:30 a.m.- 4:30 p.m., at the Westin in Downtown Indianapolis. The registration fee of \$50 includes lunch, and will provide CEUs and CMEs.

The symposium is designed to provide information about the use of medications, diagnosis and assessment, strategies for cross-system collaboration, and families' perspectives for persons who are dually diagnosed. Presentations will be made by four nationally recognized experts in the field of developmental disability and mental illness: Dr. Christopher McDougle, speaking on drug therapy; Joan Beasley, Ph.D., speaking on cross system collaboration; Lauren Charlot, Ph.D., speaking on diagnosis and assess-

ment; and Dan Dubovsky, MSW and parent, speaking on family issues.

The symposium is being coordinated by Choices, Inc. and is sponsored by Eli Lilly and Company and Indiana Protection and Advocacy Services. Symposium partners include: The Arc of Indiana, Mental Health Association in Indiana, Mental Health Association in Marion County, Indiana University School of Medicine, Indiana Institute on Disability and Community, Family and Social Services Administration, Midtown Community Mental Health Center and BehaviorCorp.

For more information about the conference program, go to: www.choiceseam.org, or call Choices, Inc. at 317-726-2121. For registration information, call the Indiana University School of Medicine, Division of Continuing Medical Education at 317-274-8353.

THE ARC OF THE U.S. CONVENTION IN BOSTON

The Arc of the United States will hold its 2004 National Convention in Boston, November 18-20, promising one of the most important national gatherings in memory. This year's event marks the first time The Arc of the United States has held a convention after a year off, making networking opportunities with chapter colleagues much more vital.

First national gathering
of The Arcs since 2002

The convention offers The Arc's members, chapters, and supporters the chance to re-connect with our mission and with one another. It is during these gatherings that new life is breathed into our movement and our constituents who help govern the organization.

This year's convention offers informative work-

shops, enlightening and entertaining plenary sessions, and plenty of opportunities for fun in beautiful, historic Boston. During our workshops, you can stay abreast of ongoing developments in future planning, fundraising, prevention, education, housing, public policy, spirituality, technology, employment, and health care. Plenary speakers will discuss how our constituents cope with feelings of loneliness and isolation, outline environmental issues affecting people with mental retardation and their families, and confront some of the "bad news" myths about our constituents. We'll also hear from some self-advocates who are forging careers as actors and a woman who specializes in helping actors with disabilities find jobs in the competitive entertainment industry.

Registration materials are available on The Arc's web site. Go to: <http://www.thearc.org/conv04/>

Grant Awarded to The Arc of Decatur County, Developmental Services, Inc.

Representatives from the city of Greensburg, The Arc of Decatur County, and Developmental Services Inc. attended a ceremony at the State House in June, where Lt. Governor Kathy Davis formally awarded them with a Community Focus Fund Grant. The grant will provide funding to add production and day program space to the facility in Greensburg that provides services and supports to people with developmental disabilities.



The city of Greensburg has received a Community Focus Fund Grant to expand the workshop operated

by Developmental Services, Inc. in cooperation with The Arc of Decatur County.

The grant was presented by Lt. Governor Kathy Davis at a ceremony at the State House in June.

The Arc of Decatur County and Developmental Services, Inc. have partnered on the workshop, which provides services and supports to people with developmental disabilities throughout the community.

The grant will allow Developmental Services to add 4,972 square feet of production space and 720 square feet of additional space to the current facility. The expansion will provide more work opportunities and additional day program space for people with disabilities who are aging, as well as space for rest areas and social activities.

The Community Focus Fund is a federally funded grant program administered by the Indiana Department of Commerce. The funding is available to small cities, towns, and counties for construction projects designed to benefit those of low-to-moderate income, or to eliminate blight in communities. Grants are awarded through competitive funding rounds to assist small communities in long-term development projects.

Arc BRIDGES Receives \$1.4 Million Grant

Arc BRIDGES, Inc., the local chapter of The Arc in Northwest Indiana, has been awarded a demonstration grant for \$1.4 million as part of the President's New Freedom Initiative.

Arc BRIDGES, like other similar agencies nationwide, continues to experience the problem of recruitment and retention of workers. This problem is expected to continue to worsen with the rate of employment growth in the field and the decline in the number of traditional workers to fill vacant positions. The relative low salary, 24-hour operation, lack of benefits, lack of respect for the position, and the physical demands of the work further exacerbate the problem.

The project, approved by the Department of Health and Human Services Center for Medicare and Medicaid Services, will improve both recruitment and retention of Direct Service Workers. A second objective is to improve the overall image of a career in Personal Care by creating career ladders and by increasing individual job pride, personal worth, and employee satisfaction. A third objective is to influence public policy to support improved salary, benefits, and other facts to contribute to recruitment, retention and job satisfaction. Finally, the project will improve communication and supervision of workers.

Recruitment and retention of direct service workers; certification, salaries and benefits to be evaluated and improved.

Partners in the project include: Indiana University Northwest, that will take responsibility for monitoring and evaluation; Ivy Tech State College, that will develop a curriculum designed both to enhance and support basic skills; and Work One, a workforce development service that will assist in the recruitment of qualified individuals and will also promote career certification.

Kris Prohl, Executive Director of Arc BRIDGES, said, "Direct Service Workers are the key to success for many of the programs operated by Arc BRIDGES. Their skill and dedication may make the difference between independence and institutionalization. Their availability supports both the individual and the family. Such workers are a critical factor to the quality of life of this population. Yet access to care is often hampered by shortage of these key individuals. Arc BRIDGES hopes to increase the number of those professionals by 50 additional positions."

"We have learned over many years and in many situations about the vital concerns of wonderful staff caring for the complex needs of people with developmental disabilities. We hope to capitalize on that knowledge to expand and professionalize the workforce and validate the career choice of direct service professionals," Prohl said.

Candidates for Governor Answer Questions at Forum on Disabilities in Statewide Telecast

The candidates for Governor, Mitch Daniels and Governor Joe Kernan, answered questions on issues of concern to people with disabilities at a forum hosted by The Arc of Indiana, INARF, and the Indiana Institute on Disability and Community on August 18. The "Conversation on Disability Issues with the Candidates for Governor," was telecast to six sites around the State.

The complete telecast can be viewed on the Internet by going to: www.arcind.org—click on "Archived Web Stream."

Mitch Daniels and Governor Kernan appeared separately to answer questions from Indianapolis, Gary, South Bend, Fort Wayne, New Albany, and Evansville. The same questions were asked to both candidates. Each candidate also gave opening and closing statements. Jim Shella, WISH-TV, Indianapolis, and host of WFYT's Indiana Week in Review, moderated the event.

Questions posed from the six sites included:

- How will the voice of people with disabilities be reflected in your administration?
- How will you address issues of funding for programs and qualified personnel to serve people with disabilities?
- How would you support a shift in funding from institutional to community based services?
- Do you envision or support changes to the structure of the Family and Social Services Administration (FSSA)?
- How do you plan to serve people who are transitioning out of special education programs and need community based services?
- How would you address the issue of mandates for coverage in health insurance, and the difficulty low-income people with disabilities have in receiving health care coverage?
- How will you address the wide-spread unemployment of people with disabilities?
- How will you address the issue of waiting lists for home and community based services?



Mitch Daniels

Mitch Daniels stated that appointments in his administration would include people with personal experience wherever possible, noting that the voice of beneficiaries should be the loudest voice we hear.

Regarding funding for programs and services, Mr. Daniels stressed that the state's finances are in need of dramatic repair, and that there will be no way to have the revenue that is needed unless the overall economy of the state grows. He also stressed that Indiana lags far behind other states in capturing federal grant dollars that could address health and human services needs. He later noted that one way to free up dollars in order to serve those who are leaving special education programs, and to serve those on waiting lists, is to do a house cleaning of state government to free up dollars that are not being well spent in

order to serve those who are truly in need.

Mr. Daniels stressed his support for shifting funding from institutional care to home and community based care to the extent that it is possible, noting that senior citizens and people with disabilities should always be given a choice in where they live and receive care.

Regarding restructuring the Family and Social Services Administration (FSSA), Mr. Daniels supports moving child protective services out of FSSA, and noted that workforce training should not be embedded in FSSA. He stressed that these changes would only be a start, and that he would look for input from advocates and others for additional changes that could be made to FSSA.

In response to the question on health insurance mandates and the difficulty people with disabilities face in receiving health care coverage, Mr. Daniels stated that some services, such as autism, may deserve to be mandated, but that mandates for coverage do need to be looked at in light of the growing cost of health care.

Mr. Daniels stated that he would support the work of agencies that provide job training to people with disabilities to the maximum extent possible, and carefully review what agencies are getting the best results as one approach to improving the employment of people with disabilities.

Governor Kernan stated that his administration has sought input from families, consumers, providers, and advocacy groups on how to better deliver services through a formal "request for information" and through seeking feedback and partnerships with those involved in the disability community.

Regarding those who work with people with disabilities, Governor Kernan said that to have the best people possible, they must be fairly compensated, provided additional training, and be given tools that will allow them to have more time to provide direct care.

Governor Kernan strongly stated that everyone who wants to stay at home (rather than enter an institution) should have the opportunity. Referring to the federal Medicaid Waiver program, Governor Kernan said that you should have to have a waiver to get into an institution, not the other way around. He spoke of the community partnerships that have allowed people to move from Muscatatuck State Developmental Center (MSDC) as an example of how partnerships can help foster the shift in funding from institutional to community based care.

In response to the question on restructuring the Family and Social Services Administration (FSSA), Governor Kernan said he has asked Lt. Governor Kathy Davis, who served as Secretary of FSSA under



Governor O'Bannon, to include a careful review of FSSA in the overall review she is conducting of state government. He also highlighted a study that is taking place of FSSA's case management systems, with the goal being to move to a system that does not require individuals and families to have multiple case managers.

Governor Kernan stated that one way to serve those on waiting lists and those coming out of special education services is to assure that those who are currently receiving services are receiving what they need, but not more than they need, in order to free up funds that could go to people in need of services. He stressed that he does not support efforts at the federal level to block grant federal Medicaid funding, and emphasized that it is the goal of his administration to move people out of institutions and make sure people do not have to go to institutions in the first place.

Regarding health insurance mandates and the difficulty low-income people with disabilities face in obtaining health care coverage, Governor Kernan said this is not just a problem for low-income Hoosiers with disabilities, but for all Hoosiers with low-incomes. A task force appointed by the Governor is currently looking at mandated benefits. Governor Kernan stated that every mandated benefit must be reviewed and balanced with the cost.

Governor Kernan said he would work to improve the employment of people with disabilities by being very aggressive in looking to hire people with disabilities, working with the private sector to encourage their participation in hiring people with disabilities, and providing job training to give people with disabilities the skills they need to be successful in entering the work place.

The Arc of Indiana thanks Mitch Daniels and Governor Kernan for their time in attending the event. Special thanks to Jim Hammond, Acting President/CEO INARF, and David Mank, Ph.D., Director, Indiana Institute on Disability and Community, for their help in co-hosting the event.

Thanks also to the facilitators at the telecast sites:

Steve Hinkle, President, Easter Seals Arc of Northeast Indiana, Fort Wayne
 Deidra Conner, Executive Director, Evansville ARC, Evansville
 Dan Harshman, Chief Executive Officer, LOGAN, South Bend
 Bettye Dunham, Rauch, Inc., New Albany
 Kris Prohl, Executive Director, Arc BRIDGES, Gary



Joe Kernan

Former MSDC Residents Enjoying Life in New Homes

Paula O'Brian Moves Back to Home Neighborhood

Paula O'Brian lived at Muscatatuck State Developmental Center (MSDC) for 33 years. Her parents were very upset when they were told that MSDC was going to close, and that Paula would have to move to a new home. They sincerely and firmly believed that supports in the community were not enough to keep Paula safe. However, with time and planning, Paula was able to move into a home on the same block as her great-aunt and grandmother.

One month after Paula moved into her new home, her mother, Lynn, sent announcements to 70 friends and relatives. The announcement read, "It's a Miracle! After 33 years of living away from my family and friends, God has truly blessed me by sending me back home. . . . Please come and visit me

whenever you are in the neighborhood. Love, Paula."

Paula and her caregiver, either Barbara or Ashley, like to take a walk in the neighborhood every day. Sometimes they go to the park, sometimes to the store. She looks forward to going to movies and to the YMCA. She loves being close to her mom and family.

Her family is not as worried about her as they were before. In fact, Mom says, "It's a relief!"



Paula O'Brian

Andy Knoch Adjusting to New Life in Northwest Indiana

Andy Knoch began living at Muscatatuck State Developmental Center (MSDC) when he was six years old. After thirty-seven years, Andy is now living in a group home in Portage, Indiana, operated by Arc BRIDGES,



Andy Knoch

Inc., the local chapter of The Arc in Northwest Indiana.

Andy lives with three other men and has his own bedroom. Arc BRIDGES Residential Program Director, Lynn Poe, shared that during the initial weeks in his new community, Andy spent time meeting with doctors to develop his local medical team. Staff is hopeful that Andy's long standing sleep-related problems can be addressed, and that this in turn will help improve behaviors. She also reports that it is the dedication of Andy's staff to him and his success that will make it possible for his participation in the community to grow.

Andy is beginning to make trips to stores in the community, and particularly likes relaxing in the backyard of his new home.

Although Andy is non-verbal, Arc BRIDGES staff is learning how to communicate with Andy, and is already seeing improvements in his behavior. Lynne Poe noted that, "Andy has a great sense of humor and loves to joke and kid with staff."

At this writing, 70 people continue to live at MSDC. The state facility is scheduled to close by January, 2005.

Dental Care Through Donated Dental Services (DDS)

Many people with developmental disabilities do not receive proper dental care and treatment. Medicare does not provide dental benefits, Medicaid limits treatment, and many dentists do not know how to address the special needs of people with developmental disabilities.

Donated Dental Services (DDS) volunteers provide direct services and treatment to this often overlooked and at-risk population. Designed by dentists, the program makes volunteering simple. And DDS is one of the largest dental health programs in the nation.

There are 588 volunteer dentists and 111 volunteer laboratories in Indiana. This year alone, 218 people have been treated, while another 139 are in the process of completing treatment. Hoosiers have received \$427,796 in donated dental treatment. Since the state's program started, almost 1,500 disabled, elderly and medically compromised people have received over \$2 million in free, comprehensive dental treatment. Nationally, volunteers have donated over \$50 million in treatment.

For more information, contact:

Indiana Donated Dental Services
P.O. Box 872
Indianapolis, IN 46206-0872
317/631-6022
Fax: 317/634-2612
www.nfdh.org

To access the application for Donated Dental Services, go to: <http://www.nfdh.org/pdf/IN.PDF>

Settlement of Class Action Lawsuit Will Bring Community Based Services to Nursing Home Residents

The settlement of a class action lawsuit filed by LOGAN Community Resources, Inc. against the State of Indiana will help move people with developmental disabilities out of nursing homes and into community based services. LOGAN, a provider of community services for people with developmental disabilities in St. Joseph county, filed the suit on behalf of 1,933 people with mental retardation living in nursing homes throughout Indiana.

A study by David Braddock, Ph.D., entitled "Developmental Disabilities Services in Indiana" revealed that Indiana has more than twice the national average of individuals with mental retardation living in nursing homes. Of the 1,933 individuals with mental

retardation living in Indiana nursing homes; 75-90% should by law have access to alternative living arrangements in community settings.

Many of these individuals have been in nursing homes waiting for a community option for more than 20 years. Many were moved from a state hospital to a nursing home as young adults.

The Federal Nursing Reform Act of 1987 addresses the widespread problem of warehousing people with developmental disabilities in nursing homes. This legislation requires that all states admit to nursing homes only individuals in need of nursing home care. The legislation also requires that individuals with developmental disabilities residing in nursing homes for more

that 30 months be given the option of moving or staying. Indiana has failed to comply with this legislation.

Law requires alternative to nursing homes

The lawsuit (Kraus vs. Hamilton) was brought against the State of Indiana by LOGAN Community Resources, Inc. and a class of Medicaid recipients. The attorneys for the plaintiffs – staff members of the Notre Dame Legal Clinics – donated their services. The lawsuit did not seek monetary damages, but did seek to require the state to move people with developmental disabilities from nursing homes to community based pro-

grams, fully funded by Medicaid.

The settlement will provide 450 Medicaid recipients with developmental disabilities who are in Indiana nursing facilities an opportunity to live in a place of their choice in the community. Indiana has agreed to fulfill this responsibility by the end of 2008. Community options will be presented by a State employee in a "face to face" meeting with each individual or a health care representative who then ultimately will decide whether to accept services in the community or a nursing facility. If the decision is to pursue a community option, a transition plan will be implemented as well as a quality assurance plan to insure that community services meet Medicaid standards.

What's Up With Snoopy?

Alan Kemp,
Trust Director for The Arc of Indiana

MetLife is a life insurance company. But it also sponsors the MetDesk. The MetDesk provides general information on a variety of estate and financial planning topics designed to help parents of children with disabilities.

How did the MetDesk come into being? As I understand it, a MetLife employee, who is also a parent of a child with a disability, went to MetLife executives and suggested that MetLife help parents of children with disabili-

ties. The MetLife executives agreed and the MetDesk was born.

Today, over 200 MetLife agents specialize in helping parents of children with disabilities plan for their child's future. As I understand it, MetLife intends to increase this number to 500.

MetLife is a corporate sponsor of The Arc of the United States. What does it mean to be a corporate sponsor? It means that MetLife has given money to The Arc of the United States. In turn, The Arc of the United States has spoken positively about the MetDesk. (On

several occasions I have written to The Arc of the United States to find out what due diligence it exercised before promoting MetLife/MetDesk. Specifically, I wanted to know why parents should choose a MetLife policy. Were MetLife policies markedly better than other options parents might consider? The Arc of the United States has never responded to my question.)

How should you, as a parent, respond to a MetDesk/MetLife presentation? I think you must recognize that MetDesk/MetLife is doing more than providing a public service. Its purpose includes the sale of life insurance. My advice? Dismiss the "feel good" features of the presentation and focus on the forthcoming sale of life insurance.

Is buying life insurance a bad thing? No. But making informed decisions about life insurance — especially cash value life insurance — is not easy. Most consumer advocates in the field of life insurance will tell you that the life insurance industry has made it impossible for lay people to make informed decisions.

So what do you do? Should you dismiss life insurance as a possible means of planning for your child's financial future? No. For many families, life insurance may be the best option.

Should you rely on an agent? Many people do, but this can be a problem. Most agents are paid by commission. The commission they receive depends on the policy they sell. Some policies pay more commission than others. How do you know the policy promoted is in your best interest?

To overcome this problem, The Arc of Indiana has an arrangement with James Hunt, a semi-retired life insurance actuary affiliated with the Consumer Federation of America. The Arc of Indiana pays Mr. Hunt a fee to (a)

guide you in making an efficient decision on the purchase of life insurance and/or (b) review your present life insurance holdings. It must be emphasized that Mr. Hunt receives only The Arc of Indiana's payment. Mr. Hunt receives no direct or indirect compensation from any insurer. Further, The Arc of Indiana has no relationship with any life insurance company. The Arc of Indiana will not profit financially from any decision you make.

If you are considering a life insurance purchase — be it MetLife or any life insurance company — and you want an informed second opinion, call The Arc Trust at 317-259-7603 or 877-589-8848. We'll be glad to help.

The Arc of Indiana Master Trust ...



When I die, how will my child's personal needs be met?

Many parents who ask this question are finding that The Arc of Indiana has a dependable answer, The Arc of Indiana Master Trust I. Trust I has operated continuously and successfully since 1988.

Trust I lets you leave funds for your disabled son or daughter without endangering eligibility for government programs such as Supplemental Security Income (SSI), Medicaid, group homes, and Indiana's Supported Living Program. To protect eligibility, The Arc serves as the intermediary with government agencies on all trust related matters. Family members need not worry about learning regulations and dealing with government bureaucrats. Trust I assumes these responsibilities.

How are we doing? Currently, we administer over 250 funded Trust I accounts. If you want experienced and knowledgeable representation for your child who is disabled, Trust I might be appropriate.

We also administer over 440 Trust II accounts. Trust II accounts are usually funded by persons who are themselves disabled. Like Trust I, Trust II continues eligibility for benefits like SSI, Medicaid, group homes, and Supported Living.

Our trust program may be the largest of its kind in the country. Over 780 families are enrolled in Trust I alone. (Trust I accounts are usually funded at the death of a family member.)

Over 500 individuals are enrolled in Trust II. Combined enrollments exceed 1,300.

For a free copy of our material call or write:

The Arc of Indiana Master Trust
P.O. Box 80033, Indianapolis, IN 46280-0033
(317) 259-7603 or toll free (877) 589-8848

*Free, Unbiased Service
from The Arc of Indiana*

Evaluation of Cash-Value Life Insurance Policies

It is very difficult to compare two or more cash-value life insurance policies. Life insurance agents can be helpful, but, because they are paid commissions, they may have a conflict of interest. The Arc of Indiana offers a free evaluation program for cash-value life insurance policies. Parents pay nothing for this service. The Arc pays a small fee to a semi-retired life insurance actuary. The actuary evaluates the policy parents are considering. We think this program can help parents make better informed decisions. For more information on this service, go to The Arc's web site at: www.arcind.org and click on "Life Insurance Assistance Program," or call The Arc Trust at: (317) 259-7603 or 1-877-589-8848.

THE ARC OF INDIANA

107 N. Pennsylvania St., Suite 300
Indianapolis, IN 46204

Call: 317-977-2375 or 800-382-9100

Web Address: www.arcind.org and www.TheArcLink.org

E-Mail: TheArc@arcind.org

The Arc News in Indiana is mailed to members of The Arc of Indiana. Contact your local Arc for membership information. Local members automatically become members of The Arc of Indiana and The Arc of the United States. If a local chapter is not located in your county, you may join The Arc of Indiana as an at-large member by sending a check for \$15 per year to The Arc of Indiana. Simply include a note with your name and mailing address, indicating the check is for "At Large Membership."

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The Arc of Indiana 2004 Convention and Annual Meeting October 14, 2004

Ramada Inn and Conference Center, Lebanon, Indiana
Hosted by Arc Rehab Services and The Arc of Tippecanoe County

"Life is like an ever-shifting kaleidoscope—a slight change, and all patterns alter."—Sharon Salzberg

Like the patterns of a kaleidoscope, the world involving people with developmental disabilities, their families and providers is ever changing. The challenge of change can be frustrating and overwhelming. But like a kaleidoscope, the new pattern that emerges *can* be better than what came before.

The Arc of Indiana's 2004 Convention and Annual Meeting, *The Challenge of Change*, will focus not only on current changes in programs and services for children and adults with developmental disabilities, but also on how parents, self-advocates, and providers can effectively advocate for changes that still must be made.

Our Keynote Speaker, David Roche; and Luncheon Speaker, Gail Williamson, are nationally respected advocates with an inspirational and motivational message you will not want to miss.

David Roche has transformed the lessons of lifelong facial disfigurement into a compelling message on how we all can take personal and professional challenges to make changes for the greater good.

The birth of her son, Blair, who has Down syndrome, led Gail Williamson on a journey that has resulted in her becoming a leading advocate for the positive portrayal of people with disabilities in the entertainment and media industry.

"We must be the change we want to see in the world." Mahatma Gandhi

Please plan to attend The Arc of Indiana's Convention and Annual Meeting, October 14, 2004, Ramada Inn and Conference Center, Lebanon, Indiana, and learn how you can be part of the kaleidoscope of change.

Pre-Convention Events, October 13

ICEArc Luncheon & Training

The Indiana Conference of Executive Directors of Arcs (ICEArc) annual luncheon and training will feature Sue Swenson, Assistant Executive Director for Chapter, Membership, and Program Services, The Arc of the United States; and Michael Komoll, National Counsel for the Human Services Program, and Senior Litigation Attorney in the CLEM Unit.

The Arc of Indiana Appreciation Dinner

The Arc of Indiana's Annual Appreciation Dinner will pay tribute to the

Registration Information

Pre-Convention Events, October 13

ICEArc Luncheon & Training
 ICEArc Member—\$40 / Non ICEArc Member—\$50
 Appreciation Dinner—\$40

CONVENTION & CONVENTION LUNCHEON, October 14

Self Advocate*—\$25
 Parent,* Family Member,* Non-Professional Advocate—\$50
 Professional, Provider,
 Agency Personnel—\$75

Ramada Inn and Conference Center
 Lebanon, Indiana, 505 South
 State Road 39, I-65, Exit 139

Overnight hotel reservations—
 \$64 single or double occupancy.*
 For reservations and information,
 contact:

Ramada Inn and Conference Center
 (765) 482-0500 or 1-800-499-3339



outstanding individuals who have made significant efforts to improve the lives of people with disabilities and their families. A highlight of the evening will be a performance by The Arc of Hancock County Dream Makers—an outstanding entertainment group of people with and without disabilities. Join the fun and celebration at the Appreciation Dinner!

For complete information on the Convention, ICEArc Training and Luncheon, and Appreciation Dinner, please visit our web site at:

http://www.arcind.org/2004_convention_.htm

* Scholarships may be available through the Governor's Planning Council for People with Disabilities' Consumer Involvement Fund. Call: (317) 233-4551. Limited financial reimbursement may be available through INSOURCE's Family Involvement Fund. Call: (574) 234-7101 or 1-800-332-4433

Coming to a town near you!

A Public Forum on Home and Community Services for People with Developmental Disabilities

Indianapolis
 September 14
 10:00 a.m. - 12:00 noon
 St. Lukes
 United Methodist Church
 100 W. 86th Street

Lafayette
 September 20
 7:00-9:00 p.m.
 Ivy Tech, Ivy Hall
 3101 S. Creasy Lane

Howe
 October 18
 6:30-8:30 p.m.
 Arc Opportunities
 0235 W. 300 N.

Elkhart
 October 19
 2:00-4:00 p.m.
 Location to be
 Announced

Highland
 October 21
 1:00-3:00 p.m.
 St. James Parish
 45th and Kennedy

Columbus
 September 20
 2:00-4:00 p.m.
 City Hall
 123 Washington Street

New Albany
 October 6
 5:30-7:30 p.m.
 New Albany-Floyd Cnty.
 Public Library
 180 W. Spring Street

South Bend
 October 19
 9:00-11:00 a.m.
 LOGAN
 1235 N. Eddy St.

Fort Wayne
 October 20
 1:00-3:00 p.m.
 Easter Seals Arc
 North Building
 4919 Projects Dr.

Evansville
 October 22
 1:00-3:00 p.m.
 Deaconess Hospital
 Health Science Bldg.
 Johnson Hall
 600 Elder Street

Why Parents, Consumers, Advocates, and Providers Should Attend

Receive up to the date information on funding and waiting lists for home and community based services through Medicaid Waivers and State funding.

If you or a loved one receives home and community based services, come and share how services make a difference in your life.

If you or a loved one is on a waiting list for services, or you never knew you could apply for home and community based supports, come and share how the lack of services impacts you and your family.

Families, providers, and advocates can offer comments on barriers to receiving services, and suggestions to removing barriers.

Come learn how you can support efforts to increase state revenue and provide critically needed funds to move people off waiting lists and into home and community based services.

Legislators and candidates are being invited to come and learn about successes and needs in their district. They will have an opportunity to make comments.

Your participation can make a difference. Please join us.

For more information:
 The Arc of Indiana
 (317) 977-2375 or 1-800-382-9100
www.arcind.org, click on "Public Forums on Home and Community Services"

Keep Up to Date on State and Federal Legislation

Sign Up for

The Arc Action E-List

The Arc of Indiana and The Arc of the United States are leaders in advocating for people with developmental disabilities and their families at the Indiana General Assembly and the U.S. Congress.

Keep up to date with public policy that impacts you and your family.

Sign up to receive timely Action Alerts and Legislative Information via e-mail.

Go to: www.arcind.org
 Click on: Arc Legislative Information Page
 Click on: Sign Up for Action E-List

If you have signed up for this service in the

past, but your e-mail address has changed, please be sure to go to this site to update your information!

If you do not have an e-mail address, but do have access to the Internet, you can read Action Alerts posted on our web site.

Go to: www.arcind.org
 Click on: Arc Legislative Information Page
 Click on: Legislative Action Center