

State Fiscal Crisis Challenge to Needs of People with Disabilities

The 2003 session of the Indiana General Assembly will be extremely challenging for policy makers, and for advocates and families of people with disabilities.

The billion dollar surplus once enjoyed by the state is gone. During the previous two budget cycles, the 317 Plan received overwhelming support. Over \$80 million was appropriated to help serve people with developmental disabilities in the community, move families off of waiting lists for Medicaid waivers for home and community-based services, help families in crisis situations, provide raises to direct care workers and for other important efforts to improve services in Indiana. However, due to the fiscal crisis, millions of dollars in funds appropriated in 2001 were cut.

Programs and services serving people with disabilities were cut by \$26 million due to the fiscal crisis.

The Arc of Indiana remains committed to improving the delivery of services.

The Governor's strong commitment to people with developmental disabilities moving into the community remains the same. Many legislators remain committed to creating a home and community-based system for people who are disabled. The needs of Hoosiers with developmental disabilities and their families remain the same and in some cases have wors-

ened. Families caring for loved ones with disabilities continue to age and sacrifice. Families of young children with developmental disabilities who are experiencing financial difficulty will soon be mandated to pay for services provided through the First Steps system—services that are currently free to those that are eligible. However, revenues for the state keep falling short of projections, and the economy of the state continues to decline.

Despite the fiscal crisis facing the state, The Arc of Indiana will continue to work to make sure that the needs of people with mental retardation and developmental disabilities remain in the thoughts of policy makers. We will also continue to look toward creative ways to finance criti-

cally needed programs and services.

The 2003 Legislative Session will be difficult. The Arc of Indiana promises to remain committed to improving the delivery of services to people with mental retardation and developmental disabilities. We will be relying on our members, chapters and friends to send a strong message—although in financial terms times have changed in Indiana, the needs of Hoosier families with developmental disabilities remain.

We need to work together with policy makers to increase economic development opportunities and therefore generate greater revenue for state supported programs. We need to work together with policy makers to see our great state out of its fiscal crisis. Together we can make a difference.

Time for Real Change in Indiana

Investment in Human Services, Investment in Economic Development

In the 2003 session of the Indiana General Assembly, legislators will make significant decisions that will affect the future of all Hoosiers. Economically we currently rank first in several categories—bankruptcies, home foreclosures, lost jobs. And we are nowhere near first in the areas that would indicate a growing economy. A strong, vibrant economy is needed to generate revenue to allow for important investments in human services, investments that can build a better Indiana for all citizens.

Yet, the current fiscal crisis places even greater constraints on the state's ability to invest in either economic or human service needs. If human services are cut further, and we fail to make economic investments, we will only further deteriorate the economic and human services situation in Indiana.

(Continued on Page 2)

Programs for People with Disabilities Cut by \$26 Million

Further Cuts Possible

The State of Indiana's budget crisis has affected the lives of people with developmental disabilities and their families. Funds allocated in the state budget for programs serving people with disabilities have been significantly reduced as part of the effort to address the budget crisis.

Some of the key funding cuts include:

Not releasing "317 Plan" funds to move people off of waiting lists for home and community-based services:	\$ 6.5 Million
Eliminating funds for wage increases for direct care workers:	\$18.8 Million
Eliminating Physical Disabled Service Program:	\$ 760,000

In addition to these direct cuts in funding, the Family and Social Services Administration (FSSA) has worked with The Arc of Indiana and INARF to refinance programs currently funded with 100% state funds, to financing under a new "Support Services Medicaid Waiver." This shift in funding has taken a tremendous burden off the state budget, freeing up significant funds for deficit reduction. State funds saved through refinancing total \$15.5 million.

Through the support of INARF, a tax on group home providers was increased by 1.75%, bringing in another \$3,937,500 in new revenue to help with deficit reduction. The move to Medicaid waivers also allowed 125 group home beds to be closed, generating another \$5.2 million in savings.

All told, funding cuts and the refinancing of programs for people with developmental disabilities has already contributed over \$50 million to address the state's budget crisis.

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Best Buddies



Best Buddies International is a non-profit organization dedicated to enhancing the lives of people with intellectual disabilities by providing opportunities for one-to-one, mutually-enriching social friendships and integrated employment.

Best Buddies International was founded in 1989 by Anthony Kennedy Shriver, whose parents established The Peace Corps and Special Olympics. Anthony grew up with the first few Special Olympics events in the Shriver's backyard and saw the wonderful interaction that the athletes had with each other and their coaches, and wondered what happened with the social lives of those with disabilities after they left the Special Olympics event.

This led him to establish Best Buddies while a student at Georgetown University. Today Best Buddies has

grown into a vibrant organization with nearly 800 chapters worldwide, in over five countries and 36 U.S. States. Over 40,000 people will participate in Best Buddies Programs worldwide this year alone, all under a \$10 million organizational budget.

Best Buddies International offers six unique programs: Best Buddies Jr. High, Best Buddies High School, Best Buddies College, Best Buddies Citizens, Best Buddies Jobs, and e-Buddies. Best Buddies participants go and do activities together twice a month and communicate with each other at least once a week. And through the e-Buddies program, participants are able to gain free computer hardware, when available, and free AOL internet access. Best Buddies programs do not cost schools or program participants anything—all funding is derived from

private donations, foundations and special events.

The Best Buddies Indiana Office opened on January 15, 2002 with funding from the Indiana Down Syndrome Foundation. It offers three of the six available programs: Best Buddies High School, Best Buddies College, and e-Buddies. Over 20 chapters of Best Buddies have already been established in Indiana.

Best Buddies Indiana will host a bike event at Eagle Creek Park in Indianapolis on April 12, 2003. To find out more about the event, about Best Buddies, be added to the Best Buddies mailing list, or make a financial contribution, contact Best Buddies Indiana State Director, Nick Parkevich at 317-917-0750, or check out the Best Buddies International website at www.bestbuddies.org.

COUNT US IN PROJECT REACHING OUT TO VOTERS WITH DISABILITIES

The Indiana Governor's Planning Council for People with Disabilities (GPCPD) has launched a new project called *Count Us IN*. The *Count Us IN* project seeks to increase the number of registered voters and also increased voter turnout among Hoosiers with disabilities.

Almost one in five Hoosiers has a disability. The Council wants to ensure, through the *Count Us IN* project, that all Hoosiers with disabilities have a say in the issues that affect them everyday.

Count Us IN is working with state agencies, advocacy groups, not-for-profit organizations and others on voter registration. People with disabilities report that many service providers have never asked them to register to vote,

despite their obligation under the National Voter Registration Act (better known as Motor Voter). *Count Us IN* is working with local leadership teams to organize nonpartisan get-out-the-vote drives and candidate forums. The project also encourages Hoosiers with disabilities to be involved as poll workers and campaign volunteers.

Last fall Congress passed the Help America Vote Act which addresses several issues of concern for voters with disabilities. This new federal law requires that every polling place in the country have at least one accessible voting machine which allows all people with disabilities to cast their ballots secretly and independently. The law also requires polling places to be ac-

cessible, and federal monies will be made available to counties to help with the costs of providing accessible technology and voting locations.

Indiana must pass legislation at the state level to implement the federal reforms. This will provide an opportunity to improve some weaknesses in the law—including the lack of standards or deadlines for polling place accessibility. *Count Us IN* volunteers will be involved in the debate on these issues to ensure that the right of citizens with disabilities to vote will not be overlooked.

To learn how you can get involved with *Count Us IN*, contact the Project Director, Julia Vaughn, at (317) 234-2226 or countusin@gpcpd.org.

INVESTMENT, from page 1

It is time for a major investment in both economic and human service development that will bring jobs and business growth to Indiana.

In a recent editorial *The Indianapolis Business Journal* called upon the state to honor its commitment to the Life Sciences Corridor—a major initiative designed to stimulate and attract high-tech business to Indianapolis. Indiana has not been able to do so because of declining resources. This is just one example of the kind of investment that needs to be made statewide.

There have been numerous editorials across the state calling on leaders in public policy to make investments in education and human services that will improve the quality of life for Hoosiers, thereby keeping and attracting business to Indiana. Further cuts in spending will not stimulate the economy and will only make Indiana a less desirable location for people to move to or keep their businesses.

Members of the Indiana General Assembly and the Governor courageously stepped forward and acted responsibly in the last special session to avoid catastrophe with the property tax system. Problems remain, and not raising taxes is *not* the answer. Now is the time to step boldly into the future with strategic investments and a long term plan for economic development, education and human services.

To give the state the tools to compete for business and raise the standard of living for all Hoosiers, it will take modernization of the current tax system and encouraging new sources of revenue.

Sue Hansen Recipient of 2002 Colts/NFL Community Quarterback Award

Sue Hansen, a member of The Arc of Indiana Board of Directors, Chairman of the Governmental Affairs Committee, and founder of Camp Awareness, was honored by The Indianapolis Colts as the second runner up of the 2002 Colts/NFL Community Quarterback Award. The recognition was accompanied by a grant of \$3,500 to The Arc of Indiana.

The 2002 Colts/NFL Community Quarterback Award is a volunteer recognition program that honors community organizations served by outstanding volunteers. It honors

individuals who exemplify leadership, dedication and a commitment to improving the communities in which they live through volunteerism.

Sue was honored for her volunteer efforts for The Arc of Indiana, and for her work in founding Camp Awareness, a summer camp for children on the autism spectrum, located in Noblesville at the Boys and Girls Club of Indianapolis facility.

Sue Hansen and her son Sean at age 3. Sean is now 16 and attends Lawrence North High School.



Executive Director's Columns

Annual dinners of local chapters of The Arc in Indiana provide a wonderful time to see old friends, meet new ones and remind ourselves just how far we have come. In November I had the chance to be in Lake and Jackson counties to share in their festivities. LCAR celebrated its 50th Anniversary and has over 500 members. And while not quite 50, the Jackson County Arc was 100 members strong for their dinner in Seymour.

But the numbers don't tell the whole story. Each chapter of The Arc represents our communities—the people we depend on to make a difference. We take this time to recognize teachers and educators, employers, staff, volunteers and self-advocates who go that extra mile. And there are so many heroes.

Someone said that heroes are ordinary people who do extraordinary things. That is so true! And we need more of those ordinary people because we are facing extraordinary times.

Indiana's state budget is facing a shortfall of

Each chapter of
The Arc represents
our communities.



John Dickerson

nearly \$1 billion as the economy drops and revenues suffer. How will our elected leaders respond?

Some are calling for significant cuts in the budget that will bring it into balance—cutting nearly \$1 billion will be impossible without eliminating entire programs. No one knows how that can be done without hurting people.

Others are calling for some cuts in the budget and some continuing work on taxes to finish the work started last session to balance the budget. But there

is no widespread support for raising taxes yet.

The Arc of Indiana believes we need to move quickly to modernize our tax structure and stimulate our economy with strategic investments that will keep good jobs in Indiana and bring more jobs to our state. To keep and attract good jobs, we must continue to have strong communities with good schools, effective human services, and family support programs.

Attracting business is difficult when we are dismantling the supports that keep families together. We must have strong communities to build a strong economy.

It is a critical time for Indiana. How we respond is important. It is perhaps less important now to be a Democrat or Republican than to be a Hoosier. The contest is not who wins the next election, but how we compete with our neighboring states to make Indiana an even better place to live. We need that leadership, those heroes that will make a difference.



TheArcLink

www.TheArcLink.org

Angie Cain and her mother Beth use the Internet to find information about programs and services for people with developmental disabilities on TheArcLink. Angie will graduate from Mount Vernon High School this spring. She can use TheArcLink to navigate the new world of programs and services for adults with developmental disabilities—vocational rehabilitation, supported employment, day program services, Medicaid waiver providers, etc.

The mission of TheArcLink is to provide resources through technology that empower individuals with disabilities and their families to make sound choices about services that support their full participation in the community.

The SBC Foundation has awarded a \$55,000 SBC Excelsator grant to The Arc of Indiana, in partnership with TheArcLink Incorporated and the Indiana Institute on Disability and Community. The grant will provide resources to public access sites like public libraries, to help people use the Internet.

Agencies Announce New Leaders

Deidra Conner Promoted to Serve as Executive Director of Evansville ARC

After an extensive nationwide search Deidra Conner was promoted to Executive Director of Evansville ARC in June 2002.

Deidra had served as Evansville ARC's Director of Finance since October 2001. Prior to her employment with Evansville ARC, she was the Manager of Internal Audit and the Corporate Compliance Officer with Deaconess Hospital. She is a Certified Public Accountant and has been a committee member for several years with the American Institute of Certified Public Accountants and the Indiana CPA Society. She was also the Past President of the University of Southern Indiana Alumni Association.

Margaret Boarman retired in December of 2002, after serving as President and CEO of Evansville ARC since 1990. Margaret led the agency with great vision to develop and expand five programs which includes an all inclusive Child Life Center for 160 children with/without disabilities; an Adult Habilitation Program offering both agency and community based activities for over 100 individuals with severe and profound disabilities; Community Job Link which provides supported employment for approximately 50-75 individuals annually; ARC Industries, an ISO 9002 registered work center that employs over 235 individuals with disabilities; and Community Living Support, which provides in-home personal attention to families with special needs children and adults.



Deidra Conner

Noble of Indiana Selects New President/CEO

Ervin J. Picha has stepped down as Noble of Indiana's president and CEO and will assume a one-year term as president of Noble Foundation. Taking his place on January 1, 2003 will be Michael R. Howland, currently Chief Executive Officer of four charity associations based in Springfield, Virginia. Howland is CEO of Christian Service Charities, Medical Research Agencies of America, Share America! and Human Service Charities of America. Howland has also served as president and CEO of Independent Charities of America in San Francisco and as a District Director and Acting Regional Administrator for the Small Business Administration. Last year Picha shared with the Noble board of directors his decision to retire from his position as president and CEO after 23 years leading the agency. Picha came to Noble in 1973 and assumed the role of president



Michael Howland

and CEO in 1979. During his tenure Noble has grown into one of the state's largest providers of services and supports to individuals with developmental disabilities, working with 2,500 children and adults and their families each year. In that time the agency pioneered, in 1983, early childhood therapy services in home and community settings, initiated the state's first Supported Employment program in 1986, and launched Noble Communitas in 2001. Today a majority of the people Noble works with are receiving their services in the community. This number is expected to grow as the agency moves more individuals into Noble Communitas, a demonstration project that utilizes intensive person-centered planning to help individuals shape their lives within the community.

Keeping Our Promise on Special Education

By U.S. Senator Jim Jeffords

Senator Jeffords, an Independent from Vermont, is a member of the Health, Education, Labor and Pensions Committee.

The year was 1975. There were 92 new members in the House of Representatives, and, in the wake of Watergate, I was one of only 17 Republicans. Having so few party colleagues gave me immediate seniority. I became the ranking Republican on the Select Education Subcommittee, charged with helping to write what would later become the Individuals with Disabilities Education Act (IDEA), also known as special education.

Responding to court decisions and litigation in more than half the states, we set out to ensure that children with disabilities received a “free and appropriate education,” as the courts would define it. It was not a matter of if we should do it. It was the only thing to do. It was the right thing to do. It was only a question of how we should do it.

We knew it would be costly, but as we wrote the legislation we agreed that since special education was a federal constitutional guarantee, the federal government had the obligation to pay its fair share. In the end we agreed that 40 percent of the additional costs of special education would be paid for by the federal government.

That was 27 years ago, and we have not even come close to meeting our obligation. In 2002 the federal government is spending \$7.4 billion on special education, or just 17 percent of the additional costs to educate children with disabilities. Our states, our towns and our local taxpayers are left to foot the bill for the federal government’s failure to keep its promise.

Repeatedly, we have heard from state legislatures around the country that full funding of IDEA is a top

priority. In my small state of Vermont we are talking about the difference between \$16 million—the amount of federal special education funding my state will receive this year—and \$38 million, which is what Vermont would have received if we had only kept our promise.

By 2007 we would be funding special education at \$21 billion annually. Against the backdrop of the president's proposed \$1.6 trillion tax cut, this did not sound at all unreasonable.

Right now my state is struggling, like so many others, to cut budgets because of the economic downturn. Education dollars will not be spared, and that additional \$22 million would have gone a long way this year towards easing the pain of the budget crunch. If we had only kept our promise.

The chronic under funding of special education is inexcusable. It was also a major factor in my decision to leave the Republican Party last year and declare myself an Independent.

In the spring of 2001, as chairman of the Senate Health, Education, Labor and Pensions Committee, I pushed my colleagues to fulfill our obligation, and I took my case to the Republican leadership and to the White House. On May 3, 2001 the Senate passed an amendment, which I joined in introducing, that would have increased special education funding by \$2.5 billion each year over six years, so that by 2007 we would be funding special education at \$21 billion

annually. Against the backdrop of the president’s proposed \$1.6 trillion tax cut, this did not sound at all unreasonable. And finally, we would be keeping our promise—albeit 32 years after we made it.

My hopes soared when that amendment passed by voice vote, but they hit rock bottom when the amendment failed to be included in the final version of the “No Child Left Behind Act.”

The Senate has repeatedly cast symbolic votes to fully fund IDEA, but these votes have been nothing more than that: symbolic. It is time to move beyond the symbolism.

We have seen much progress since we passed the initial IDEA legislation. Children with disabilities are now being educated alongside their peers in unprecedented numbers, and we know that education helps these children lead more independent and fulfilling lives.

But there will be tremendous funding pressure in the years to come. I recently saw figures from the U.S. Census Bureau showing that one of every 12 children in the United States has a physical or mental disability. This marks a significant increase from the previous decade.

We must remember one thing as we consider this issue: This fight isn’t solely about special education. It is about the education of all of our children, because when we under fund one area, other areas suffer. If our schools did not need to worry about backfilling the federal government’s shortfall, our educators could dedicate more time and resources to areas such as early education, which we know plays a critical role in child development. But that and other tremendous opportunities have been lost.

If we had only kept our promise.

U.S. Dept. of Labor Awards Indiana Grant for Outreach to Youth with Disabilities

The Arc of Indiana is partnering with the Indiana Institute on Disability and Community, and Interlocal Association (IA) to carry out a model demonstration project in Johnson County, Indiana to help move youth with disabilities into the workforce. The project is funded by one of eight grants provided nationally by the U.S. Department of Labor. IA is the staff support organization for the Circle Seven Workforce Investment Board of Indiana.

The two-year project will provide funding for a parent trainer to help parents understand the barriers their child faces in transitioning from school to work, and how to overcome those barriers. Training on transition services will be developed and offered to all stakeholders, and an outreach program will be developed to link youth with disabilities to Workforce Investment Act programs. The Indiana Institute on Disability and Community will assist in developing a curriculum to assist youth seeking services from school, VR, and Workforce Investment Act programs.

Betty Williams Attends DPI Conference in Japan

Betty Williams’ self advocacy efforts have taken her far—all the way to Sapporo Japan to attend the Disabled People’s International (DPI) World Assembly in October. Betty is a member of The Arc of Indiana Board of Directors and leader of Self-Advocates of Indiana.

Betty was invited to attend the 6th DPI World Assembly by Sue Swenson of the Kennedy Foundation and former Commissioner for the Administration on Developmental Disabilities. Betty was one of only twenty-five people from the United States invited to attend the international conference.

As one of the attendees, Betty had the opportunity to make recommendations to the United Nations about supports and services needed by people with disabilities world wide.

Shortly after the conference began, Betty quickly learned that she needed to speak out strongly that a starting point would be to fully include people with developmental disabilities in the conference itself. She was frustrated and surprised that it was difficult to find other people with developmental disabilities at the conference, and that people with developmental disabilities were not even on the agenda to make recommendations about their needs.

“Even though it was a conference for people with disabilities, we were excluded and it was frustrating.

I learned that I had to speak up to let people know that we needed to be part of the recommendations. We had to keep talking about our needs and why we needed to be part of a cross disability coalition. It helped me see how hard it is to advocate for what you need and want,” Betty said.

“I learned that even people with disabilities can have preconceived notions of what people are like, even if it is not true. I thought that the people in Japan would not be nice, but they were really nice. This shows why it is important for people to get to know each other. It is not just a disability issue, it is a human issue,” Betty said.

Betty concluded, “At first I did not want to go out of the country, but then I thought, ‘Why Not?’ It will be a great learning experience.’ And it was a great experience. It helped me in the Women’s Studies class I am taking. At the conference, I attended sessions about the women’s movement and the disability movement, and a session about women with disabilities and violence. I had been having a hard time on a project I had to do for the class, and I was able to use the experience of attending the conference to tell my own story about my life, and how it led me to going to Japan.”

Betty is working to obtain a degree in Human Services from Indiana University East.

THE ARC OF INDIANA 2003 PUBLIC POLICY AGENDA

GUIDING PRINCIPLES

The Arc of Indiana is committed to all people with mental retardation and other developmental disabilities, and will work to develop programs, funding and public policy that will assist them in realizing their goals of learning, living, working and recreating in the community.

The Arc of Indiana is committed to families, and will work to develop programs, funding, and public policy that will help support families who have loved ones with mental retardation and other developmental disabilities. In addition, The Arc of Indiana is committed to reducing the incidence of mental retardation and other developmental disabilities.

COMMUNITY-BASED SERVICES AND SUPPORTS

The Arc of Indiana will support and work for the continued efforts to end the waiting lists for Medicaid waivers for Home and Community-Based Services for the thousands of Hoosier families waiting for community services. We will continue to work for better utilization of federal funds for Medicaid, Medicaid waivers, and Vocational Rehabilitation.

The Arc of Indiana will work with the Governor's Commission on Home and Community-Based Services in implementing its objectives and goals to see people of all disabilities and ages living successfully in the community.

The Arc of Indiana believes that person-centered planning is critical in the lives of people with developmental disabilities and their families and will work to ensure that choices are given and the rights of the consumer for home and community-based services are known.

The Arc of Indiana believes that it is critical that people with disabilities have guardianship services available to them to assist them in making choices to live successfully in the community. We will work to include guardianship and advocacy services as part of the service options available through existing funding streams.

The Arc of Indiana will continue to monitor the implementation of its Medicaid Buy-In Program which will allow people with disabilities to maintain their health insurance while they choose to go back to work.

The Arc of Indiana realizes the importance in increasing wages to direct care workers. We recognize the inability to attract qualified workers, and will work to increase training and benefits to direct care workers.

The Arc of Indiana will continue discussions surrounding the loss of level

of care issues facing people and families with developmental disabilities. We will work to ensure that all long term care, residential and family support services provide for quality assurance, regardless of the funding source.

STATE OPERATED FACILITIES

The Arc of Indiana will continue to work with the State for the appropriate movement of people out of Indiana's State Operated Facilities and into the community. We will work to ensure the highest level of quality assurance is put into place for all people with disabilities, no matter where they live.

The Arc of Indiana will also work to ensure funding streams follow people and that sufficient funds are provided both for the initial placement and ongoing services.

CRIMINAL JUSTICE ISSUES

The Arc of Indiana recognizes the increased opportunity of people with mental retardation and developmental disabilities to become involved in the criminal justice system, both as offenders and victims, as more people choose to live in the community. People with mental retardation who commit crimes should be held accountable for their behavior, but should be provided the appropriate supports to make their experience with the criminal justice system fair and equitable. People with mental retardation who become victims of crime should be treated fairly and provided the appropriate supports to protect their rights.

The Arc of Indiana also recognizes the importance and need for training and education of those involved in the criminal justice process at all levels.

EARLY INTERVENTION

The Arc of Indiana is committed to infants and toddlers with mental retardation and other developmental disabilities. We will continue to evaluate the impact of the First Steps, Early Intervention Program for Infants and Toddlers. The Arc of Indiana will work to support the design of the First Steps program so that it will promote principles of best practice in early intervention, including the support of a developmental/consultation model of service delivery and a commitment to appropriate levels of service for all eligible children. In addition, The Arc of Indiana will continue to closely monitor the implementation of the cost participation/sliding fee scale for families to ensure that all childhood programs and services are affordable and meet the needs of infants and toddlers with disabilities, or at risk of disability and their families.

SPECIAL EDUCATION

The Arc of Indiana will work to ensure that children in special education services in Indiana receive fair and equitable treatment and testing in achieving a high school diploma and are given every opportunity available to continue their education after high school.

The Arc of Indiana supports the expansion and funding of teacher learning and professional development programs in order to meet the wide range of abilities of all students served by our public schools.

INSURANCE

The Arc of Indiana will continue working with families, the state and players in the insurance industry to provide quality health insurance coverage and services to children and adults with developmental disabilities. We will support efforts to ensure that Indiana addresses the health insurance needs of children with disabilities in Indiana through the Children's Health

Insurance Plan and will work to improve access to needed prescription drugs for people with developmental disabilities.

The Arc of Indiana will oppose changes to the Indiana Comprehensive Health Insurance Association which would result in increased costs to policy holders and force them to become uninsured. We will also oppose any legislation that allows insurance companies to write health insurance policies that waive or exempt pre-existing conditions.

PREVENTION SERVICES

The Arc of Indiana will support efforts to educate the public about the dangers and long term effects of fetal alcohol syndrome, shaken baby syndrome and lead poisoning. We will also support efforts that address the importance of good prenatal care and folic acid during pregnancy to reduce the risk of mental retardation and other developmental disabilities.

News You Can Use

Keep Up to Date on Public Policies Affecting People with Developmental Disabilities: Legislative Action Center

The ability of people with disabilities to live, learn, and work in communities throughout Indiana is greatly impacted by Federal and State laws, and funding of programs and services for people with disabilities.

The combined voices of people with disabilities and their families have made a difference—all children, regardless of disability, are entitled to a public education; Medicaid funding is now available for home and community-based services—not just services in an institution; and federal and state laws and funding are helping to open the door to employment.

People with disabilities and their friends and family can and must continue to impact public policy and funding of programs and services by keeping their U.S. and state representatives informed.

One way to keep informed via the Internet and e-mail is The Arc's Legislative Action Center. It provides up-to-date information about key issues impacting people with developmental disabilities, and provides quick and easy access to send e-mail messages to elected officials.

How do you find the Legislative Action Center?

On the Internet, go to: www.arcind.org. Click on: Arc Legislative Information Page. Then click on: Legislative Action Center.

You can also sign up to receive *Legislative Alerts* from The Arc of the United States and The Arc of Indiana. To receive *Legislative Alerts* via e-mail, go to: www.arcind.org. Click on: Arc Legislative Information Page. Then click on: Sign-Up for Action E-List.

Keep up to date with The Arc's Weekly E-Memo

The Arc of Indiana publishes *Weekly E-Memo* to get information to local Arc chapters, The Arc of Indiana Board of Directors, and leaders in the field of developmental disabilities.

The *Weekly E-Memo* consolidates the myriad information that comes through our office via faxes, e-mails, newspapers and meetings. It is sent via e-mail and also posted on The Arc of Indiana's web page. Go to www.arcind.org. Then click on: Weekly E-Memo.

Open Letter from Martin C. Jischke, President, Purdue University

December 6, 2002

Dear Member of The Arc of Indiana:

As you know, Indiana is facing tough economic times, and we must pull together as a statewide community to help our leadership find ways to help solve this crisis. That is why I applaud The Arc of Indiana for getting involved in the economic development debate. At Purdue, we are also finding solutions to assist in this effort.

During the 2003 session of the Indiana General Assembly, Purdue will propose funding for the state's first-ever public university undergraduate degree program in Biomedical Engineering. The initiative will allow for the education of outstanding students who will learn engineering science, analysis, design, and problem solving solely in the context of biomedicine. These biomedical engineers will supply Indiana medical device and biotechnology companies with new ideas and capabilities to develop leading-edge clinical technologies.

Purdue will request funding of \$5 million per year to support the biomedical engineering undergraduate school and expansion of our graduate program and its related discovery research technology and transfer. The support would allow:

- Hiring of 15 new faculty members in biomedical engineering, at least two of who will be internationally prominent scientists at the full professor level.
- Hiring of four new faculty in the biomedical engineering-related disciplines.



Jischke

- Education of 75 new biomedical engineers each year at the bachelor's level and 25 at each of the master's and doctorate levels, after an initial curriculum development and growth period.
- Addition of 10 academic support staff including instructional laboratory coordinators and counselors.
- Support of 25 outstanding graduate students as teaching assistants to the undergraduate program and fellowship recipients.
- Development of unique instructional and research laboratories in biomedical engineering with state-of-the-art scientific equipment.
- An increase in sponsored research of at least \$5 million annually.

Further, consistent with Governor O'Bannon's new Energize Indiana plan, Purdue's capital budget request to the Legislature also proposes \$13 million for a new \$25 million state-of-the-art building to house the Department of Biomedical Engineering. The remaining \$12 million will be raised from private resources.

A vibrant and well-trained workforce is crucial to the future success of our Indiana economy. I hope you will join with Purdue and talk to your legislators about this important initiative. You can find out more information about how you can help by contacting Susan Brock Williams, Purdue's Legislative Initiative Coordinator, at swilliams@purdue.edu. Thank you.

Sincerely,
Martin C. Jischke, President

Community programs offer greater independence for many

RALPH GROEGER lived at Muscatatuck State Developmental Center (MSDC) from the time he was an infant, until about two years ago, when his whole life changed. At that time, he moved to a group home in Fishers, and began receiving services under a Medicaid waiver for home and community-based services.

With assistance from Noble Community Support Services Instructor, Cindi Cavelage, Ralph enjoys exercising at the YMCA and working as a volunteer at the Fishers Parks Department.

He is learning new life skills, including eating with a knife and fork, rather than eating with his fingers; learning signs for "yes" and "no," and using a communication board to make choices about what he wants to do. For example, Cindi put various restaurant logos on the communication board, and now Ralph can choose where he wants to go to eat. Cindi was told Ralph would never be able to speak; however, he can now say "more" and "bye-bye;" and when Cindi recently asked if he was ready to go out, Ralph surprised everyone when he replied, "ready!"

Cindi sees Ralph progressing every day, she says, "There is nothing that Ralph won't try. His future is wide open."

Story and photo provided by Noble Arc of Greater Indianapolis



DENNY KNELLER had a dream to visit Graceland to see the home of Elvis Presley. He even had a garage sale to help fund his trip. His dream came true when he made the trip to Graceland last year.

Denny has also made a personal journey that has led from Fort Wayne State Developmental Center, to a nursing home, to a group home that he shared with seven other men, to a three bedroom home in Columbia City that he now shares with two roommates. He enjoys playing the guitar, which he purchased from his job delivering papers; and is taking lessons at Denny's Music Store in Columbia City.

Denny has been able to make his journey from life in a state institution, to a home in the community, with the support of Passages Community Supports Program, funded by a Medicaid waiver for home and community-based services.

Story and photo provided by Bi-County Services, Inc. & Passages, Inc.



WAYNE GOINS was placed at Fort Wayne State Developmental Center (FWSDC) in 1960 when he was only six years old. He lived there for sixteen years. Wayne moved from FWSDC to an adult foster home, where he lived for the next nine years. In 1986, Wayne moved to a residential program operated by LCAR, where he lived until 2001. In November of 2001, Wayne was able to move to a two bedroom apartment that he shares with a friend, with supports from LCAR's supported living program.

Employed at the Highland Meijer store since 1999, Wayne works 12 hours a week in the Deli Department where he does janitorial work. He loves his job, and his supervisor has given him excellent job reviews. Wayne enjoys participating in a weekly bowling league, attending church with his friends, dancing, and amazing friends and acquaintances with his vast knowledge of automobiles.

Story and photo provided by Lake County Foundation for the Retarded

Trip to Tulsa Provides Information on Community Services for People with Severe Disabilities

With the support of a grant from the Governor's Planning Council for People with Disabilities (GPCPD), The Arc of Indiana facilitated a trip to Tulsa, Oklahoma in early February, 2002 to learn how people with severe disabilities—who once lived at Hissom Memorial Center, a state institution—made the transition from living in an institution to living in neighborhoods throughout Tulsa.

Indiana's delegation to Tulsa included: Marilyn Schultz, former Director, Division of Disability, Aging, and Rehabilitative Services and currently State Budget Director; Chris Newman, Deputy Director, Quality Improvement Services; Doug Beebe, former Deputy Director, Integrated Field Services and currently Deputy Director, Aging and In-Home Services; Carolyn Ernstberger, sister of a resident of Muscatatuck State Developmental Center (MSDC); David Tevebaugh, brother of a resident of MSDC; Ilene Younger, mother of a resident of MSDC (Ilene's daughter, Susan, passed away last winter); Becky Smitha, MSDC Occupational Therapist; Jim Van Dyke, Executive Director, St. Vincent New Hope; and Sally Morris, Director of Communications, The Arc of Indiana.

Why Tulsa? The system of community programs for people with severe disabilities in Oklahoma have been



Ilene Younger and Becky Smitha at one of the homes visited in Tulsa, OK.

looked to as a national model. The program was developed as the result of a court order to close Hissom Memorial Center and move all residents into community programs.

Although Indiana has a long history of serving people with developmental disabilities in group homes and in small, residential programs funded by the Medicaid waiver, people who are considered "medically fragile" have typically not been served in small, community-based programs. The trip

to Tulsa was organized to gain first hand knowledge about their programs, and to meet with state officials, direct care staff, and case managers.

On the first full day of the trip, the group from Indiana split up in two teams, each touring six residential programs. During the visits, there was an opportunity to talk with direct care staff and case managers; and to see how medical equipment and assistive technology was integrated into typical homes.

The second day of the trip was spent meeting with key staff, including the state nursing director; the training director of Oklahoma State University—which carries out much of the training required for the community programs; the director of the quality assurance program; and the director of ETL (Effective Teaching/Learning), an organization providing direct services and intensive training in working with people with severe behaviors and those who are mentally ill and developmentally disabled.

Reflecting on what she learned from the trip, Becky Smitha said, "It was clear from the home visits and meetings that successful transitions were made by careful and detailed planning before people moved into the homes; direct care staff and case managers received intensive, high quality training; a strong system of checks and balances help to provide quality assurance; and that people who had lived in an institution for many years were thriving in their home due to this strong system of supports. I liked that parents took the time to come meet us and tell us about how scared they were about their son or daughter leaving the institution several years ago; but that now, after a lot of hard work and some rough times, things are good and that they are happy about the move into the community."

Update on Muscatatuck State Developmental Center

Jim Quiett liked the care his brother received at Muscatatuck State Developmental Center (MSDC). But, as he testified before the MRDD Commission, he is extremely pleased with how his brother's life has changed since he moved from MSDC to a home near him in Columbus. His brother is just one of nearly 100 people who have moved from MSDC to the community since the closure of the facility was announced in 2001.

One of the biggest changes Mr. Quiett has seen in his brother's life is that they now can go to church together every Sunday. The church even removed a row of pews to allow room for his brother's wheelchair so he may sit with his family.

Yet not everyone is pleased with the

announcement, and both federal and state lawsuits have been filed on behalf of parents seeking to slow the closure process and provide greater assurances of quality care for their loved ones. Several families wish to see the facility remain open.

There are now court orders in place that require the Family and Social Services Administration (FSSA) to assure no guardian is pressured into making a move until they are assured of quality

care in a setting they choose, and can clarify who may act as a health care representative for those persons without a guardian. In addition, the 2002 Indiana General Assembly passed SB 217, which allows the facility to stay open beyond the July 1, 2003 closure date passed by the 2001 Indiana General Assembly.

FSSA estimates they are working with 80 families and guardians who will oversee the movement of their

loved ones by the July 1, 2003 date, leaving approximately 100 persons on the campus after that time. Since the deadline to close the facility has been extended, a major challenge facing the state is how to pay the operating costs of MSDC which now exceed \$750 per person per day.

FSSA has pledged that, in accordance with the court order, anyone who moves out and must return will be allowed to do so until any problems can be resolved. Two persons have returned to MSDC since the closure of the facility was announced.

The Arc of Indiana believes that families will see positive changes in their loved ones, as Mr. Quiett has, as careful planning and selection of new providers opens new doors to the community.

The 2002 Indiana General Assembly passed SB 217 which allows the facility to stay open beyond the July 1, 2003 closure date.

Workshops on Medicaid Waiver Program Offer Information to Families

The Arc of Indiana, in partnership with the Indiana Institute on Disability and Community, Indiana University and The Indiana Parent Information Network has formed The Waiver Information Network (WIN) to provide up-to-date information on Indiana's Medicaid waiver programs and how they can help provide eligible people with disabilities the supports they need to live in the community. The project is funded by a grant from the Governor's Planning Council for People with Disabilities (GPCPD).

Medicaid waivers help families care for a child or adult with a disability or provide supports to help an adult with a disability live in the community. Medicaid waivers are available to people with developmental and physical disabilities or disabilities related to aging who need the level of care provided by a group home, nursing home, state developmental center or other long term care institution. Waivers can provide up to 24-hour support

for eligible people. Unlike other Medicaid programs, parental income and resources are not counted when determining eligibility for a child.

Nanette Whightsel, WIN Training Director, conducted workshops throughout Indiana in the fall of 2002 to educate families and people with disabilities about Medicaid waivers for home and community-based services.

Nanette's daughter, Suzette, lived at New Castle State Developmental Center (NCSDC) for many years. When NCSDC was closed, Suzette was able to use the Medicaid waiver to move to a home nearby her mother in Indianapolis.

Those who were unable to attend a workshop, but who would like information on Indiana's Medicaid waiver programs, can contact the Governor's Planning Council for People with Disabilities (GPCPD) at: (317)232-7770 to request, "*Indiana Medicaid Home and Community-Based Services, A Guide for Consumers.*" The guide is also



Nanette Whightsel, Waiver Information Network (WIN) Training Director, makes a presentation at one of 28 workshops held in 17 locations on Indiana's Medicaid waiver programs for home and community-based services.

available on the GPCPD website: <http://www.in.gov/gpcpd>. It is the first document in both the "Publications" and "What's New" sections. The workshop will soon be available on video. To request a

copy of the video, contact The Arc of Indiana at (317) 977-2375 or 1-800-382-9100.

WIN will conduct more workshops in the spring. Watch The Arc website for information: www.arcind.org.

Individuals Urged to Apply for Medicaid

Shift from State Funding to Medicaid Funding Will Save State Dollars

Across the state thousands of Hoosier families whose loved ones participate in a day program for people with developmental disabilities have been asked to apply for Medicaid in order to have the services provided to their loved ones paid for by Medicaid rather than state dollars. Each person whose program is paid for by Medicaid will save the state over 60% of the cost of the program.

Families should talk with local agency staff to determine what steps need to be taken to complete the application. If the person is not eligible for Medicaid, they will continue to receive services with state funds.

By moving as many people as possible to Medicaid funding, state funding is available to cover projected cuts in federal funding and to continue services to people throughout the rest of the year. By being on Medicaid funding, consumers have greater assurance of having services continue year-round.

Support Services Waiver New Addition to Indiana's Medicaid Waivers for Home and Community-Based Services

A new Medicaid waiver for Home and Community-Based Services, the Support Services Waiver, is now available to eligible people with developmental disabilities. The Support Services Waiver was approved by the Centers for Medicare and Medicaid Services, effective April 1, 2002.

This Waiver will allow people with developmental disabilities who meet the appropriate "Level of Care" criteria to receive non-residential community-based services to help them remain in the community. Individuals will be able to receive up to \$13,500 annually in support services, \$2,000 of which can be for respite services. It is anticipated that 7,000 individuals will make

use of these services.

Who qualifies for the Support Services Waiver?

To be eligible for the Support Services Waiver, you must have a developmental disability, require the "level of care" provided in an Intermediate Care Facility for the Mentally Retarded (ICF/MR), and meet Medicaid disability, income, and resource guidelines. Medicaid disability guidelines require that the disability is expected to last at least 4 years. If you are eligible for the Support Services Waiver, the income allowed will be modified from the standard Medicaid income. Under this waiver your income can be at or

below 300% of current SSI—currently \$1,635 per month. (This modified income guideline also applies to the Developmental Disability Waiver.)

As with other waivers, parental income and resources are disregarded when determining eligibility for a child.

Can I apply for and receive services from the Support Services Waiver, while I wait for another Waiver?

Yes. The waiting list for the Developmental Disabilities (DD) waiver remains long. If you are on the waiting list for the DD waiver, you can apply for and, if eligible, receive services under the Support Services waiver while you continue to wait for the DD waiver.

If you are not on the waiting list for the DD waiver, you should apply for both the DD waiver and the Support Services waiver.

How Do You Apply for the Support Services Waiver?

Contact your local Bureau of Developmental Disabilities Services (BDDS). Call 1-800-545-7763, Ext. 2, and ask for the phone number of the BDDS office for your county.

What Services are available under the Support Services Waiver?

Adult Day Services, Adult Foster Care, Behavior Management/Crisis Intervention, Community Educational/Therapeutic Activities, Com-

munity Habilitation and Participation, Enhanced Dental Services, Expenses of Unrelated Live-In Caregiver, Family and Caregiver Training, Health Care Coordination, Music Therapy, Nutritional Counseling, Occupational Therapy, Personal Emergency Response Systems, Physical Therapy, Pre-Vocational Services, Psychological Therapy, Recreational Therapy, Respite Care, Specialized Medical Equipment and Supplies, Speech/Language Therapy, Supported Employment, and Transportation.

SPEND-DOWN AND MEDICAID ELIGIBILITY

by Alan Kemp, Trust Director, The Arc of Indiana

When a person with a mental or physical disability applies for Indiana's Medicaid Disability program (the standard Medicaid program), eligibility is based on more than disability. The person's **income** must be below a specified maximum. For unmarried persons, the current maximum (as of January 1, 2003) is \$552 a month. If the person is married, he and his spouse are **not** allowed \$552 each. Instead, their combined income can be a maximum of \$829.

Assets must also be below a specified maximum. For an unmarried individual, the current maximum is \$1,500. If the person is married, the current maximum is \$2,250 for the couple.

What if a person who is disabled has excess income and/or excess assets? Is he automatically excluded from Medicaid? No. He can receive Medicaid through what is called "spend-down." Spend-down is a feature in Indiana's Medicaid program that allows people with excess income and/or excess assets to receive Medicaid when their excess income or assets are not sufficient to pay their medical bills.

Here is how spend-down works: Each month, to be eligible for Medicaid in that month, a person's medical expenses must equal his spend-down. Once medical expenses equal spend-down, then Medicaid coverage is available to that person for the remainder of the month. For example, if a person's medical expenses equal his spend-down on the 10th day of the month forward, he will have Medicaid coverage for the remainder of the month.

When Medicaid is approved, the person will receive a notice giving the spend-down amount.

This amount is determined through a formula set by Medicaid. The formula subtracts the person's income and/or assets from the maximum allowed.

Here are two examples of how spend-down works, one applies to excess income; the other, to excess assets. Each example applies to persons who are not married.

Each example is correct for Medicaid Disability and for several of the Medicaid waiver programs. The examples, however, **are not correct for two specific waiver programs** – the Support Service waiver and the Developmental Disabilities waiver. Why? Because these two waiver programs have higher, special income levels. These higher income levels, and how they impact spend-down, are discussed later.

Income: If a person's monthly income is \$852 and the maximum income allowed is \$552 his spend-down for the month is \$284. Here is how the spend-down of \$284 is determined: \$852 the person's monthly income) minus \$552 the maximum income allowed) minus a **standard deduction** of \$15.50 equals \$284.50. The \$284.50 is rounded down to \$284.

The first \$284 of medical bills in the month will **not** be paid by Medicaid.

\$284 but only \$100 is needed to cover medical expenses? In this example, Medicaid is not available in that month. Why? Because the person's spend-down is \$284 but the actual amount of medical expenses is \$100. The person does, however, remain in "spend-down status." If, in the next month, his medical expenses equal \$284, then, in that month, he will have Medicaid.

Assets: If a person's assets total \$2,000 (a combined checking and sav-

ing account, for example) and the maximum allowed is \$1,500, his spend-down for the month is \$500 (\$2,000 minus \$1,500 equals \$500). To become eligible for Medicaid, the person would reduce his assets by \$500. As with the previous example, he (or an advocate or helper) would keep a record of expenses and contact the local Medicaid office when spend-down is met. Medicaid is then available to pay other

Spend-Down and Two of Indiana's Medicaid Waiver Programs

Indiana has several Medicaid waiver programs (known collectively as the Medicaid Waivers for Home and Community-Based Services). These include the Autism waiver, the Developmental Disabilities waiver (the DD waiver replaced the ICF/MR waiver), the Medically Fragile Children waiver, the Aged and Disabled waiver, and the Support Services waiver. All of these waivers **exclude** parental income and assets from counting when determining a minor child's eligibility for a Medicaid waiver. But, all of these waiver options **include** their minor child's income and assets. Thus, if their minor child who is disabled has too much income or assets, eligibility for one of these waivers is jeopardized.

Two waivers, the Developmental Disabilities waiver and the Support Services waiver, also **modify the income** that an applicant or recipient (minor or adult) can have and still be eligible for either waiver.

The Developmental Disabilities waiver and the Support Services waiver do not eliminate entirely an applicant's or recipient's income, but they do increase income significantly. **Thus, under these waivers, spend-down, because of excess income, is still possible, but less likely.**

Under the Developmental Disabilities waiver and Support Services waiver, the income limit is \$1,635 a month. Only if a person's income exceeds \$1,635 a month, would spend-down come into play.

Determining Spend-Down Under Any of the Waiver Programs

People who are eligible under any of the Medicaid waivers are eligible to receive that waiver's specially approved services. They are also eligible to receive services available through Medicaid Disability. If these persons are subject to spend-down, they have only **one** spend-down. They can use the Medicaid Disability services to meet their spend-down as well as the special waiver services.

Spend-Down and Assets

With regard to **assets**, the limits set under the Medicaid Disability program (\$1,500 for a single individual and \$2,250 for a couple) are identical to the limits set under all of the waiver programs. Individuals receiving any Medicaid Home and Community-Based Service waiver are subject to the same

(Continued on page 10)

Spend-down is a feature in Indiana's Medicaid program that allows people with excess income and/or excess assets to receive Medicaid when their excess income or assets are not sufficient to pay their medical bills.

These bills are the responsibility of the person who is disabled. He (or an advocate or helper) keeps a record of medical expenses and contacts the local Office of Family and Children when his spend-down is met. Medicaid is then available to pay other medical expenses for that month.

What happens if the spend-down amount is not met? For example, what happens if the spend-down amount is

ings account, for example) and the maximum allowed is \$1,500, his spend-down for the month is \$500 (\$2,000 minus \$1,500 equals \$500). To become eligible for Medicaid, the person would reduce his assets by \$500. As with the previous example, he (or an advocate or helper) would keep a record of expenses and contact the local Medicaid office when spend-down is met. Medicaid is then available to pay other

Eligibility Overview for Medicaid Home and Community-Based Services

WAIVER	CATEGORIES COVERED	ELIGIBILITY RULES
Autism	Low-income families; Aged, Blind, Disabled; MED Works.	Regular eligibility; Pkental income and resources excluded.
Assisted Living	Aged, Blind, Disabled; MED Works. protection rules for couples.	Regular eligibility for singles; Spousal impoverishment
Aged and Disabled	Low-income families; Aged, Blind, Disabled; MED Works. cluded.	Regular eligibility; Parental income and resources ex
Developmental Disabilities	Low-income families; Aged, Blind, Disabled; MED Works.	Special income level (SIL); Parental income and re sources excluded.
Medically Fragile Children	Blind; Disabled; MED Works; Children under 18 only. excluded.	Regular eligibility; Parental income and resources
Support Services	Low-income families; Aged, Blind, Disabled; MED Works.	Special income level (SIL); Parental income and resources excluded.
Traumatic Brain Injury	Low-income families; Aged, Blind, Disabled; MED Works. excluded.	Regular eligibility; Parental income and resources

- The regular eligibility income level is the same as the maximum benefit rate of the SSI program, currently \$545 (September 9, 2002). This amount increases annually in January equal to SSA's COLA.
- The Special Income Level (SIL) is 300% of the SSI maximum benefit. The SIL is currently \$1,635 and also increases annually in January based on the SSA COLA.
- The resource limit is \$1,500 for an individual and \$2,250 for a couple (excluding spousal impoverishment protection situations, which apply only to the AL waiver).

Indiana Family & Social Services Administration, Division of Family and Children, September 9, 2002

The Arc of Indiana's Life Insurance Assistance Program

The Arc of Indiana, through The Arc of Indiana Master Trust, has made arrangements with James H. Hunt, a semi-retired life insurance actuary affiliated with the Consumer Federation of America (see www.consumerfed.org/backpage/evaluate_insurance_policy.htm), to help parents who are considering using life insurance as a way to plan for their disabled child's financial future.

The Arc of Indiana is concerned that uneducated purchases of life insurance or the continuation of low-value policies may lead to disappointing results. With this in mind, The Arc of Indiana will pay Mr. Hunt's 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.

Except in unusual circumstances,

guidance about a prospective life insurance purchase will require no further payment on your part. The review of existing policies, however, can be difficult and time-consuming.

The Arc of Indiana is concerned that uneducated purchases of life insurance or the continuation of low-value policies may lead to disappointing results.

Mr. Hunt's general review of your life insurance portfolio will draw on his 45 years of life insurance experience, which includes reviewing sev-

eral thousand life insurance policies in the last 15 years under CFA's program noted above. Inevitably, many policies will be well worth keeping, others not so, with a large middle ground that may need specific analyses, which will usually require fees paid by you. See the website above or contact The Arc for a description of the CFA service and what is needed for it.

Should you be interested in the purchase of a new policy, Mr. Hunt will recommend one or more of a very limited number of life insurers that are known to provide top-notch value.

It must be emphasized that Mr. Hunt will receive only Arc fees and those you pay; he will receive 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. The entire purpose of this service is to help you make informed decisions that are in your best interest.

If you prefer to work with a local agent of another insurer, Mr. Hunt will assist you in securing a policy that minimizes acquisition costs. Minimizing the acquisition costs maximizes the long-run funding for your child who is disabled.

Should you wish to take advantage of The Arc of Indiana's program of life insurance assistance, contact The Arc of Indiana through its master trust program:

The Arc of Indiana Master Trust
P.O. Box 80033
Indianapolis, Indiana 46280-0033
317-259-7603 or 800-382-9100

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 200 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 300 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. Almost 700 families are enrolled in Trust I alone. (Trust I accounts are usually funded at the death of a family member.) Over 300 individuals are enrolled in Trust II. Combined enrollments number over 1,000. 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 (800) 382-9100.



SPEND-DOWN, from page 9

asset limit as those not receiving waiver services.

Important Tips

1. Medicaid does not require that you pay your medical expenses in order for these expenses to count for spend-down. Of course, you do have an obligation to your medical providers to pay your bills. However, for the purpose of meeting spend-down, Medicaid counts both paid or unpaid expenses.
2. If you have old bills from before you were eligible for Medicaid, those bills can be used to meet spend-down if you are still legally liable for them.
3. A married couple has one spend-down amount for both husband and wife, even if only one spouse receives Medicaid. The couple's combined medical expenses are used to meet spend-down. When spend-down is met, either husband or wife or both are eligible for the remainder of the month.

4. The asset spend-down described above does not apply to everyone whose assets are over the limit. It applies only to people receiving SSI or who meet SSI financial requirements.

If your assets are more than \$2,000 (the SSI limit), asset spend-down won't apply to you in that month. You can, however, still reduce your assets to become eligible for Medicaid, but your eligibility cannot start until the next month when they are within the Medicaid limit. Here is an example of how you can reduce your assets in one month to become eligible for Medicaid in the next month: In May, your assets total \$2,100. The maximum allowed is \$1,500. You spend \$600 from your assets. In June, your assets are now \$1,500 and you meet the asset limit. In this example, you were not eligible for Medicaid in May, but you were eligible in June.

This material has been read for accuracy by Cindy Stamper, Manager, Medicaid Eligibility Unit, Indiana Family and Social Services Administration.

The Arc of Indiana 2002 Award Recipients



Amy Cook Lurvey
Sycamore Award



Robin Dempster
Citizenship Award



Carolyn Hartvig
Cathleen Clark
Professional Service
Award



Senator Potch Wheeler
Public Policy
Award



Andrea Neal
The Indianapolis Star
Editorial Board
Media Award



FSSA – Special Recognition

Each year, The Arc of Indiana recognizes and thanks outstanding individuals who have made a difference in the lives of people with developmental disabilities. Recipients of our 2002 awards were recognized at The Arc of Indiana's Annual Appreciation Dinner, *Celebrate!*, on April 23rd.

In 2003, the Appreciation Dinner will be moved to the Fall, and will take place during The Arc of Indiana's convention. Following are recipients of our 2002 awards.

2002 Sycamore Award

Amy Cook Lurvey

2002 Citizenship Award

Robin Dempster,
ADEC, Elkhart

**2002 Cathleen Clark
Professional Service Award**

Carolyn Hartvig, Jay Randolph
Developmental Services, Semi-
Independent Living Program

2002 Public Policy Award

Sen. Harold "Potch" Wheeler

(Senator Wheeler retired from the State Senate following the 2002 legislative session.)

2002 Media Award

Editorial Board of *The Indianapolis Star*

Accepted by Andrea Neal, Editor of the Editorial Pages The Editorial Board of *The Indianapolis Star* also received the **The Arc US 2002 Media Excellence Award**. The award was accepted by Tim Swarens, Assistant Editor, at The Arc US Convention in Columbus, Ohio in November.

2002 Living

in the Community Award

CYO Camp Rancho Framasa,
Nashville

Accepted by Mary Beth O'Brien, Assistant Camp Director.

CYO Camp Rancho Framasa also received the **The Arc US 2002 Boggs/Mitchell Award**. The award was presented at The Arc US Convention in Columbus, Ohio in November.

Special Recognition

Indiana Family and Social Services Administration (FSSA)

Members of the Indiana Family and Social Services Administration (FSSA) received special recognition for their efforts in developing and gaining approval of the Support Services Medicaid Waiver for Home and Community-Based Services.

**2002 Development
of The Arc Award**

United Way of Central Indiana
Accepted by Jim Smith, Vice President of Research and Development

2002 Education Award

Council of Volunteers and Organizations for Hoosiers with Disabilities

Accepted by, Russ Dawson, Chairman of COVOH's education committee and Director of Special Education, Richmond Community Schools (Russ retired at the end of the 2002 school year, and is now relaxing in Florida.)



Jim Smith
Development
of The Arc Award



Russ Dawson
COVOH
Education Award



Mark Maurer
Employment Award



The Vaughn Family
Individual and Family Support Award



Mary Beth O'Brien
Camp Rancho Framasa
Living in the Community
Award

2002 Employment Award

Mark Maurer,
Liberty Auto Salvage,
Evansville

**2002 Individual and Family
Support Award**

The Vaughn Family,
Fort Wayne—Ann, Ron,
Andrew, Ashley, and Jeff

2002 Convention Highlights



Mark Kevitt welcomes attendees.

The Arc of Indiana's 2002 Convention was held at the Holiday Inn Conference Center, Columbus, Indiana, October 2-3, 2002.

The success of the convention would not have been possible without the efforts of the Planning Committee, lead by chairman Mark Kevitt; and a wonderful Local Arrangements Committee, lead by Bennita Kennedy. Special thanks to all our convention sponsors, listed on page 12.

The convention opened with a round of workshops, featuring the Waiver Information Network's (WIN) presentation of, "Everything You Need to Know About Medicaid Waivers, but Did Not Know to Ask," the annual meeting of Self-Advocates of Indiana, and a public forum hosted by the Indiana Rehabilitation Network.

A complimentary Networking Luncheon provided an opportunity for convention attendees to discuss various topics of concern to people with developmental disabilities and their



Karen Staley
President, The
Arc of the US

families.

Karen Staley, President, The Arc of the United States, was the keynote speaker for the first general session. Karen—the parent of an adult child with a developmental disability, former local Arc President, and special education teacher—spoke on effective legislative advocacy.

Concurrent workshops provided information on Parent Advocacy, Best Buddies and Peer Tutors, Positive Behavioral Supports, and Personal Safety.

The day ended with a wine and cheese reception, hosted



Masoud Moazami



Bill Gaventa

by The Arc of Bartholomew County, a walking tour of Columbus, and The Arc of Bartholomew County's Annual Meeting and Awards Program.

Day two of the convention began with a presentation by Masoud Moazami, Founder, Effective Teaching and Learning Institute, on "Striving Toward Quality Life."

Concurrent workshops provided information on the Effective Teaching and Learning program, Self-Advocate Groups and Aktion Clubs, Meeting the Special Needs of Brothers and Sisters, and Transitioning from School to Work.

The luncheon featured a dynamic presentation by Bill Gaventa, M. Div., Coordinator, Community and Congregational Supports, The Boggs Center, on Tapping into the Oldest Natural Community Resource.

The final round of workshops focused on Strategies for Collaborating with Congregations and Faith Networks, Cultivating Natural Systems of

(Continued on Page 12)

Thanks to 2002 Sponsors and Donors

In striving to reach our goals of all people with mental retardation and other developmental disabilities having the opportunity to realize their goals of learning, living, working and playing in the community, the following organizations and individuals have made The Arc of Indiana's work possible by showing their dedication and support:

2002 Appreciation Dinner Sponsors

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David M. Cook Foundation
ICEArc

Lake County Foundation
for the Retarded

Silver Sponsor

Jay-Randolph Developmental
Services

REM-Indiana

Bronze Sponsor

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Christole, Inc.

DSI

Indiana Beverage Alliance

Indiana Council of
Community Mental Health
Centers

Passages, Inc.

Putnam County

Comprehensive Services

Sharon Gary

Donor

Instant Signs, Lake Plaza,
Indianapolis

2002 Golf Tournament Sponsors

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Timothy & Denise Cook

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Ernst & Young, LLP

Instant Signs, Lake Plaza,
Indianapolis

2002 Convention Sponsors

Platinum

Indiana Protection
& Advocacy Services

National City

Silver

Developmental Services, Inc.

Bronze

Clarence E. Custer and Inez
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TheArcLink

2002 Phantom Gala

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Morton's Steakhouse

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We Moved!

The Arc of Indiana moved to a new office in August 2002. Our new address is:

The Arc of Indiana
107 N. Pennsylvania St., Suite 300
Indianapolis, IN 46204

Call: (317) 977-2375 or
1-800-382-9100

Web Address: www.arcind.org
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 for \$15 per year.

Broad Ripple Laser Type, Pre-press (rcoalson@netzero.net)
Daily Reporter, Greenfield, Printer

CONVENTION, from page 11

Support, and Constructing Training Programs for Direct Care Workers.

Last but not least, the convention featured exhibitors, a

successful Silent Auction, and opportunities for attendees to meet and learn from each other.

The Arc of Indiana's 2003 convention will once again be

held in the Fall . . . be watching for information in the next issue of *The Arc News in Indiana*, and on our web site: www.arcind.org.