

State looks to Providers and Consumers for Help in Controlling Waiver Costs

No cushion for projected shortfall of \$21 million

The Indiana Family and Social Services Administration (FSSA) estimates that unless changes are made, spending on the Developmental Disability and Autism Medicaid Waivers will exceed allocated revenue by over \$21 million.

FSSA believes there are several reasons for the projected shortfall—individual budgets of those already on the Waiver have grown, 300 new waiver slots are costing more than projected, and moving people from 100% state funded services to waiver funded services did not achieve projected savings. In addition, emergency funds must be set aside to assure that services are available for the adult children of the estimated 250-300

parents who will die, requiring immediate services for their children.

There is no financial cushion to absorb the projected \$21 million shortfall. Last year, the Bureau of Developmental Disability Services gave back over \$26 million to the state general fund to help offset the state's fiscal crisis—a crisis that continues today. Indiana's total projected state budget shortfall is \$810 million.

What are providers and families being asked to do?

FSSA has announced cost saving measures that will maintain services to people in the community without making potentially dangerous across the board cuts.

The Arc of Indiana believes that Hoosier families want to be responsible stewards of tax dollars.

Families on the DD and Autism Waivers are being asked to review individual Medicaid waiver budgets with their case manager and providers. The goal is to make every effort to provide services and supports in the most cost effective way. This includes taking advantage of other community day services, sharing staff where appropriate and seeking out roommates to share costs. Community Habilitation and Participation (CHPI) is being eliminated as a service on these Waivers. However, it will be replaced with Residential Habilitation and Support (RHS), which is billed at a lower hourly rate.

The Arc of Indiana believes that Hoosier families want to be responsible stewards of tax dollars. No one is being asked to give up services or supports that they need; rather, families are being asked to consider: "Is there a better way to achieve these results, that can save funds, at least for a while? If we had to pick one service to do without, what would it be?"

At the same time, FSSA must also address regulatory and bureaucratic policies that drive up costs. It is not just up to providers and families. State government must also be efficient and save resources in every way possible.



our state could make. Rather than making across the board cuts, the overall system needs to be changed to make it more responsive and cost conscious.

Nearly 8,000 people continue to wait for home and community based services. Not all are in crisis, but many could stay out of crisis with just a little bit of help. In addition, a recent study reports that over 10,000 Hoosiers over the age of 60 continue to care for an adult son or daughter with a developmental disability in their family home. It is projected that between 250-300 elderly caregivers will die each year. Whether or not Indiana will be able to meet the needs of those who continue to wait for services, and step in when elderly caregivers can no longer provide care, will greatly depend on how well we work together—consumers, providers and the state administration—to use the public resources entrusted to us.

Additional information on cost containment is posted on our web site at: www.arcind.org, click on: "Medicaid Waivers & Medicaid," then click on: "Waiver Cost Containment."

What happens if budgets are not controlled?

Some say that the only way to control costs is to cut service rates across the board. The Arc of Indiana believes this would be the worst step

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THE ARC OF INDIANA'S 2003 AWARD RECIPIENTS

The Arc of Indiana is honored to recognize recipients of our 2003 Awards. Awards were presented at The Arc of Indiana's Appreciation Dinner on October 8th in Indianapolis by Steve Powell, President of The Arc of Indiana.



Employment Award

Meijer's Corporation

The Employment Award recognizes persons, organizations, or businesses who employ persons with mental retardation, and who have made significant efforts to increase employment opportunities in an integrated setting. Meijer's was nominated by BRIDGES, the local chapter of The Arc in Lake County. Meijer's employs twenty-four individuals from BRIDGES. Meijer's was recognized not only for their outstanding effort to hire and train people with developmental disabilities, but also for their practice of making them full partners in their employment. The award was presented to Alyce Garcia on behalf of Meijer's Corporation.

Education Award

Kids First and The Welborn Foundation

The Education Award recognizes individuals or organizations that have improved the quality and accessibility of integrated education for children or adults with special needs. This year, two awards were presented in this category. **Kids First** was nominated by The Arc of Tippecanoe County. Kids First uses the Kids on the Block puppet program to provide eleven different educational programs using puppets with various disabilities. In 2002, Kids First performed for over 6,000 people—providing a message that emphasizes the similarities among people, while fully recognizing the differences. The award was presented to Gail McCormick, Kids First Coordinator.

The Welborn Foundation was nominated by Evansville ARC. Over the past two years, the Welborn Foundation has provided nearly \$285,000 to Evansville ARC's *The Best Practices in Early Education for Children* project.



ect. The award was presented to Patrick Jackson, Program Officer for the Welborn Foundation.

Individual and Family Support Award



Angela Touseull

The Individual and Family Support Award recognizes individuals, families, or organizations that develop innovative programs, or provide outstanding advocacy efforts, to support families or individuals with mental retardation in the community. Angela Touseull, nominated by the Indiana Down Syndrome Foundation, launched Indiana's first Buddy Walk in the fall of 1998, raising over \$35,000. The success of the Walk led Angela to help establish the Indiana Down Syndrome Foundation. The Foundation supports individuals with Down syndrome and their families by providing information, awareness, and advocacy. The Buddy Walk has continued to grow, allowing the Foundation to increase its impact throughout the state. Over 1,000 people attended the Buddy Walk last year, raising \$100,000.

Living in the Community Award

Ride Solution

The Living in the Community Award recognizes individuals, organizations, or businesses that have improved the availability, quality, and opportunities of persons with mental retardation to live a whole and meaningful life in the community. Ride Solution, nominated by Four Rivers Resource Services, offers transportation services through several agencies in Daviess, Greene, Martin, Pike, and Sullivan Counties. It was formed through a \$250,000 federal grant and local matching grants, obtained by Four Rivers and the Southern Indiana Development Commission. In 2002 over 79,000 one way trips were provided to people with disabilities and the general public. Mike McClure, Chairperson of the Transportation Advisory Council, accepted the award on behalf of Ride Solution.



Public Policy Award

Senator Vi Simpson

The Public Policy Award recognizes an elected official who has made significant efforts to use public policy to advance the ability of people with mental retardation to live, learn, work, and play in Hoosier communities. Sena-



tor Vi Simpson, nominated by Stone Belt Arc, has been a strong advocate for people with disabilities throughout her 19 years at the Indiana General Assembly. She played a

key role in securing over \$80 million dollars to implement the first two phases of the 317 Plan. In the 2003 session Senator Simpson consistently spoke out against flat-lining the Medicaid budget, and fought for the passage of legislation to require funds to follow people out of institutions and into community supports. Senator Simpson also sponsored legislation which became law to allow the criteria for determining disability for SSI to be used in determining eligibility under the Medicaid disability program and legislation to make voting polls accessible.

Cathleen Clark

Professional Service Award

Donna Van Hook

The Cathleen Clark Professional Service Award recognizes a staff person who works directly with people with mental retardation for their outstanding contribution toward the lives of these individuals. Donna Van Hook has worked with students with significant developmental disabilities in the Greater Clark County Schools system since 1987. Her primary goal has always been not only to assist these students in becoming a part of the school, but also a part of the community. In her nomination of Donna, Ann Schnepf, Director of Special Populations for Greater Clark County Schools, said, "Donna respects each individual, but recognizes that for some individuals it is more difficult to have a job, friends, and a place in the community; so she has made sure that she works to that end with each of her students. She does so with no fanfare and no request for recognition. She just does it because it is the right thing to do."



Citizenship Award



Sam Chapala

The citizenship award recognizes an individual with a developmental disability for outstanding participation in and contribution to the com-

munity. This year's recipient, Sam Chapala, was nominated by Rauch Inc. and long-time neighbor, Janet Streepey. Through his participation in Special Olympics Sam has won 5 gold, 6 silver and 1 bronze medal in competitions. He also participates in non-disabled weight lifting competitions, in which he has broken state records. Sam began services with Rauch, Inc. through high school transition for community employment in 1999. He continues to work at a local restaurant, where everyone includes him in their circle of friends. He shares an apartment with a college graduate and enjoys shopping for and cooking his own meals. Over the last few months, Sam has learned to be financially independent—making deposits, balancing his checkbook, and paying all of his bills.

Sam volunteers his time, including working at New Albany High School football games, where he has been a member of the chain crew since 1999. He has a group of men he works out with, and another group that he bowls with every week.

Of Sam's many accomplishments, his mother, Millie, said, "Sam has succeeded far beyond our expectations. I think his greatest attribute is that when a person first meets Sam, he or she sees him as a person with a disability, but after being around him for a while, they see him as a person. Tom and I are very proud of Sam and pleased that he is so independent and happy. That makes us very happy."

Sycamore Award

Wilbur Rodenberg

The Sycamore Award, the highest award given by The Arc of Indiana, recognizes a person or voluntary organization whose long term support has contributed significantly to the goals of The Arc of Indiana.

Wilbur "Rody" Rodenberg, nominated by Dan Stewart, Executive Director, Green Acres Inc., was honored for his long time commitment to the Wayne County Council for Retarded Children and Green Acres, Inc. "Rody" began this affiliation in 1966. While his official title for the next twenty years would be "Executive Director," he wore many hats, including bookkeeper, driver, janitor, personnel director, and whatever else it took to get the job done.

He worked tirelessly with a number

(Continued on Page 7)



Executive Director's Column

Stepping up to new challenges

It seems that I have been using the word *challenging* a lot lately. Just ask The Arc of Indiana Board and local Arc executive directors. Both would tell you we have had more than our share of challenges—we don't need any more. But, here I come talking about new ones that place just about everything we hold dear at risk.

From the federal level we see major change proposed in the federal/state partnership in education and community living. At the state level, a flat-lined budget means ever-increasing needs and no new resources to meet those needs. Existing programs are



John Dickerson

under intense scrutiny, as detailed in our front page article.

Locally, schools are stretched; and with the prospect of high-stakes testing like ISTEP and the No Child Left Behind legislation, we are hearing reports of principals wanting to move students with special needs out of the classroom or even out of their school entirely. Decades of work leading to effective inclusion programs may be threatened by an effort to rank all schools and classrooms by test scores.

County government does not escape the pressure. With our current property

tax reassessment problems and the delay in getting budgets approved, many counties are threatening to reduce the permissive funding they give community agencies that serve people with developmental disabilities.

But as Mary McGraw of Rushville, one of our founders, once told me when I felt *challenged*, "John, when do you ever think it was easy?"

Our path was started by people 50 years ago who faced and met challenges as great or greater than those we face today. And they only had their belief in one another and their sons and daughters to go on. Today we have dedicated professionals, some of the best and brightest, dem-

onstrating what can be done. We have data that shows what people can do. And we still have that belief in one another.

We must remember that getting through this time will take all of us—providers, advocates, families and consumers pulling together. We have started that process with a 317 Renewal effort to bring everyone that made the original plan so successful back to the table to plan the next phase. That will make a difference. And so will you.

I often thank you for all you do. Today I want to thank you for what I know you are yet to do. We have many challenges, but we have thousands of everyday heroes that, I am confident, will help us meet that challenge.

Judy O'Bannon Presented with Quilt in Recognition of Governor's Legacy

A special quilt was presented to Mrs. Judy O'Bannon at The Arc of Indiana's Appreciation Dinner on October 8th. The quilt was accepted by Governor O'Bannon's Chief-of-Staff, Tim Joyce.

Our special thanks to Judy Abbott, The Arc of Indiana Board of Directors, who created the quilt. The quilt pattern was based on the "Let Us IN!" Quilt, created in 1999 by Judy and the Heritage Quilters of Crown Point, as part of the campaign to enact the recommendations of the 317 Commission to reduce waiting lists and improve home and community-based services.

The Arc of Indiana was honored to receive the following thank you letter from Mrs. O'Bannon:

October 23, 2003

Dear John,

During the past few weeks, I have continually been amazed at the outpouring of support and kindness that my family and I have received from people from all across the state. I have always believed that when groups of people come together in times of triumph and tragedy, they demonstrate the beauty of people living, working, and breathing together—the beauty of a community. Truly, I have witnessed this beauty and become aware of the power of being part of God's diverse family like never before.

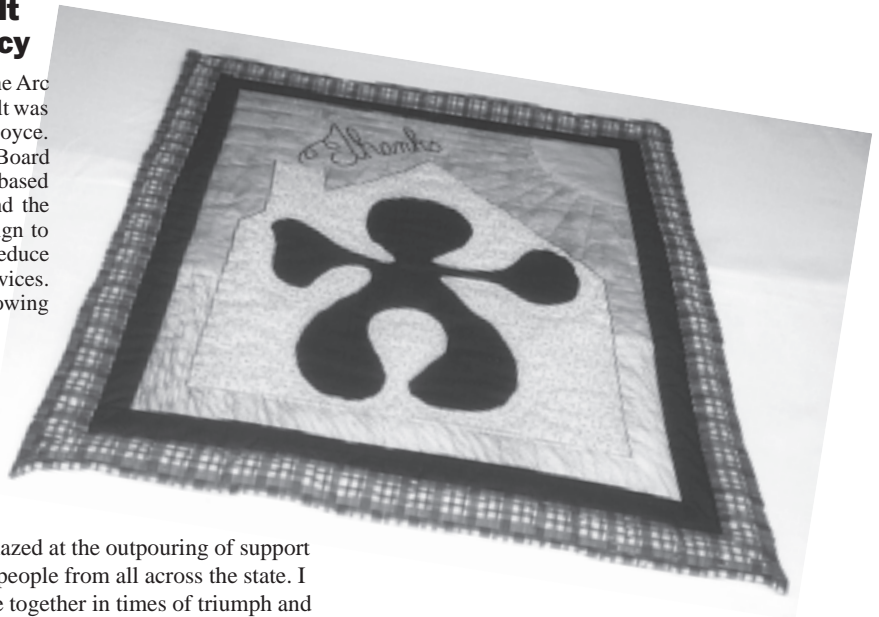
It has felt so good to come home to the thoughts and prayers that family and friends have sent from all over the country. Thank you, John, for your thoughtful gift of a wall hanging. You helped fill these days with comfort and love for our family.

When we look back on this time, I am confident that we will all find comfort in the fact that Frank's life has been honored most appropriately through the actions of so many people for a common purpose. Together, through grief and a celebration of life, we have grown stronger, because of our association with Frank O'Bannon, and with God.

My family and I thank you for your thoughts, prayers and kindness.

Sincerely,

Judy O'Bannon





GOVERNOR JOE KERNAN AND TOM REGAN appear together in a public awareness ad for LOGAN, a non-profit provider of services for people with developmental disabilities in St. Joseph County.

The ad features Tom working at LOGAN, hanging out with friends at the firehouse, bowling, and walking along the St. Joseph River with Governor Kernan—while the Frank Sinatra tune, “World on a String,” plays in the background. The ad closes as the song, “Someone Like Me,” plays along with images of people served by LOGAN, and the invitation, “Get to know me...we might be friends” is extended.

Tom and Joe (as Tom calls him) did in fact become long time friends through the Governor’s long association with LOGAN and Special Olympics. When then Lt. Governor Kernan was asked to participate in the public awareness campaign last spring, and learned that Tom would be featured, he willingly gave up an afternoon to spend the day with Tom filming the ad.



LT. GOVERNOR KATHY DAVIS previously served as Secretary of Indiana’s Family and Social Services Administration (FSSA), where she was instrumental in developing and beginning the implementation of Indiana’s 317 Plan — a comprehensive plan for services and reforms for people with developmental disabilities in Indiana. The Arc of Indiana extends their congratulations and best wishes to Lt. Governor Davis in her new leadership role in Indiana state government.

No Place Like Home for the Holidays

Guest Column by Steve Cook, Director, Division of Disability, Aging, and Rehabilitative Services, Indiana Family and Social Services Administration

There’s no place like home for the holidays. Ask Patrick Lee, a 49-year-old man who has cerebral palsy, moderate mental retardation and is quadriplegic. Until last year, Lee hadn’t spent a Thanksgiving or Christmas at home in 32 years. He had lived most of his life at Muscatatuck State Developmental Center, separate from his family and segregated from his community.

But last Christmas was different. After Lee moved out of the institution and into an apartment in Columbus, he had the family Christmas party at his place. Now he’s thriving as an active member of the Columbus community, traveling with caregivers to a monster truck show and a country music concert and meeting NASCAR driver Tony Stewart and the Indiana University cheerleaders.

And he’s even going to host the family Christmas gathering again this year.

Lee is just one of thousands of people with disabilities across Indiana who will be home for the holidays this year, some for the first time in decades. Thanks to the state’s efforts to help people transition into community settings, the number of people with disabilities in state-run institutions has dropped by 79 percent since 1990, to about 400 today.

In large cities and rural towns, more than 8,000 Hoosiers with developmental disabilities live in community settings, with appropriate support and care. They might be your neighbors, co-workers or a member of your family.

At the Family and Social Services Administration we see the movement to community living as both a victory and a right for people with developmental disabilities—a fundamental right affirmed by the U.S. Supreme Court in 1999.

Helping people with disabilities transition from institutions and thrive in communities is one of FSSA’s most important initiatives, and we realize the appropriate care must be in place. That’s why we’re committed to working with families to find the

right settings and care in the community for their loved ones.

Lee is just one of thousands of people with disabilities across Indiana who will be home for the holidays this year.

The transition process for residents of Muscatatuck, for instance, takes up to a year and requires that each step in an 82-page manual be completed before someone can be placed in the community. There are also follow-up services to ensure the placement is successful down the road.

An independent study released in June by the Indiana University Institute on Disability and Community is strong evidence that helping people with disabilities live in the community allows them to thrive.

The results show that nearly 90 percent of the families of former Muscatatuck residents who were surveyed say their loved ones are more satisfied living in the community. Almost none were worried about quality of life in the community.

Our work is not done, however. Communities across Indiana need more options for people with disabilities, which is why the Governor’s Commission on Home- and Community-Based Services has offered \$750,000 in mini-grants to help communities expand and improve local services. We must continue to build on the success of Indiana’s 317 Plan, which has offered people with disabilities more individualized choices and allowed more than 1,600 people on waiting lists to receive new services in the community since 1999.

And as individuals, we must commit to the idea that people with disabilities share the same rights, dreams and hopes we all do, especially at this time of year.

We all want to be home for the holidays. Just think how sweet it is for Patrick Lee.



Jeff, Carol and Patches

Jeff Enjoying Life in Sullivan

Jeff lived at Muscatatuck State Developmental Center (MSDC) for 29 years. Now, he is living back in his home community of Sullivan, Indiana.

The first day that Jeff moved into his new home he would not get in the shower. The first day Jeff saw the food in the refrigerator, and realized it was his food, he wanted to eat everything at once. Now, Jeff can shower independently and no longer refuses this daily routine. Now, he eats his meals without protecting his plate. When he is full, he saves his food to have later.

Jeff loves his dog Patches and likes that he can play with him in his backyard whenever he wants. Jeff enjoys watching birds, doing puzzles, drawing with a crayon and shopping. He also likes his volunteer job with Meals on Wheels in Dugger, Indiana.

Jeff now lives only fifteen miles away from his mother, Carol. They both are enjoying his visits, and the fact that he can now join her on holidays and birthdays.

2004 PUBLIC POLICY AGENDA

Legislators will face significant challenges and make decisions that will affect the future of all Hoosiers in the 2004 session of the Indiana General Assembly. Indiana continues to face revenue shortfalls. Though some suggest the economy is in an upswing, it will take time before any positive change is felt. The fiscal crisis places even greater constraints on the state's ability to invest in either economic or human service needs. A strong, vibrant economy is needed to generate the revenue necessary to provide the human services investments to build a better Indiana.

A major investment in both the economy and human services is needed to bring jobs and business growth to Indiana. Yet further budget cuts to human service programs are a real threat. Morton Marcus, an expert on Indiana's economy, has stressed that further cuts in spending will do nothing to stimulate the economy and will only make Indiana a less desirable location to live and work.

We cannot simply put out our hands and ask for help. We must be open to talking about increasing taxes or creating new taxes to address growing and unmet needs. Now is the time to step boldly into the future with a long-term plan of strategic investments in economic development, education and human services.

Community Based Services and Supports

The Arc of Indiana will continue to work to move the thousands of Hoosiers who continue to wait for home and community based services off of waiting lists for Medicaid Waivers. We will continue to work for better utilization of federal funds for Medicaid, Medicaid Waivers and Vocational Rehabilitation.

The Arc of Indiana will continue to collaborate with other organizations in the planning and implementation on the next phase of the 317 Plan—a comprehensive plan to provide home and community based services to people with developmental disabilities and their families.

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 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 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 regarding how the loss of level of care impacts 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. We will work closely with parents to help them with the transition of their loved ones into the community.

The Arc of Indiana will also work to ensure funding streams follow people and that sufficient funds are provided both for initial placement and ongoing services. We will work aggressively with other organizations and task forces to eliminate institutional biases that exist within the State's budget system.

*Now is the time for Indiana to step
boldly into the future with a long-term
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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. The Arc of Indiana supports efforts to increase training of law enforcement personnel, jail officers, probation officers and correctional officers to assist them in interacting with people across all disabilities, including mental illness.

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 are 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.

The Arc of Indiana will advocate with other organizations for the development of a plan by the Commission for Higher Education, the Professional Standards Board and the Division of Exceptional Learners to address the severe shortage of special education teachers and related service providers, and to review the limited license certification requirements and procedures as they impact special education.

We will continue to monitor the reauthorization of the Individuals with Disabilities Education Act (IDEA) and the implementation of No Child Left Behind to ensure that focus remains on academic improvement without diminishing the rights and protections afforded to children with disabilities and their families.

Insurance

The Arc of Indiana will continue working with families, the state and 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 advocate for the continuation of the Indiana Comprehensive Health Insurance Association (ICHIA) program that improves access and quality health care for members.

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.

Autism Commission Hears Testimony on Non-Nutritive Beverage Fee

The Commission on Autism, chaired by Senator Kent Adams (R-Warsaw), spent two meetings discussing the needs of people with autism and their families and possible solutions. One solution presented to the Commission was the passage of a Non-Nutritive Beverage Fee that would raise revenues that would be dedicated to Medicaid to help families needing services.

The concept of a Non-Nutritive Beverage Fee was presented by a group of Brebeuf high school students who learned about the fee from a presentation made by The Arc of Indiana's

Governmental Affairs Committee Chairman, Susan Hansen, and Director of Government Relations, Kim Dodson.

A coalition, Hoosiers for Options, made up of organizations, individuals and groups advocating and providing services to the elderly and people with disabilities, did the research on the Non-Nutritive Beverage Fee and hopes to get a bill introduced in the 2004 session of the General Assembly.

The Non-Nutritive Beverage fee is a small fee on the syrup or powder used in the manufacture and bottling of non-

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Budget Crunch Hurts Families Waiting on Disability Waivers

The following report was filed by Gene Rodriguez, WISH-TV Indianapolis; and aired on October 3, 2003.

The deficit in the state budget affects all of us. When the Indiana Division of Disability, Aging and Rehabilitative Services had to revert \$15 million to the general fund, it meant that the disabled waiting for state funds would have to wait longer. Those awaiting state waivers are worried about the future of their disabled dependents.

Vickie Collins has Down's syndrome and severe arthritis. At 32 years old, her parents, Don and Shirley Collins have cared for Vickie her entire life.

"When you take care of someone like this and you take care of them for so long, you don't think about it. It's just something that you do," said Shirley. But they're concerned about what will happen to Vickie in the event that one or both of them dies. "We're both 68, and we're not going to be around forever," said Don.

"The thing that preys on your mind a little bit: obviously, one of us is going to go first," said Don.

For the past three and a half years, Vickie has been on a waiting list for the state's developmentally disabled waiver. It would provide money for the services Vickie needs.

"Last year we targeted approximately 350 people to come in off the waiting list. This year we are not targeting any folks in that area," said

Steve Cook, FSSA Disability Division director.

The Collinses received a letter informing them they would be waiting much longer for the state funds—as long as six and a half years. "We had gone through so much disappointment and things. It was just one more disappointment," said Shirley.

They are not alone. Right now there are 6,000 Hoosiers waiting for the same kind of funding—a developmental disability waiver. Two thousand wait for an autism waiver, and 6,800 wait for the support services waiver.

"We are prepared to meet emergencies. Unfortunately we are not going to be able to expand the number of people served through the people coming off the waiting list," said Cook.

Since the fiscal year began on July first, the state has helped 35 disabled individuals with emergencies. In most cases their primary caretaker died.

As for the Collinses, they will wait. They've already learned they can't do what they used to. "The first time I noticed it was when I could not lift her up from the bottom of the bath tub, and I thought, 'Oh, golly,' and it was something I had never thought about before. Now I think about it."

Vickie is the youngest of five children. When her parents pass away, one of her sisters will take care of her. But the financial burden is what worries Don and Shirley. That's why the waiver is so important.

VR UPDATE

Michael Hedden, Deputy Director, Vocational Rehabilitation Services

As in many areas of human services, major changes are taking place in Indiana's vocational rehabilitation program. Michael Hedden, Deputy Director, Indiana Vocational Rehabilitation Services, highlights key changes taking place in Indiana.

Consumer and Community Partner Involvement

Vocational Rehabilitation has started the process of consumer and community partner involvement with a series of meetings with representatives from Community Rehabilitation Programs and Mental Health Centers from across the state. The purpose of these and other forums is to solicit consumer, provider, and staff input for program initiative validation and design. Issues that have been discussed include program consistency, Supported Employment Follow Along, and staff training. This concept needs to be expanded to consumer advocacy groups. Although some preliminary work has taken place, the forums need to be structured to allow consumer input to be consistent and ongoing.

Order of Selection

"Order of Selection" is a federally mandated method to organize waiting lists for VR services. It prioritizes services to those with the "most significant disabilities," and is used when it is anticipated that demand for VR services will exceed available resources. It has become an unwelcome yet necessary consideration. VR management, with the support of FSSA and DDARS administration, is making every attempt to reduce costs to avoid or at least minimize the degree to which access to programs will be restricted. At this point, it is too early to determine if Indiana will be required to implement Order of Selection. However, work is being done to add Order of Selection to the VR State Plan, so that it is available to use as a last option.

Results Based Funding (RBF) Pilot

A Results Based Funding Pilot with Community Rehabilitation Programs is scheduled to begin in 2004. The intent of this project is to determine if changing the VR payment process for employment services to one that pays for employment outcomes will improve the quantity and quality of VR employment outcomes. RBF participants include: Cardinal Center, Goodwill of Michiana, Michiana Resources, Marshall Starke, Opportunity Enterprises, Pathfinder

Bona Vista, Peak Community Services, CDC, Goodwill Industries of Central Indiana, Crossroads, Child-Adult Resources, Evansville ARC, Gibson County Rehabilitation Center, Four Rivers, DSI, Blue River Services, Stone Belt Arc, and Green Acres. A similar pilot with Community Mental Health Centers began nearly two years ago. It is important to understand that RBF is being viewed only as a pilot – not a prelude to statewide requirements.

Supported Employment Follow Along (SEFA)

SEFA was the focus of a forum jointly sponsored by BDDS and VR in cooperation with The Arc of Indiana, INARF, and the Indiana Institute for Disability and Community in mid November. The intent of the training was to give local staff and partners information to use for decision making involving SEFA and consumer services. It also provided a forum to receive input for future policy and procedure changes.

School-to-Work Transition

School-to-Work Transition is a state and national initiative. Activities that have taken place in Indiana include a major statewide conference held last year, numerous school-to-work publications, and a change in VR policy allowing services to be provided to youth that is still in school. Additional initiatives can be expected to take place if legislation pending in Congress becomes a reality. VR will work with the Department of Education, consumer advocates, and community partners to look at a variety of approaches to this critical issue.

Workforce Development

No discussion of current VR issues can be complete without a review of our relationship to our partners at Workforce Development. This is a big issue nationally. It is likely Indiana we will see a mandate for Workforce Investment Act (WIA) partners to pay a "fair share" of WIA "infrastructure costs." As there are no additional funds to help meet these costs, funding will have to come from VR Agency operating costs. The level of support could range from a percentage of one percent to unlimited authority to Governors to make those determinations. Indiana has a good start on this process as "cost sharing" arrangements with WIA partners is already taking place.

The Arc Can Help with Winter Heating Assistance

This winter, for the fourth year in a row, The Arc of Indiana through The Arc of Indiana Master Trust will help low-income people with disabilities with their winter heating bills. The Arc of Indiana's Board of Directors has approved \$20,000 for this purpose. Checks of \$100 apiece will be drafted to utility companies to help pay heating bills.

This is a statewide program and is based on \$100 per recipient household. For example, if two people with disabilities live together in the same household, only one can apply for this assistance.

To apply for assistance, contact your local Arc or local agency providing services to people with developmental disabilities. You can also apply through your local community mental health center, Independent Living Center, Area Agency on Aging, or your district office for the Bureau of Developmental Disabilities Services. All of these agencies know about our winter heating assistance program and have the necessary form.

Applications will be accepted on a first-come, first-served basis, so delaying an application can work against you. We want to distribute this money

as equally as possible around the state. In order to do so, participation is capped at 7 approved applications per county.

Even though applications are being accepted now, the checks cannot be drafted until 2004. (This is not at our choice; it is to satisfy our auditor.) As soon as an application has been accepted, and assuming the seven cap limit has not been met, the agency submitting the application will receive confirmation. Then, in January or February of 2004, we will mail the check to the disabled person's utility company with instructions to apply the check to his or her heating bill.

The criteria for the \$100 in heating assistance are basic. The agency submitting the application needs to confirm that the person is disabled and is a recipient of Supplemental Security Income (SSI). (*We will need something from Social Security documenting that the person is a recipient of SSI. We cannot approve the request without SSI documentation.*) Also, the agency will need to certify that the \$100 will be used to supplement, not supplant, other sources of revenue used to pay the person's monthly bills. Those are the only requirements for approval.

Why are we requiring the person be a recipient of SSI? The Arc Trust has a blanket exclusion on payments that normally interfere with SSI. Usually, if anyone helps pay for food, clothing, or shelter for an SSI recipient (heating assistance is a form of shelter), the help is deemed "In-Kind Support and Maintenance." The outcome is a dollar-for-dollar reduction from the person's SSI. For example, if \$100 was given to help with food, clothing or shelter, and if the person's regular SSI check is \$552, the next check could be \$452. This clearly

discourages people from helping with food, clothing or shelter. The Arc Trust's blanket exclusion is an important exception to this rule.

Where is The Arc of Indiana getting the money to help pay for winter heating assistance? The money comes from remainder shares left to The Arc Trust. We think this is a good use of a portion of these funds. Over the past three winters, more than \$45,000 in remainder shares has been used to help low-income people with disabilities with their winter heating bills.

Free Unbiased Service

Evaluation of Cash-Value Life Insurance Policies

It is very difficult for lay people to compare two or more cash-value life insurance policies. Life insurance agents can be helpful, but, because they are paid commission, they may be in a conflict of interest. The Arc of Indiana offers a free evaluation program for cash-value 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 toll free at 1-877-589-8848.

AWARD RECIPIENTS, from page 2

of community and civic organizations to raise funds to build Green Acres Center. Under his leadership, funding was obtained for three additional expansions.

Rody also was instrumental in founding residential services in the Wayne county area. In 1975, he wrote a grant to the Eli Lilly Foundation and worked with several community organizations to build three group homes. These homes were among the first in Indiana.

Rody retired in 1986, but he would not be gone for long. In 1988 he was asked to serve as Interim Executive

Director for one year. After retiring for a second time, he continued to be involved as a non-voting community member of the Board of Directors. In 1998, he was elected to the Board of Directors of Wayne County Council for Retarded Citizens, and in 1999 he was elected President of the Board, a position he continues to hold.

Most recently, Rody established a committee of board members, community leaders, parents, and staff to consider a remodeling and expansion of Green Acres to meet the future needs of people with disabilities.

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 240 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 430 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 750 families are enrolled in Trust I alone. (Trust I accounts are usually funded at the death of a family member.)

Over 430 individuals are enrolled in Trust II. Combined enrollments exceed 1,150.

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

Steve Green's The Arc of Indiana Golf Tournament

Thanks to the sponsors of Steve Green's The Arc of Indiana 2003 Golf Tournament, Ted Bishop and the Legends of Indiana, and volunteers, for their help and support in making this a successful event. Special thanks to former Pacers who attended the tournament to show their support for Steve Green and The Arc of Indiana: Darnell Hillman, Wayne Radford, Tom Thacker, and former coach Bobby "Slick" Leonard.

The tournament raised \$12,600 to benefit The Arc of Indiana.

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Steve Green with his wife Lana and daughter Jessica at The Arc of Indiana's Appreciation Dinner in October, where Jessica was the guest speaker.

THE ARC OF INDIANA

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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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Commission on Mental Retardation and Developmental Disabilities Proposes Legislation on Criminal Justice Issues

The Commission on Mental Retardation and Developmental Disabilities (MRDD), chaired by Senator Marvin Riegsecker (R-Goshen), spent the fall receiving updates on various areas of services to people with disabilities. It was questions and issues surrounding the criminal justice system that peaked the Commission's interest and prompted them to introduce legislation regarding police training.

As people with disabilities integrate more and more into local communities, the possibility of their becoming involved with the criminal justice system, either as victims or offenders, increases.

Key players in the criminal justice system, including police officers, are not adequately trained on how to handle a situation involving a person with a disability.

After much testimony and dialogue, the MRDD Commission passed Preliminary Draft 3402. It would require the Law Enforcement Training Academy to include training in interacting with persons with mental illness, addictive disorders, mental retardation, and developmental disabilities as part of their curriculum. The training would be required for law enforcement personnel, jail officers, probation officers and correctional officers. The

legislation also requires that the training be provided by persons approved by the Secretary of the Family and Social Services Administration. Furthermore, the legislation will require that the Commission of the Department of Correction give priority in issuing community corrections grants to programs that provide alternative sentencing projects for persons with mental illness, addictive disorders, mental retardation and developmental disabilities.

The Commission on Mental Health, Chaired by Senator Connie Lawson, (R-Danville), also spent a substantial amount of time this fall discussing criminal justice issues. The MRDD Commission and the Commission on Mental Health both passed a Preliminary Draft supporting a Concurrent Resolution urging the Commissions to meet jointly during the 2004 interim to consider issues of interaction between the populations the Commissions represent and the criminal justice system.

These approved Preliminary Drafts will be introduced as legislation during the upcoming Session of the Indiana General Assembly. Please watch for weekly alerts from The Arc of Indiana for ways you can help these Bills become law.

NON-NUTRITIVE BEVERAGE FEE, from page 6

nutritive beverages such as soft drinks. The fee would be collected at the point of manufacture or distribution, and would equal approximately a half a cent per soft drink can.

The fee could raise an estimated \$61.8 million in state dollars. These funds could be used to draw down an additional \$103 million in federal Medicaid dollars, providing more than \$164 million dollars that could be targeted for services to children and adults who are elderly or disabled.

A similar fee in Arkansas has generated hundreds of millions of dollars for Medicaid over the past ten years.

Although the Autism Commission did not vote to support legislation for a Non-Nutritive Beverage Fee, Representative Vanessa Summers (D-Indianapolis) expressed interest in seeing legislation proposing the fee. Susan Hansen, a member of the Autism Commission, vowed to continue her grassroots effort to pass the Non-Nutritive Beverage Fee.

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Thanks to sponsors of The Arc of Indiana's 2003 Convention and Appreciation Dinner for their support!

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