

The Arc of Indiana 2005 Public Policy Agenda

The 2005 session of the Indiana General Assembly will be one of great challenge and great opportunity. Legislators will face significant challenges as they prepare the biennial budget and make decisions that will impact the future of all Hoosiers. Indiana continues to face a large budget deficit, making more cuts to human service programs a real threat.

Governor Mitch Daniels and his administration will focus much of their attention on economic development and job creation, both of which The Arc of Indiana agrees are essential to improving the state's fiscal situation. A strong vibrant economy is needed to generate the revenue necessary to provide funding for investments in human services—investments that are also critical to build a better Indiana.

The Arc of Indiana's 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 playing 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 and creating public awareness.

The Arc of Indiana is committed to our local chapters of The Arc, and will work to develop programs and public policy that will help support them in their missions of providing quality services to people with men-

tal retardation and developmental disabilities.

Community Based Services and Supports

The Arc of Indiana is committed to helping families receive the support and services they need to keep their loved ones at home, and to assuring people with developmental disabilities can live safely in the community when families can no longer provide for them at home.

The 317 Plan

The Arc of Indiana remains committed to the 317 Plan, Indiana's comprehensive plan for services for people with developmental disabilities. This year we will ask the Indiana General Assembly to invest in Phase III of the 317 Plan. Currently, it is estimated that over 15,500 people are waiting for Medicaid Waiver Services in Indiana.

The Arc of Indiana supports additional appropriations to end the wait-

ing for the thousands of people who are in need of services and supports. As part of the 317 Plan, we will also ask the State to provide funds specifically for emergency and crisis situations.

The Arc of Indiana continues to see the direct care workforce decline. We are committed to increasing training and benefits earned by direct care workers.

The Arc of Indiana believes that person centered planning is critical in the lives of people with developmental disabilities and their families. We will work to ensure that consumers have choices and that they are knowledgeable about their rights.

Guardianship Services

Guardianship and advocacy services are very important to individuals with mental retardation and developmental disabilities to assure that they have the supports necessary to keep them healthy and safe in the community.

The Arc of Indiana believes that it is critical that people with disabilities have guardianship services available to them. We believe that guardianship works best when a personal interest in the individual is present. We will work to include guardianship and advocacy services as part of the service options available through existing funding streams.

Loss of Level of Care

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.

Increased Revenue

The Arc of Indiana is committed to working with the State to assure every dollar in developmental disability services is used efficiently. We will continue to work for better utilization of federal funds for Medicaid, Medicaid Waivers and Vocational Rehabilitation.

(Continued on Page 2)

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The Arc of Indiana
107 N. Pennsylvania St.
Suite 300
Indianapolis, IN 46204
(317) 977-2375



U.S. Government students from Brebeuf Jesuit Preparatory School in Indianapolis, led by teacher Linda Smoot, are learning how Indiana government works by studying the legislative process and following action taken on issues impacting people with developmental disabilities.

Brebeuf students, pictured above, came to the State House on organization day in November to distribute information to State Senators and Representatives on the status of the 317 Plan and the need for home and community based services.

Kelly Collins, a Senior from Brebeuf, met with Representative Michael Murphy (R-Indianapolis).

2005 PUBLIC POLICY AGENDA, from page 1

The Arc of Indiana, as well as legislators, must be open to talking about increasing taxes or creating new taxes to address growing and unmet needs in our State.

The Arc of Indiana will continue its work with the *Hoosiers for Options* Coalition to discuss and advance the idea of a "Non-Nutritive Beverage Fee" as a revenue source for home and community based services.

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 placements 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.

Criminal Justice

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 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 will monitor closely the pilot projects that currently exist for training of police officers and those involved in the criminal justice process.

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 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.

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 Individuals with Disabilities Education Act (IDEA) and 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. The Arc of Indiana recognizes the difficulty in the Zero Tolerance Discipline Procedures adopted by many school systems. We are committed to working with families, students and schools to the work through the difficulties that arise with special education students.

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 advocate for the continuation of the Indiana Comprehensive Health Insurance Association (ICHIA) program that improves access and quality health care for members.

The Arc of Indiana will oppose any efforts to eliminate or decrease any of the health insurance mandates utilized by people with developmental disabilities. The Arc of Indiana is committed to people with mental retardation and developmental disabilities having access to quality health care.

Prevention

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. We will continue to discuss the effects of alcohol and other controlled substances during pregnancy.



Betty Williams Joins The Arc of the United States Board of Directors

Betty Williams, a long-time advocate for people with disabilities, has been elected to the Board of Directors for The Arc of the United States.

In her nomination speech Betty said, "In 1985 my life changed when I came to work in the local Arc which is now called Achieva Resources in Richmond, Indiana."

Betty served on The Arc of Indiana Board of Directors from 1996-2004. She currently serves as President of Self-Advocates of Indiana, and is the Region 5 Representative of Self-Advocates Becoming Empowered (SABE). Betty also serves on the state MRDD Commission, having been appointed by former Governor Frank O'Bannon.

"The most important thing I do is help improve the lives of my friends with disabilities.

"I don't like to sit back and watch things happen in our lives.

"My favorite saying is, 'Boldly go where everyone else has been before,' which means that we can achieve our dreams just like everyone else." Betty said.

Congratulations to Betty on her latest achievement.

Keep Up to Date on State and Federal Legislation

***** Sign up for *****

The Arc Action E-List

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

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

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

Go to: www.arcind.org

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Executive Director's Column



John Dickerson

The Arc of Indiana Welcomes Continued Opportunities with New Administration

The Arc of Indiana looks forward to continued opportunities to improve the lives of people with developmental disabilities and their families under the administration of Governor Mitch Daniels, new FSSA Secretary Mitch Roob, and new leadership in the Indiana House of Representatives.



Governor Daniels

The Arc of Indiana has always worked in a strong, bi-partisan fashion to pass legislation and secure funding for programs and services. One of

our strengths is that because disabilities impact families from all socio-economic groups, faiths, races, and political beliefs, we have always had the ability to communicate effectively with a wide variety of policy makers.

Disabilities impact families from all socio-economic groups, faiths, races, and political beliefs.

The results show in the successes we have had for nearly 50 years—through many administrations, Republican and Democratic leadership in the House of



FSSA's Mitch Roob

Representatives, and long-time Republican leadership in the Indiana Senate. The Arc of Indiana Board, staff, and membership is well prepared to continue our 48-year mission of advocating for people with mental retardation and related disabilities and their families as our new Governor, new FSSA Secretary, and the Indiana House of Representatives and State Senate begin their work.

The Arc of Indiana 2004-2005 Board of Directors

Congratulations to the newly appointed officers and directors of The Arc of Indiana.

OFFICERS

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George Rowlas, Fort Wayne

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SECRETARY

Mark Kevitt, Columbus

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2005 CALENDAR FEATURES STORIES OF SUCCESS

The Arc of Indiana's 2005 calendar features stories and photos of thirteen people with developmental disabilities who are leading successful lives in communities throughout Indiana, thanks to the supports they receive from providers of home and community based services, made possible through state and federal funding. Following are two of the stories featured in the calendar.

Ralph Palmer and Terry Moyer became friends while working at Passage's sheltered workshop in Columbia City, Indiana. Now, they work and volunteer with supports provided by Passage's Community Supports Program. For many years, Ralph lived at home with his mother. When she was admitted to a nursing home, Ralph was able to continue living in his community with supports through Passage's Community Supports Program. Without funding for emergency services, Ralph may not have been able to continue to live in the community in Columbia City.

Ralph Benjamin was born in Knightstown, Indiana in 1940. When he was nine years old, Ralph's parents were no longer able to care for him at home. At that time, there were not supports for Ralph's family to help them meet his medical and behavioral issues and profound mental retardation. Ralph was placed at Muscatatuck State



Ralph Benjamin lived at MSDC for 51 years. Today he goes to the library and to a fitness program at the YMCA.



Palmer and Moyer enjoy a leisurely summer's day.

Developmental Center (MSDC), where he was to spend the next fifty-one years.

At the age of sixty, Ralph moved from MSDC to a home in Indianapolis and began receiving community based services from Arc Rehab Services, the local chapter of The Arc in Boone County; and Indiana Mentor.

Special thanks to all the sponsors of The Arc of Indiana's 2005 calendar:

- Arc Opportunities, Howe
- Arc Rehab Services, Lebanon
- Bi-County Services, Inc., Bluffton
- Damar, Camby
- Evansville ARC, Evansville
- Indiana Mentor, Indianapolis
- KCARC, Vincennes
- Lake County Foundation for the Retarded, Gary
- Noble of Indiana / The Arc of Greater Indianapolis
- Passages, Inc., Columbia City
- Pathfinder Services, Inc., Huntington
- Peak Community Services, Logansport
- Rauch, Inc., New Albany
- Stone Belt Arc, Bloomington
- Wabash Center, Lafayette

THE ARC OF INDIANA

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

Call: 317-977-2375

or 800-382-9100

Web Address:

www.arcind.org and

www.TheArcLink.org

E-Mail: TheArc@arcind.org

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

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Summary of the Individuals with Disabilities Education Act of 2004

IDEA, the Individuals with Disabilities Education Act, was last reauthorized in 1997. After many months of negotiation by the U.S. House and Senate and advocates for children with disabilities, including The Arc of the United States, IDEA has been reauthorized.

According to the Disability Rights Education and Defense Fund (DREDF), “. . . we can say now that the voices of parents and advocates were heard loud and clear, that we DID make a difference in the outcome, and that, given the political and strategic circumstances and the situation on the Hill during this reauthorization process, our hard work and dedication paid off in getting our children the best possible bill we could get. Is it perfect or ideal? No. Is it fully funded? No. But we need to keep fighting and not be defeated by any sense of despair or failure.”

“. . . we held back ferocious assaults on discipline provisions and due process protections, and we prevailed in several key areas, from an increase in the number of certified special education teachers, to expanded access to assistive technology, to sanctions on states that do not comply with the law. And we retained continued services for students moved to alternate placements, attorney fee reimbursements for parents who prevail in due process hearings, and functional behavior assessments and manifestation determinations. There are also provisions for alternate assessments, positive behavioral supports, school to life transitions, assistive technology, and personnel standards.”

“Everyone’s efforts resulted in the bill being better than we feared, but not as good as we would have liked. . . . In the main, the principles of IDEA are preserved. The extremely negative provisions in the House bill have been eliminated, and parents’ rights remain largely intact. The final bill does contain a few changes that are weaker or that can be interpreted to be weaker than current law. Thus it is important that parents and advocates have the best strategies to deal with these new provisions. Now is the time to disseminate accurate information about the changes, develop advocacy strategies, and ensure that parents of IDEA students are trained in the new 2004 provisions.”

Following is a summary of major provisions of IDEA 2004:

- Protects the civil right of students with disabilities to a free appropriate public education
- Vigorously enforces provisions by giving the U.S. Secretary of Education and state education agencies greater power and new tools to measure compliance and impose sanctions when schools fail to meet standards.
- Requires states to develop a plan, establish targets and meet them in the delivery of a free appropriate public education, general supervision, transition services, and disproportionate representation of minorities.
- Makes agreements in dispute resolution and due process binding.
- Establishes competency standards for the training of hearing officers.

- Provides new opportunities for parents and schools to address concerns before the need for a due process hearing and encourages parents and schools to resolve differences by clarifying that mediation is available at any time.

Negative provisions in the House bill have been eliminated, and parents’ rights remain largely intact.

- Provides greater flexibility for parents and schools by allowing them to agree to make minor changes to a child’s IEP during the school year without reconvening the IEP team, and encouraging the consolidation of IEP and reevaluation meetings.
- Increases parental involvement in IEP meetings by allowing the use of teleconferencing, video conferencing, and other alternative means of participation.
- Provides increased resources to assist parents with complaint resolution and due process through Parent Training Institutes.
- Requires that initial evaluations occur within 60 days of referral unless the state currently has a policy that establishes a timeline for evaluation.
- Encourages Parent Training Institutes to focus on improving parent-school collaboration and early, effective dispute resolution.
- Enhances the preparation, professional development, and support for special educators and other school personnel working with students with disabilities to ensure that these educators possess the necessary skills and knowledge to provide instruction to students, including by creating a new grant program for institutions of higher education focused exclusively on training beginning special educators.
- Provides quality services and instruction at all stages, from early childhood through graduation from high school.
- Maintains early intervention and preschool special education programs for infants, toddlers, and preschoolers with disabilities, including allowing states to create a system that gives parents the choice to have their child continue early intervention services until the age of five.
- Requires that infants and toddlers who are abused, neglected, drug-exposed, or have experienced family violence, be referred for early intervention.
- Allows for the development of new approaches to determine whether students have specific learning disabilities by clarifying that schools are not limited to using the IQ-achievement discrepancy model.
- Authorizes local educational agencies to use up to 15% of IDEA funds to develop a comprehensive educational support system for students without disabilities in grades K-12 who require additional academic and behavioral supports to succeed in a general education environment.
- Establishes a state-level risk pool fund to assist local educational agencies in providing FAPE to high-need children.
- Requires schools to provide short-term objectives for students with significant disabilities, and for all students, quarterly reports to parents on their child’s progress toward meeting annual IEP goals and how that progress is being measured.
- Emphasizes academic achievement and functional performance within a child’s individualized education program (IEP).
- Simplifies the rules for transition services (activities that help a student begin planning for life after high school) by requiring that substantive transition services and planning begin at age 16.
- Provides an option for 15 states to develop a 3-year IEP for students ages 18 to 21, to focus parents and schools on long-term goals for helping the student transition to postsecondary activities.
- Provides for the establishment or designation of a National Instructional Materials Access Center, to provide schools with a one-stop provider of textbooks or other materials for students who are blind or with other disabilities. [on HOLD]
- Strengthens the involvement of the State vocational rehabilitation system with disabled students who are still in secondary school.
- Requires all special education teachers to be highly qualified by the 2006-2007 school year and designates 100% of state program improvement grants to support professional development of teachers. [timeline on HOLD]
- Improves outreach and services to homeless, foster care and other youth by clarifying state child find responsibilities, simplifying parent or guardian involvement and improving coordination between schools.
- Improves Discipline and Ensures Safety.
- Improves current discipline provisions by simplifying the framework for schools to administer the law, while ensuring the rights and the safety of all children.
- Requires schools to determine if a child’s behavior was the result of their disability or poor implementation of their IEP when considering a disciplinary action.
- Requires that schools conduct functional behavioral assessments and give behavioral services to students who are disciplined beyond 10 days, in order to prevent future behavior problems.
- Requires that schools continue providing services that enable students who are disciplined to participate in the general curriculum and meet their IEP goals.

(Continued on Page 5)

Biennial Budget Must Address Growing Need for Home and Community Based Services

The Wait Goes On

As of August, 2004 there were over 23,470 people on waiting lists in Indiana for Medicaid Waivers serving people with developmental disabilities and autism. This is a duplicated count—one person may be on all three waiting lists. The unduplicated count shows that 15,500 individuals are waiting for home and community based services funded by a Medicaid Waiver.

Autism Waiver—2,478 people waiting
Developmental Disability Waiver—12,797 people waiting
Support Services Waiver—8,195 people waiting
Waiting List Total—23,470 duplicated count
Waiting List Total / Unduplicated—15,500

For thousands of families, the wait has lasted for years, dating as far back as 1997. The Bureau of Developmental Disability Services (BDDS) is targeting people on the waiting list for the Developmental Disabilities waiver with the following application date, depending on their local BDDS district.

District 1 / Merrillville: January 15, 1998
District 2 / South Bend: September 24, 1997
District 3 / Fort Wayne: May 15, 1997
District 4 / Greencastle: July 30, 1997
District 5 / Indianapolis: March 26, 1997
District 6 / Muncie: November 10, 1997
District 7 / Evansville: June 12, 1998
District 8 / Clarksville and Seymour: July 11, 1997

The Autism waiver is being targeted for people with application dates of April 4, 1998.

The Support Services Waiver is serving only those with application dates of April 1, 2002.

It is estimated that over 57,000 persons with developmental disabilities in Indiana live with family care givers. Of those, over 14,500 lived with care givers over the age of sixty, over 20,000 live with care givers over the age of forty, and over 22,600 live with care givers under the age of forty. It is not known how many of these families are actually represented on waiting lists.

Indiana Government Efficiency Commission Calls for Shift to Community Based Supports to Save on Rising Medicaid Costs

The Indiana Government Efficiency Commission, created by the Indiana General Assembly in 2003, has recommended that Medicaid recipients should move into community settings and out of nursing homes and other institutions to help the state better manage the cost of their care.

The commission also recommended that Indiana should look to other states regarding how they have utilized Medicaid Waivers for home and community based supports; and recommended restraint in imposing any further provider reimbursement cuts or freezes for Medicaid services beyond those currently enacted. The Commission further recommended that the General Assembly strongly consider enacting a dedicated revenue source for the state portion needed for federal matching funds.

The Arc of Indiana has long advocated for the

Why do thousands continue to wait, despite efforts begun in 1998 to fund home and community based services?

The state biennial budget passed in 1999 provided \$39.3 million to implement the first phase of the 317 Plan. The budget approved in 2001 provided \$43.6 million for the second phase. State funds were used to match federal Medicaid funds, providing a total of \$157 million in new state and federal funds from FY 2000 through FY 2003 for the 317 Plan. However, the state fiscal crisis forced the reversion of state dollars appropriated to match federal Medicaid funds for Fiscal Years 2002-2003. This essentially ended the planned growth of the Medicaid Waiver to move people off of waiting lists.

As Indiana's fiscal crisis continued, no new funds were included in the biennial budget approved for Fiscal Years 2004-2005. No new funds were provided to fund emergency and crisis residential services. No new funds were provided to fund people currently living in Medicaid funded residential programs who would lose eligibility for Medicaid to fund those services. No new funds were provided to serve children who would transition out of residential services funded by the Division of Family and Children and the Department of Education. No new funds were provided to move people off of waiting lists for home and community based services.

Focus on Movement to Smaller Community Programs

There continues to be positive progress to move people from large, congregate care to smaller community based programs.

In 1999, 834 people in Indiana were living in Large Private Intermediate Care Facilities for persons with Mental Retardation (ICFs/MR). As of July, 2004, 310 people were living in ICFs/MR. Seven of the ten large ICFs/MR in operation when the 317 Plan was initiated have closed.

Group homes, licensed as Small Private ICFs/MR, continue to serve people with developmental disabilities, but the focus is shifting toward serving

those in need of higher levels of care.

Muscatatuck State Developmental Center (MSDC) is scheduled to close by February 28th of this year, and efforts are being made to move people from Fort Wayne State Developmental Center and to limit new admissions.

Indiana continues to over-utilize nursing homes to care for people with developmental disabilities—the second highest utilization rate in the nation. 1,775 people with developmental disabilities live in nursing homes in Indiana. The settlement of a recent class action lawsuit requires Indiana to provide 450 Medicaid recipients with developmental disabilities who are in Indiana nursing facilities an opportunity to live in a place of their choice in the community. Indiana has agreed to fulfill this responsibility by the end of 2008.

The 317 Plan called for the movement of people to smaller, community based settings, and The Arc of Indiana has fully supported this effort. However, funds must be made available not only to better serve those currently receiving services, but also those who continue to live at home with families who remain on waiting lists.

Next Steps — Action Needed

The Indiana General Assembly has begun their work to develop a budget for Fiscal Years 2006-2007. This budget must not only provide funds for services that *must* be provided—emergencies and crisis, people losing “level of care” in a Medicaid funded residential program, and children transitioning out of Division of Family and Children and Department of Education programs—but must

(Continued on Page 6)

SUMMARY OF IDEA 2004, from page 4

- Establishes a new program to develop and enhance behavioral supports in schools while improving the quality of interim alternative education settings.
- Integrates the Individuals with Disabilities Education Act with the Elementary and Secondary Education Act.
- Provides for a national study of valid and reliable alternate assessment systems and how alternate assessments align with state content standards.
- Ensures that local educational agencies measure the performance of students with disabilities on State or district-wide assessments, including alternate assessments aligned to the State's academic content standards or extended standards.
- Clarifies the IEP team's role in determining whether a child with a disability should take regular assessments with or without accommodations, or alternate assessments, consistent with State standards governing such determinations.
- Aligns the personnel preparation and personnel certification with No Child Left Behind.

Congratulations to The Arc of Indiana's 2004 Award Recipients

Janice Durham,
The Arc of Indiana
Board's Awards
Committee Chair,
Jayland Arc
Portland, Indiana



Congratulations to all recipients of The Arc of Indiana's 2004 Awards.

Awards were presented at The Arc of Indiana's Appreciation Dinner on October 13, 2004.

Special thanks to Janice Durham, Chair of The Arc of Indiana's Awards Committee; and our Master of Ceremonies, John Ketzenberger, *Indianapolis Business Journal*.

Learn more about the outstanding achievements of our 2004 award recipients by going to our web site: www.arcind.org; click on "Congratulations to Our 2004 Award Recipients."



Individual and Family Support Award
Ned Campbell
Indianapolis, Indiana



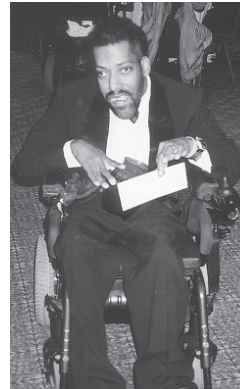
Education Award
Lillian Hardaway
Gary, Indiana



Employment Award
Buehler's Buy Low
Evansville, Indiana
Accepted by
Ron Phillips, Store Manager



Media Award
Evansville Courier & Press
Evansville, Indiana
Accepted by Abbie Garrett,
Evansville ARC



Citizenship Award
Doug Hughes
Beech Grove, Indiana



Cathleen Clark Professional Service Award
Connie Vonderau
Fort Wayne, Indiana



Development of The Arc Award
The Sertoma Club of Broad Ripple
Indianapolis, Indiana
Accepted by Cal Niquette



Living in the Community Award
Sharon Gary
Greenwood, Indiana



Public Policy Award
Senator Tom Wyss
Fort Wayne, Indiana



Public Policy Award
Representative Peggy Welch,
Bloomington, Indiana
with Betsy Higgins, Stone Belt
Arc and The Arc of Indiana
Board of Directors

BIENNIAL BUDGET MUST ADDRESS NEED FOR HOME AND COMMUNITY BASED SERVICES, from page 5

also provide funds specifically to move people off the growing waiting list for home and community based services.

In addition, improvements are needed within FSSA to properly administer the programs and services people with disabilities need to live safely. Direct-care workers are grossly underpaid and local provider agencies have a difficult time attracting quali-

fied workers to care for Indiana's most vulnerable citizens. Funding should be provided to allow for increases in wages paid to direct care workers, assisting providers to attract qualified people, and provide funds for staff training.

Join The Arc's Legislative Action Center

You can e-mail your State Senator and State Representative directly from

The Arc's Legislative Action Center.

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

You can keep up to date with public policy that impacts you and your family by signing up to receive timely Action Alerts and Legislative Information from The Arc of Indiana via e-mail.

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

The Arc Trust Twelfth Annual User Satisfaction Survey

The Arc of Indiana intends for its trust service to be easy to use. "How are you doing?" To answer this question, each year we send a User Satisfaction Survey to people using our service. The survey asks about our responsiveness to requests from the time people call and make a request to when they receive the check in the mail.

This survey provides valuable feedback for us. It identifies potential problem areas. It also helps families thinking about enrolling. "Is The Arc Trust easy to access?" some might ask. "Is getting approval difficult?" As the survey shows, we are very accessible and rarely turn down requests.

Each question in the survey has five possible answers and scores. They are: Never (0), Rarely (25), Sometimes (50), Usually (75), Always (100). A score of "Usually" or "75" is an acceptable score for all questions but Question 3. For Question 3, the acceptable score is "Rarely" or "25." Here is an example: For Question 6, "When I make a request for using the trust, my request is approved" a score of "75" or "Usually" is acceptable. A lower score is not acceptable. From our perspective, our system would be fundamentally flawed if requests were denied more often.

Here are the questions and scores from our twelfth annual survey. The average score for each question is in

parentheses. Scores from the previous nine years are also included. Scores are listed with the most recent year first. For example, the score for Question 1 in 2004 was 80%. In 2003, the score was 81%.

1. When I call to use the trust, the person with whom I must speak is immediately available. (80%, 81%, 79%, 76%, 75%, 78%, 73%, 80%, 86%, 82%.)

We want our service easy to access. Calling rather than writing is easier for most people, and we encourage people to call rather than write. This score meets our goal. It shows that people "usually" get through immediately. In human services, having success with immediate contact is atypical. Telephone tag is more common.

But what if we are not in when someone calls? Or what if we are already on the phone with someone else?

2. When the person with whom I must speak is not immediately available, he/she does return my call and is able to speak with me within two business days of my request. (94%, 96%, 96%, 96%, 96%, 96%, 96%, 98%, 98%, 97%, 100%.)

This score is very good. We almost always return the initial call and actually speak with the caller within two business days. Maintaining such a high

score, year after year, is a challenge. While a score in the 90s may not continue indefinitely, we intend to keep this score very high. We understand the frustration of playing telephone tag or not having calls returned.

3. Making contact with this person is a problem. He/she is not available when I call, and I am not available when he/she returns my call. (8%, 9%, 10%, 13%, 12%, 12%, 7%, 8%, 7%, 6%.)

This is our way of measuring frustration. Such a low score indicates a minimum amount of frustration.

NOTE: Frustration is more likely for professionals than for family members and other non-professionals. Why?

Because it is harder to make contact with professionals than non-professionals. With most professionals, our contact is limited to their work day. But contacting family members and other non-professionals is not limited to anyone's work day. If we can't speak with family members and non-professionals during the day, we call them in the evening or over the weekend.

4. Requesting disbursements is a positive experience for me. The person with whom I speak is receptive to how I want the trust used. He/she is encouraging and supportive of my efforts. (93%, 94%, 94%, 96%, 93%, 93%, 92%, 94%, 97%, 98%.)

(Continued on Page 8)

Shane Service Joins Arc Trust as Associate Trust Director

Shane Service has joined the staff of The Arc Trust as Associate Trust Director. Shane joins Alan Kemp, Trust Director, and Sonya Grace, Executive Assistant for The Arc Trust.



Shane Service

Shane is a native of the Indianapolis area, having been raised in Franklin, Indiana. He studied Philosophy, Religion and Biology at Franklin College, where he was named a Ben Franklin Distinguished Scholar. Upon graduation, he worked as a Job Coach for Gateway Services/The Arc of Johnson County in Franklin. Shane left Gateway to attend law school at Baylor University School of Law in Texas.

After returning home from Texas, he practiced law for four years, concentrating on first and third party insurance defense, complex insurance coverage issues, arson and fraud litigation, airborne pathogen litigation, products liability litigation, and domestic and criminal law.

Additionally, Shane brings to The

Arc Trust previous knowledge of disabilities, and has in the past been invited to speak to financial professionals on the funding of special needs trusts.

Shane is a member of the Indiana Bar, the Indiana Bar Association, and the Indianapolis Bar Association. He is actively involved in the Indianapolis community and volunteers his time with various inner-city volunteer programs. He is a member of the Indianapolis Judges and Lawyers Assistance Committee.

He is also a volunteer for the Indiana Judges and Lawyers Assistance Program (JLAP), which is associated with the Indiana Supreme Court and provides assistance to judges and attorneys throughout Indiana who are struggling with mental illness, substance abuse, physical disabilities and illnesses, and aging-related disabilities. Shane was recently nominated to serve as a member of the JLAP Board. Shane lives in Carmel, Indiana and enjoys running, reading and playing the piano in his spare time.



Sonya Grace

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 260 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 460 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 800 families are enrolled in Trust I alone. (Trust I accounts are usually funded at the death of a family member.)

Over 520 individuals are enrolled in Trust II. Combined enrollments total over 1,300.

For a free copy of our material call or write:

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

TWELFTH ANNUAL TRUST SURVEY, from page 7

This is another good score. If we are doing a good job, this score will always be high. We intend to be receptive, encouraging and supportive.

5. When I call with a question on non-trust matters or need advice, the person with whom I speak is willing to help. (95%, 94%, 96%, 95%, 95%, 97%, 97%, 97%, 98%, 99%.)

Our primary purpose is to supplement, not supplant, government benefits like Medicaid, SSI, and Indiana's Supported Living program. But, when asked for other kinds of assistance, we try to help.

"Trying to help" and "Helping" are not always the same. If we cannot do what a caller wants, then, no matter how sympathetic we are, and no matter how clear and rational our explanation, this particular client might characterize our response as being "unhelpful" for this particular experience.

6. When I make a request for using the trust, my request is approved. (92%, 91%, 92%, 93%, 92%, 93%, 93%, 94%, 96%, 94%.)

As the score shows, requests are rarely denied. When a request is denied, what is the reason? There are two main reasons: First, the request, if approved, could result in the beneficiary

losing benefits like Medicaid, SSI, and Supported Living. We don't want Arc Trust beneficiaries losing these benefits. Second, the item or service requested is already available through Medicaid, SSI, or Supported Living. Our purpose is to supplement, not supplant, these benefits. If Medicaid, etc. denies approval, then The Arc Trust can, and is, used.

7. The time that passes from when I submit a bill for reimbursement to when I receive the check is two weeks or less. (94%, 95%, 95%, 94%, 94%, 93%, 97%, 97%, 95%, 92%.)

Good service means getting the check out quickly. Our goal, from the time a bill is submitted to us to the time the person receives the check, is two weeks or less. We have almost always met this goal.

Conclusion

Each score meets or exceeds the level we believe is acceptable. As pleased as we are with high scores, equally rewarding is our consistency. We serve more people each year, but serving more people has not lowered our quality. As these scores show, consistently—year after year—the quality of our service remains strong and at a high level.

Why Support The Arc of Indiana?

The Arc of Indiana strives to help people with mental retardation and related disabilities realize their dreams of working, living, playing and learning in communities around our great state.

Every day our staff is helping families become connected with providers of services, educated in knowing their loved ones rights, informed in the process of Medicaid eligibility and helping plan for their loved one's future.

For over 48 years, The Arc of Indiana has been there for families to lean on. We want to continue our advocacy and expand to provide even more opportunities to families and their loved ones with disabilities.

The advocacy efforts of The Arc of Indiana are made possible, in part, by the individual donations we receive. Your generous tax deductible donation will help continue the legacy.

Yes, I want to support The Arc of Indiana with a gift of:

___\$500 ___\$250 ___\$100 ___\$50 ___Other

Please make your check payable to **The Arc of Indiana**, and return to:

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

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The Arc of Indiana 2004 Convention

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Wabash Center



Steve Green stands alongside this year's Hole-In-One Prize, a Ford F150 Extend Cab Truck donated by Burd Ford.