

The Arc of Indiana's 2004 Public Policy Effort Leads to Booster Seat Law, Training Initiative for Law Enforcement



When the 2004 Indiana Legislative Session began, it was expected that legislators would address tax reassessment problems, the budget deficit, jobs, and economic development initiatives. Instead, the 2004 Legislative Session will be remembered for a walkout regarding same sex marriage, an attempt at full-day kindergarten and the passage of a booster seat law.

The Arc of Indiana is proud of our efforts, made in partnership with Parents for Child Safety, to pass **HB 1098 – Child Restraints in Motor Vehicles**. The bill, sponsored by Representative Peggy Welch (D-Bloomington) and Senator Tom Wyss (R-Fort Wayne), requires a person who operates a motor vehicle with a child who is less than 16 years of age to restrain the child by a child restraint system or a safety belt. It also requires

children ages five through seven to be in a child restraint system. A violation of this law does not add points to the driver's traffic report or count toward habitual violator status. The Arc of Indiana believes HB 1098 is important to preventing injuries in children that can cause death, or lead to life long disabilities.

Law enforcement officials to receive training in interacting with persons with developmental disabilities

Another priority bill approved by the General Assembly that was spearheaded by The Arc of Indiana, **SB 271 – Law Enforcement Training** – was amended into and passed in **HB 1437**. The bill requires law enforcement

personnel, jail officers, probation officers, and correctional officers to receive training in interacting with persons with mental illness, addictive disorders, mental retardation and developmental disabilities. SB 271 was sponsored by Senator Marvin Riegsecker (R-Goshen) and Representative Sheila Klinker (D-Lafayette). HB 1437 was sponsored by Representative Bill Crawford (D-Indianapolis) and Senator David Long (R-Fort Wayne). It creates a forensic diversion program to provide community treatment and mental health and addiction services for offenders suffering from mental illness or addictive disorders who have not been charged or convicted of a violent crime, and establishes a forensic diversion study committee.

SB 188 – Birth Problems Registry and Cancer Registry – will, for the first time, allow for the collection of data on the incidence of autism in

Indiana. The bill, sponsored by Senator Bev Gard (R-Greenfield) and Representative Bill Crawford (D-Indianapolis), allows the State Department of Health to include pervasive developmental disorders and fetal alcohol spectrum disorders as birth problems, and requires these disorders to be recorded in the birth problems registry if recognized in a child before the child is five years of age. It also changes the age at which a birth problem may be recognized and recorded in the birth problems registry for other disorders until the child is three years of age.

The Arc of Indiana also worked for the passage of **SB 363 – Council for People with Disabilities**. The bill establishes by state statute the Governor's Council for People with Disabilities and the board of directors of the Council to implement the federal Developmental Disabilities *(Continued on Page 4)*

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Study Finds Tremendous Progress in Indiana's Community-Based Services

Continued Progress Critical to Address Unmet and Growing Needs

Indiana has made tremendous progress in reducing reliance on institutions and expanding community services, according to a comprehensive study of services to people with developmental disabilities. However, Indiana must continue to improve and expand community services in order to meet the needs of those on waiting lists for services, and the growing need of aging caregivers and aging persons with developmental disabilities.

The report, *Developmental Disabilities Services in Indiana: 2004 Progress Report*, by David Braddock, Ph.D and Richard Hemp, M.A., the Coleman Institute, University of Colorado, found that, "Indiana has made substantial progress in the past four years in reducing reliance on institutions and in establishing the HCBS (Home and

Community Based Services) Waiver as a major federal funding source for community developmental disabilities service expansion. The state is positioned well to continue to make significant progress in the years ahead." Following are key excerpts from the report.

Community Services in Indiana

In July, 1998 Governor O'Bannon's "317 Task Force" of consumers, advocates, and state officials delivered its report on *A Comprehensive Plan for the Design of Services for People with Developmental Disabilities*. The Plan addressed key issues confronting the State of Indiana including waiting lists for services and the provision of necessary resources to support people with developmental disabilities in their homes and at work. The Indiana 317 Plan recommendations have provided the framework for extensive program development activities by the Indiana

Family and Social Services Administration (FSSA).

Indiana has indeed made substantial progress . . . (Indiana's) 2004 institutional placement rate of 9 per 100,000 is below the projected U.S. rate of 10 per 100,000. From 2000 to 2004, Indiana . . . reallocated resources from institutional facilities that closed and downsized and provided expanded funding for community services programs . . . federal Medicaid spending for the HCBS Waiver in Indiana increased 360% from 2000-2004, while federal spending for Intermediate Care Facility/Mental Retardation spending dropped 16% . . .

Today, the HCBS Waiver is the primary federal funding source for Indiana community services programs. The total number of persons with developmental disabilities in residential settings increased 34% from 2000 to 2004, and individuals residing in smaller settings for 6 or fewer persons increased from 44% of

(Continued on Page 6)



Members of the Bloomington Rotary work with consumers from Stone Belt to create a banner.

Stone Belt Art Project Brings Consumers and Community Together

For the consumers at Stone Belt, local chapter of The Arc in Monroe County, art is a valuable form of expression and communication. Stone Belt consumers have been involved in a number of collaborative art projects that have brought together persons with disabilities and volunteers from the community to create large-scale masterpieces.

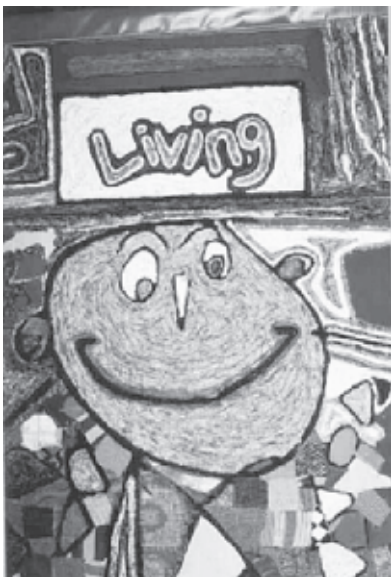
One project, titled "Celebrating Our Community—Living, Learning, Working, Playing," included the creation of colorful banners and magnetic sculptures reflecting consumers' perspectives on living, learning, working and playing in the community. Stone Belt consumers created drawings that were then projected and traced onto canvas, banners and magnets. The groups then attached colorful yarns and fabrics to create their masterpieces. The largest piece is a 7 by 10 foot canvas.

Under the direction of local collaborative artist, Joe LaMantia, the creation of these art pieces took approximately 12 weeks, with at least one two-hour session each week. Sessions were held in the community as well as Stone Belt's facility. Community partners included Indiana University Kelley School of Business students, Bloomington Rotary Club members, Middle Way Houses' Rise Program participants, Indiana University Art Docents, and others.

"Creating these art pieces has provided a valuable and fun forum for Stone Belt consumers and the community to come together," Stone Belt CEO Leslie Green explains. "Our consumers were introduced to a diverse group of individuals with various age and cultural backgrounds in our community. And, community members have gained exposure to individuals with disabilities and what they contribute to the community."

Upon the project's completion, the pieces were displayed at Bloomington City Hall and College Mall before being permanently installed at Stone Belt's 10th Street facility for clients, staff and visitors to enjoy.

The consumers at Stone Belt also participated in a project creating 17-foot-tall venue sculptures for the Lotus World Music Festival; and, in celebration of Stone Belt's 45th Anniversary, consumers are working on another large scale piece to represent Stone Belt that will be displayed in the building for visitors to enjoy.



A banner created for the art project celebrates living in the community.

Katie Cortelyou "Health Care Hero"



Cortelyou

Katie Cortelyou, a young woman with Down syndrome, received a Volunteer Finalist award from the *Indianapolis Business Journal (IBJ)*, in recognition of her volunteer work at the St. Vincent Hospital Down Syndrome Clinic. Katie was honored by the IBJ at a breakfast for "Health Care Heroes" on February 27, 2004.

Katie has worked as a volunteer at St. Vincent's Down Syndrome Clinic for over two years.

In the *IBJ* article, written by Jolene Ketzenberger, about Katie's volunteer work, Katie said,

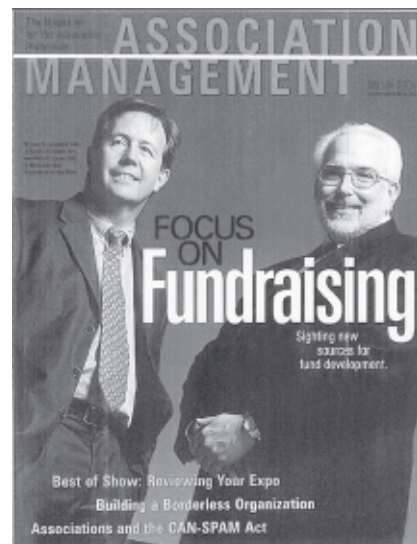
"I want to show people that even a person with intellectual disabilities can be a part of life and the community . . . You don't have to be afraid to have a child with Down syndrome. Their kids can grow up and be proud of themselves and hold their heads up high and be a part of the world. Part of my

message is to influence them not to consider placing their kids in an institution."

Katie graduated from Lawrence North High School in 1999 with a high school diploma. In addition to her volunteer work, she is employed at Community Hospital North, delivering ice and water to patients and helping people find their way around the hospital.

Katie is involved with Best Buddies of Indiana, volunteers for the Indiana Down Syndrome Foundation, belongs to Noble of Indiana's Ladies Auxiliary, and assists Noble with their annual "Evening in the Garden" fundraising event at the Flower and Patio Show in Indianapolis. Noble of Indiana is the local chapter of The Arc in Marion and Hamilton counties. She has also volunteered for the United Way.

The *IBJ* article on Katie's many accomplishments ended with the following words from Katie, "I want to give back to the community because I want the important people to understand that we do have a voice, but most of all that we do have feelings."



Association Management Features Noble of Indiana CEO, Michael Howland

Michael Howland, CEO of Noble of Indiana, local chapter of The Arc in Marion and Hamilton Counties, is the 2003-2004 Chairman of the American Society of Association Executive's Philanthropic Organizations Committee. The March, 2004 issue of *Association Management* features an article, "Finding Fundraising Focus, Creative Development Techniques for Tapping Philanthropic Funding Sources," he co-wrote with Wells Jones, CEO of Guide Dog Foundation for the Blind. Michael Howland and Wells Jones are also featured on the cover of the magazine.

Executive Director's Column

Achieving New Frontiers

In recent weeks, I have had the joy of attending 40th, 45th and 50th anniversaries of several local chapters of The Arc of Indiana. I say joy, because at each one it has been so exciting to see the results of so many pioneers' early work.

At many of the events, people were present who were there at the beginning—people who had a belief and a vision for what could be. The results are in the faces of the people who are proud of what they do today, because of what was started those many decades ago.

Betsy is proud that she can live on her own. Sam showed me the key to the office where he works—proud that he is trusted. Mary has her apartment that she shares with Karen and Sue. She knows that even though her mom has passed on, she got to visit her new apartment before she died and knows she is okay.

This did not just happen. Many late night meetings of The Arc—develop-



John Dickerson

ing plans, raising funds, getting legislation passed, building community—got us to this point. Across Indiana, in the 44 local chapters of The Arc, we owe so much to so many.

At each of these events I also visited with young families—many just starting out on a journey that will be rocky at times, and yet much smoother than ever imagined by those that came before. I think they realize how much has been done by these pioneers, but also see what is yet to be accomplished. It can be daunting.

With a country at war, an economy struggling and a nation and state facing huge deficits, one might think this is absolutely the worst time to be working on behalf of people who need the support of the community to live, learn, work and play in cities and towns throughout Indiana. Yet, it may be the best time.

As we enter this summer, we will be

unveiling the Renewal of The 317 Plan—the next strategic investment in Hoosier's with developmental disabilities and their families. We will be asking our legislators to invest resources to continue implementation of major reforms to improve and expand home and community-based services. The ground work laid by those pioneers many years ago, and reforms accomplished due to the efforts of new pioneers in the first six years of The 317 Plan, make this the best of times to continue to improve and expand opportunities for people with developmental disabilities and their families.

The results are in the faces of the people who are proud of what they do today.

Working together, pioneers from the early days of The Arc and new

pioneers who are just starting their journey, we can and will achieve new frontiers.

P.S. – All in a Name

Sometimes it is the little things that say so much. At one recent celebration I saw old friends, the Melloyes of Indianapolis. Cindy Melloy regaled me about her job at a major company in town. Mom and Dad filled me in on their latest dealings with the system, and we caught up on everyone's life. As we were leaving, Cindy told me she now uses email, and I went to pull out a pen to write down her email address. Instead she pulled out her cards which she had printed. She was so proud of them, and of course I had run out of mine. Her cards have made quite a hit, as a number of her friends now are doing the same. There was a time when many doubted Cindy. Mom and Dad and dedicated people at The Noble Arc of Central Indiana did not. That small card signified so much more than a few inches of paper and drops of ink. Congratulations to Cindy and to all who made that story possible.

New Film Training Series on Dual Diagnosis

A film training series about working with people who have a dual diagnosis of mental illness and developmental disability (MI/DD) is available from Peak Community Services.

The film series was developed to inform and educate the community about common challenges faced by people who have a mental illness and developmental disability. A workbook was also developed to provide a training tool for agencies and entry-level healthcare and community service workers. Each portion of the workbook has three distinct sections: the narrative that is read in the corresponding film; a quiz that can be used in whatever form the trainer chooses; and an answer guide for the quiz. A separate "Definition" section includes additional information that could not be included in the films.

Peak Community Services, Inc. produced the series in cooperation with Logansport State Hospital's Jayne English Treatment Center and Four County Counseling Center, Inc.

Peak Community Services is the umbrella agency for Woodlawn Center and Pulaski Developmental Services—the local chapters of The Arc in Cass and Pulaski Counties.

Film #1: Ben's Day.—Until a few years ago either of Ben's conditions—MI or DD—might have resulted in him being placed in a state institution. Today, new medications and behavioral therapies allow individuals like Ben to live in the community. The

guarantee of treatment in the least restrictive setting possible is Ben's constitutional right, and that right comes with some responsibilities. Now that Ben has moved out of the hospital, he needs a chance to learn new skills to get along responsibly in the community.

Film #2: Ben's Behavior. Ben is thriving in his new environment—not because he does everything with 100% success, but because he is putting 100% effort into the new opportunities. Each day offers more challenges and opportunities. With proper support, guidance and intervention, these will be met with positive results leading to increased growth and independence.

Film #3: Ben's Medication. The interaction between Ben's medications, medical conditions, psychiatric conditions, developmental disability and learned behaviors can make it difficult for staff to determine the causes of some behaviors. Medical conditions often mimic psychiatric illnesses or medication reactions. Because Ben cannot verbalize certain problems, both he and staff members can be frustrated.

To Order Films and Workbooks

To order, call, fax or email Kathi Thompson at Peak Community Services

Phone: (574) 753-4104

Fax: (574) 753-9861

Email:

kthompson@peakcommunity.com

As long as quantities last, the VHS

or DVD films are available at no charge, with only a minimal shipping and handling fee of \$3.00. Workbooks are also available at no charge if the person placing the order can accept a PDF document through email. If the workbook is mailed, there is a minimal charge of \$3.00.

When the supply of films purchased with grant funds are gone, both the VHS and DVD can be purchased for \$6.00, plus shipping and handling.

While these films are available at no charge while they last, there is a

limited quantity of "free" films. Donations would be appreciated, and can be made to Peak Community Services, designating the Dual Diagnosis Training Series as the project being supported.

Funding for the series was provided through a Real Systems Change Mini-Grant from the Indiana Family & Social Service Administration. Blackwater Productions provided filming and editing. The films and the workbooks are in the public domain. Anyone receiving the documents may make as many copies as necessary.

Governor Kernan Proclaims March Mental Retardation Awareness Month

Noting that the month of March has been designated as National Mental Retardation Awareness Month, Governor Joseph Kernan proclaimed March Mental Retardation Awareness Month in Indiana. In part, the proclamation states:

Whereas, mental retardation is a condition which affects more than 7 million Americans and their families, including residents of Indiana; and public awareness and education enhance a community's understanding of the issues affecting people with mental retardation and other developmental disabilities; and people with mental retardation and other developmental disabilities can

be vital and vibrant contributors to our communities, improving the quality of life for all of us; and

The Arc of Indiana is a leader in Indiana in advocating for and with persons with mental retardation and related disabilities and their families; and

Whereas, local chapters of The Arc of Indiana are leaders in advocating for and with persons with mental retardation and related disabilities in their cities and counties;

... I, Joseph E. Kernan, Governor of the State of Indiana, do hereby proclaim the month of March 2004 as Mental Retardation Awareness Month in the State of Indiana.

THE ARC OF INDIANA'S 2004 PUBLIC POLICY AGENDA, from page 1



Samuel Bryan, seven, demonstrates how a booster seat might save his life. Without a booster seat, the seatbelt cuts across his neck. With a booster seat, the seatbelt is properly secured over his chest and waist.

Assistance and Bill of Rights Act. The Council has operated for the past 30 years under a series of Executive Orders. SB 363 was sponsored by Senator Bob Jackman (R-Milroy) and Representative Jeb Bardon (D-Indianapolis).

Other legislation passed this year that will impact the lives of people with mental retardation and developmental disabilities include the following bills that, at this writing, await the Governor's signature:

SB 41 – Home Health Care and Hospice Services Council – Senator Pat Miller (R-Indianapolis) and Representative Charlie Brown (D-Gary). Creates the home health care services and hospice services council and allows the council to propose rules and act as an advisory body.

SB 42 – Chronic Disease Management and Registry – Senator Pat Miller (R-Indianapolis) and Representative Charlie Brown (D-Gary). Allows the State Department of Health to add chronic diseases to the chronic disease registry by administrative rule. Adds public and private third party payers as persons to be used by the Office of Medicaid Policy and Planning (OMPP) in implementing a disease management program and as persons that may report chronic disease cases for the chronic disease registry.

SB 296 – Property Tax Deductions – Senator

Teresa Lubbers (R-Indianapolis) and Representative Peggy Welch (D-Bloomington). Increases certain property tax deductions by 108%. Applies to the following deductions: elderly; blind or disabled; wartime service disabled; disabled veteran; surviving spouse of a WWI veteran; WWI veteran; residential property rehabilitation; historic property rehabilitation; and residentially distressed area property rehabilitation.

SB 449 – CHOICE Program – Senator Greg Server (R-Evansville) and Representative Charlie Brown (D-Gary). Allows the Health Finance Commission to study the implementation of long term care services. Requires FSSA to present a report to the Health

Finance Commission.

HB 1178 – Volunteer Advocates for Seniors and Guardians – Dennis Avery (D-Evansville) and Senator Gary Dillon (R-Pierceton). Permits a court to appoint a volunteer advocate for seniors to represent and protect for a limited period the interests of an incapacitated or protected person who is at least 55 years of age. Requires a volunteer to report to the court and make recommendations regarding the incapacitated or protected person. Provides civil immunity for a volunteer, a volunteer advocate for seniors program, and a guardian.

HB 1204 – State Institution Reuse Authority – Representative Mark Lytle (D-Madison) and Senator Robert Meeks (R-LaGrange). Authorizes a municipality to establish a reuse authority to develop, manage, and plan for the use of real property of a state mental health institution that is conveyed to the municipality.

HB 1320 – Human Services – Representative Brain Hasler (D-Evansville) and Senator Pat Miller (R-Indianapolis). Provides that the maximum appropriation and tax levy for community mental health centers must be annually recalculated based on the increase in the assessed value growth quotient. Separates the laws governing the funding of community mental health centers from the laws governing the funding of community mental

retardation and other developmental disabilities centers. Requires the Select Joint Commission on Medicaid Oversight to study certain effects resulting from the repeal of continuous eligibility under the Indiana Medicaid program and CHIP.

HB 1344 – 211 Services – Representative Peggy Welch (D-Bloomington) and Senator Jim Merritt (R-Indianapolis). Recognizes as state policy the encouragement of the use of the 211 dialing code for public access to human services information and referrals. Prohibits a state human services agency from (1) establishing a telephone line for information or referrals without first consulting with a 211 service provider in the area to be served, and (2) notifying the utility regulatory commission of the consultation. Prohibits disseminating information about the availability of 211 services except as permitted in a rule or order of the IURC.

In preparation of the 2005 Legislative Session, The Arc of Indiana will hold public forums throughout the state to discuss upcoming budget issues.

HB 1365 – State and Local Administration – Representative Bill Cochran (D-New Albany) and Senator Larry Borst (R-Greenwood). Makes numerous actions relating to state and local administration. Authorizes local governments to impose an optional property tax abatement fee; provides that the value of federal income tax credits awarded under Section 42 of the Internal Revenue Code may not be considered in determining the assessed value of low income housing tax credit property. Provides for state employee group health insurance program eligibility for certain individuals who retired from Muscatatuck State Developmental Center.

HB 1438 – Economic Development – Representative Sheila Klinker (D-Lafayette) and Senator Ron Alting (R-Lafayette). Establishes the enterprise zone study commission and changes the appointing authority for the board of the Indiana economic development corporation.

Plans Underway for 2005 Legislative Session

The Arc of Indiana will be issuing a questionnaire to the candidates for Indiana Governor that will be published in a future newsletter. Discussions are also underway with the candidates for Governor to participate in a Disability Forum sponsored by The Arc of Indiana, INARF and COVOH in early August.

No action was taken in the 2004 Legislative Session to solve the State's large and growing budget deficit. Governor Kernan announced in his Annual State of the State Address that he could manage the deficit without opening up the State's budget to legislation. He issued a notice early in the Session that he would likely veto any bill with a negative fiscal impact. State revenue forecasts continue to come in under budget, which will make next year's budget writing session more difficult.

In preparation of the 2005 Legislative Session, The Arc of Indiana will hold public forums throughout the state to discuss upcoming budget issues. As plans become definite, we will keep you informed.

Keep Up to Date on State and Federal Legislation Sign Up for The Arc Action E-List

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

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

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

Go to: www.arcind.org

Click on: Arc Legislative Information Page

Click on: Sign Up for Action E-List

If you have signed up for this service in the past, but your e-mail address has changed, please be sure to go to this site to update your information!

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

Go to: www.arcind.org

Click on: Arc Legislative Information Page

Click on: Legislative Action Center

Consumers' Rights

The Right to Vote

Voter Registration

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

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

Who can vote?

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

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

Voters Needing Assistance

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

Accessible Polls

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

Traveling Voting Boards

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

Registration Deadlines

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

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

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

Register to Vote

Consumers' Rights

Medicaid Waiver Cost Containment

Thanks to the Indiana General Assembly's support of The 317 Plan, a comprehensive state plan for services for people with developmental disabilities, there has been record growth in home and community-based services for people with developmental disabilities over the last six years. Now the state is trying to manage that growth and control costs.

Over the past few months, the Indiana Family and Social Services Administration (FSSA) has announced several changes in the Medicaid Waiver program to reduce current spending and control future costs. This "cost containment" effort has required families and consumers on the Developmental Disabilities (DD) Waiver and Autism Waiver to review their plan of services and waiver budgets and make changes.

The goal of cost containment is two fold:

- Make sure resources are used effectively to ensure people get the services and supports they need.
- By controlling costs, ensure there will be resources in the future to serve people in the community who are on waiting lists.

Decisions on making any changes in services should be done as a team.

This should not be a one-sided process for consumers—a take-it-or-leave-it proposition—dictated by a case manager or provider. The "cost containment" process should begin with a meeting with your case manager and providers to review the current budget, the person-centered plan, and the approved waiver budget. There should be an open discussion of what services are being used and how those services tie back into the person-centered plan. Decisions on making any changes in services should be done as a team. Changes should never be dictated by any one person.

Following are some of the major changes that have been made in the DD and Autism Waivers that should be discussed with your providers and case manager:

CETA, the \$1,000 per year flexible funding for individuals to participate in community activities, is no longer available. This was a very good service that

The Arc of Indiana supported. However, this service was misused by some, leading to its cancellation for all.

A prime concern of the Exception Review Team is the health and safety of each individual.

Residential Habilitation is now limited in the number of hours available. This primarily effects whether people will need roommates. The waiver system was built on the idea that more people could be served if staff and housing expenses were shared. While some may need to live alone for very specific reasons, which the team should justify, The Arc of Indiana believes having one or two roommates is appropriate. Teams can request a 90-day extension to find appropriate – and we do stress appropriate – roommates.

Respite has a "soft cap" of \$2,000 per year. For many people this guideline will be adequate. For others, respite is the key service they need. This may be particularly true for caregivers who are elderly or in poor health, those who care for a person who is severely disabled, and single parents. For these families, higher levels of respite may be justified. The need for additional hours of respite should be documented, and a request should be made to go beyond the "soft cap" of \$2,000 per year in respite services.

What happens if spending levels set by the state are not met?

FSSA has established an Exception Review Team to look at each case that exceeds the cost containment guidelines. Your team should submit the budget to the Exception Review Team, along with extensive documentation as to why the budget is appropriate. A prime concern of the Exception Review Team is the health and safety of each individual. Appeals should focus on those areas.

What if I disagree with proposed changes in the Medicaid Waiver Plan of Care and Budget?

There is a process to dispute problems at the local level. Each of the regional Bureau of Developmental Disabilities has a person assigned to meet with the team and try to resolve disputes. If you do not know

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Absentee Voting

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

Requirements for Service Providers and Case Managers

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

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

TheArcLink Now Offers Internet Instruction for Librarians Serving People with Disabilities

TheArcLink, www.thearc.org, is now offering an Internet based instruction program, *Internet Instruction for Librarians Serving People with Disabilities*. Training modules have been designed for librarians who work with people with disabilities as they attempt to use the Internet. The project was developed because libraries provide an environment for free access to the Internet, and are often the location service providers refer people with disabilities to for information.

The workshop is presented in three sessions.

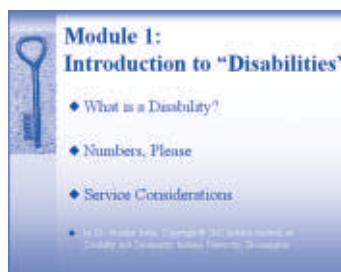
The first session provides an introduction to disabilities—what is meant

by that word, who qualifies, and service considerations.

The second session provides an overview of assistive technology used to access the Internet. Information includes what assistive technology can do, the types of devices that are available, who uses it, and where additional information can be found.

The final session provides information on TheArcLink—a web site with valuable information for people with disabilities and their families. This is followed by a resource file of additional readings that might be helpful in working with people with disabilities.

Each of the three sessions is provided in the following formats:



PowerPoint slides with voice-over narration to support auditory learners. People with visual impairments should be able to access the information from this format using screen reader software, although some may

prefer the other format.

Print transcripts. People with hearing impairments can access information presented on the slides and text of the narration in print format.

PowerPoint slides without narration. This format is presented for those who want to look at the PowerPoint slides, but would rather not listen to the narration.

The workshop was developed by Dr. Marilyn Irwin of the Indiana Institute on Disability and Community at Indiana University, Bloomington.

Funding for this project was contributed by SBC Communications through grants to The Arc of Indiana, TARC (Tulsa OK) and The Arc of Texas.

STUDY FINDS TREMENDOUS PROGRESS IN INDIANA'S COMMUNITY-BASED SERVICES, from page 1

the total system in 2000 to 67% in 2004.

Aging Caregivers, Aging of People with Disabilities

A particularly critical finding of the report is the growing, unmet need of aging caregivers and the aging of people with developmental disabilities.

"The baby boom generation will begin to reach age 65 in 2011. The proportion of Americans aged 65+ years, now 13%, will grow steadily over the next three decades and reach 22% of the U.S. population in 2030. There has also been an impressive increase in the lifespan of individuals with developmental disabilities."

The report notes that in the 1930s, persons with mental retardation typically died before the age of twenty, and before the age of 60 in the 1970s. In

1993, the average lifespan for a person with mental retardation was 66, compared to 70 for the general population. Persons with Down Syndrome lived only to the age of nine in the 1920s, 31 in the 1960s, and 56 in 1993.

The study found that over 57,000 persons with developmental disabilities in Indiana live with family caregivers. Of those, over 14,500 lived with caregivers over the age of sixty, over 20,000 live with caregivers over the age of forty, and over 22,600 live with caregivers under the age of forty. "Clearly, many of these individuals need services now or very soon in the future."

Recommendations for the Future

The study makes key recommendations regarding what Indiana must do to continue to develop quality programs and services for people with developmental disabilities. Following is a sum-

mary of those key recommendations:

Reduce Reliance on Public and Private Institutions

- Indiana should continue to responsibly downsize the remaining state-operated institutional facilities (Muscatatuck and Fort Wayne State Developmental Centers); developmental disability units at state mental hospitals in Logansport, Evansville, and Madison; and large private Intermediate Care Facilities for the Mentally Retarded (ICFs/MR). Resources from the downsizing should be reallocated to strengthen and expand community services.

- Indiana continues to over utilize nursing homes to care for people with developmental disabilities – the second highest utilization rate in the nation. Over 1,700 people with developmental disabilities live in nursing homes in Indiana. The report recommends that resources should be reallocated to allow the majority of these individuals to live in community settings.

Continue Expansion of Community Services and Related Supports

- Over 10,000 people remain on waiting lists for home and community based services. The need for additional Waiver services will continue to grow rapidly in the future due to the growing needs of aging caregivers. Indiana will need to continue to expand Waiver services to meet this need.

- Indiana should consider developing additional support programs for families, including a cash subsidy program similar to those used in Illinois, Michigan, and Minnesota.

Build the Community Infrastructure

- Wages and benefits for community-based direct support staff should be increased over the next several years to reduce staff turnover and improve service quality.

- The quality assurance and quality improvement system that is being implemented by the Bureau of Developmental Disabilities and the Bureau of Quality Improvement Services should continue to be refined and expanded.

- The state must address the need for the Division of Disability, Aging, and Rehabilitative Services to have adequate staff to manage the continued expansion of community based services.

Dr. Braddock presented his findings to fiscal analysts for the Indiana House of Representatives and the Indiana Senate on March 15th. The Arc of Indiana and INARF, a trade association for providers of services for people with developmental disabilities, will also share the report with state legislators and state officials, as part of our advocacy efforts to continue implementation of The 317 Plan to improve and expand home and community based services.

The report was prepared for The Arc of Indiana, INARF, Indiana Governor's Planning Council for People with Disabilities, and the Indiana Institute on Disability and Community, Indiana University.

David Braddock, Ph.D., is the Executive Director of the Coleman Institute, University of Colorado. The Institute was founded in 2001 to "catalyze and integrate advances in science, engineering, and technology to promote the quality of life and independent living of people with cognitive disabilities."

COST CONTAINMENT, from page 5

the phone number of your regional BDDS office, call (317) 233-2320 or 1-800-545-7763 and ask for the phone number for the BDDS office in your area. If you cannot come to an agreement at that level, you can file an appeal with the Bureau of Quality Improvement Services (BQIS) and ask for an immediate review. If you do not reach agreement at this level, the last level of appeal would be to file for an Administrative Review Hearing. Medicaid rules prohibit the change of any program without adequate review and protections. You should state that current services must be maintained to protect the health and safety of the individual during the appeal process.

Why is The Arc of Indiana supporting "Cost Containment"?

The Arc of Indiana believes the system of services to people with developmental disabilities must and can be improved. People deserve to receive the services they need and value. At the same time, people should not receive more services than what they really need, and abuse of the system cannot be tolerated. We also see and talk daily to individuals and families who continue to wait for services on waiting lists that now exceed 8,000 people. Unless every dollar appropriated by the Indiana General Assembly is used wisely and efficiently, we will not have funds to move people off of waiting lists.

Eleventh Annual Arc Trust User Satisfaction Survey

The Arc of Indiana intends for its trust service to be easy to use. "How are we 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.

Calling rather than writing is easier for most people, and we encourage people to call rather than write.

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

Free, Unbiased Service from The Arc of Indiana

Evaluation of Cash-Value Life Insurance Policies

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

system would be fundamentally flawed if requests were denied more often.

Here are the questions and scores from our eleventh annual survey. The average score for each question is in parentheses. Scores from the previous eight years are also included. Scores are listed with the most recent year, 2003, first. For example, the score for Question 1 in 2003 was 81%. In 2002, the score was 79%.

1. When I call to use the trust, the person with whom I must speak is immediately available. (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. (96%, 96%, 96%, 96%, 96%, 98%, 98%, 97%, 100%.)

This score is very good. We almost always return the initial call and speak with the caller within two business days. Maintaining such a high score, year after year, is a challenge. While a score in the high 90s is not likely to 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. (9%, 10%, 13%, 12%, 12%, 7%, 8%, 7%, 6%.)

This is our way of measuring frustration. We are exceeding our target score of 25% or less.

NOTE: Frustration is more likely for professionals than for family members and other nonprofessionals. Why? Because it is harder to make contact with professionals than non professionals. With most professionals, contact is limited to the work day. Contacting family members and other nonprofessionals is not limited to the work day. If we can't speak with family members and nonprofessionals during the work day, we can 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. (94%, 94%, 96%, 93%, 93%, 92%, 94%, 97%, 98%.)

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. (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. For example, if we can't do what a caller wants, no

(Continued on Page 8)

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 400 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 760 families are enrolled in Trust I alone. (Trust I accounts are usually funded at the death of a family member.)

Over 460 individuals are enrolled in Trust II. Combined enrollments exceed 1,220.

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

USER SATISFACTION SURVEY, from page 7

matter how sympathetic we are, and no matter how clear and rational our explanation, the experience, for this caller, might not be positive.

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

As the score shows, requests are rarely denied. When a request is denied, what are the reasons? 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 our beneficiaries losing these benefits. Second, the item or service requested is already available through benefits like Medicaid, SSI, or Supported Living. We explain that the request should first be made to these sources. If they deny approval, then The Arc Trust can be 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. (95%, 95%, 94%, 94%, 93%, 97%, 97%, 95% and 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. To date, we have almost always met this goal.

Conclusion

Each score meets or exceeds the level we believe is acceptable. Indeed, with every question but Question 1, scores far surpass what we accept as satisfactory. And with Question 1, our score is better than the experience most callers have with most human service agencies.

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.



The Arc of Indiana, along with other organizations advocating for people with disabilities, hosted a reception in December to welcome Kathy Davis to her new appointment as Indiana's first female Lieutenant Governor. Pictured are: John Dickerson, Executive Director; Sally Morris, Director of Communications; Lt. Governor Kathy Davis; and Kim Dodson, Director of Government Relations and Development.

The Arc of Indiana 2004 Events

September 17
Steve Green's The Arc of Indiana Benefit Golf Tournament
The Legends of Indiana, Franklin

October 13
Indiana Conference of Executive Directors of Arcs (ICEArc), Luncheon and Training

The Arc of Indiana Annual Appreciation Dinner
Ramada Inn and Conference Center, Lebanon

October 14
The Arc of Indiana Convention and Annual Meeting, The Challenge of Change
Ramada Inn and Conference Center, Lebanon



THE ARC OF INDIANA

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 Indianapolis, IN 46204

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

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

E-Mail: TheArc@arcind.org

The Arc News in Indiana is mailed to members of The Arc of Indiana. Contact your local Arc for membership information. Local members automatically become members of The Arc of Indiana and The Arc of the United States. If a local chapter is not located in your county, you may join The Arc of Indiana as an at-large member 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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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 45 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:

\$1,000 \$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

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Telephone: _____ E-Mail: _____

I prefer to make my donation by: Visa MasterCard

Card Number: _____ Exp. Date: _____

Signature: _____