

State Fiscal Woes Worsen – People with Disabilities Could be Harmed

Medicaid Funding and Services at Risk

As *The Arc News in Indiana* goes to press, the Biennial State Budget Bill, HB 1001, flat-lines Medicaid funding. What does that mean? It means that there is no increased appropriation for services provided under the Medicaid program for Fiscal Years 2004 and 2005. If the cost for “mandatory” services under Medicaid—such as nursing home care and medical care—increase, the State *must* pay for those increased costs. The money can only be made up by making cuts in “optional” Medicaid services. Services most critical to people with developmental disabilities that could be cut or eliminated include:

- Medicaid Waiver services
- intermediate care for the mentally retarded (including group homes)

- case management
- dental services
- emergency hospital services
- eyeglasses
- inpatient psychiatric services for children
- nursing facility services for children
- occupational therapy
- physical therapy
- prescription drugs
- psychological services
- rehabilitative services
- speech, hearing, language disorder services
- transportation services
- home health services provided by home health agencies

The Family and Social Services Administration estimates that it would need an additional \$263 million to stay even with the projected population and cost growth for Medicaid. For people with mental retardation and developmental disabilities, the Budget Bill looks grim. Many of the services that are essential for people with disabilities to live successfully in the community on their own or stay with their family are in jeopardy. Although these services are categorized as “optional” under Medicaid, they are *mandatory* for people with disabilities to stay out of institutions and live in the community.

Funding for Home and Community Based Services Tied to Tobacco Settlement Funds

Another critical funding issue facing people with developmental disabilities is ongoing funding for home and community-based services. In addition to the budget bill, HB 1008 and HB 1009 include items critical to the overall State Budget and many programs and services.

HB 1009 includes \$33.3 million in funding currently used for home and community-based services for over 1,500 people with developmental disabilities. These funds were appropriated in 2001 to implement the second

phase of the 317 Plan—a plan to reduce waiting lists and provide home and community-based services for people with developmental disabilities. Without these funds, over 1,500 people would lose services they are currently receiving.

HB 1008 is the important *Energize Indiana* plan supported by Governor Frank O’Bannon and Lt. Governor Joe Kernan. HB 1008 calls for the securitization of part of the Tobacco Master Settlement Fund, and puts forth several economic development strategies to stimulate Indiana’s economy. The Arc of Indiana supports Governor O’Bannon’s *Energize Indiana* plan. Unless ways are found to grow Indiana’s economy, funding for important human service programs will always be at risk.

What Can You Do?

Medicaid services are seriously endangered. Ongoing funding for existing home and community-based services must be maintained. Your voice can make a difference in preventing cuts or even the elimination of critical services to people with developmental disabilities.

It is critical that legislators receive phone calls, letters, and e-mail messages. Ask your legislators to:

- restore—not flat line—Medicaid funding in HB 1001, the Budget Bill.
- maintain funding for existing home and community-based services in HB 1009.
- support efforts to grow Indiana’s economy by supporting HB 1008 and the *Energize Indiana* plan.
- support the Hoosiers for Options proposal to develop a funding resource for home and community-based services by adding a fee on non-nutritive beverages (see *Hoosier for Options* article on this page.)

If you do not know who your state legislators are, go to: www.arcind.org, click on “Arc Legislative Information Page,” then click on “Legislative Action Center.” You can search for your state legislators from this section.

The Arc of Indiana Joins Hoosiers for Options

Hoosiers for Options is a coalition of consumers, advocates and providers united in calling for a new funding stream for long term care options. As the fiscal news in the State of Indiana continues to worsen, Hoosier’s continue to age, and they need options of where they and their loved ones receive care.

Hoosiers for Options is responding to this need. This unprecedented coalition, made up of organizations across the health care spectrum, believes that a small fee on syrup or powder used in the manufacture of non-nutritive beverages such as soft drinks can be used to leverage federal Medicaid dollars in support of long term care options.

Hoosiers for Options supports a fee of \$2.00 per gallon on fountain drink syrup and \$.105 per gallon on carbonated soft drinks and fruit drinks (less than 10% fruit juice).

The fee would raise an estimated \$61.8 million in State dollars. The revenue would be dedicated to a Long Term Care Continuum fund within Medicaid where it would leverage an additional \$103 million.

Three quarters of the new funding would go to develop and expand home and community-based options for Hoosier seniors, persons with physical disabilities, and persons with developmental disabilities.

The remaining quarter would be used to assist nursing homes in providing quality care for those persons who choose this level of care.

How Can You Help?

You can help by contacting your State Senator and State Representative. Tell them you support adding a small fee on syrup for non-nutritive beverages to create the Long Term Care Continuum Fund within Medicaid to support the development and expansion of Home and Community-Based Services for People with Developmental Disabilities.

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Problem of Premature Birth Focus of March of Dimes WalkAmerica 2003



Volunteers for the March of Dimes are championing a new theme for the 2003 WalkAmerica as they step out to help save babies in the 33rd annual WalkAmerica campaign in Indiana throughout the spring. The Arc of Indiana is committed to reducing the incidence of mental retardation and other developmental disabilities. As part of that commitment, we urge members to support the efforts of the March of Dimes by participating in a WalkAmerica event in their community.

The March of Dimes is focusing on the growing problem of premature birth with the theme "Prematurity—it's a bigger problem than you think." Volunteers will help drive home that message with these statistics about the problem:

- More than 10,000 babies are born prematurely each year in Indiana.
- The current rate of preterm birth is 11.8% or more than 1 in 10.
- The rate of premature birth has increased over the last three decades; 19% in the last ten years.
- Nearly half of all premature births have unknown causes.
- Prematurity is the leading cause of death in the first month of life.
- 50 percent of babies born early suffer from lifelong health problems.

The aims of the campaign are to:

- Invest in more scientific research to find causes of and interventions for preterm labor.
- Raise public awareness of the problem.
- Educate women of child-bearing age about the warning signs of preterm labor.
- Assist health professionals in improving detection of high-risk pregnancies and addressing risk factors.
- Expand access to health insurance to improve prenatal care and infant health outcomes.

WalkAmerica events are held in 49 sites across Indiana. These events bring thousands of people together to support the March of Dimes fight to save babies' lives in their respective communities. Volunteers are needed. Please call 1-800-BIG-WALK to join the WalkAmerica effort.

The March of Dimes is a national voluntary health agency whose mission is to improve the health of babies by preventing birth defects and infant mortality. Founded in 1938, the March of Dimes funds programs of research, community services, education, and advocacy to save babies. For more information, visit the March of Dimes website at www.marchofdimes.com.

Positive Behavior Supports Guideline

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There are many resources for professionals on positive behavior supports, and much of it is available online. The Center for Positive Behavior Interventions and Supports at the University of Oregon (<http://www.pbis.org>) is a good place to begin. Another source is the Center for Effective Collaboration and Practice. (<http://cecp.air.org/fba/default.htm>) Both websites contain suggestions, strategies and alternatives for best practices that have been useful elements of successful positive behavior support plans.

Many state and national advocacy organizations have adopted excellent policy statements regarding positive behavior supports, including The Arc of the United States and TASH (<http://www.tash.org>). This guideline is an attempt neither to duplicate these sources nor to create another policy statement.

The rest of this guideline is for people with disabilities and their families who must select a positive behavior support provider who best suits their needs, based on the information they can find.

At its simplest level, all behavior is communication. It is what people do to get what they want or need, or to get away from something, someone or some place they do not want. People do not engage in problem behaviors because they have developmental disabilities or other cognitive disabilities. They engage in behaviors that have worked for them.

People do not "have" behaviors. Rather, they use behavior for very specific reasons. Whenever people use behavior, they are communicating how they are feeling or what they are thinking.

Positive behavior support is a way to help people get what they want or to get away from what they do not want, in a way that is helpful and safe for them and others. Its goal is to create environments and patterns of support around people to help them look upon their problem behaviors as wastes of time and energy.

Many state and national advocacy organizations have adopted excellent policy statements regarding positive behavior supports

A professional who uses positive behavior supports will conduct a range of assessments to determine the function of the person's behavior. The professional then will support the person to find new ways to achieve his/her goals in ways that are pleasing, or that, at the least, do not cause harm or injury to themselves and/or others.

The purpose of a positive behavior support plan should be to listen to what the person is saying with their behavior and then to respond to their communication in a way that uses

their strengths to meet their needs and does not harm themselves or others.

A good positive behavior support strategy may be as simple as changing where a person is sitting in a classroom or in the work place. It may recognize that some people learn best by seeing, others by doing, others by hearing. It may include giving people something they like when they engage in a desired behavior.

Positive behavior supports never use *aversives*, things people don't like or which give them pain.

In summary, a plan for positive behavior supports addresses and supports the person, not just the behavior.

Key Ingredients of an Effective Positive Behavior Support Plan

1. A written, functional assessment studies the environment (schedules, activity patterns, curriculum, support staff, physical settings) and the behavior of the person. The assessment helps the person and everyone involved to understand why the problem behaviors occur and develop workable ways to achieve better alternatives. *If there is no assessment, there is no plan.*
2. The person served by the plan participates in its creation and implementation to the greatest possible extent. The plan gives the person it serves the means and/or skills to accomplish the goals and directions that he or she has chosen. If one exists, the guardian also supports and participates in the plan.

3. Everyone else who relates to the person served in any important way receives training on how to participate in the plan.
4. Data collection and analysis determine if the plan is achieving its desired results. People often make important progress one tiny step at a time. Similarly, only someone who is tracking, documenting and reporting can catch problems early.
5. Whenever people make progress in meeting their plan's goals, the team reports and celebrates it.

A support person should spend the majority of time and effort in finding and using these positive strategies, training others in their use and analyzing the data.

Unfortunately, what passes as positive behavior support is often nothing more than indiscriminate positive reinforcement with no real plan or creative thinking to guide it, and no tracking to monitor its progress.

Use of Crisis Intervention Techniques and Aversive Interventions

Another common mistake is to confuse crisis intervention with positive behavior support. None of the techniques below has anything to do with positive behavior support. Crisis intervention should only be used as a last resort to make sure people are safe. When they are used inappropriately, they can result in serious physical injury or death.

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Executive Director's Column

I am writing to you having just returned from our Annual Governmental Affairs Seminar in Washington, D.C. We are living through an historic period in our nation as our leaders make decisions that will affect us for years to come.

Over 400 people attended the Seminar and again demonstrated the strength of this marvelous organization to bring people together around the issues that are important both here in Indiana and across the country. Families from Minnesota, Texas, Florida, New York, and nearly every other state were there to speak out on education, the budget, tax cuts, and key programs that affect people with disabilities.

We were delighted to see 18 students from Indianapolis' Brebeuf High School in attendance. Led by their Government teacher, Linda Smoot, and The Arc of Indiana board member, Susan Hansen, they had researched the issues and made appointments with members of Congress and the administration. They learned firsthand the issues that affect people with disabilities and what is needed to influence decision makers. Congratulations to them all. Their contribution to this cause is far from over.

This year also marked the unveiling of an exciting new partnership between The Arc of the United States and UCP (United Cerebral Palsy) of America. The two national organizations are working on a new Public Policy Collaboration that is strengthening the efforts of both organizations on Capital Hill. In such times as these we must work more closely together than ever before.

By the time you receive this newsletter, many expect we will be heading for a special session of the Indiana General Assembly. I hope you are tracking

the issues through our weekly legislative alerts. If you are not yet receiving these by e-mail, you can sign up by going to our web site: www.arcind.org. Click on "Arc Legislative Information Page" and then click on "Sign Up for Action E-List."

If you have access to the Internet but do not have an e-mail address, you can find our Alerts posted on our web site. Click on "Arc Legislative Information Page" and then click on "Legislative Action Center."

We are in a fiscal crisis which threatens many of the programs we hold dear. The answers to the problems with the budget are not easy. We need both short-term solutions which save critical programs and long-term solutions which improve the state's economic health.



John Dickerson

We must build for the future, and that includes protecting the important strides we have already made.

For the long term, The Arc of Indiana supports Governor O'Bannon's *Energize Indiana* plan to stimulate our economy and build a better Indiana. This investment in business and education can only lead to a stronger and more prosperous Indiana, better able to support Hoosiers who need help.

Local, State Arcs Carry Message to Washington D.C.

Thirty-two representatives from Indiana joined advocates from around the nation at The Arc of the United States Governmental Affairs Conference in Washington D.C., March 9-11.

The participants from Indiana represented The Arc of Bartholomew County; ARC Opportunities/LaGrange County; Noble of Indiana/Marion County; and also included John Dickerson and Kim Dodson from The Arc of Indiana; Susan Hansen, The Arc of Indiana GA Chairman; David Mank, Indiana Institute on Disability and Community; Elbert Johns, TheArcLink; and eighteen senior government class students from Brebeuf Jesuit Preparatory School, Indianapolis, and their teacher. Susan Hansen has worked with the class for several months and has involved them in several projects at the state level to advance The Arc of Indiana's Public Policy Agenda.

At the forefront of The Arc's national agenda is **S. 138** or **H.R. 816** – the State Budget Relief Act. These bills would provide temporary state fiscal relief by increasing the federal share of Medicaid spending or the federal medical assistance percentage (FMAP). The bills differ slightly in the amount and time allotted for the relief, but both would bring in several hundred million dollars to Indiana's State Medicaid Program. The money is desperately needed

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News You Can Use

Revisions to Indiana's Medicaid Waiver for Persons with Autism

The Centers for Medicare and Medicaid Services (CMS) has approved a renewal for Indiana's Medicaid Home and Community-Based Services Waiver for Persons with Autism for a five year period from January 1, 2003 through December 31, 2007. This renewal will make significant changes to the Autism Waiver to make it consistent with the DD Waiver. The Autism Waiver Policy Manual has been revised, and is posted on FSSA's website at:

<http://www.in.gov/fssa/servicedisabl/pdf/autismman.pdf>

BDDS Legal Handbook on the Web

A legal guide to laws concerning people with developmental disabilities, produced by the Bureau of Developmental Disabilities Services (BDDS) is now posted on The Arc of Indiana's website. To view the handbook, go to: http://www.arcind.org/bdds_legal_handbook.htm

Plan to Attend—Quality!

Person Centered Planning, Beyond the Paperwork Please plan to attend—"Quality! Person Centered Planning, Beyond the Paperwork"—a conference to take place at the Indiana Government Center, May 29th and May 30th. Cost for this two day conference is \$100 per person, but only \$300 for a team of up to six people—teams should be comprised of consumers, family members, direct care staff, behavior management specialists, case managers, and administrators. In order to come as a team, the team must include two people from the

For the short term, The Arc of Indiana continues to point to the budget shortfall and asks the members of the Indiana General Assembly to look carefully at proposals before them, and to support ones which address the deficit yet avoid making cuts that harm people. The choices are not easy. No one is looking at raising taxes—although that was the one unfinished piece of business in the last session, and a significant part of the tax restructuring effort.

The legislature addressed business and property taxes, cutting many and allocating nearly a third of the state's general fund budget to property tax relief. Yet now we face devastating cuts in basic services. There must be an answer.

One solution offered is to delay for a year the property tax reassessment and use the new sales tax revenue for the budget in order to save key programs until the economy rebounds. This seems to many a workable concept, yet others oppose any delay of the long-awaited reassessment.

What is clear is our leaders need to hear from you.

Oregon recently underwent massive cuts in programs, including cutting five weeks from the school year and eliminating entire categories of services to people. I do not think Hoosiers wish to see that happen here.

Like the 18 high school students from Brebeuf, we all must speak out and let our legislators know that what we hold dear is important to us and to our future. However we do it, we must build for the future, and that includes protecting the important strides we have already made.

Your voice counts. Add yours to the chorus of people from across the state calling on our legislators to act now.

following three areas—consumer, family member, or direct care staff.

Look for registration on The Arc of Indiana's website: www.arcind.org

Medicaid Spend Down, MED-Works, and Life Insurance Assistance Program Fact Sheets

Check out the new fact sheets on The Arc of Indiana's website, researched and written by Alan Kemp, The Arc of Indiana's Trust Director. The fact sheets provide excellent and up-to-date information on: Medicaid Spend Down, MED-Works, and The Arc of Indiana's Life Insurance Assistance Program.

To access the fact sheets on The Arc of Indiana's website, go to: www.arcind.org and click on "Fact Sheets."

Medicaid Waiver Consumer Guide on the Web

The Medicaid Waiver Consumer Guide is available on the Governor's Planning Council for People with Disabilities (GPCPD) website: <http://www.in.gov/gpcpd/>. It is the first document in both the *Publications* and *What's New* sections. Guides can also be ordered by calling GPCPD at (317) 232-7770.

TheArcLink

Individuals and families seeking resources and advice on home and community-based services can find detailed information on service providers within this Website. TheArcLink's goal is to provide an open forum that empowers individuals to make sound choices based on accurate, up-to-date information. Go to: www.TheArcLink.org

A Powerful Partnership for Individual Special Education Advocacy

— IEP advocacy support now available for families —



The Arc is partnering with Fape Solutions to provide Individual Education Program (IEP) consulting services—IEP Action Plan, IEP Progress Report and Individualized Support Services. This is a great benefit of membership in The Arc.

What is the Partnership Between The Arc and Fape Solutions?

Fape Solutions is a unique company whose mission is to help parents, advocates, and others throughout the US develop and implement better Individualized Education Programs (IEPs). Like The Arc, Fape Solutions serves individuals with developmental disabilities throughout the country.

The Arc of the United States and Fape Solutions have formed a partnership to promote Fape Solutions' products and services to all of The Arc's chapters and their members. A small royalty is paid to The Arc for any referral that results in a customer for Fape Solutions. More importantly, we're work-

ing together to help families requiring special education to navigate the system.

What Does Fape Solutions Do?

Fape Solutions provides fee-based, personalized IEP assistance for individuals throughout the US. Their approach is to provide its customers with excellent, actionable information while taking a minimum of their time. Usually starting with an existing IEP, detailed analysis and recommendations are provided. Fape Solutions offers:

IEP Action Plan A comprehensive analysis of any IEP with suggestions on what you can do to make it better and how to do it. A typical IEP Action Plan for a 20 page IEP contains 70 or more pages of detailed, useful information.

IEP Progress Report A collection of colorful charts that describe a student's progress with their IEP goals and objectives and recommendations to improve progress.

Individualized Support Services Fape Solutions can help draft IEP goals and objectives, write or edit letters, and provide other personalized IEP assistance to provide the specific help you or a parent needs with their IEP.

How Can Fape Solutions Support the Work of The Arc's Chapters?

Parents often turn to The Arc for help with their child's IEP. If you know someone who needs help with an IEP, Fape Solutions can help, especially in these situations:

- Your chapter does *not* provide individualized educational advocacy
- Your chapter does provide special education advocacy, but your advocates may not be able to respond in the time frame the parents require
- Parents want additional help beyond what your chapter can currently offer

Contact Fape Solutions at: www.fapesolutions.com or have them call toll free at (800) 651-6512 for information, pricing, and an order form.

Fape Solutions also offers consultations to chapters of The Arc. If you are providing special education advocacy and need additional help or just want another opinion, Fape Solutions is a ready resource.

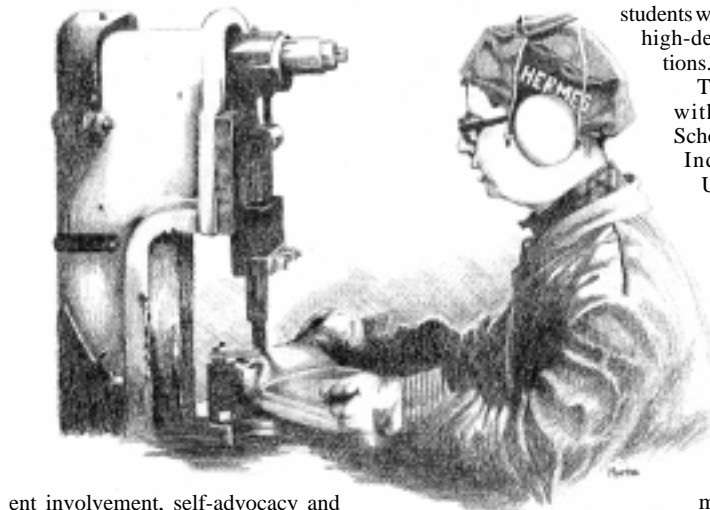
FEDERAL, STATE GRANTS TO BENEFIT CENTRAL INDIANA STUDENTS WITH DISABILITIES

Integration of Students with Disabilities into Workforce Goal of DOL Grant

The Circle Seven Workforce Investment Board (C7 WIB) has received a \$500,000 federal grant from the United States Department of Labor (DOL) that will support the President's New Freedom Initiative goal to integrate Americans with disabilities into the workforce in central Indiana. One of eight funded nationally, the project will develop model demonstration programs that would enhance the capacity of the Department of Labor's various youth programs to serve youth with disabilities in central Indiana.

The Interlocal Association will administer and oversee the development and implementation of the project. The grant requires that youth with disabilities and relevant experts work jointly to develop and implement innovative programs. Collaborating partners in the project are Indiana University's Institute on Disability and Community and The Arc of Indiana. Initial programming activities will occur in Johnson County and will involve the local WorkOne office, Johnson County Special Services, Franklin Community School Corporation and Johnson County ARC/Gateway Services.

"The C7 WIB is committed to ensuring that young people with disabilities have full access to employment opportunities in the 21st Century workforce," said chairperson Doug Warnecke. "This grant will help to develop model programs and innovative approaches to promote increased employment of people with disabilities." The basic tenets are full inclusion, person-centered planning, youth and par-



ent involvement, self-advocacy and empowerment, and informed decision-making.

Lance Ratliff, executive director for the C7 WIB, identified the project's activities to include outreach and recruitment; involvement of parents; training of staff, teachers, partners and parents; and curriculum development. The grant has been awarded for a two-year performance period.

High Tech Grant to serve Youth with Disabilities

C7 WIB has also received a \$20,000 grant from the state of Indiana to improve academic achievement and the development of skills of high school

students with disabilities for high-skill/high-demand/high-wage occupations. The C7 WIB, in partnership with Franklin Community School Corporation, The Arc of Indiana and Indiana University's Institute on Disability and Community will implement the "High School/High Tech Program" (HS/HT), providing opportunities for students with disabilities to explore careers in science, mathematics and technology. HS/HT students learn about careers through site visits, mentoring, shadowing and paid summer internships.

High School/High Tech students will be encouraged to develop career goals and to take the academic preparation necessary to achieve their goals.

The local grant is one of 55 providing \$1.3 million in training and employment grants that will benefit Indiana students, teachers and communities. Funds for this HS/HT grant will be used to provide direct service supports to those youth with disabilities who are participating in the United States Department of Labor's Youth with Disabilities Demonstration Project.

Support Services Waiver Update

The Support Services Waiver was born in the midst of cutbacks in government spending because it allows the state to refinance the 100% state-funded cost of people currently receiving services under Title XX. Transferred to the Support Services Waiver, they acquire 62% federal Medicaid dollars. Refinancing frees up state dollars to provide the state's share (38%) to match Medicaid's funding.

The Support Services Medicaid Waiver is at capacity for year one of the waiver, less than one year from its approval date. The Support Services Waiver was approved in April, 2002 to phase 7,000 people into services over a three-year period.

Designed to give families some assistance short of 24-hour support, applications for the Support Services Waiver have exceeded 7,000 people in under 12 months.

Of the 7,000 plus people who have applied, 2,307 people have been approved for the Waiver and have approved plans of care. The approval status of an additional 1,112 people who have applied is pending—in most cases their status is pending approval for Medicaid eligibility.

Assuming they are approved for Medicaid, they will be approved for the Support Services Waiver and will be able to receive services under the Support Services Waiver. In addition, approximately 3,600 applications are moving through the application process at the local level. It is not clear at this time when these individuals will be phased into receiving services under the Support Services Waiver.

The Family and Social Services Administration (FSSA) notified the regional Bureau of Developmental Disabilities Services (BDDS) offices in late February that people may still apply for the Support Services Waiver, but they should be told that they may be put on a waiting list because of the number of applications that have been received.

The Support Services Waiver was born in the midst of cutbacks in government spending because it allows the state to refinance the 100% state-funded cost of people currently receiving services under Title XX. Transferred to the Support Services

Waiver, they acquire 62% federal Medicaid dollars. Refinancing frees up state dollars to provide the state's share (38%) to match Medicaid's funding.

This refinancing effort is a true win/win situation. The state saves money, our federal tax dollars are brought back to Indiana, and new people from the community/waiting lists for the DD and Autism waivers have finally been able to get some help from the Support Services Waiver.

The success of this effort can be seen in the numbers of people now receiving services. Nearly 800 of the 2,307 people who have approved plans of care under the Support Services Waiver are from the community/waiting list. Over 600 of the 1,112 who have applied and are pending approval are from the community/waiting list.

We expect that additional people who have applied for the Waiver, but who are still moving through the application process at the local level, will also be from the community/waiting list.

Two critical factors in how many of these people will be able to receive services under the Support Services Waiver are:

(1) How many of those pending approval are people currently receiving services from Title XX funds (100% state dollars)

(2) What plans of care cost for people coming into the program from the community/waiting lists.

If a large number of people coming onto the Support Services Waiver free up dollars due to moving from Title XX to Medicaid, more people may be able to be served. On the flip side, if every new person hits the maximum amount of \$13,500 per person, fewer people will be served.

Support Services Waiver—Quick Facts

The Support Services Waiver is a new Home and Community-Based Services Waiver. This Waiver allows people with developmental disabilities who meet the appropriate "Level of Care" criteria to receive non-residential community-based services to help them remain in the community. Individuals may receive up to \$13,500 annually in support services, \$2,000 of which can be for Respite services.

Who qualifies for the Support Services Waiver?

To be eligible for the Support Services Waiver, you must have a developmental disability, require the "level of care" provided in an Intermediate Care Facility for the Mentally Retarded (ICF/MR), and meet Medicaid disability, income, and resource guidelines.

Medicaid disability guidelines require that the disability is expected to last at least 4 years. If you are eligible for the Support Services Waiver, the income you can have has been modified from traditional Medicaid income requirements. Under this waiver, your income can be at or below 300% of current SSI—currently \$1,635 per month. (This modified income guideline also applies to the Developmental Disability Waiver.)

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

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

Yes. The waiting list for the Developmental Disabilities (DD) waiver remains long. If you are on the waiting list for the DD waiver, you can also apply for services under the Support Services waiver, while you continue to wait for the DD waiver. If you are not on the waiting list for the DD waiver, you should apply for both the DD waiver and the Support Services waiver. Waiting lists are now being started for the Support Services waiver.

How Do You Apply for the Support Services Waiver?

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

What Services are available under the Support Services Waiver?

Adult Day Services, Adult Foster Care, Behavior Management/Crisis Intervention, Community Educational/Therapeutic Activities, Community Habilitation and Participation, Enhanced Dental Services, Expenses of Unrelated Live-In Caregiver, Family and Caregiver Training, Health Care Coordination, Music Therapy, Nutritional Counseling, Occupational Therapy, Personal Emergency Response Systems, Physical Therapy, Pre-Vocational Services, Psychological Therapy, Recreational Therapy, Respite Care, Specialized Medical Equipment and Supplies, Speech/Language Therapy, Supported Employment, Transportation.

POSITIVE BEHAVIOR, from page 2

If you observe intervention techniques that are in conflict with any of the following guidelines, feel free to share this information with the provider. If you are not satisfied with the results, you may want to consider following the procedures for reporting abuse in your state.

For information on incident reporting in Indiana, go to: www.in.gov/fssa/servicedisabl. Abuse can also be reported to Adult Protective Services by calling: 1-800-992-6978.

Several states, including Minnesota and Tennessee, have prohibited restraint on the floor. Minnesota regulations go so far as to prohibit restraint on the floor in community-based programs. The General Accounting Office and the Harvard Center for Risk Analysis have researched deaths due to restraints, and estimate that 50 to 150 people a year die because of restraint on the floor or mechanical restraints. If restraint on the floor and/or mechanical restraints are proposed as an emergency response, check with an advocacy organization to see if there are limits in your state.

Manual or Mechanical Restraints

If an individual's behavior has the potential to cause serious harm or injury, the professional should only consider methods for manual or mechanical restraint that keep the person safe and free from harm. Mechanical restraints are any type of restraint other than human contact, like a belt, strap or sash.

Staff must administer manual restraint in a way that maintains the normal body alignment for that person and causes no pain. Hyperextension of joints is never an acceptable component of manual restraint.

Some guidelines suggest that manual restraints should be time-limited to one minute or less, with a maximum time limit of five minutes. The goal of manual restraint should be to protect people from harm, not to restrain people until they are "calm." Restraints that last longer than five minutes put both the individual restrained and the individual(s) doing the restraining at serious risk of harm.

Manual restraints of all four limbs or mechanical restraints of any part of the body are highly intrusive procedures that should be used only in cases of extreme pending danger to the safety of the individual and/or others. They are traumatizing events that pose serious risk of injury to all concerned. The use of these restraints should always be accompanied by due process procedures, including but not limited to, prior approval by the legal guardian and/or individual served.

Most guidelines suggest that the maximum amount of time which mechanical restraints are used should be no more than one hour.

Seclusionary Time-out

Seclusionary time-out (placing an individual into an area from which they cannot leave until others decide they can) is another highly intrusive procedure that should only be used as a last resort where there is a risk of immediate danger to others.

The use of seclusionary time-out should always be prohibited in cases of self-injurious behavior.

This procedure is likewise a traumatizing event that poses serious risk of injury to all concerned. It should always be accompanied by due process procedures, including, but not limited to, prior approval by the legal guardian and/or individual served. Most guidelines suggest that the maximum amount of time which seclusionary time-out is used be limited to one hour.

Please note: Before anyone authorizes the use of crisis intervention, the individual served, the legal guardian (if any), the professional authorizing the use of the intervention, and staff implementing the intervention should experience the intervention and receive training in its use.

If a person's behavior is so threatening that, after one hour in either mechanical restraint or seclusionary time-out, the behavior of others and/or self is at risk, then the person may have a neurological, psychological or medical issue that must be addressed. The use of physical restraint should be discontinued until an individual treatment plan has been developed that considers these issues.

Indiana's Bureau of Developmental Disabilities Services considers the use of restraint to be highly invasive and accepts such use only in situations in which the threat of serious harm exists for the individual or others. Restraint is to be used only after all other attempts to change potentially harmful behavior, including teaching alternative behaviors, increasing communication skills, environmental change, redirection, and de-escalation have failed. The use of restraint is to be included in a Individualized Support Plan and utilized only after a thorough functional analysis of an individual's behavior, including medical, physical, communication, and psychological components, has been completed.

The ArcLink is deeply indebted to Bob Bowen, who wrote and revised the original draft of this guideline. He is the author of the Positive Behavior Support module that is currently taught as part of The Mandt System®. Thanks also to the following people who made written suggestions and com-

Medicaid Select: Managed Care for Indiana's Aged, Blind and Disabled Begins Roll Out

Northern Region: July 1, 2003

Southern Region: October 1, 2003

Indiana's Medicaid-eligible aged, blind and disabled population will begin to receive health insurance through a new program—*Medicaid Select*. Similar to Hoosier Healthwise, Medicaid Select requires members to choose a Primary Medical Provider (PMP) to serve as their medical home. The PMP coordinates the Medicaid Select Member's health care.

It is important to note that people who receive services under a Medicaid Waiver for home and community-based services, and people on spend down, are excluded from Medicaid Select.

Medicaid Select began operations on January 1, 2003 in Marion County, and is being phased in across the state on a quarterly basis. Following is the rollout schedule of the four phases:

Marion County: January 1, 2003

Central Region: April 1, 2003

As each region of the state begins the Medicaid Select roll out, eligible members will receive letters alerting them that they will now join Medicaid Select. The member will then have the opportunity to select a PMP of their choice. Each member will have 60 days (compared to 30 days in Hoosier Healthwise) to select a PMP. If the member does not select a PMP in 60 days, they will be auto-assigned a PMP.

To assist Medicaid-eligible blind, aged and disabled individuals and their families, The Indiana Family and Social Services Administration, Office of Medicaid Policy and Planning, has set up both a toll-free information line (1-877-MEDSELECT) and web page: www.medicaidselect.com

LOCAL STATE ARCS CARRY MESSAGE, from page 3

in light of the State's falling revenue and the State Budget Bill.

Also on the agenda is the Family Opportunity Act. The bipartisan Act will soon be reintroduced. It will give states the option to offer families of children with severe disabilities, who do not qualify for Medicaid, the opportunity to buy into Medicaid on a sliding fee scale. This would give thousands of children access to the full range of Medicaid services, many of which cannot be obtained in the private insurance market.

The President's budget proposal for fiscal year 2004 could cause serious harm to people with developmental disabilities and their families. The Budget proposal contains provisions that call for tax cuts that will further exacerbate the budget deficit.

It further calls for massive cuts in domestic programs including Medicaid. The proposal would give states the option of accepting federal funding for the Medicaid Program in lump sum allotments—one for acute care and one for long term services. The plan would present states with a difficult choice: they could receive some modest addi-

tional funding for the next few years, but only if they agreed to convert much of their Medicaid Program into a block grant, under which federal funding no longer would automatically rise to meet increases in need due to recession, epidemics, demographics, or other factors.

Finally, the proposed budget would provide no other fiscal relief for states—nor allow for an increase in the Federal Medicaid Assistance Percentage (FMAP).

The President's Proposal makes Indiana's fiscal crisis worse, not better. People with developmental disabilities could see cuts in programs and services they depend on.

The Arc of the United States GA Conference provided an opportunity not only to learn about critical national issues, but also to meet with Indiana's Congressional delegation. During these difficult economic times, it is important to continue to address the needs of people with developmental disabilities and their families. That message was carried to Indiana's Representatives and Senators by all who attended the GA Conference.

ments regarding this statement when it was featured in an online forum: Peter Alexander, Ron Rubin, Sharonlyn Harrison, David Rotholz, Bridget Walker, Gene McConnachie, Alan J. Petersen, Ellen Russell, Nancy Weiss, the Executive Director of TASH and Freda Brown, Tim Knoster and Rob O'Neill, members of the TASH Positive Approaches Committee, and to "Jake," "Karen" and "Lylemer" (whoever you are).

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Resources for Families



THE DISABILITY RESOURCE LIBRARY

Following are books available through the Disability Resource Library. Books can be ordered by calling: (800) 686-6049, open 24 hours. Prices are subject to change without notice. Other titles can be reviewed on their on-line book store at: www.disabilityresource.com. A free catalog of all titles can be ordered by sending your street address via e-mail to: Books@disabilityresource.com or call (800) 686-6049.

Editors note: Information regarding books, including prices, provided by The Disability Resource Library. Books have not been reviewed by The Arc of Indiana, and prices may have changed.

Quick-Guides to Inclusion 3 Ideas for Educating Students with Disabilities Edited by M.F. Giangreco, Ph.D. (2002, 168 pages) The easy-to-use third volume presents pertinent information and advice on literacy, self-determination, friendship, differentiated instruction, and high school inclusion. Item

#0424B.... Retail \$24.95 / **Disability Resource Library Price** \$22.46

Building Blocks for Teaching Preschoolers with Special Needs by S.R. Sandall, Ph.D. & I.S. Schwartz, Ph.D. (2002, 232 pages) The building blocks model provides three practical methods used to include young children with disabilities: Curriculum Modifications, Embedded Learning Opportunities, and Child-Focused Instruction. Item #0422BP.... Retail \$29.95 / **Disability Resource Library Price** \$26.96

Disability is Natural Revolutionary Common Sense for Raising Successful Children with Disabilities by K. Snow (2001, 632 pages) Teaches parents how to recognize that disability is not the problem and allow their children to lead successful, natural lives at home, in school, and in their communities. Item #0419BH Retail \$26.95 / **Disability Resource Library Price** \$24.26

The Arc of Indiana Master Trust . . .



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

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

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

How are we doing? Currently, we administer over 200 funded Trust I accounts. If you want experienced and knowledgeable representation for your child who is disabled, Trust I might be appropriate.

We also administer over 300 Trust II accounts. Trust II accounts are usually funded by persons who are themselves disabled. Like Trust I, Trust II continues eligibility for benefits like SSI, Medicaid, group homes, and Supported Living.

Our trust program may be the largest of its kind in the country. Over 700 families are enrolled in Trust I alone. (Trust I accounts are usually funded at the death of a family member.) Over 340 individuals are enrolled in Trust II. Combined enrollments exceed 1,000. For a free copy of our material call or write: The Arc of Indiana Master Trust, P.O. Box 80033, Indianapolis, IN 46280-0033. (317) 259-7603 or (800) 382-9100.

The Arc of Indiana's Life Insurance Assistance Program

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

The Arc of Indiana is concerned that uneducated purchases of life insurance or the continuation of low-value policies may lead to disappointing results. With this in mind, The Arc of Indiana will pay Mr. Hunt's fee to (a) guide you in making an efficient decision on the purchase of life insurance and/or (b) review your present life insurance holdings.

Except in unusual circumstances,

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

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

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

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

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

It must be emphasized that Mr. Hunt will receive only Arc fees and those you pay; he will receive no direct or indirect compensation from any insurer. Further, The Arc of Indiana has no relationship with any life insurance company. The Arc of

Indiana will not profit financially from any decision you make. The entire purpose of this service is to help you make informed decisions that are in your best interest.

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

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

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

MUSCATATUCK CLOSURE UPDATE

The Family and Social Services Administration continues to work with those families who are planning for the move of their loved one from Muscatatuck State Developmental Center (MSDC).

FSSA has approved providers to open two new 4-bed group homes in Jennings County for people with high medical needs. This new category of group homes has a higher level of staffing and medical support for those deemed to need that level of care. Additional homes will be opened in other parts of the state for those wanting to be closer to family.

Over 140 people have moved from the facility to community-based settings as part of the closure process that started in April, 2000. Legislation passed in 2002 provides for the facility to remain open until January, 2005. It is expected that approximately 130 people will remain at the facility on June 30, 2003.

The Arc of Indiana's 2002 Phantom Gala Winners

Thanks to all who purchased tickets to The Arc of Indiana's 2002 Annual Phantom Gala. Congratulations to the following winners:

Dan Stewart of Green Acres won our Grand Prize Drawing. Dan won a fabulous one-week stay in Cape Hatteras, donated by Elbert and Chris Johns.

Mike Anderson of Anderson won our Second Prize Drawing: a Downtown Indianapolis Getaway—complimentary room at the Omni Hotel and gift certificate to Morton's Steakhouse of Chicago.

Steve and Sally Carbide of Indianapolis won our Third Prize Drawing. Steve and Sally are now \$100.00 richer.

CONGRATULATIONS to our winners and THANK YOU for supporting The Arc of Indiana!

Save the Date ... Pass the Word ...

Come to The Arc of Indiana's
2003 Convention !

Paving a Path
to the Future...Together

The Arc of Indiana
2003 Convention
October 8-9, 2003

Adam's Mark Hotel
Indianapolis - Airport

Hosted by Noble of Indiana

WIN Conducting Person Centered Planning Workshops

The Waiver Information Network (WIN) is conducting *It's My Choice . . . Getting Started with Person Centered Planning* workshops throughout the state.

Why come? All people, including people with disabilities and their families, have hopes and dreams for the future. Sometimes we can work towards those hopes and dreams on our own, but many will need support and planning to be achieved.

Person Centered Planning (PCP) brings people together to talk, listen, and plan about the goals people with disabilities and their families want to achieve. PCP provides a time to talk about the things someone likes to do, what they don't like to do, what are individual strengths, and what may be barriers to reaching goals. It is a way to think, talk, and plan about where someone is going and what kinds of supports they need to get there.

Who should come? The program is designed primarily for family members who have a loved one with a developmental disability and people with developmental disabilities. It will be particularly helpful to those receiving, or who have been targeted to receive, home and community based services from a Medicaid waiver. Families who have a young adult who is transitioning out of special education services will also find it helpful.

Participants will not only learn about Person Centered Planning, but will also begin to develop Person Centered Plans using the *It's My Choice* workbook, which all participants will receive.

It's My Choice . . . Getting Started with Person Centered Planning, has already been held in Evansville, Washington, New Albany, Madison, and Columbus. Please see box at left for remaining workshop locations.

All workshops will be held from 10:00 a.m. to 2:00 p.m., local time. Please bring a brown bag lunch; soft drinks will be provided. There is no cost to attend. However, due to limited seating, registration is required.

Terre Haute, April 7, Vigo County Public Library, 1 Library Square

Muncie, April 8, Muncie Public Library, Kennedy Branch, 1700 W. McGalliard

Indianapolis, April 9, Indianapolis Public Library, Pike Branch, 6525 Zionsville Rd.

Lafayette, April 22, Ivy Tech, Ivy Hall, Rm. 1106, 3101 S. Creasy Lane

Kokomo, April 23, Kokomo Public Library, South Branch, 1755 E. Center Rd.

Bluffton, April 25, Wells County Public Library of Bluffton, 200 W. Washington St.

Merrillville, May 6, Lake County Public Library, 1919 W. 81st St.

South Bend, May 7, Logan Center (Cafeteria), 1235 N. Eddy St.

LaGrange, May 8, LaGrange Public Library, 203 N. Spring St.

Rensselaer, May 20, Rensselaer Public Library, 208 W. Susan St.

Logansport, May 21, McHale Performing Arts Ctr., Logansport High School (Rehearsal Room), 1 Berry Lane

Fort Wayne, May 22, Plymouth Congregational Church, 501 W. Berry St.

THE ARC OF INDIANA

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

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

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

E-Mail: TheArc@arcind.org

The Arc News in Indiana is mailed to members of The Arc of Indiana. Contact your local Arc for membership information. Local members automatically become members of The Arc of Indiana and The Arc of the United States. If a local chapter is not located in your county, you may join The Arc of Indiana as an at-large member for \$15 per year.

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To register return the Registration Form to:

The Indiana Parent Information Network
4755 Kingsway Drive, Suite 105
Indianapolis, IN 46205
(317) 257-8683 or 1-800-964-4746, Fax (317) 251-7488.

Please remember to call IPIN to cancel your reservation if you cannot attend.

All locations are wheelchair accessible. If you need other accommodations, request no later than two weeks prior to event.

Registration Form

Name _____

Address _____

City _____ St _____ Zip _____

Phone (_____) _____

E-mail _____

I will attend *It's My Choice...Getting Started with Person Centered Planning* in _____ on _____

(City)

(Date)