

## Special Education Law Debated by Congress

by John Dickerson, Executive Director

As Congress winds down its work this fall, one item getting intense scrutiny is the future of special education and the role of the federal government. The House of Representatives passed its version of the reauthorization of the Individuals with Education Act (IDEA), HR 1350, last April.

In a prepared release, House leadership reported, "The Improving Education Results for Children with Disabilities Act (H.R. 1350) calls for reforms to strengthen accountability and results for students, reduce the IDEA paperwork burden for teachers, provide greater flexibility for local school districts to improve early intervention strategies, reduce the number of children who are wrongly placed in special education classes, reduce litigation and restore trust between parents and school districts, and align IDEA with the bipartisan No Child Left Behind Act signed by President Bush in January 2002." The legisla-

### IDEA reauthorization has many concerned

tion did increase the basic state grant for special education by \$1 billion.

Yet, Paul Marchand, Staff Director for The Arc and UCP Public Policy Collaboration calls it, "The worst national public policy since before Congress enacted the right to education for students with disabilities almost 30 years ago." The House version was passed despite overwhelming opposition from many in the special education community.

The Arc, along with thirty-eight other national organizations, hand-delivered letters to every member of the House expressing our continued and strenuous opposition to HR 1350. In addition, tens of thousands of letters, e-mails and faxes came from individual families and teachers impacted by the changes contained in the bill.

### HR 1350—Critical Concerns

- HR 1350 changes the definition of a "Free and Appropriate Public Education," which will lead to increased litigation.
- Discipline and Due Process provisions will create adversarial relationships between parents and schools, punish students for having a disability, and make children with disabilities much more likely to be removed from the classroom.
- Due process provisions are weakened leaving students and parents more vulnerable.
- Changes in the IEP reduce accountability of the school.
- Paperwork reductions could result in the loss of IEPs, due process, related services, and other vital protections under the law.
- Commitment to fully funding IDEA remains unmet.

The Arc, along with other national organizations has adopted "Principles for the IDEA." The following are some of the key components of legislation that would leave no special needs student behind:

### Principles for IDEA

1. All children should be provided a quality public education that promotes academic success.
2. Each child's education should be tailored to meet his or her unique needs.
3. Parental involvement is critical to providing appropriate education to children with and without disabilities.
4. All educational personnel, including administrators, principals, teachers, paraprofessionals and related services personnel, must be qualified to educate students with disabilities.

5. Shortages of qualified personnel must be decreased and eventually eliminated.
6. Early Intervention and preschool services must be available to all children.
7. IDEA should give increased attention to racial, ethnic and linguistic diversity to prevent inappropriate representation of minority children in special education.
8. Fully-funding IDEA is paramount to ensuring all eligible students receive quality services.
9. Procedural safeguards are necessary to assure that educational decisions are determined appropriately.
10. Cessation of services should be prohibited.

(See Special Education Law Debated, page 8)

### Principal, Staff Make Difference

The Arc of Indiana received the following e-mail message from a family following John Dickerson's presentation at FUSE, an organization for families of children in special education.

*I just wanted to say thank you so much for coming to speak to the FUSE group of dads & moms last evening. You had a lot of information to address and you are a good resource for the special education community at large.*

*I also wanted to say that when you were talking about schools and the principal being the key, our son Brandon attends Liberty Park Elementary School in Warren Township (Indianapolis), and his principal, Dena Cushenberry, is the best!*

*Last year was the opening of the new school, and she made everyone feel welcome and really got in touch with the special needs children so that the other children in school would see how she treats and deals with these children as an example to follow, and she continues this model to this day. Their school motto is, "Pride and Excellence, In Everyday, In Every way, United We Soar!"*

*They're the Liberty Park Patriots,*



Kallin family

*and their symbol is the soaring eagle! He also has the best teacher and teachers assistants. We've been in Warren Township since preschool began at WECC, and then he went to Eastridge, and now he's at Liberty Park, and we can't say enough about the Warren Township school staff!*

*Paul, Brenda, & Brandon Kallin*

IDEA has generated thousands of success stories just like this across Indiana and millions throughout the country. This is not the time to take apart a program that is working and working well. Instead, Congress must meet the full funding obligation with bipartisan support for this important program.

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## Self Advocates Speak Out on Training Needs

In response to the overwhelming need for consistent, unified, quality training for people who work with people with developmental disabilities, a Statewide Education and Training Planning Group has been meeting for the past several months. As part of the process of developing recommendations for what should be included in a training curriculum, Self-Advocates of Indiana is developing a list of items that they believe should be included in training programs. A draft of their recommendations, as of August 2003 is listed below.

Self-Advocates of Indiana is seeking additional comments. If you have a loved one with a developmental disability, talk with them about what they would like direct care workers to know. If you are a person with a developmental disability, what ideas do you have for helping direct care workers learn how to work with you?

Ideas and suggestions can be sent to Self Advocates of Indiana, IIDC, 2853 E. 10<sup>th</sup> St., Bloomington, IN 47408-2601 or e-mail at: mfmoooney@indiana.edu.

### Quality Assurance / Quality of Life

Means I will have a better life  
Encourage me, don't discourage me  
Assist me with my goals  
Try to understand my point of view  
Problem solve with me  
Listen to me  
Respect me and I will respect you—mutual respect is important  
Be a team player with me  
Be friendly  
Don't take it personally if I am upset  
Don't hold grudges

### Behavior Supports

Try to understand why I am upset  
Try to figure out what is wrong  
Be there for me to talk to  
Let me have a time out if I ask for it  
Explain the reason behind your request  
Use plain language that I can understand  
Don't, however, talk down to me

### Health and Safety

Plan for my recuperation at home after an illness or injury, just as you would do for yourself  
Teach me about my medications, what they are for, the side effects, and how to take them  
Be aware of changes in me, such as my attitude or energy level, and realize they could be symptoms of a health concern

Consider that a change in my health may be the reason for the general change in me

Understand that we understand and experience grief over a loss and need to work through our grief just as you do

Provide education about the criminal justice system for us, what the laws mean, and what is expected in the community

Provide an opportunity for us to educate police, firemen, and others about our abilities and support needs

### Self-Determination

I want to make informed choices so help me to investigate the choices before you ask me to decide

I want to be able to speak up for myself

I should have paid vacation and sick time just as you do

Be willing to problem-solve with me

### ISP Development and Implementation

Person Centered Planning comes before Individual Support Plan

I need to be the one who helps write up my goals

Let me try to do things on my own

Let me be the one who asks for support

Challenge me

Don't stereotype me

Don't assume



**QUALKINBUSH:** My 47 years of involvement with The Arc have truly been a journey of commitment, devotion, and love—love for The Arc, the wonderful people I have met and worked with, and for all the people we have chosen to represent and serve. Thank you, NCE for this honor.

**HINKLE:** This award gives me goose bumps, especially in light of the challenges we've faced in the last two years. An award from my peers means the world to me. From the bottom of my heart, thank you.



## NCE Honors Steve Hinkle, Ilene Younger Qualkinbush

The National Conference of Executives of The Arc (NCE) has honored Ilene Younger Qualkinbush, a founder of The Arc of Indiana, with the Life Long Achievement Award; and Steve Hinkle, President, Easter Seals Arc of Northeast Indiana, with the Executive Excellence Award. The awards were presented at NCE's Awards Luncheon in August.

### Life Long Achievement Award Ilene Younger Qualkinbush

That Ilene Younger Qualkinbush originally chose nursing as her profession is testament to how strongly she feels the calling to serve others, a calling that has now extended into its sixth decade.

Ilene began her involvement with The Arc as a volunteer in 1956. In 1963, Ilene became The Arc of Indiana's first paid staff member, serving in a number of capacities until her "retirement" in 1981. At that point, she became a tireless volunteer at the local, state, and national levels of The Arc. Her work on innumerable boards, committees, and task forces has improved the quality of more lives than perhaps she'll ever know.

*A tireless volunteer*

Her efforts have helped bring about positive changes in the lives of people with developmental disabilities throughout Indiana. Children once excluded from schools are now learning alongside their peers. People who once had no choice but to live in an institution are now living in neighborhoods. Countless cases of mental retardation have been prevented due to the prenatal screening program Ilene lobbied for and worked to implement.

Almost fifty years after first volunteering for The Arc, Ilene continues to advocate for people with disabilities. In January, 2002 Ilene traveled with others from Indiana to Tulsa, Oklahoma, to learn how people with severe disabilities were successfully moved from a large institution to community-

based programs and how similar programs could help move people from Muscatatuck State Developmental Center. Ilene's daughter, Susan, lived at MSDC for many years and passed away shortly after the trip. Ilene continues to attend meetings at MSDC, which is scheduled to close in 2004. Most recently Ilene served on The Arc of Indiana's awards committee. The Arc, both at the national and state level, is fortunate that Ilene sees her work as being far from over.

### Executive Excellence Award Stephen L. Hinkle, President, Easter Seals Arc of Northeast Indiana

Thirty-one years as a leader within The Arc proves more than just aspiration to excellence; it is the realization of that goal. Stephen Hinkle has served 27 years as president of Easter Seals Arc of Northeast Indiana, four years as executive director of The Arc of Johnson County, and four years as a special educator: all of which adds up to nearly a lifetime in pursuit of The Arc's mission.

As the demands for services have changed and as the environment within which chapters operate has increased in complexity and uncertainty, Steve has worked to ensure that the needs of people with developmental disabilities are met in creative ways.

*A lifetime in pursuit of The Arc's Mission*

Under Steve's management, Easter Seals Arc of Northeast Indiana has initiated comprehensive service programs, from infant assessments and early intervention to age-and-interest-appropriate services for aging people with developmental disabilities. It's difficult to calculate just how many lives Steve's work has changed for the better.

The core values of The Arc are exemplified in his work to develop the first group homes in Indiana, to initiate programs for people with severe and multiple disabilities, to encourage self-advocacy and self-determination, and to infuse all of these endeavors with compassion.

## Update—The 317 Plan

In July 1998, the 317 Task Force released the “*Comprehensive Plan for the Design of Services for People with Developmental Disabilities*”—more commonly known as the 317 Plan. (See “*A Look Back—History of the 317 Plan*” on this page). The intent of the 317 Plan was to design and implement a system for providing persons with developmental disabilities in Indiana with individualized choices and supports to live, learn, work, and play in the community. The 317 Plan contained several key recommendations to achieve specific goals. Following is a summary of how these recommendations have been implemented to date.

### Secure financial resources to respond to the demand for persons with developmental disabilities.

Funding for the 317 Plan provided \$157 million in new state and federal funding from FY 2000 through FY 2003. The biennial budget bill passed by the 1999 Indiana General Assembly included \$39.3 million in state funding for the 317 Plan for State Fiscal Years 2000-2001. The biennial budget bill passed by the 2001 Indiana General Assembly included \$43.6 million in state funding to implement the second phase of the 317 Plan. A large portion of these state funds were used to match federal Medicaid funds, bringing in additional dollars for the 317 Plan.

Due to the state’s fiscal crisis, approximately \$26 million of the state funds appropriated in the 2001 legislative session was never allowed to be spent. This loss of state funds was partially made up by efforts to maximize the use of federal dollars. This was accomplished by moving people who had been receiving services with 100% state funds to Medicaid Waiver funding—approximately 62% federal funding and 38% state funding. This not only helped to offset the loss of state funds, but also provided an additional \$25 million that went toward the state budget crisis.

### Funding provided from FY 2000 through FY 2003:

- Allowed 1,502 people who lost “Level of Care” in a Medicaid funded facility or the Medicaid Waiver to continue to receive services.
- Allowed 181 young adults to transition from non-DDARS services, such as the Department of Education and CHINS (Children in Need of Services), to DDARS services.
- Expanded services to 1,673 people, such as waivers, emergency placement and family support.
- Provided services to 127 people on

the autism waiver waiting list.

- Provided services to 1,681 people on the DD Waiver waiting list.
- Funded projects to improve technology and provided crisis services.
- Added staff for key positions including service coordinators in BDDS and BQIS.
- The refinancing effort allowed over 1,000 people who were receiving Day Services on SSBG/Title XX with 100% state funding to have their services funded by the Support Services Waiver. 1,327 individuals who were receiving residential services with 100% state funding were moved to the DD Waiver, allowing the State to draw down federal matching funds.

Of the 1,681 people who came off the DD Waiver Waiting list, only 474 were not already living in some other type of residential program, or did not have an emergency that required immediate services. 391 lost level of care in a Medicaid funded facility and

needed Waiver services to continue needed supports; 91 were young adults who aged out of programs funded by the Department of Education or Division of Family and Children; 252 were living in a group home or institution; and 222 had an emergency. Of the 443 people who received emergency services, only 222 people were already on a waiting list. The other 221 people had not previously applied for services.

Due to the state’s fiscal situation, no new funds were included in the biennial budget bill approved in the 2003 session of the Indiana General Assembly. Over the next biennium shortfalls in state funding will continue to be a challenge. People needing emergency residential services will require services, even though no new money was appropriated to meet this growing demand. BDDS has stated that, “Difficult decisions may need to take place to address the shortfall.”

### Allow funding to follow the person

Progress has been made through the development and implementation of an individualized funding system utilizing an Individualized Community Living Budget (ICLB) to identify a variety of funding sources to pay for programs and services for people in residential programs. (See ICLB article on page 4.)

### Implement person centered principles and planning.

New regulations established in May 2003 mandate using a person centered planning process (PCP), including the development of an individualized support plan (ISP), for all individuals provided services authorized by the Bureau of Developmental Disabilities Services (BDDS). This includes those receiving supported living services (typically funded by a Medicaid Waiver), and people who live in group homes or

(See Update on 317 Plan, page 6)

## A LOOK BACK—HISTORY OF THE 317 PLAN

In 1997, Governor Frank O’Bannon signed Senate Enrolled Act 317 into law. This law, passed in a bi-partisan effort, called for the development of a task force made up of consumers, advocates and state officials to study services for people with developmental disabilities. This came to be known as the 317 Task Force.

In July 1998, the 317 Task Force released the “*Comprehensive Plan for the Design of Services for People with Developmental Disabilities*”—more commonly known as the 317 Plan. The report identified over 6,000 people as waiting for home and community based services, and called for a new direction in the delivery of services for people with developmental disabilities in Indiana.

The 317 Plan made the following recommendations, to achieve the goal of designing and implementing a system for providing persons with developmental disabilities in Indiana with individualized choices and supports to live, learn, work, and play in typical community settings.

- Implement and improve person centered planning and person centered funding designs for all persons with developmental disabilities served by FSSA.
- Redirect funding away from congregate settings to integrated residential, day services, and

employment settings based on choices of individuals and families and principles of person centered planning.

- Assure and improve the quality of services delivered to individuals with developmental disabilities.
- Build the community capacity to provide individualized and person centered services in typical community settings across Indiana.
- Secure financial resources to respond to the demand for services of persons with developmental disabilities and their families.

Priority needs identified by the plan included:

- Support children aging out of residential services funded by sources other than the Bureau of Developmental and Disability Services (BDDS).
- Fund emergency cases when caregivers are no longer able to provide care.
- Provide services to over 1,300 Hoosiers on long waiting lists for services.
- Prevent crisis situations by providing support services to keep families together.
- Respond to crisis cases that need immediate attention and long-term supports.
- Maintain existing services to keep people at home and at work.

The biennial budget bill passed by the 1999 Indiana General Assembly included \$39.3 million for services for people with developmental disabilities—full funding for the 317 Plan—for State Fiscal Years 2000-2001. Governor Frank O’Bannon signed the budget bill, and July 1, 1999, marked the day that funds began impacting the lives of individuals with developmental disabilities.

The biennial budget bill passed by the 2001 Indiana General Assembly included \$43.6 million to implement the second phase of the 317 Plan. Money from the federal Tobacco Settlement was used as the source of the funding. Due to the state’s fiscal crisis, approximately \$26 million of this appropriation was never allowed to be spent. However, efforts to maximize the use of federal dollars by moving eligible persons receiving services from 100% state funded services to Medicaid Waiver funding, which is approximately 62% federal funding and 38% state funding, not only helped to offset this loss, but also provided an additional \$25 million that went toward the state budget crisis.

Due to the state’s fiscal situation, no new funds were included in the biennial budget bill approved in the 2003 session of the Indiana General Assembly.



# Supported Living and the ICLB . . . What it Will and Won't Pay For

by Alan Kemp, Trust Director for The Arc of Indiana

Supported Living is becoming the predominant residential option for many people with developmental disabilities who no longer live with their parents. This program is administered through the Bureau of Developmental Disability Services (BDDS). If your child who is developmentally disabled is thinking about moving from your home, it is important to learn about Supported Living.

Supported Living relies on several funding sources. One source is your child. Your child's income (earned and unearned) helps pay the costs of Supported Living. Another source (if your child is eligible) is a Medicaid Waiver. Two such waivers are the Developmental Disabilities (DD) waiver and the Autism waiver.

Waivers can pay for a variety of services. However, they are specifically prohibited from paying for basic monthly living expenses. BDDS counts on your child's income to cover basic monthly living expenses. But what if your child's income cannot cover all these expenses? How might they be paid? One source of payment is state money appropriated by the Indiana General Assembly to BDDS for this purpose.

To determine how much (if any) state money will be available to pay for your child's basic monthly living expenses, BDDS uses something called an Individual Community Living Budget (ICLB). The ICLB identifies all the funding sources for all the services and supports your child will receive. Your child will be required to apply for all entitlements to which he or she might be eligible. These include, but are not limited to, Food Stamps, HUD low income housing, Medicaid (including the Medicaid Waiver), and SSI. These benefits are reflected in your child's ICLB, and help reduce BDDS funds that might otherwise be needed. The available funding sources are compared with your child's basic monthly living expenses. Only if the funding sources are insufficient will BDDS dollars be used. The ICLB is approved (or denied) by BDDS staff.

BDDS specifically prohibits payment for some expenses. What won't BDDS pay for? Based on the May 1, 2003 version of the ICLB Instructions, here are some BDDS prohibitions. These prohibitions are not definitive. They can, however, help you identify excluded expenses you value and for which you are willing to pay.

BDDS funding cannot be used to pay: (1) the premiums on a life insurance policy for your child; (2) a burial trust for your child; (3) costs for pets or companion animals; (4) costs associated with being your child's guardian or representative payee; or (5) maid service for your child.

Also, BDDS does not reimburse for counseling services. Counseling is a service that is covered by Medicaid. Per BDDS instructions, if your child is a recipient of Medicaid and chooses a provider of counseling services who does not accept Medicaid, your child can continue using this provider, but your child (or you) will pay for the service. BDDS wants to be flexible. Thus, in cases where certain counseling may not be covered under the Medicaid state plan or in instances where a person does not have Medicaid, BDDS funding might be used. These situations, however, are likely to be the exception to the rule.

BDDS funding *can* be used to pay for community activities for your child through a service whose

acronym is CETA—Community Educational and Therapeutic Activity. CETA services are intended to enable your child to reside successfully in his or her own home or family home, increase independence, add to quality of life, and enhance community integration.

It is important for you and your child's case manager to address the need for CETA funding. CETA funding should be included in your child's Individualized Support Plan (ISP). If the plan does not address this need, no CETA money will be available. Cost reimbursement through BDDS under CETA is a maximum of \$1,000 a year.

It is important to note that CETA funding *cannot* be used to pay for staff to accompany your child to community activities. BDDS considers these costs part of the provider agency's administrative costs. The agency's administrative costs are covered in its service rates. Thus, it is important for you and the service agency to anticipate these costs so they are included in the agency's administrative cost/service rate. If your child will be accompanied by friends, family, and other unpaid personnel, they are expected to pay their own way.

BDDS funding will not pay for general repairs and maintenance or capital improvement to your child's residence, be it your child's own home or a residence owned by others. BDDS assumes that most participants in Supported Living will live in rental property. Per BDDS instructions, the general repair and maintenance of rental property, including repair of major appliances and HVAC systems, should be included in the lease/rental agreement with the landlord. BDDS may consider requests for repairs due to unusual damage caused by your child's behavior. However, as a condition for evaluating these requests, BDDS staff will consider whether the provider agency has implemented effective behavior management and supervision techniques.

In general, BDDS funding cannot be used to make mortgage payments. BDDS wants to allow for exceptions, but exceptions are likely to be based on the ability to meet the routine costs of home ownership, such as taxes, maintenance and repair. BDDS says it shall not fund on-going maintenance or capital improvements to property owned by individuals or providers. Also, even if BDDS funding is used for mortgage payments, it cannot be used to purchase major appliances the home might need. Examples include a refrigerator, stove, furnace/heating units, air conditioner, and washer/dryer, furniture, and houseware items for the home. Some other source must be found to meet these costs.

In general, BDDS won't pay for your child's moving costs. One exception is start-up costs, now called Community Transition Services Costs, (CTSC) associated with your child's first move into the community from a facility or from the family home. CTSC cover a wide range, including housing and utility deposits (phone, electricity, water, etc.), furnishings, and even clothing. But CTSC are limited to a maximum of \$1,000 per individual. And, they are only available when the "lack of financial resources" is a barrier to your child's moving. No definition is provided on what is meant by "lack of financial resources." Also, if \$1,000 is insufficient for the initial move, some other source of revenue must be found.

It is important to emphasize that BDDS expects

that many costs under CTSC, such as housing and utility deposits (phone, electricity, water, etc.) and hook-ups will be transferred with your son or daughter when he or she makes a subsequent move.

**A Suggestion:** If your child receives CTSC funding through BDDS, even if the provider agency says it will keep the records, you should keep a copy yourself. Personnel from provider agencies are well-intended, but personnel turnover is likely to be high. Records can be lost or forgotten. If you keep a copy, you reduce the likelihood of problems later on. By keeping a copy, you increase the likelihood of deposits following your child on future moves. Lacking copies, your child might become responsible for costs he or she should not bear.

**BDDS Guidelines:** Supported Living is intended to provide for your child's basic needs. Per BDDS, basic needs should not exceed 150% of the federal poverty level for a single individual. For FY 2003, the Federal Poverty Level for one person is \$8,860. Therefore, monthly living expenses for one individual should be no more than \$1,108. This amount can be exceeded if the provider agency offers written justification and the justification is accepted by BDDS. The amount can also be exceeded if your child has other sources to pay the difference.

As of May 1, 2003, the following are the parameters BDDS recommends for monthly living expenses:

Housing	\$450 (single), \$650 (double), \$850 (triple)
Utilities	\$150
Telephone	\$40
Groceries	\$200
Personal necessities*	\$80*
Property insurance	\$18
Medical—not insured	\$10
Cable	\$50 per household

Per BDDS, not all monthly living expenses are expected to be at the top level of the categories.

If a monthly living expense exceeds the parameter, BDDS requires a justification statement.

\*Personal necessities include, but are not limited to, such expenses as postage, laundry, and basic hygiene. Personal necessities also includes clothing. Given the BDDS parameter of \$80 a month, don't expect this category to pay for much clothing. Find another source.

Also, the personal necessities category will not provide "pocket money" for your child. You child is expected to use his or her personal income to pay this cost. If your child has no personal income (work income, for example), then you will need to find another source.

## Your Role

While alive, if you want, you can pay the costs that are not paid through Supported Living (or not paid through other benefits your child receives). Just as you currently supplement other government benefits, such as Medicaid and Supplemental Security Income (SSI), so, too, can you supplement Supported Living.

How might your supplement continue after you have died? One possible answer is through a trust. One possible trust is The Arc of Indiana Master Trust. Currently, we administer over 500 funded

(See ICLB, page 6)

# Dreams Come True, New Dreams Await to be Achieved

Mollie Noble has achieved many of the dreams she had for her life two years ago. Now she is looking forward to achieving new dreams, through her connection with Noble Communitas, a demonstration initiative of Noble of Indiana.

In June of 2001, Mollie received a Certificate of Completion from Cardinal Ritter High School in Indianapolis. Although she had a summer job, Mollie's parents managed all of her money and organized her schedule.

Mollie had dreams for what she would like to do—attend college, work full-time, have more friends, and live independently. Mollie and her person-centered planning team worked together to make these dreams a reality.

In January 2002, Mollie was taking four classes and living in a dorm at Marian College in Indianapolis. Her parents funded her class fees and room and board, and public and private resources funded the supports she needed. Mollie learned how to track all of her activities on a calendar and to make more choices independently, and began learning how to manage her money. She became a volunteer at Robin Run and participated in a variety of activities on campus including membership in a booster club, mentoring and serving on the Clare Hall Board, and as a eucharistic minister on campus. Her many activities brought her new friends with whom she did homework, rode to class, and ate meals.

By September 2002, Mollie was tak-

ing classes for a third semester at Marian college, organizing her person-centered planning circle meetings, keeping a notebook for reminders and schedules, and working part-time at LePeep restaurant where she made new friends.

This past summer, Mollie celebrated two years at Marian College in a completion ceremony.

Her new dream was to secure full-time employment so she could save money to live in her own apartment. Mollie and her Community Guide gathered many job applications. Mollie interviewed for a job at Parisian Department Store and secured full-time employment with full benefits. Four of her

managers attended her most recent Person Centered Planning circle meeting at her home.

*Mollie has a full-time job at Parisian with full benefits. Four of her managers attended her most recent Person Centered Planning circle meeting.*

Mollie is currently working on understanding and developing a budget that will allow her to live in her own apartment and has set new dreams and goals for herself, including organizing a scrapbook class and increasing her social connections.

The dream of Noble Communitas began many years ago, as Noble looked to find a way to offer options to individuals and families who had been in traditional services. Lilly Endowment gave Noble a grant to begin Noble Communitas in January 2001.

A planning tool called Person Centered Planning Maps has been essential to Communitas' goal of affecting long term change in a consumer's life by facilitating new choices, decision-making and increased access to the community. In the first year, thirty-six individuals began receiving services that were based on their dreams rather than existing traditional programs. Currently, 116 individuals are being served in this innovative service.



## FORMER RESIDENT OF MSDC NOW ENJOYING HOME IN RICHMOND

Mary (Sissy) Jenkins lived at Muscatatuck State Developmental Center (MSDC) for 30 years. The decision to move her out was traumatic, according to her mother, Barbara.

After months of searching for an agency that could accommodate Sissy's needs, the decision was made for her to move into an accessible home operated by Green Acres, Inc., in Richmond, Indiana. The home was built thanks to the collaborative efforts of First Bank Richmond and Green Acres, Inc., who worked together to obtain an Affordable Housing Grant. The three bedroom home was financed through the Federal Home Loan Bank in Indianapolis.

Sissy moved into her new home in January 2003. The home is staffed 24 hours a day through funding provided by the Developmental Disabilities Medicaid Waiver. Her mother has observed that Sissy's health, physical strength, and muscle tone has improved since moving into her new home.

Sissy is now able to communicate some of her needs, sit independently for short periods of time, feed herself, and fold clothes. She enjoys participating in a day program at Green Acres, grocery shopping, eating out and other community outings, and just relaxing at home on her deck.

When Sissy lived at MSDC, her mother was only able to visit her every three weeks due to the long drive. Now, she lives just minutes away and is able to visit Sissy daily.

Sissy's story is featured in The Arc of Indiana's 2004 calendar, thanks to the sponsorship of Green Acres, Inc., the local chapter of The Arc in Wayne County.



*Photo by Scott Mahoney*

## UPDATE ON 317 PLAN, from page 3

large private Intermediate Care Facilities for persons with mental retardation and developmental disabilities (LPICFs/MR). The goal of the PCP process and the development of an ISP is to direct funding based on the needs, hopes and dreams of individuals receiving services from BDDS; and give all individuals the opportunity to choose their providers for services.

### **Redirect funding away from congregate settings to integrated residential, day services and employment settings; and expand capacity in the community to support people with developmental disabilities in typical community settings across Indiana.**

In 1999, 834 people in Indiana were living in Large Private Intermediate Care Facilities for persons with Mental Retardation (LPICFs/MR). By the end of 2003, 343 people will be living in LPICFs/MR. There were ten LPICFs/MR in operation when the 317 Plan

was initiated. Since that time, three facilities have closed, four are expected to close by December, 2003, and three will remain in operation. In addition, 300 people have moved from Indiana's state operated developmental centers, Muscatatuck State Developmental Center (MSDC) and Fort Wayne State Developmental Center (FWSDC). There are now less than 500 persons living in these facilities. BDDS projects that 200 people will remain in State Developmental Centers by 2005.

In 1999, the group home program was the largest residential program administered by BDDS. Since 2002, the number of group homes has been reduced from 535 to 517, and the number of group home beds has been reduced from 3,654 to 3,579. Currently the supported living program serves 8,000 people. Funding for group homes that have closed has been redirected to fund persons who moved from group homes to supported living.

There has also been steady growth

in the number of people served in integrated employment. In 2000, approximately 1,800 persons were receiving supported employment follow along services after achieving competitive employment. In 2001, that number was approximately 2,100 and in 2002 approximately 2,300. The Division of Disability Aging and Rehabilitative Services (DDARS) has a goal to serve approximately 3,700 in supported employment follow along services by June 30, 2005.

### **Assure and improve the quality of services delivered to individuals with developmental disabilities**

The Bureau of Quality Improvement Services (BQIS) was established in January 2000. This Bureau has the responsibility to develop and implement quality assurance and quality improvement systems throughout DDARS. In a two-year period this bureau has grown from a staff of two to a staff of thirty-five. Funding for additional positions was made available through the use of 317 dollars as well as utilizing resources from New Castle and Muscatatuck State Developmental Centers as closing and downsizing took place. Following are components of the BQIS system that have been developed as part of the implementation of the 317 Plan.

- Passage of state regulations that provide standards for the providers of supported living services and supports. This rule includes provider qualifications, defining the roles of providers (including case managers), the process for approval of providers, rights and protections for individuals provided services, a monitoring and sanctioning process for providers, and standards for providers relating to such things as training mandated for staff, policies relating to incident reports and other health and safety policies and procedures which are mandated.
- Passage of state regulations for the Individualized Support Plan and Person Centered Planning process.
- Development of a survey process. This includes an Agency Survey to assure compliance with state regulations, a Residential Services and Supports Survey, and a Vocational/Habilitation Survey. The survey process began in June 2003. An automated system to track surveys will be implemented September 1. This should allow the state to generate data by provider and statewide information.
- Development of a transition process, whereby individuals residing in state operated facilities, nursing homes and LPICFs/MR have a pre-transition survey completed by BDDS or BQIS

staff prior to moving to the community. BQIS staff then conducts a post transition survey at 7 and 30 days and continues to follow the individual as needed. The transition process is in place to assure that the necessary services and supports are in place prior to the move and then are ongoing. Approximately 400 individuals have been followed as they are transitioned to community based services from MSDC, FWSDC, and LPICFs/MR.

• Complaint process—complaints are received by BQIS and investigated. Processes are in place to track the investigation (by provider, by type of complaint, by severity, etc.). The numbers of complaints that are substantiated, partially substantiated or not substantiated can be tracked. As of the end of July 2003, BQIS has investigated 379 complaints—some minor and unsubstantiated, and others of significant concern.

• An incident reporting policy and process has been established. This sets the criteria for reportable incidents by providers. Approximately 1,000 initial incident reports are received on a monthly basis. Two full-time staff members review every initial incident report and the follow-up reports. Regulations establish the criteria for reporting and the responsibility for follow-up on reported incidents. The process includes tagging critical incidents that should receive immediate attention.

• A Risk Management Committee was established and has representation from families of individuals with disabilities, case managers, residential and day service providers, behavioral support specialists, Office of Medicaid Policy and Planning, the DD Ombudsman, the Bureau of Developmental Disabilities Services and the Bureau of Quality Improvement Services. The role of this committee is to review the aggregate data from the incident reporting process and to provide the Consumer/Community Advisory Committee with systemic and training recommendations.

• A Mortality Review Committee was established to review the deaths of all individuals with developmental disabilities and to provide systemic and training recommendations to the Consumer/Community Advisory Committee.

• Indiana joined the National Core Indicators Project in 1997. This is a collaboration among participating state Developmental Disability agencies with a goal of developing a systematic approach to perform outcome measurement. Indiana has been involved in a consumer survey, provider survey, and family surveys.

## ICLB, from page 4

trusts. For free information, call or write. We will send you a complete booklet.

The Arc Trust  
P.O. Box 80033  
Indianapolis, IN 46280-0033  
1-800-382-9100 or 317-259-7603

**A Word of Caution:** As Trust Director for The Arc of Indiana Master Trust, one of my responsibilities is learning the rules for benefits our trust beneficiaries receive. A major advantage to our trust is our knowledge of the regulations. We report all trust disbursements to affected government agencies. Our reports explain why trust usage does not interfere with continuing eligibility for benefits. We provide expertise and consistency. A concern I have with trusts not administered by The Arc is the trust administrator's lack of adequate knowledge of the rules. Not knowing the rules can cause problems.

With benefits like Medicaid and Supplemental Security Income (SSI), this lack of knowledge can result in the complete loss of these benefits. How can eligibility be lost? Programs like Medicaid and SSI have limits on what your child can have in the way of income and resources. If the trust is spent in ways that create income or countable resources, eligibility can be lost. An effective trust administrator will thoroughly understand the rules. The trust, if properly administered, will not create income or countable resources.

With Supported Living, my concern is different. I don't think BDDS will

set impediments to spending. If the trust, for example, chooses to pay for most of your child's rent, electric, and food, and all community activities, BDDS is not likely to protest. But payment for these costs is something that might be met through BDDS funding. If the trust administrator does not know the rules, I believe the trust will be misused, i.e., it will supplant, not supplement, Supported Living.

(I want to be clear. I do not fault BDDS or the provider agency for allowing a trust to supplant BDDS funding. I think the responsibility is on the trust administrator. If the trust is intended to supplement, not supplant, benefits such as Supported Living, it is the trust administrator's responsibility to learn the rules.)

When the trust replaces a benefit to which your child is eligible, it likely goes against the very purpose for which it was intended. Rather than adding to what your child would otherwise have through BDDS funding, the trust replaces that funding. If you are setting up a trust for your child, is this what you intend the trust to do? Make sure the trust administrator is prepared to learn and stay current with the rules, and report correctly all trust expenditures to the appropriate government agencies.

For more details on Supported Living, contact BDDS and request copies of its Policy and Procedure Manual; Service Definitions and Standards Manual; and Individual Community Living Budget Instructions. Call: (317) 232-7842.

## IN TRIBUTE TO GOVERNOR FRANK O'BANNON

The Arc of Indiana Board of Directors and staff sends their thoughts and prayers to the family of Governor Frank O'Bannon.

Governor O'Bannon was a strong advocate for people with developmental disabilities and their families for over thirty years. It was his vision and leadership that took the bi-partisan approved 317 Plan forward by swiftly appointing the 317 Task Force and charging FSSA Secretary Kathy Davis to come back with a plan within one year. Governor O'Bannon's commitment to carrying out the recommendations of the 317 Task Force has led to fundamental change in programs and services for people with developmental disabilities. Thousands of people have come off waiting lists; hundreds have moved from large, congregate care to homes in the community throughout Indiana; person centered planning and allowing funding to be more individualized to a person's needs is now required by state regulation; a Bureau of Quality Improvement Services has been established and staffed; new funds were appropriated; and creative ways were found to shift funding from state to federal funds, allowing people to receive services in fiscally difficult times.

We were proud and touched to read in a tribute to the Governor on his web site that of his many accomplishments, the movement of people

with developmental disabilities from state institutions to less-restrictive community settings was one that stood out personally to the Governor. You can read this very moving tribute at: <http://www.in.gov/gov/>, click on, "Governor Frank O'Bannon, 1930-2003"

In his 1997 Inaugural Address, Governor O'Bannon said: "... as I stand here today, looking to the future, I'm reminded of the words of



John Dickerson, Executive Director, The Arc of Indiana; and Governor O'Bannon, April 2000

George Bernard Shaw . . . 'I am convinced that my life belongs to the whole community. And as long as I live, it is my privilege to do for it whatever I can. The harder I work, the more I live. Life is no brief candle for me. It is a sort of splendid torch which I got hold of for a moment. And I want to make it burn as brightly as I can before turning it over to future generations.' I think

you from the bottom of my heart for entrusting this new administration with this adventure . . . we will never forget that this government belongs to all of us. It is our challenge—together—to make the torch flame burn brightly. And to light the way for a brighter future for all our families. Thank you."

Governor O'Bannon will continue to live on through his many good works. Thousands of people with

developmental disabilities will lead a better life because of his actions and commitment to assuring a brighter future for all Hoosiers, including those with developmental disabilities and their families.

Expressions of memorial can be made in Governor O'Bannon's name to:

O'Bannon Foundation  
Union Federal Bank  
45 N. Pennsylvania St.  
Indianapolis, IN 46204

### 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 230 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 700 families are enrolled in Trust I alone. (Trust I accounts are usually funded at the death of a family member.) Over 400 individuals are enrolled in Trust II. Combined enrollments exceed 1,100.

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

### Free and Unbiased Service

## Evaluation of Cash-Value Life Insurance Policies

It is very difficult for lay people to compare two or more cash-value life insurance policies. Life insurance agents can be helpful, but, because they are paid commission, they may be in a conflict of interest. The Arc of Indiana now offers a free evaluation program for cash-value policies. Parents pay nothing for this service. The Arc pays a small fee to a semi-retired life insurance actuary. The actuary

evaluates the policy parents are considering. We think this program can help parents make better informed decisions.

For more information on this service, go to The Arc's web site at: [www.arcind.org](http://www.arcind.org) and click on "Life Insurance Assistance Program," or call The Arc Trust at: (317)259-7603 or 1-800-382-9100.





## Thanks to Our 2004 Calendar Sponsors

Thanks to the sponsors of The Arc of Indiana's 2004 calendar. Now in its 17<sup>th</sup> year, the calendar project, which features photos and stories of people with developmental disabilities, has raised over \$100,000 for The Arc. More importantly, the calendar helps educate public officials about the needs, hopes, and successes of people with developmental disabilities. The 2004 calendar will be distributed to members of the Indiana General Assembly and state officials.

**Arc Opportunities, Inc., Howe**

**Bi-County Services, Inc., Bluffton**

**Easter Seals Arc of Northeast, Fort Wayne**

**Evansville ARC, Evansville**

**Green Acres Inc., Richmond**

**KCARC, Vincennes**

**Lake County Foundation for the Retarded, Gary**

**LOGAN Community Resources, Inc., South Bend**

**Noble / The Arc of Greater Indianapolis**

**Passages, Inc., Columbia City**

**Pathfinder Services, Inc., Huntington**

**Rauch, Inc., New Albany**

**Stone Belt Arc, Bloomington**

**Wabash Center, Lafayette**

## SPECIAL EDUCATION LAW DEBATED, from page 1

11. All schools should establish and implement research-based, effective programs that prevent school violence.

*All children should be provided a quality public education that promotes academic success.*

The Senate is now considering its version of reauthorization of IDEA, S 1248. This bill has received a much more favorable response from the special education advocates and professionals. And while S 1248 also makes several changes to IDEA which concerns advocates, as an alternative to HR 1350, the Senate version is acceptable.

A number of amendments will be sought on the floor of the Senate, some to strengthen and others in our view to weaken the legislation. Consideration is being given by the leadership in the Senate to those amendments and to limiting the number and content of amendments in order to reach agreement on the legislation.

In an important move on September 11, 2003, the full Senate approved by a voice vote the Dodd (D-CT)-Hagel (R-NE)-Jeffords (I-VT) IDEA amendment that adds \$1.2 billion to IDEA funding for FY 2004, bringing the total state grant funding increase to \$2.2 billion.

The next step for IDEA Appropriations, which is separate from the overall reauthorization of the law itself, is the House/Senate conference committee that

will meet in the near future to resolve the differences in the spending authorizations.

As for overall reauthorization of IDEA, Congress must act before the 108<sup>th</sup> Congress adjourns at Thanksgiving. While Senators Richard Lugar and Evan Bayh are not on the key committees dealing with IDEA reauthorization, both are respected members of the Senate and their party leaders. Your contact now is essential. Ask for their support of S 1248. Ask them to not weaken the Senate bill with any of the provisions coming from the House of Representatives. Please thank them for their efforts on the full funding of IDEA.

Once the Senate passes their bill, a special House and Senate Conference Committee will begin meeting to come up with a compromise between the two bodies. There is much work to be done and the voice of parents, teachers and those impacted must be heard.

*Your contact now is essential.  
Ask for...support of S 1248.*

**CONTACT YOUR U.S. REPRESENTATIVE  
AND SENATORS LUGAR AND BAYH**

**E-mail:** If you have access to the Internet, go to: [www.arcind.org](http://www.arcind.org), and click on "Arc Legislative Information Page," then click on "Congressional Delegation" You can e-mail your U.S. Representative and Senators Lugar and Bayh from this site.

**Call:** Call the U.S. Capitol Switchboard at (202) 224-3121 and ask for your senators' and/or representative's office.

At this time it is not advised to mail letters. Security concerns have resulted in all mail being inspected, greatly delaying mail delivery to members of Congress.

**Sign up for The Arc's Action E-List:** If you are not yet signed up to receive legislative Action Alerts from The Arc US or The Arc of Indiana, sign up at [www.arcind.org](http://www.arcind.org). Click on "Sign-Up for Action E-List."

## Hoosier Prairie Arc Joins Local Chapters of The Arc of Indiana

The Arc of Indiana welcomes a new local chapter of The Arc to The Arc family. Hoosier Prairie Arc has joined as the local chapter of The Arc in Jasper, Newton, and White Counties. The Arc of Indiana is made up of 48 local chapters, representing 61 counties throughout Indiana.

## Indiana Conference for People with Disabilities Focuses on Community

The 2003 Indiana Conference for People with Disabilities will challenge participants to "Catch the Community Spirit." The conference will be held December 2-3 at the Westin hotel in downtown Indianapolis.

The conference will feature workshops on topics such as political strategies, housing, self employment, the Help America Vote Act, faith-based initiatives, inclusive education, positive behavioral support, and creating inclusive communities.

Tuesday's keynote speaker will be Marca Bristo, president and CEO of Access Living and former chairperson of the National Council on Disability. Tuesday's luncheon will feature Alana Yvonne Wallace, founder and artistic director of Dance De-tour, Chicago's first professional mixed-abilities dance company.

Rachel Simon, professor and author of *Riding the Bus with my Sister: A True Life Journey*, will speak during Wednesday's luncheon about her sister, who has an intellectual disability, and their relationship. Leading disability rights attorney Steve Gold, J.D., and policy analyst Mary Kay Rizzolo will present a dual plenary session on housing and the State of the State of People with Developmental Disabilities.

The registration deadline is November 17 (or October 24 for scholarship applicants). Registration is discounted for nonprofessional people with disabilities and their families. People on SSDI, SSI, or TANF can apply for scholarship assistance. Anyone who receives the Council's *On Target* newsletter should have received a registration form in late September. Others can download the form from the council's website at: <http://www.in.gov/gpcpd/>

### THE ARC OF INDIANA

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Indianapolis, IN 46204

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

Web Address: [www.arcind.org](http://www.arcind.org)  
[www.TheArcLink.org](http://www.TheArcLink.org)

E-Mail: [TheArc@arcind.org](mailto: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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