2013 Session Offers Challenges, Opportunities

The 118th Indiana General Assembly is set to convene on Monday, January 7, 2013 at the Indiana State Capitol, and must adjourn by April 30. Over those four months, five key issues—the state budget, health care, employment, education and transportation—will be the focus of debate.

The elections will bring many newly elected officials to the State House, including Governor Mike Pence, Lt. Governor Sue Ellspermann, State Superintendent of Public Instruction Glenda Ritz and 28 new legislators. When combined with the 19 new legislators elected in 2012, there will be 47 state lawmakers with less than 3 years of experience in the State House.

Another change is that Republicans will hold a “super majority” of 69 members, allowing them to conduct state business without democrats present. There will be a new chairman of the critical House Ways and Means Committee, State Representative Tim Brown (R-Crawfordsville), as well as a new minority leader for the committee, State Representative Greg Porter (D-Indianapolis).

Despite all of these changes, the work of The Arc of Indiana will continue as it has from the time we were founded in 1956. Our nearly 20,000 members, local Arc chapter leaders, Executive Director John Dickerson, and Associate Executive Director Kim Dodson will continue to build relationships with legislators and educate them on issues important to people with intellectual and developmental disabilities.

The Arc of Indiana’s 2013 Public Policy Agenda was adopted at the December 2012 meeting of our Board of Directors. The range of issues we will be following and championing include:

- Biennial State Budget
- Employment / Career Pathways
- Home and Community Based Services
- Education / Passage of Legislation on Seclusion and Restraint
- Early Intervention, Prevention & Prenatal Care
- Insurance Reform
- Public Transportation
- Guardianship
- Criminal Justice
- Direct Support Professionals
- Self-Advocacy

Learn more about the public policy agenda on page 4, and by visiting us at www.arcind.org.

Get Involved to Make a Difference

State Representative Ed Clere

It takes a lot of people to make the legislative process work, and the most important person is you, the constituent.

The Indiana General Assembly is composed of 100 representatives and 50 senators, and that’s just the beginning. Little would be accomplished without legislative staff, which works tirelessly behind the scenes and does much of the heavy lifting. Lobbyists don’t get much love, but they also play an important role.

Whether they realize it or not, every Hoosier is represented by multiple lobbyists. In a fast-moving process, lobbyists keep an eye on what’s happening, provide information to legislators and advocate for organizations ranging from corporations to nonprofits to churches. The Arc of Indiana has a lobbyist, Kim Dodson, who keeps up with what’s going on and is there to speak up for The Arc’s interests at a moment’s notice.

When a legislator has heard from their families, self-advocates, job without you! Legislators need to hear from families, self-advocates, and individuals who work with people with intellectual and developmental disabilities every day. We encourage you to be involved in the legislative process by staying informed and up-to-date through our Action Alerts and Legislative Memos, and by contacting your legislators when you receive that “call to action.” We would also love to see you at our annual Valentine’s Day Event at the State House on February 14. Learn more on pages 5 and 6.

The 2013 legislative session will offer many challenges, and opportunities, toward making positive change in the lives of people with I/DD and their families. The Arc of Indiana will be there to ensure people with I/DD are respected, remembered and represented.

As always, the strength of The Arc is our members. We cannot do our job without you! Legislators need to hear from families, self-advocates, and individuals who work with people with intellectual and developmental disabilities every day. We encourage you to be involved in the legislative process by staying informed and up-to-date through our Action Alerts and Legislative Memos, and by contacting your legislators when you receive that “call to action.” We would also love to see you at our annual Valentine’s Day Event at the State House on February 14. Learn more on pages 5 and 6.

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Michelle Fischer and subscribe to her blog, “Behind the Mic,” michellefischersmic.blogspot.com.

Our podcast hosted by Michelle Fischer.

And past broadcasts of Professionals of Indiana, and INARF The Arc of Indiana, Direct Support Professionals of Indiana, and INARF with Count Me In!, a campaign to get people registered to vote and signed up for the waiver. For one week in September, there were 45 events in 27 countries that hosted an event, giving people the chance to stand up and be counted. It is so important for people with disabilities to go out and vote on Election Day—and we heard from many self-advocates who did just that on November 6.

But, don’t stop there! We need to keep this going for the next four years and beyond, to make sure our elected officials keep their promises. Go out and talk to your legislators and let them know how you feel about the issues. One of the ways you can work with Self-Advocates of Indiana is to join us at the State House for a very good day. On Valentine’s Day (February 14, 2013), we are going to talk to our legislators, give them a nice card, maybe some candy. It makes their day. But we also will talk to them and let them know what is important to us as a person.

How to Get Involved

- Find your Indiana legislators here: www.in.gov/legislative
- Write a letter or call them. You can contact them all year long, not just during elections!
- Make a nice Valentine’s card for them and bring it with you to the Indiana State House on February 14 (following an SAI Statewide meeting, details TBD).

Can’t make the event on February 14? Send it to ‘The Arc of Indiana office by February 11.

Consider a trip to Washington, DC for the Public Policy Seminar, April 15-17. Join SAI and The Arc of Indiana to meet with U.S. Representatives and Senators in our nation’s capital!

Our voice counts all year long. Make sure people hear it and stay involved in the process!

See you at the State House!

Sincerely,

Melody Cooper
President, SAI

Election 2012: The Process Continues!

Self-Advocates of Indiana has been talking about voting a lot in 2012 and how important it is to us to get out and vote. Now that the election is over, there is still much to do; so let’s work together and talk about it one more time!

In September, we teamed up with The Arc of Indiana, Direct Support Professionals of Indiana, and INARF with Count Me In!, a campaign to get folks to register and vote on November 6.

But, don’t stop there! We need to keep this going for the next four years and beyond, to make sure our elected officials keep their promises. Go out and talk to your legislators and let them know how you feel about the issues. One of the ways you can work with Self-Advocates of Indiana is to join us at the State House for a very good day. On Valentine’s Day (February 14, 2013), we are going to talk to our legislators, give them a nice card, maybe some candy. It makes their day. But we also will talk to them and let them know what is important to us as a person.

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See you at the State House!

Sincerely,

Melody Cooper
President, SAI

The Arc of Indiana thanks Jim Hammond, CEO and President of INARF, upon his retirement, for his 46 years of service to people with intellectual and developmental disabilities.

INARF is the principal membership organization in Indiana representing providers of services to people with disabilities. During his years at INARF, and in previous positions with agencies serving people with developmental disabilities, including Stone Belt Arc in Monroe County, Jim made a positive impact on the lives of thousands of people with I/DD.

Much of Jim’s work and passion focused on employment for people with disabilities, starting in his early years at INARF where he championed the State Use Program. The program, established in 1976, offers a broad selection of products and services while giving people with disabilities employment opportunities throughout Indiana.

As CEO and President of INARF, Jim worked to ensure that Indiana has a strong system of providers, dedicated to offering quality services and supports to people with I/DD throughout the state.

As we thank Jim for his many years of service, we also congratulate Kim Opsahl, who has been chosen to succeed Jim as CEO and President.

Learn more about Jim and how his years of service made a difference to thousands of people with I/DD by visiting our YouTube Channel, www.youtube.com/arcadvocate, and clicking on “Uploaded Videos” and “Thanks to Jim Hammond.”
Executive Director’s Column

Great Expectations

I was recently asked at a gathering of families about my feelings for the future. My response, “I am excited about the opportunity for positive change,” surprised them. The reason I am so optimistic is the growing impact and strength of The Arc at the national, state and local level.

Recently President Obama invited 15 major organizations to the White House to talk about the future of Medicaid. The Arc’s Peter Berns was the only person from the disability community to be invited to meet with the president to talk about this critical issue.

In December, a parent of twin daughters with significant disabilities and a tireless advocate for The Arc, met with Vice President Joe Biden along with six other individuals to share his story about how a middle class tax increase would impact his family’s ability to pay for disability-related expenses.

As I write this column, I am attending a national meeting of The Arc where we are discussing the many directions states are taking regarding Medicaid managed care for people with intellectual and developmental disabilities. I am amazed at the level of expertise shared by our national staff and state leaders.

In Indiana, Governor Elect Mike Pence and Lt. Governor Elect Sue Ellspermann have reached out to The Arc and the entire disability community, including many of our local leaders, asking for our input as they make plans for the new administration.

Thanks to an invitation from The Arc of Greater Boone County, Representative Tim Brown, the new chairman of the House Ways and Means Committee, met with leaders and families of The Arc prior to the start of the legislative session to listen to their concerns.

Another reason I am so positive about the future: You! The Arc of Indiana is nearly 20,000 members strong, and growing. It is part of The Arc’s history to tackle the tough problems at the local, state and national level. Together, we have met many challenges. And together, we will again.

Blueprint for Change

Celebrating Those Who are Making it Work

The following stories, featured in our 2012 calendar, exemplify the good work that is happening through local chapters of The Arc to help individuals with I/DD build career pathways and utilize their unique gifts – key goals of the Blueprint for Change.

Easter Seals Arc of Northeast Indiana

Local Chapter of The Arc in Allen, Dekalb, Huntington and Steuben Counties

Vickie Roop is a longtime, valued employee at McDonald’s in Fort Wayne – with 32 years of service. She is proud of her independence and the apartment where she has lived for 25 years, with supports from Easter Seals Arc of Northeast Indiana, family and friends.

With minimal, but important, supports, Vickie gives back every day to her Fort Wayne community as a valued and loyal employee, a good neighbor and a friend to many.

The Arc of LaGrange County

Todd Shorter volunteers monthly at Miller’s Merry Manor nursing home and shares his love of animals at the LaGrange County Animal Shelter. The puppies and cats love the attention Todd showers on them and the dogs look forward to taking long walks with him. He plans to expand on his volunteer work by learning how to care for the animals at the shelter.

Through his volunteer activities, Todd brings joy to others, and he takes personal pride in the difference he makes in the LaGrange community.

Carey Services, Inc.

Local Chapter of The Arc in Grant and Blackford Counties

Jacob Miller is a jack of all trades at Brook’s Upper Crust Pizza in Marion, Indiana.

Through work training and job support from Carey Services, Inc., local chapter of The Arc in Grant and Blackford Counties, Jacob enjoys having a career and his employer appreciates having a valued employee.
Direct Support Professionals

The Arc recognizes the importance of a high quality workforce of Direct Support Professionals (DSP). The ability to hire, train and retain quality staff is vital to the growth, sustainability and quality of services for people with I/DD.

We support all efforts to ensure a competitive, living wage for DSPs, including provider reimbursement rates that should support competitive wages and benefits.

Indiana’s innovative workforce development program, the Direct Support Professionals Project, was eliminated in 2012 due to budget cuts. We support the development of innovative ways to fund this important program and to make it available to all DSPs statewide.

Early Intervention, Prevention and Prenatal Education

The Arc supports efforts to educate the public about the dangers and long term effects of the use of alcohol, tobacco and controlled substances during pregnancy. We will support efforts to increase the awareness of fetal alcohol syndrome, shaken baby syndrome and lead poisoning. We will also support efforts which address the importance of good prenatal care and folic acid supplementation during pregnancy.

The Arc of Indiana is committed to infants and toddlers with I/DD receiving early intervention services. We will work to protect family choice in selecting qualified providers, and will strongly oppose any efforts to remove children who meet eligibility guidelines and who are in need of services from the First Steps program.

Funding

The Arc is committed to working with the state to ensure services for people with I/DD are provided efficiently and effectively, while promoting the health, safety and meaningful outcomes for all individuals served.

We will continue to work with the state to identify areas of cost-savings which do not jeopardize the health and safety of individuals with I/DD.

We will continue to work for the best utilization of federal funds, including Medicaid, Medicaid Waivers and Vocational Rehabilitation Services; and will work with the state to identify and pursue federal grants and other resources for programs and services for people with I/DD.

We will continue to seek ways to foster the inherent resourcefulness of individuals with I/DD, families, providers and communities.

We are committed to our local chapters and will work to find solutions to stabilizing the funding they receive from local governments.

Legislative Priorities

• Support state budget appropriations that ensure the state draws down every federal dollar available for vocational rehabilitation services.
• Support appropriate funding levels that continue to foster the movement of people with I/DD into home and community based services through the Medicaid Waiver.
• Support the restoration of a portion of the state’s savings into key areas of the budget that support people with I/DD.

Guardianship Services

Guardianship can be very important to ensuring individuals with I/DD have the necessary supports to live healthy, safe and meaningful lives. It is critical for people with I/DD to have guardianship services available to them, should they need them. Yet, Indiana is one of only a handful of states that does not have a state supported system of providing adult guardianship services.

Legislative Priorities

• Restore $2.5 million in the state budget to create a state-wide guardianship program for people with I/DD. Funding would allow for the establishment of an Office of Adult Guardianship within the Indiana Supreme Court, Division of State Court Administration; establish a system of community-based volunteer guardian services, and establish a registry to collect data and issue reports on adult guardianship cases and guardians appointed by the courts.

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We are committed to our local chapters and will work to find solutions to stabilizing the funding they receive from local governments.
We will closely monitor the implementation of the Community Integration and Habilitation Medicaid Waiver to ensure that those in need of critical services are able to receive services.

We will work to ensure funding streams follow people from institutional settings to community services, and ensure sufficient funds are provided both for initial placements and ongoing services. We will work aggressively with other organizations to eliminate institutional biases which exist within the State’s budget system.

With more people with I/DD living in communities throughout the state, it is increasingly important for law enforcement and fire safety personnel to receive proper training in responding to situations involving people with I/DD. We are committed to working with appropriate stakeholders to ensure that training is developed and/or made available to public safety professionals.

Insurance

The Arc strongly believes that people with I/DD must have quality health and life insurance available to them. We will work with the Office of Medicaid Policy and Planning and the medical community to ensure people with I/DD have access to primary care physicians and medical specialists. We will work closely with self advocates and the health care community to find ways to make wellness programs and preventative care more available to people with I/DD.

Legislative Priorities:

• Monitor and support a Health Exchange within the Affordable Care Act that provides protections and coverage of key issues and health benefits important to people with disabilities.

• Propose legislation that updates language regarding health insurance coverage for pervasive developmental disorders to be consistent with the fifth edition of the Diagnostics and Statistics Manual.

Public Transportation

A major obstacle to the employment of people with I/DD is transportation. People with I/DD also depend on public transportation to attend medical appointments and patronize local businesses. The Arc supports efforts to increase the availability of public transportation in order to provide a greater opportunity for people with I/DD to work and gain independence.

Legislative Priority

• Support legislation that seeks to create a system of mass public transit.

Self-Advocacy

The Arc believes in a strong network of state and local self advocate organizations. We will continue to work with Self-Advocates of Indiana and partners with them in their efforts to increase employment opportunities for people with I/DD and to seek additional resources to reach their goals.

We support day services that provide substantive opportunities for people with I/DD to realize self-empowerment, experience lifelong learning, achieve optimal health and develop relationships through community inclusion. We will work to promote and ensure the availability of these meaningful day services, driven by person-centered approaches, to accomplish these outcomes in all Indiana communities.

Education

Indiana is one of only nineteen states that does not have a law protecting students from the use of seclusion and restraints in schools. We will closely monitor the use of seclusion and restraints in Indiana’s education programs and will advocate for proper training, documentation and notification regarding the use of seclusion and restraint.

We believe all students receiving special education services deserve the right to earn a high school diploma that allows them the option of choosing vocational training, post-secondary education, and/or competitive employment with a living wage. If passing the End Of Course Assessment (ECA) is not attainable, parents and students throughout the state must be able to access the option of opting out of the Core 40 diploma and entering into either the evidence based waiver or the work readiness waiver. In addition, transition planning should focus on the development of employment skills, help students connect with Vocational Rehabilitation Services and ensure students with disabilities have service options available to them following high school.

We will work with schools and educators to decrease the incidence of bullying.

We support the expansion and funding of educator learning and professional development programs in order to meet the wide range of abilities of all students served by public, charter and private schools.

We will work with the Department of Education and other organizations to seek ways to increase preschool funding.

Legislative Priorities:

• Pursue legislation that protects all students from the improper use of seclusion and restraints in schools.

• Support legislation that seeks to reduce the incidence of bullying in schools.

• Monitor legislation regarding the waiver process of earning a high school diploma.
The Arc has a long history of representing people with intellectual and developmental disabilities at the Indiana General Assembly and in the halls of Congress.

The first lobbyists for The Arc of Indiana were two mothers, Ilene Younger and Dorothy Burnside, who volunteered their time at the State House beginning in the mid ’50s and continuing for many years. The Arc brought on its first paid lobbyist in 1977 and continues to have a full-time presence at the State House.

Legislators want and need to hear how issues are impacting their constituents. Phone calls, letters, emails and personal visits DO make a difference.

We hope our Advocacy Guide will give you the tools and information you need to get informed, stay informed and be involved.

Guides to the Indiana General Assembly and U.S. Congress
You will find a wealth of information about the Indiana General Assembly by visiting: www.in.gov/legislative. There you will find:

- Who is your State Representative and Senator
- State House Committees
- Bills and Resolutions
- Calendars for Legislative Action
- Link to Watch the General Assembly Live

For information about the U.S. House of Representatives visit: www.house.gov

For information about the U.S. Senate visit: www.senate.gov

How to Contact Your State Senator and State Representative

**CALL**
State House Telephone Center .... 317-232-9600
State House Switchboard .......... 800-382-9842
State Senate Telephone Center .... 317-232-9400
State Senate Switchboard .......... 800-382-9467

- Call the State House Switch Board.
- Ask to speak to your Representative or Senator.
- If your legislator is not available, ask to speak to his or her legislative assistant.
- If the legislator or the assistant is not available, you may leave a brief message with the operator.
- State the reason for the phone call, including the bill number and subject matter when possible.
- State the position you want the legislator to take (support or oppose).
- Explain how the legislation affects you and your family. Briefly tell your story.
- Ask the legislator what his or her position is on the issue.
- If the legislator’s position is the same as yours, express agreement and thanks.
- If your position differs from the legislator’s, offer some factual information and ask if there is any additional information you can provide that would change his or her mind.
- State the facts as you see them. Try not to get emotional.
- If appropriate, follow up the telephone call with a letter or e-mail to the legislator.

**WRITE or EMAIL**

**Name of Elected Official**
State House
200 West Washington Street
Indianapolis, IN 46204

State Representative
h(insert district number)@in.gov
State Senator
s(insert district number)@in.gov

- When e-mailing, include the bill number or subject of the legislation in the subject line.
- Start with “Dear Representative/Senator.”
- Keep your message brief, friendly and respectful.
- Make it clear that you are a constituent.
- State your issue and what you are asking clearly at the beginning.
- Refer to bill numbers when possible.
- Explain how the legislation affects you and your family. Briefly tell your story.
- Write in your own words without copying verbatim from a sample or form letter.
- Ask the legislator for a response specifying his/her position and the reasoning.
- Whether writing or emailing, be sure to include your name, address and phone number.

Keep Up to Date on State and Federal Legislation

**Sign up for The Arc Action E-List**
The Arc of Indiana and The Arc of the United States are leaders in advocating for people with developmental disabilities and their families at both the Indiana General Assembly and the United States Congress.

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

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

Go to: www.arcind.org
Click on: Public Policy Advocacy
Scroll down and click on: Sign-Up to Receive Action Alerts

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

Go to: http://capwiz.com/thearc/in/home
The Arc Master Trust
Reflecting On and Celebrating 25 Years of Service

Tom Ewbank, Co-founder, The Arc of Indiana Master Trust

Way back in 1986 I was asked to serve on a special committee of The Arc of Indiana to explore the need for and the feasibility of The Arc creating a special needs trust program. The need seemed readily apparent to the committee, especially those of us who had children with special needs and who worried how we would provide for their future care.

The feasibility was another question. What would it take to start a pooled special needs trust? How could such a trust become viable, not be a financial burden to the finances of The Arc, and, most importantly, keep a hard and fast promise to families and their loved ones that it would be there to provide for their future. Many had in mind an entity at that time who had promised many Indiana families lifetime care and housing for their loved ones through their trust program, but, due to unrealistic financial assumptions, went bankrupt. We were determined that if we were to build a trust, we would not repeat the mistakes of others.

The committee recommended that $200,000 would need to be raised as a base to begin a trust program. It also projected that even with this base $200,000 was raised and by 1988 we were ready to begin.

I enrolled my son, Curt Ewbank, as the first beneficiary of The Arc of Indiana Master Trust. Of course, because I was still living his trust was not yet funded; but at least he was enrolled and I continue to have the peace of mind that when I am no longer here, the trust will be there to provide for Curt.

Alan Kemp, the first Trust Director, and I expected to wait five years, plus or minus, before the first trust would be funded, but it did not take that long. We soon had trusts funded by parents, grandparents, siblings and from court orders terminating guardianships and other trusts. And like me, many parents enrolled their loved ones in the trust, and through enrollment and annual renewal fees the trust was on its way to becoming solvent and self-supporting.

In the 25 years since The Arc of Indiana Board approved The Arc Master Trust it has exceeded all of our expectations. Over the past 25 years, 2146 people have enrolled in The Arc Master Trust, and over $30,500,000 is invested in Trust I.

The trust staff has grown from 1, to 2, to 3, and recently to 4 employees, and nearly 2,000 checks are distributed each month to benefit the 2,206 beneficiaries of our Trust I and Trust II programs.

The Arc Master Trust continues to be recognized as the nation’s premier special needs trust, serving as a model for many others to follow.

It is with pride that I celebrate The Arc of Indiana Master Trust’s 25th anniversary. And it is with equal pride that I know the strong base we established 25 years ago will allow the trust to continue to grow, enjoy financial security and, most importantly, continue to serve our trust beneficiaries over the next 25 years and beyond.
Every Hoosier has two legislators—a representative and a senator. Get to know them and become a trusted resource for them. It’s no different than developing any other relationship. It takes time to get to know someone and build trust. This can happen in town hall meetings or at community or advocacy group meetings at which a legislator is present. Look for other opportunities as well. For example, take time to introduce yourself at local events, such as fairs or other similar, relaxed settings. The time you invest in building relationships with your legislators will pay dividends when an important issue is up for consideration and they turn to you for information and advice.

During session, there’s still no substitute for a visit to the Statehouse. In lieu of that, a letter or email message to your legislators can be effective. A phone call is a quick way to reach out, but follow up with a note. If you plan to visit the Statehouse during session, call ahead to schedule appointments with your legislators. Try to come with constructive suggestions and possible solutions—not just criticism and opposition—and avoid making threats.

In odd-numbered years, the legislature meets for a so-called “long session,” which starts in early January and may—and almost always does—continue until the end of April. The long session is when the legislature writes the two-year state budget. The 2013 session will be a long session, and the budget will run from July 1, 2013, to June 30, 2015. In even-numbered years, the legislature meets for a “short session,” which also starts in early January and must end by mid-March. The 2013 legislature will convene on January 7.

Getting a bill filed is only the first step in a long and difficult process. Most bills never even receive a committee hearing, let alone become law. In the last two sessions, a bill had less than a one-in-five chance of becoming law.

Part or all of some bills that don’t make it through the process on their own end up in other bills. This can happen when language from a House bill is amended into a Senate bill, or vice versa, either in committee or on the floor. It can also happen during the conference committee process. That’s the time at the end of the session when appointees from the House and Senate try to work out differences between versions of a bill.

The legislative process is often compared to a sausage factory. People may like the finished product, but they don’t necessarily want to know how it’s made. Conference committees can be the legislative equivalent of a sausage grinder.

At its best, the legislative process provides for open and robust discussion and debate of issues. At its worst, the sausage-making analogy is apt. Sausage or not, the most important ingredient is you.

State Rep. Ed Clere, R-New Albany, was re-elected in November to a third term in the Indiana House of Representatives. He represents most of Floyd County. Rep. Clere is the newly appointed chairman of the House Public Health Committee. He was also appointed to the House Public Policy Committee and re-appointed to the House Education Committee, on which he has served for four years.