

# family @ linkages newsletter

## Celena L. Barnes Family Leadership Inspiration Award

The Celena L Barnes Family Leadership Award was presented on November 11, 2015 in Traverse City, Michigan at the Early On Conference by Celena's family to Crista Burns of Dearborn, Michigan. Crista Burn's journey with *Early On* began when her son, Andrew, was eligible for *Early On* special education services as an infant. Crista was an engaged *Early On* parent and took advantage of every opportunity offered to help her in Andrew's development. Because of Crista's commitment to the larger early intervention system, she was encouraged to become part of the Wayne County Interagency Coordinating Council. Crista soon became a "go-to" person when any project or committee needed input. This included a small workgroup to brainstorm ideas to move Wayne County *Early On* towards the statewide target percentage for Family Outcomes, SPP Indicator 4. Crista was instrumental in developing the "white-board" that highlighted the three family outcomes which service providers/coordinators could discuss and leave with families on a home visit. Crista was also a co-lead for the physician outreach initiative. Crista was organized and efficient as she helped developed outreach materials and met with physicians' office staff to explain the basics of *Early On* and how to refer a child.

Celena had a vision for Wayne County *Early On* to develop a transition packet for families to help them understand the whole process. Crista was instrumental in researching topics and helping to review and provide feedback on the content as well as organizing the first-round assembly of the packets. Both Crista and Celena shared a strong commitment to provide relevant information to families so that they could participate more fully in early intervention services for their child. The transition packets are also well received by service coordinators who value the content materials to help explain the intricacies of the process to families. Yet another project Crista took the lead with is the Wayne *Early On* Parent Newsletter. She researches and puts together the content for each newsletter. Crista is now the secretary of the Wayne ICC. Her commitment to helping the *Early On* system work for families is evident to all. She is in the process of starting parent meetings to help new LICC parents be important voices for the *Early On* system. She has a strong commitment to help Wayne County families with infants and toddlers eligible for *Early On* services and supports. Congratulations Crista!

*(The Celena L Barnes Award is dedicated to the legacy of a tireless advocate for her daughter and all children in Michigan with special needs, a committed leader, mentor, inspiration to other families, and overall phenomenal woman who was a voice for families of children with special needs in her community, throughout the state of Michigan and the country serving as a passionate member many local, and state level councils and committees including the Michigan Family Voices Advisory Committee. For more information about nominating a family leader for the award contact Barb Schinderle at (517) 241-2591*



## **ACTION ALERT**

### **Immunization Bills Would Remove Non-Medical Waiver Education Requirement**

Two bills introduced this month in the state Legislature would curtail efforts to improve Michigan's childhood immunization rate.

Introduced by Representative Thomas Hooker, House Bills 5126 and 5127 would eliminate the rule requiring parents seeking non-medical waivers to receive balanced education about the benefits and risks of immunizations from their local public health department. The bills also would strip a local public health department's ability to exclude children with a communicable disease or those who lack vaccine protection, from attending school during an outbreak.

The Michigan Council for Maternal and Child Health (MCMCH), in partnership with a group of statewide advocacy organizations working to improve immunization rates in Michigan, is seeking individuals who can speak to how vaccines benefit them and their family. Whether it's someone touched by vaccine-preventable disease or a family who has an infant too young to be fully immunized, or an immuno-compromised child or older adult in their life.

Please consider sharing information with your network, via a newsletter or other communications, as we attempt to recruit as many potential speakers as possible. If you are willing to be part of this vaccine positive network, or would like to learn more, please send an e-mail to MCMCH Associate Director Bree Anderson at: [banderson@mcmch.org](mailto:banderson@mcmch.org).

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## **ACTION ALERT**

### **Restraint and Seclusion Legislation HR 927**

The Michigan Developmental Disabilities Council Public Policy Committee has been working on HR 927, Keeping All Students Safe Act. Its purpose is to prohibit the use of Restraint and Seclusion in our public schools. This is federal legislation. Now it's time to advocate with our Federal congressmen and women on this important issue. A sample letter follows that you may use to write your Congressman or woman. Simply put your legislators name on the top of the letter, and sign it on the bottom.



Dear (Man/Woman *Fill in the name of your congressional representative and use proper gender*):

I urge you to support HR 927, Keeping All Students Safe Act. If you are not currently a co-sponsor, please add your name and public support to this vital piece of legislation.

The purpose of this bill is to prohibit the use of Restraint and Seclusion in our public schools.

Why it is important:

- According to a 2009 Government Accountability Office (GAO) report delivered to congress, “GAO did find hundreds of cases of alleged abuse and death related to these methods [restraint and seclusion] on school children during the past two decades”
- In 2003, two students in Michigan died due to restraint
- There is greater protections against restraint and seclusion for people in prison than that for our children in public schools
- Restraint and seclusion is harmful to the physical and mental well-being of our children

Please feel free to contact me should you have any questions.

Sincerely,

(Your Name)

(Address)

(City, State Zip code)



Written by: Chris Simmons, Michigan Statewide Independent Living Council Policy Coordinator

## Michigan Formally an *Employment First State*

On November 19, 2015 Lt. Gov. Brian Calley signed Executive Order 2015-15 formally making Michigan an *Employment First State*. The order directs state agencies to align their services for persons with disabilities to a goal of competitive employment in an integrated setting. The State Rehabilitation Council is charged with the oversight on this order, including the creation of measurable goals and objectives towards implementing this order.



We applaud the efforts of all state agencies who contributed to the language of this order, and especially congratulate the Michigan Developmental Disabilities Council for their continued advocacy towards this effort. We look forward to offering our contributions to the efforts of the State Rehabilitation Council, and echo Lt. Gov. Calley's sentiment that this is but a step towards a day when the full employment of persons with disabilities is no longer something remarkable.

*Analysis on this executive order:* The Executive Order does a few notable things in requiring a realignment of state programs towards a goal of competitive, integrated employment for persons with disabilities. The first notable item is that all state programs, including *funding*, are to be aligned to this goal. This would therefore include all programming from MRS, BSBP, and Community Mental Health. We will be awaiting word from the State Rehabilitation Council on a process for determining the outcomes and metrics towards implementing this directive.

Another notable item is that the preservation of individual choice is maintained. The data collected from Centers for Independent Living in the state indicates that employment is not always the barrier that individuals are seeking assistance in overcoming. This order does not remove the personal choice of the individual receiving state services.



The final item of note is that the order provides a definition of integrated setting and competitive employment that emphasizes there should be no difference between these employment opportunities and those available to anyone else in the community at large.

We look forward to the implementation of this order, and will be monitoring and contributing to ensure that the outcome meets the intent.



*This article contains excerpts from section 529a interim guidance regarding certain provisions of proposed regulations relating to qualified able programs. Notice 2015-81*

Written By: Brett Williams  
Public Policy Analyst  
Michigan Developmental Disabilities Council

# Michigan-Achieving a Better Life Experience (ABLE) Update



Over the last several months, there has been progress made on both the state and federal levels regarding ABLE accounts. The ABLE Act is a law that was signed by President Obama, in December of 2014, which will allow people with disabilities to establish a 529-type savings account (529(a) account). This gives the account holder the ability to save up to \$100,000 and not lose their SSA/SSDI benefits. Another important feature of this savings account is that contributions made to a person's ABLE account are tax deductible up to a specific amount. Once a person has over a \$100,000 in their account, their SSA/SSDI benefits will be "suspended" until the account balance dips below \$100,000.

In Michigan, a single person can contribute up to \$5,000.00 into an ABLE account, \$10,000 as a couple, for a tax-exempt contribution. The total amount of monies deposited into an ABLE account cannot exceed \$14,000 in yearly contributions from all sources combined.

Late November of 2015, the Department of Treasury and the Internal Revenue (IRS) service released interim guidance on three notable areas of ABLE accounts. The first focuses on disability certification. The Department of Treasury and the IRS have agreed that a person with a disability does not have to provide the administrator of the ABLE program with a physician's diagnosis. However, the holder of the ABLE account must present a physician's diagnosis if asked by the IRS or the administrator of the ABLE program.

Second, it will not be required to have all contributor's tax identification number (TIN) at time of contribution if the program/administrator has a way of prohibiting excess contributions into an able account. If that system fails, they will need to have the contributors TIN.

The last issue focuses on distributions from an ABLE account for disability related expenses. Some of the guidelines are:

- Distributions for housing expenses will not have to be recorded
- It will not be required, for any federal income tax purpose, a qualified ABLE program to create safeguards to "distinguish between distributions used for qualified disability expenses and other distributions"<sup>1</sup>
- "The designated beneficiary will have to categorize distributions in order to properly determine the designated beneficiary's federal income tax obligations"<sup>2</sup>

On the state level, Michigan Developmental Disabilities Council remains in close contact with the Michigan Department of Treasury for the most current updates regarding the progress of ABLE accounts in Michigan. The state has begun the process of finalizing a Request for Proposal (RFP) to solicit entities interested in administering our (Michigan's) ABLE accounts. Through our communications, we have also learned that a target date for rollout of the ABLE program in Michigan is targeted for mid-summer, 2016.

Should you have any questions regarding ABLE accounts in Michigan, you can contact Brett Williams at [WilliamsB18@michigan.gov](mailto:WilliamsB18@michigan.gov) or 517-335-3139. You can also send questions to [MIABLE@michigan.gov](mailto:MIABLE@michigan.gov)

<https://www.irs.gov/pub/irs-drop/n-15-81.pdf>

<https://www.irs.gov/pub/irs-drop/n-15-81.pdf>



## Michigan ABLÉ Act Signed Into Law



On Oct. 28, 2015, Lt. Gov. Brian Calley signed into law a package of bills creating the Michigan ABLÉ savings accounts. HB 4542, HB 4543, HB 4544, and SB 360, now Public Acts 160, 161, 162, and 163 of 2015, authorize the Michigan Department of Treasury to create an ABLÉ savings program.

We applaud the work of Representative Anthony Forlini as the prime advocate for this effort, along with Rep. Nancy Jenkins and Sen. Rebekah Warren as bill sponsors, for creating another tool to be used to support the financial independence of persons with disabilities.

## Celebrating Bills Removing Offensive Language from Law



A ceremonial bill signing was held on September 29, 2015 with Governor Rick Snyder to celebrate the passage of bills to update language in a number of Michigan statutes by removing references to “crippled children.”

House Bills 4203, 4204, 4205 and Senate Bills 112, 113 and 114 respectively, removed all offensive references to “crippled children” from state law. The bills are now Public Acts 89-94 of 2015 which modernizes state law by eliminating outdated language considered offensive when referring to children with disabilities. The references in law will now be described as “children or youth with special health care needs”

One of the bills, HB 4205 sponsored by Representative Schor (D-Lansing), also modernizes the section of the Public Health Code that recognizes Michigan’s Children’s Special Health Care Services Program.

We commend State Representatives Mike Callton, Joe Graves and Andy Schor and State Senators Curtis Hertel, Jim Marleau and Margaret O’Brien for leading the change in legislative language to be more sensitive and less offensive for children and youth with special health care needs.



# ADVOCACY/LEADERSHIP TRAINING OPPORTUNITY

COMING SOON TO THE TRAVERSE CITY AREA!

Leaders in Policy Advocacy (LIPA) is a leadership development program for adults with developmental disabilities and parents of minor children with developmental disabilities. The project trains and supports participants to become leaders in the disability rights movement. It is funded by the Michigan Developmental Disabilities Council and administered by The Arc Michigan.

Topics include:

- Disability History
- Inclusive Education
- Assistive Technology & Social Media
- Self-determination and Alternatives to Guardianship
- Person-centered Planning
- Access to Housing and Employment
- Benefits and Systems of Support
- Systems Change



Participation in LIPA requires a significant time commitment. Six (6) weekend sessions begin on Fridays at 12:30 pm and end for the day at 9 p.m. The class resumes at 8:30 a.m. on Saturdays and concludes at 3:00 p.m. There is no cost to participate in the training. Participants will be asked to share a hotel room with another class member, if lodging is needed. Meals will be provided, including to caregivers, and participants will be reimbursed for mileage to and from the training sessions. No child care will be provided on site, however, assistance with the cost of child care may be available.

**Dates and Venue: TO BE ANNOUNCED SOON**

To apply, go to <http://www.arcmi.org/new/lipa.htm>, where you can complete an application form online or download and print one to fill out and mail in. Please contact Project Coordinator Salli Christenson if you have questions or need help in applying. She can be reached at 1-800-292-7851, ext. 130, or [salli.c@arcmi.org](mailto:salli.c@arcmi.org)





## ADVOCACY/LEADERSHIP INVOLVEMENT OPPORTUNITY

Michigan Family Voices is seeking Family Leaders to take part in community stakeholder meetings in

- Southwest Michigan (Allegan, Barry, Berrien, Branch, Calhoun, Cass, Kalamazoo, St. Joseph, Van Buren Counties) and
- Southeast Michigan (Wayne, Oakland and Macomb Counties)
- Upper Peninsula

A family leader ...

- is a family member of a child and/or youth with special health care needs including physical, behavioral, or emotional and/or disabilities.
- A family member includes: youth guardians: adoptive, biological, foster and step-parents, domestic partners who co-parent, grandparents, siblings, aunts/uncles, nieces/nephews, cousins, neighbors, communities, religious leaders and any other person the individual defines as a family member
- has personal or professional leadership experience in/with community organizations that serve individuals, families of children and youth with special health care needs (including physical, behavioral, and emotional) and/or disabilities
- serves on a Local Great Start Coalition, Parent Advisory Committee, Local Interagency Coordinating Council, Regional Interagency Coordinating Council, Local Transition Council, Local CMH Board etc.
- is passionate and interested in policy/legislation and system development/reform
- has advocated on behalf of a family or families with a program director, agency director, legislator or other policy-makers
- has participated in training related to advocating and partnering in policy-making for individuals and families of children and youth with special needs or disabilities
- possesses skills, has experience and/or specializes in advocating, networking, policy/legislation and system development/reform

If you are interested and/or have questions please call (800) 292-7851 x 472 or email [info@michiganfamilyvoices.org](mailto:info@michiganfamilyvoices.org) for further information.



## COLLABORATIVE LEARNING OPPORTUNITIES

### **Helping Families Tell Their Stories (Part 2)**

January 13, 2016

10:00 am – 1:00 pm

Family Resource Center

1901 Maple Street

Saginaw, MI 48602

Visit the Michigan Family Voices Website for most updated advocacy, leadership, and learning opportunities at: <http://michiganfamilyvoices.org> or contact:

Michigan Family Voices at (800) 292-7851 extension 427 or [info@michiganfamilyvoices.org](mailto:info@michiganfamilyvoices.org)

### **Who Should Attend Collaborative Learning Opportunities?**

Individuals and family members of young children, teen and young adults with special needs/disabilities (including: youth guardians; adoptive, biological, foster and step-parents, domestic parents who co-parent, grandparents, siblings, aunts/uncles, nieces/nephews, cousins, neighbors, religious leaders, and others who person defines as a family member), organizations and service providers of families of young children, teen, young adults, and individuals with disabilities

We encourage individuals and families to invite people who provide support and services to you and your family. Providers are encouraged to invite individuals and families you support and serve. Forming partnerships between people served and those providing services is crucial in building collaboration and partnering in decision-making at all levels with individuals and families of children and youth with special needs/disabilities.



<http://on.fb.me/1UgikhK>



<http://bit.ly/1JmU9ZD>