

Volume 2 issue 18 Winter 2018

In 2017 there was a lot of congressional activity around the Affordable Care Act (ACA). Legislators spent over half a year trying to repeal ACA.

Individuals and families in Michigan and throughout the country spent endless hours calling, writing and meeting with their representatives and senators during coffee hours, in their offices and at town hall meetings.

Telling their stories of how ACA helped them and their families. Their hard work paid off on July 28, 2017 when the bill to repeal ACA was defeated in a 40-51 vote.



Efforts were then made to repeal ACA as part of the Tax Cut and Jobs Act. Individuals and families continued reaching out to elected officials sharing their stories. This Act did pass and was signed into law by President Trump on December 22, 2017. However, the only part of ACA that was repealed was the **Individual Mandate** which requires most individuals either to have health insurance coverage or pay a fine. No other portion was repealed even though you may have heard ACA was repealed altogether. The patient protections are still in place and include the following:

- health insurance companies can't refuse to cover you or charge you more just because you have a **“pre-existing condition”**
- prohibits health plans from putting a lifetime dollar **limit** on your coverage
- young adults can stay on their parents' health care plan until age 26



The Trump administration issued guidance to states on January 11, 2018 that will allow them to compel people to work or prepare for jobs in order to receive Medicaid for the first time in the history of the program. The guidance outlines what states need to do to mandate that certain Medicaid enrollees work to qualify for

benefits. The agency is expected to start approving state waivers promoting "community engagement activities" in upcoming weeks. The historic move will make a significant change in how the government health insurance program operates.

## Legislative Update

**House Bill 5317** – Requiring Medicaid enrollees to participate in job training and education unless temporarily or permanently exempt due to age, disability or other medically documented inability to participate, a recipient of supplemental social security, or otherwise exempt as outlined in the bill. HB 5317 was introduced by Representative Gary Glenn and referred to the House Committee on Appropriations. State Senator Mike Shirkey, considered the primary architect of Michigan Healthy Michigan Plan (Medicaid expansion), has commented that this is a “go sign to test all kinds of ideas”.

## ADVOCACY/LEADERSHIP INVOLVEMENT OPPORTUNITY



We are continuing to build our Family Leadership Network. Seeking individuals and families of children and youth with special health care needs/disabilities who have participated in leadership training and/or have experience in changing policies at the local, state or federal level. To participate in informing and educating policy makers, serve on committees, work groups and or providing feedback on the following issues/topics:

1. Policy and Legislation-An individual or family that has input regarding: foster care, health care financing, mental health services, transportation, housing, employment, and transition to adulthood.
2. Medicaid- A Medicaid recipient receiving services that is experiencing barriers in the system: health care, mental health,
3. Children's Special Health Care Services-A family member of a child with a genetic condition, cleft palate, diabetes, severe asthma, cerebral palsy, or hearing impairment,
4. Maternal, Infant, Child Health, or Community Health Services-A recipient or family member of a child receiving or have received services through a home visiting program, maternal, infant, and/or child health program,
5. Early On and/or Special Education Services-A family member of child receiving or have received Early On services or Special Education services.

### **For More Information about Leadership Opportunities contact:**

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

Visit: <http://michiganfamilyvoices.org/leadership-network/>



### **Nominations for Family Representative Coming Soon**

Are you a member of Michigan Division of Early Childhood of the Council for Exceptional Children (MiDEC)? Would you like to expand your role? Consider a position on the MiDEC Executive Board! A call for nominations for the Family Representative will be coming up soon. It is a two-year term, running from July 1, 2018 through June 30, 2020. The Family Representative's Duties include connecting with and recruiting family members, representing the subdivision in coordinating efforts with agencies and/or organizations that are connected with families, and providing a family perspective on all subdivision efforts. If you aren't a member consider joining. MiDEC Michigan's source for information, resources, and guidance related to young children with special needs and their families.

## Association of Children's Mental Health Seeks Youth Leaders



The Association for Children's Mental Health (ACMH) is currently accepting applications for its Statewide Youth Advisory Committee. Application for a seat on the ACMH youth advisory committee is open to all youth, ages 15-20 in the state of Michigan who have had or are currently experiencing a mental health or behavioral challenge. Involvement is NOT limited to young people with experience in any particular system, such as public mental health, foster care, juvenile justice or special education. All youth ages 15-20 who are passionate about mental health issues and have personal experience will be considered. Up to 15 youth will be selected to serve on the committee. Once selected, youth members will be asked to serve for one year.

### Criteria for Participation:

- Be between the ages of 15-20 years old;
- Have had personal experience or are currently dealing with a mental health or behavioral challenge;
- Possess the passion and desire to advocate for positive systems change for children's mental health;
- Have the ability to work in collaboration with fellow committee members.

### How to Get Involved:

Interested youth who meet criteria for participation will follow the required steps to submit an application. By doing so, youth agree to fulfill the roles and responsibilities as described. As part of their application process, applicants will be asked to select an adult sponsor to help support them in their participation on the committee. This sponsor will:

- Provide a letter of recommendation, speaking on the strengths the youth will bring to the committee;
- Serve as a mentor to the youth;
- Support the youth's involvement in committee meetings, events and related activities;
- Help connect youth to leadership trainings, educational events, and development opportunities in their local community.

Examples of adult sponsors may include employees or volunteers of youth serving organizations, therapists, coaches, neighbors, teachers, etc. The ACMH Youth Coordinator can help the applicant identify a sponsor if needed. Please contact Krissy Dristy, ACMH Youth Coordinator with any questions at: Phone: 517-643-3314 Email: [kdristy@acmh-mi.org](mailto:kdristy@acmh-mi.org)

## Michigan State University Seeks Families of Young Children to Participate in Study

Michigan State University (MSU) is conducting a research study of children's language and literacy development. Information from this study will help researchers to develop a new measure of phonological awareness that will be accessible to children with disabilities. Researchers hope to understand how children are learning about the sound structure of language (e.g., what rhymes with cat?).



Participation is easy. The test takes about 30 minutes to complete. It is broken down into as many sessions as the child needs. Can be onsite before or after school, in the home, or in the research lab. So far, most children have liked the new assessment; plus, participating families get a storybook and a \$10 gift card.

This work would not be possible without families voicing concerns over the years and without your participation in this study. Contact ([skibbelo@msu.edu](mailto:skibbelo@msu.edu)) or Norma Eppinger, Project Manager (517)432-0893; [eppinge1@msu.edu](mailto:eppinge1@msu.edu)) for more information.

**PROJECT: Partners Advancing Self-Determination (PAS)** Done in collaboration with the Michigan Department of Health and Human Services, Behavioral Health and Developmental Disability Administration and funded by the Michigan DD Council.

## **Project Goals**

“Provide state-level technical assistance, training, and support to Advancement Teams that include:

- Community Mental Health Service Providers (CMHSPs or CMHs),
- Prepaid Inpatient Health Plans (PHIPs),
- Intermediate School Districts (ISDs),
- People with intellectual/developmental disabilities (I/DD), and their family members

## **Project Facts**

...to address the issues with **consistency, availability, and access to the tools and supports** that people with I/DD need to control their services and live self-directed, self-determined lives.”

- Two Advancement Teams piloted in FY 2018
- Three Advancement Teams developed each future project FY 2019-2021
- Teams selected across the state
- PAS Advisory Council recommends SD best practices, technical assistance, performance measures & enforcement methods

## **PAS Selected Advancement Teams commit to:**

- Participate in education and training of others about arranging services that promote self-determination & authentic use of Person-Centered Planning
- Promote & encourage the use of self-determination arrangements including those with high and complex needs
- Provide education & training opportunities that include ISD students and their teachers and/or transition coordinators
- Include people with disabilities & families/allies, CMHSP support coordinators & other key staff, PHIP staff and members from the special education/ISD system.



For more information please contact Jill Gerrie, Project Coordinator

[jill.gerrie@arcmi.org](mailto:jill.gerrie@arcmi.org)

(517) 492-5029 or toll free (800) 292-7851, ext. 114

# ADVOCACY/LEADERSHIP TRAINING OPPORTUNITY



The Michigan Developmental Disabilities Council (MDDC) is hosting its annual Legislative Day Event on March 6, 2018. This event is for people with intellectual / developmental disabilities, not parents or guardians, to discuss important issues with their legislators in a one-on-one setting.

It is vital that people with disabilities (PWDs) share their stories with our state lawmakers so they will have a better understanding of how policies help PWDs to live independent, inclusive lives.

The day begins at 8:30 and ends at 4:00. It will be hosted at the Anderson House Office Building (House of Representatives) 124 N Capitol Ave. Lansing, Michigan. Please contact Brett Williams at [Williamsb18@michigan.gov](mailto:Williamsb18@michigan.gov) or by phone at 517-284-7289. Registration is required.

To prepare for this event, there are several self-advocacy trainings scheduled around the state. They are approximately three hours in length and covers many items on how people can become strong self-advocates as well as information about the Legislative Day Event. These sessions are free and are open to PWDs, parents, and others. The trainings scheduled thus far are:

**February 9, 2018 at Noon**

Red Sky Stage  
445 East Mitchell Street  
Petoskey, MI 49770

**February 12, 2018 at 6:00**

Westgate Library- Westgate Shopping Center  
2429 West Stadium Boulevard  
Ann Arbor, MI 48103

**February 13, 2018 at 1:00**

Royal Oak Public Library,  
222 East Eleven Mile Road, PO Box 494  
Royal Oak, MI 48068-0494

**February 15, 2018 at 10:00**

Arc Detroit  
51 West Hancock  
Detroit, MI 48021  
313-831-0202

**February 16th, 2018 at 1:00**

Manistee Public Library  
95 Maple Street  
Manistee, MI 49660

**February 22, 2018 1:00 – 4:00**

Peter White Public Library  
217 N. Front Street  
Marquette, MI  
Arts and Culture Room in the lowest level

**February 26, 2018 Noon – 2:00**

Cristo Rey Church  
201 West Miller Rd.  
Lansing, MI 48911

**February 28, 2018 10:00- 12:00**

HOPE Network - Education Center Building 3  
775 36th Street South East  
Grand Rapids, MI 49548



**IEPs and Advocacy**

February 3, 2018

9:00 am – 3:00 pm

Oakland Schools- Conference Room A

2111 Pontiac Lake Road Waterford, MI 48328

**Rethinking Guardianship Facilitating Life-Long Self Determination with Dohn Hoyle**

February 7, 2018

12:00 pm – 3:00 pm

Caroline Kennedy Library

24590 George Avenue Dearborn Heights, MI 48127

**Rethinking Guardianship Facilitating Life-Long Self Determination with Dohn Hoyle**

March 2, 2018

9:00 am – 12:00 pm

The Arc Livingston

2980 Dorr Road Brighton, MI 48116

**Can You Hear Me Now? With Cheryl Levine**

March 8, 2018

5:00 pm – 7:30 pm

Hoyt Public Library

505 Janes Avenue Saginaw, MI 48607

**Can You Hear Me Now? With Cheryl Levine**

April 16, 2018

11:00 am – 1:00 pm

Ferndale Public Library

222 E. 9 Mile Road Ferndale, MI 48220

**Skills for Effective Parent Advocacy with Kanika Littleton**

May 1, 2018

8:30 am – 10:00 am

Oakland Schools Technical Campus-Southwest

1000 Beck Road Wixom, MI 48393

Register at: <https://www.michiganallianceforfamilies.org/upcoming-events/eventregistration/>

We have additional events scheduled! Check our website:

<http://www.michiganallianceforfamilies.org/upcoming-events/>

Be sure to view our selection of free On Demand Webinars available for viewing at home

[www.michiganallianceforfamilies.org/webinar](http://www.michiganallianceforfamilies.org/webinar)

## **COLLABORATIVE LEARNING OPPORTUNITIES**

### **How to Better Understand Your Mental Health Rights**

February 15, 2018

6:00 pm - 8:00 pm

Ann Arbor CIL

3941 Research Park Dr.

Ann Arbor, MI. 48108

[www.surveymonkey.com/s/DG5BXSX](http://www.surveymonkey.com/s/DG5BXSX)

### **Helping Families to Tell Their Stories**

March 24, 2018

10:00 am – 12: pm

Allendale Township Central Library

6175 Library Lane

Allendale, MI 49401

[www.surveymonkey.com/r/L2JQKH3](http://www.surveymonkey.com/r/L2JQKH3)

### **How to Better Understand Your Medicaid Rights**

April 12, 2018

6:00 pm - 8:00 pm

Ann Arbor CIL

3941 Research Park Dr.

Ann Arbor, MI. 48108

[www.surveymonkey.com/r/DG5BXSX](http://www.surveymonkey.com/r/DG5BXSX)

### **How to Better Understand Your Medicaid and Mental Health Rights**

April 19, 2018

10 am – 2 pm

Power Hope Grace Bible Church

6495 W Warren Avenue

Detroit, MI 48210

[www.surveymonkey.com/s/DG5BXSX](http://www.surveymonkey.com/s/DG5BXSX)

### **Everything I Need to Tell My Child about Sexuality**

April 26, 2018

10 am – 3 pm

Compassionate Heart Ministry

404 Centerstone Ct

Zeeland, MI 49464

[www.surveymonkey.com/r/TX5MRH6](http://www.surveymonkey.com/r/TX5MRH6)

### **How to Better Understand Your Medicaid and Mental Health Rights**

May 3, 2018

Community Advocates

3901 Emerald Drive

Kalamazoo, MI 49001

[www.surveymonkey.com/s/DG5BXSX](http://www.surveymonkey.com/s/DG5BXSX)

### **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.

### **For More Information about Collaborative Learning Opportunities contact:**

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

Visit: <http://michiganfamilyvoices.org/learning/> for up-to-date schedule

# SAVE THE DATE

Michigan Family Voices will be partnering with the Brain Injury Association of Michigan and several other organizations to host Civic Engagement Day” on **March 22, 2018** in Lansing. Civic Engagement Day is designed to educate and inform individuals, their families, caregivers and professionals on how to advocate for themselves and the people for whom they provide care and assistance. It is designed for everyone in health care, mental health and disability communities.

The event is free. Participants will visit members of health and disability related committees, committee meetings to observe legislation in action, tour the capitol and be recognized in the gallery by the House of Representatives. Flyers will be distributed soon. In the meantime for more information contact Lisa Cook-Gordon at (800) 292-7851 ext. 427