

# family @ linkages newsletter

A way to connect families of children and youth with special needs in Michigan  
with information, education and support

Jacob West, son of Lori and Steve West of Nashville, Michigan, lost his battle with chronic illness and technology dependency on May 16th, 2013. For 26 years, Jacob and his family were partners in creating positive change in Medicaid policy toward Family Centered practice and quality services. The West family encouraged true partnerships between policy makers and families and was part of pioneering efforts to open Home and Community Based Waivers for children, while gently teaching all they encountered the importance of respectful relationships and caring conversation.

Their efforts have led to policy development and change for programs serving children and youth with special health care needs including:

- ✿ Early On Michigan where Lori served in partnership with representatives from the Michigan Department of Community Health, Education and Human Services to develop policy and procedures for infants and toddler with developmental delay and established medical conditions needing early intervention services.
- ✿ Children's Special Health Care Services CHILDS (Children's In-Home Locally Delivered Services) which Lori helped to create to provide in-home medical services to children who would otherwise have to be hospitalized to receive.
- ✿ Lori served as a Community Parent Liaison in the Department of Pediatrics and Human Development at Michigan State University, coordinating the Partners in Care Conference and consulting with Medical Professionals specific to Family Centered Care.

Most recently, the Wests began to impact program and policy change in the adult service world around the dire need to ensure health care coverage and medical service providers are available and accessible to young adults with chronic illness, technology dependence and special health care needs transitioning from children's to adult services.

**The West Family would like to establish: THE JACOB WEST MEMORIAL FUND** in remembrance of their son Jacob. This fund will support opportunities for policy makers and families who partner to positively influence Medicaid policy in the state of Michigan for the betterment of services provided to individuals with special health care needs. If Jacob's family, and your paths have crossed or if you are so moved, please consider contributing to the Jacob West Memorial Fund so that the work the West family has done continues. *Contributions can be made to:*

**Jacob West Memorial Fund-Michigan Family Voices**  
c/o Arc Michigan  
1325 S. Washington Avenue  
Lansing, MI 48910

## #1 Spartan Fan



# NURTURING MEN — Thriving Children



**“A Practitioner’s Network”**

[www.michiganfatherhood.org](http://www.michiganfatherhood.org)

**Father’s Day is a day when we visit with our father, talk with our father or remember our father for what he has done to nurture us.**

Being a loving, caring and nurturing father is what makes this day special to so many children both young and old.

The relationships that we have with our own father are instrumental in how we grow and develop as children and adults. These relationships have a direct influence on how we parent our own children and develop positive co-parenting relationships as adults.

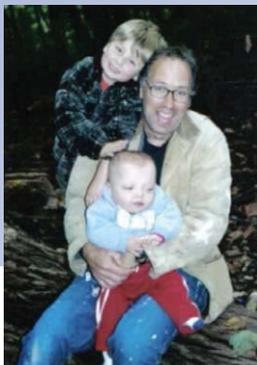
Please visit with your father, talk with your father and remember your father for what he has done to positively influence you, not only on Father’s Day but as often as you can.

The Michigan Fatherhood Coalition would like to honor all of the fathers who have given their children the love and nurturing that we all deserve.

## Happy Father’s Day!

As a father I always look forward to Father’s day, but more than that I look forward to each day enjoying what it means to be a father, spending time with my family. My second favorite thing to do is to interact with other dads and male caregivers of children with special needs.

**Come join me with this upcoming opportunity:**



**We Welcome Fathers of Children with Special Needs to Join Us**

June 10, 2013 • 7:00 PM – 8:00 PM

For an informational Family Voices Teleconference  
Please RSVP by email or phone:

[info@michiganfamilyvoices.org](mailto:info@michiganfamilyvoices.org) or (800) 292-7851 box 472



# The Early On<sup>®</sup> Michigan License Plate



In order to provide another stream of revenue for *Early On* Michigan Services, House Bill (HB) 4004 would create the *Early On* Michigan license plate.

On May 14, 2013, the House Transportation and Infrastructure Committee heard wonderful testimony about *Early On*. The next step is to convince Committee members to bring the bill to a vote — and to vote “yes.”

Passionate parents and educators throughout Michigan are needed to encourage Committee members to bring HB 4004 to a vote — and to vote “yes.”

Michigan Family Voices will be holding a **Contact Your Representative Day** on June 10, 2013.

If your family has benefited from *Early On* Services we ask that you contact Committee Chair Wayne Schmidt (R) 104th District (Grand Traverse) at [WayneSchmidt@house.mi.gov](mailto:WayneSchmidt@house.mi.gov) or by phone at (517) 373-1766.

**Or contact other committee members listed below, particularly if you live in their districts, to ask them to take HB 4004 to vote and vote “yes.”** District locations are approximated below by offering the county in parentheses where the district is located.

**Ben Glardon (R) Majority Vice-Chair, 85th District (Shiawassee/Gratiot)**

Phone: (517) 373-0841 FAX: (517) 373-7937  
Email: [BenGlardon@house.mi.gov](mailto:BenGlardon@house.mi.gov)

**Kevin Daley (R) 82nd District (Lapeer)**

Phone: (517) 373-1800  
Email: [KevinDaley@house.mi.gov](mailto:KevinDaley@house.mi.gov)

**Kurt Heise (R) 20th District (Western Wayne)**

Phone: (517) 373-3816  
Email: [KurtHeise@house.mi.gov](mailto:KurtHeise@house.mi.gov)

**Bradford Jacobsen (R) 46th District (Oakland)**

Phone: 517-373-1798  
Email: [BradJacobsen@house.mi.gov](mailto:BradJacobsen@house.mi.gov)

**Margaret O'Brien (R) 61st District (Kalamazoo)**

Phone: (517) 373-1774  
Email: [MargaretOBrien@house.mi.gov](mailto:MargaretOBrien@house.mi.gov)

**Peter Pettalia (R) 106th District (Crawford/Otsego/Ogemaw/Roscommon)**

Phone: (517) 373-0833  
Email: [PeterPettalia@house.mi.gov](mailto:PeterPettalia@house.mi.gov)

**Dan Lauwers (R) 81st District (St. Clair and Macomb)**

Phone: (517) 373-1790 FAX: (517) 373-9983  
Email: [DanLauwers@house.mi.gov](mailto:DanLauwers@house.mi.gov)

**Michael McCready (R) 40th District (Oakland)**

Phone: (517) 373-8670 FAX: (517) 373-5868  
Email: [MikeMcCready@house.mi.gov](mailto:MikeMcCready@house.mi.gov)

**Marilyn Lane (D) Minority Vice-Chair, 31st District (Macomb)**

Phone: (517) 373-0159 FAX: (517) 373-5893  
Email: [marilynlane@house.mi.gov](mailto:marilynlane@house.mi.gov)

**Scott Dianda (D) 110th District (Western UP–Gogebic)**

Phone: (517) 373-0850 FAX: (517) 373-9303  
Email: [scottdianda@house.mi.gov](mailto:scottdianda@house.mi.gov)

**David Rutledge (D) 54th District (Washtenaw)**

Phone: (517) 373-1771 FAX: (517) 373-5797  
Email: [davidrutledge@house.mi.gov](mailto:davidrutledge@house.mi.gov)

**Gretchen Driskell (D) 52nd District (Washtenaw)**

Phone: (517) 373-0828 FAX: (517) 373-5783  
Email: [gretchendriskell@house.mi.gov](mailto:gretchendriskell@house.mi.gov)

**Tom Cochran (D) 67th District (Ingham)**

Phone: (517) 373-0587 FAX: (517) 373-9430  
Email: [TomCochran@house.mi.gov](mailto:TomCochran@house.mi.gov)

**Charles Smiley (D) 50th District (Genesee south and east)**

Phone: (517) 373-3906 FAX: (517) 373-5812  
Email: [charlessmiley@house.mi.gov](mailto:charlessmiley@house.mi.gov)

**Thank you for supporting this important opportunity!**



## Background Information for People Contacting Their Representatives for House Bill 4004

### ➔ What is *Early On*® Michigan?

*Early On* Michigan provides services to families of infants and toddlers, birth to age three, who are eligible because they have a delay in development or a medical condition that is likely to result in a delay. The requirements for services are outlined in the Individuals with Disabilities Education Act (IDEA).

### ➔ Why do families need *Early On* Michigan?

Parents who find themselves caring for children with special needs, from minor delays to significant disabilities, often need services for their children (such as speech therapy or physical therapy) and support (such as strategies for feeding and bathing) in order to help their children develop to their fullest potential. Children — and their families — need support so that they can grow, develop, and be as ready as possible for success with friends, in school, and in life.

### ➔ Why support an *Early On* Michigan license plate?

An on-going visual reminder of services and supports for Michigan's infants and toddlers through a designated license plate will alert parents, grandparents, and other family members and friends to Michigan's desire to support of their needs. In addition, current federal funding is not adequate to meet the needs of eligible infants and toddlers and their families. The *Early On* license plate would provide additional revenue to support quality intervention for our youngest, most vulnerable children.

Hello, my name is \_\_\_\_\_

I'm contacting you to ask you to take HB 4004 to a vote and to vote "yes" so that *Early On*® Michigan will have a license plate. House Bill 4004 does not ask for an allocation of funds — it will not cost the state any money. It will, however, allow individuals who see the benefit of *Early On* to purchase a plate and support the system. And it will provide awareness to the public about the availability of services through *Early On*.

My child, (*name*), has been involved in *Early On*. (*He or She*) was eligible for *Early On* because . . .  
The services have helped (*him/her*) by (*tell how*).

Federal funding for *Early On* Michigan has gone from over \$13 million to serve about 15,000 children and their families to a little over \$11 million to serve over 20,000 children and families. Please provide this opportunity for an additional revenue source so that young families with children in need may still benefit from these important supports and services. Please bring HB 4004 to a vote and vote YES!

Sincerely,

## Michigan Update from



Michigan Consumers  
for Healthcare

Written by: Brett Williams, Mid-Michigan Regional Coordinator, Michigan Consumers for Healthcare

The Michigan Legislature is focusing on two distinctly different, but equally important pieces of legislation.

**Medicaid Expansion for Families: House Bill 4714 (HB4714)** was introduced in the Michigan House of Representatives by Representative Matt Lori (R, St. Joseph-Cass) on May 9, 2013. This piece of legislation has opened the door for talks surrounding Medicaid expansion in Michigan to 133% of the Federal Poverty Level (FPL). Even though the door may be open, there are many conversations and changes that must be made before this legislation would be palatable. Michigan Consumers for Healthcare (MCH) fully supports the idea of changing Medicaid eligibility to 133% of the FPL, however, in a way that is consumer friendly and helps those who need it most.

Other aspects of the bill include:

- ◆ Under the proposed guidelines outlined in this legislation, it would limit eligibility for benefits to 48 total months. To express a scenario,  
*if someone were receiving benefits for 45 months and became seriously ill, they would only have 3 months of benefits available to them. From that point forward, they would be cut off.*
- ◆ There is a restriction on age. The bill as presented would limit benefits to those 21 and over to the age of 65. This leaves a great portion of Michigan population uncovered for their medical needs.

- ◆ There is also verbiage that would mandate “nondisabled” adults enrolled in Medicaid to make contributions of up to 5% of their annual income into their accounts based on the Michigan Department of Community Health’s (MDCH) determination of their ability to pay. Contributions could include, but are not limited to, deductibles, copayments, premiums, or other applicable charges, as determined by MDCH.

**Requirements for Navigators to Assist Families: Senate Bill 324 (SB324)** is focusing on establishing guidelines that would impact all Community Based Organizations (CBO’s) wishing to become Navigators in the newly to be formed Healthcare Marketplace set to begin enrollment October 1, 2013. This legislation would place very strict requirements that every potential Navigator must meet prior to certification as well as maintaining these certifications on an annual basis. Some items being discussed are mandates that require finger printing all perspective Navigators and conducting thorough criminal background checks at the expense of those who file, licensure guidelines that far exceed federal requirements, fees and cost that would make it prohibitive for many organizations to become navigators. On the positive side, Senator James Marleau (R-Oakland) who introduced this legislation is open to discuss revisions to SB324. MCH has been in contact with his office and look forward to productive talks ensuring that the people of Michigan have highly trained Marketplace Navigators at their disposal without placing undue barriers on those who wish to become Navigators.

## Michigan Partners for Freedom



**Michigan Partners for Freedom (MPF)** whose sole purpose is to build statewide demand for self-determination for citizens with disabilities, has released a new DVD **“Owning the Process: Individual Budgeting”** which highlights meaningful supports in the public mental health system. “Owning the Process: Individual Budgeting” The DVD connects the stories of five MPF Local Leaders who “own the process” and oversee the payment from tax dollars for the services they receive. MPF has created a **Viewing Guide** (pdf) to assist viewers to understand the concepts

presented and facilitate discussions using the viewing questions. Produced by Avalon Films, a full-service production company based in Royal Oak, Michigan, Owning the Process was made possible through a grant from the Michigan Developmental Disabilities Council to the Michigan Arc for MPF and is available for viewing at [www.mifreedom.org](http://www.mifreedom.org).

To arrange a presentation by a MPF Local Leader near you, contact:

**Jill Gerrie, Project Coordinator**

**The Arc Michigan**

**Direct Line: (517) 487-5426 • Toll Free: (800) 292-7851, extension 114 • Email: [jill.gerrie@arcmi.org](mailto:jill.gerrie@arcmi.org)**

# How Healthcare Reform Impacts YOU!

*A free Seminar on the changes healthcare reform will bring  
to you and your family.*

Please join us in one of these free educational presentations on  
Healthcare Reform in America.



The information is non-partisan and discusses what healthcare  
reform is, how it will impact your family and what is in it for YOU.

## **JUNE 14, 2013**

1 PM-3 PM

Jackson County Health  
Department

1715 Lansing Avenue, Suite 221  
Jackson, MI 49203

## **JUNE 25, 2013**

5 PM-8 PM

Distance Learning Room  
Midland County ESA

3917 Jefferson Ave.  
Midland, MI 48640

## **JULY 24, 2013**

5 PM-8 PM

Tuscola Technology Center  
1401 Cleaver Road  
Caro, MI 48723



PLEASE RSVP TO:

**Lisa Cook-Gordon**

[lisacookgordon@michiganfamilyvoices.org](mailto:lisacookgordon@michiganfamilyvoices.org)



## Workshops & Webinars



Michigan Alliance for Families' upcoming workshops can be viewed at:

[www.michiganallianceforfamilies.org/upcoming-events/](http://www.michiganallianceforfamilies.org/upcoming-events/)

Michigan Alliance for Families' archived Webinars are located at:

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

## Michigan Family Voices Trainings: Dates/Times/Locations

We are in the process of scheduling trainings for 2013-14 which will start in October 2013. Please stay tuned for a schedule to be released in August.

If you are interested in hosting a training or receiving a schedule please email:

[info@michiganfamilyvoices.org](mailto:info@michiganfamilyvoices.org)

## Welcome to the new Michigan Family Voices Website, Facebook and Twitter.



We have recently developed means of getting information to families of children and youth with disabilities and special needs through our new website [www.michiganfamilyvoices.org](http://www.michiganfamilyvoices.org) as well as Facebook and Twitter. Followers will receive daily updates on disability and health care topics and policies.



To become a follower on Face book visit

<https://www.facebook.com/pages/Michigan-Family-Voices/517493244973999?ref=ts>.

To become a Twitter follower, visit: <https://twitter.com> and type in **Michigan Family Voices**.

## Leaders in Policy Advocacy Leadership Training Opportunity!



Michigan Developmental Disabilities Council

Interested in taking your leadership and advocacy skills to a higher level?

The Arc Michigan is pleased to announce an intensive leadership training program for adults with developmental disabilities and parents of children with developmental disabilities. *Leaders in Policy Advocacy*, a grant project funded by the Michigan Developmental Disabilities Council and administered by the Arc Michigan, will support participants to become leaders in the movement for people with disabilities to claim full, productive lives in their communities. Participants will learn about disability history, inclusive education, assistive technology, self-determination, systems change, access to employment, housing and recreation and more!

*Leaders in Policy Advocacy* training requires a commitment to attend overnight sessions. There is no charge for the program, which will begin this July in the Lansing area. The training will eventually be offered across the state.

If you would like to apply to participate, or just want more information, please contact Salli Christenson at the Arc Michigan. She can be reached at (800) 292-7851, ext. 130 or [salli.c@arcmi.org](mailto:salli.c@arcmi.org).

**Download application (pdf) Share this message (pdf)**

