

SUPPORTED DECISION-MAKING

Jake Schaafsma, Certified Peer Mentor and Peer, Sexuality Educator

Mary Shehan, Michigan Developmental Disabilities Council

Stephanie Nicholls, Michigan Alliance for Families



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A Family Member's Experience

Overwhelmed! *That is the best term to describe how I felt for several years - especially after my son turned 16.*

- *From 16 on, families are continually asked “What are your plans once school is done?”*
- *Many families don't know or understand options. It isn't enough to hear about agency services just one time*
- *The systems are so different from the school and are confusing for many families*
- *Some of our friends are having a guardian appointed and some are not.*

“I need help!”

A Teacher's Experience

When a father came to our school, he was under the impression that he was the guardian of his adult son because his son had a disability. So, at that point when we asked him for guardianship papers. He said, “Well, what do you mean? I don’t know what those are?”

- *It’s not uncommon for families to think guardianship is automatic*
- *It’s not uncommon for families to be unaware that guardianship is a court process.*
- *Immediately families then ask how to get guardianship, putting school personnel in an awkward situation.*
- *Parents want a resource to contact and find out if they really want guardianship*

“I am a teacher - not a lawyer!”

A Person's Experience Under Guardianship

In 2001, at the age of 17, I was in a motor vehicle accident that caused me to slip into a 3-month coma.

- I sustained a serious coup-contra-coup traumatic brain injury, causing my left arm to become paralyzed and subsequently be amputated.
- I was a minor while in the hospital
- I was about to turn eighteen when ready to leave the hospital, and the hospital promoted guardianship to my parents.
- Given my father's experience as a Community Mental Health worker, my family went a different route.
- I was able give input, about my life at this point. We as a family chose to get a representative payee and a Medical Power of Attorney instead.
- I returned to high school to graduate with my class and went on to obtain my bachelor's degree in Organizational Leadership in Mental Health and Human Services from Grand Valley State University.
- Many of the things I have in my life now could not have happened under guardianship.



Supported Decision-Making Video Resource

Tash Connection, 2017

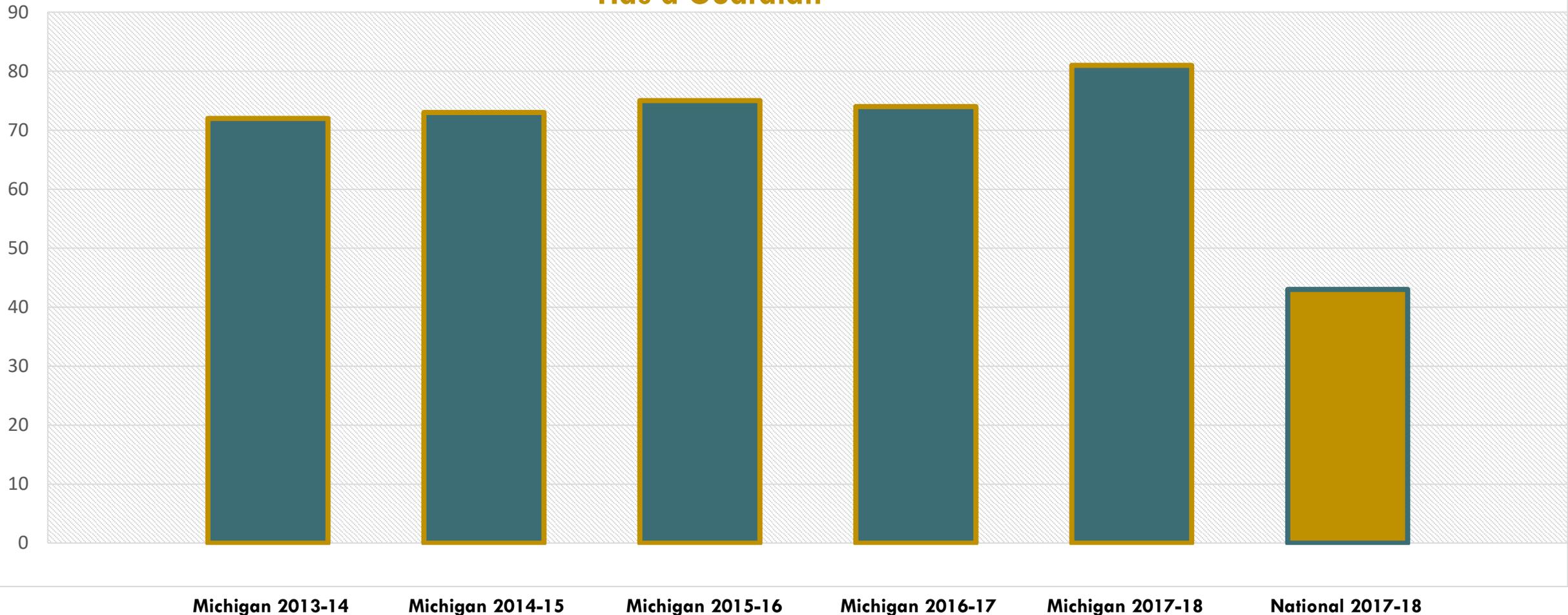
“We all make decisions-big and small-every day. We may take for granted that we have the right to exercise such autonomy over our lives and that we often have a network of trusted friends and allies with whom we consult to make the important decisions that affect our lives. This is not always the case for people with disabilities.”

For far too long in Michigan, few options other than guardianship have been offered

Demographic Characteristics of Adults with I/DD (%) National Core Indicators

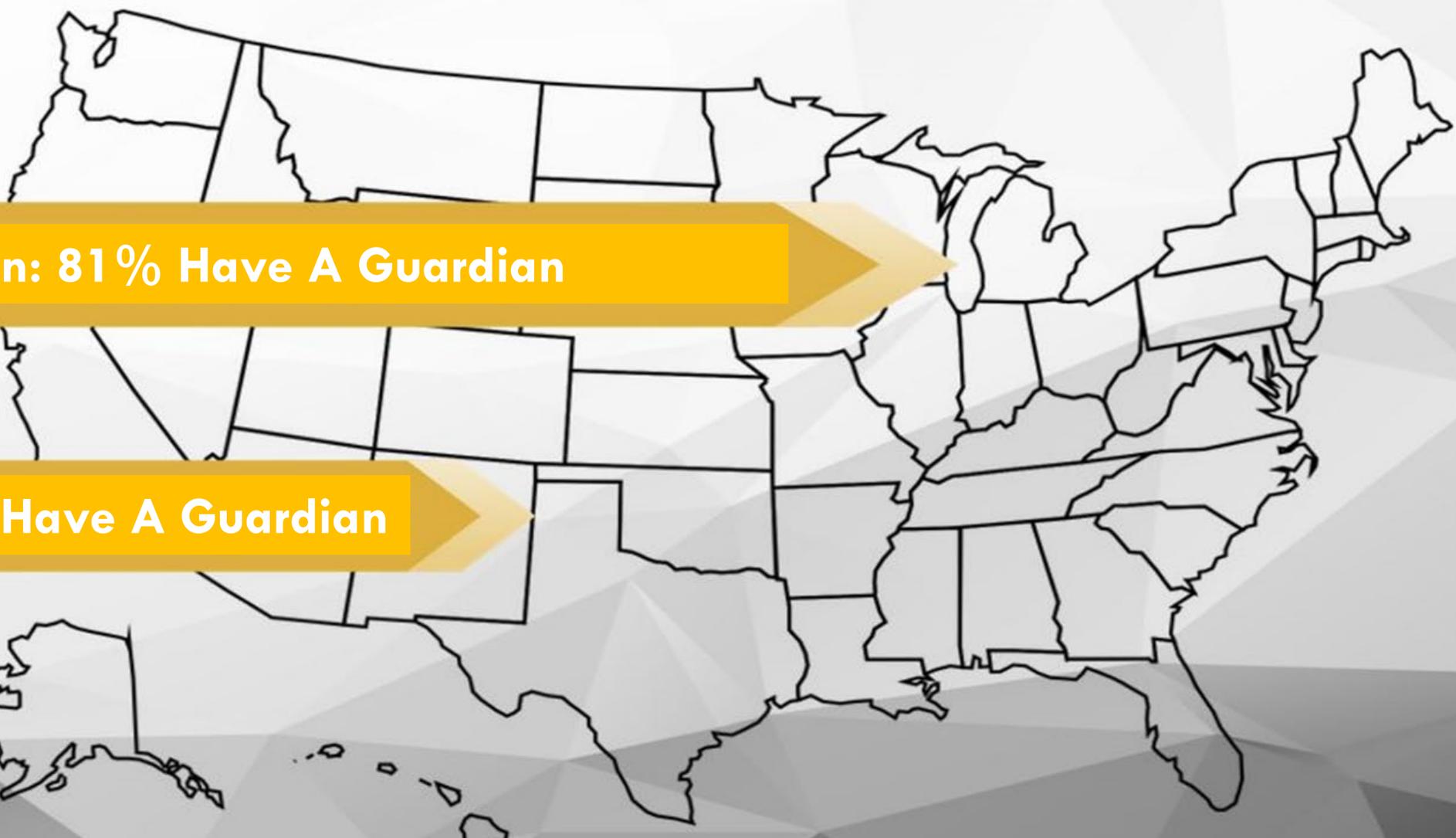


Has a Guardian

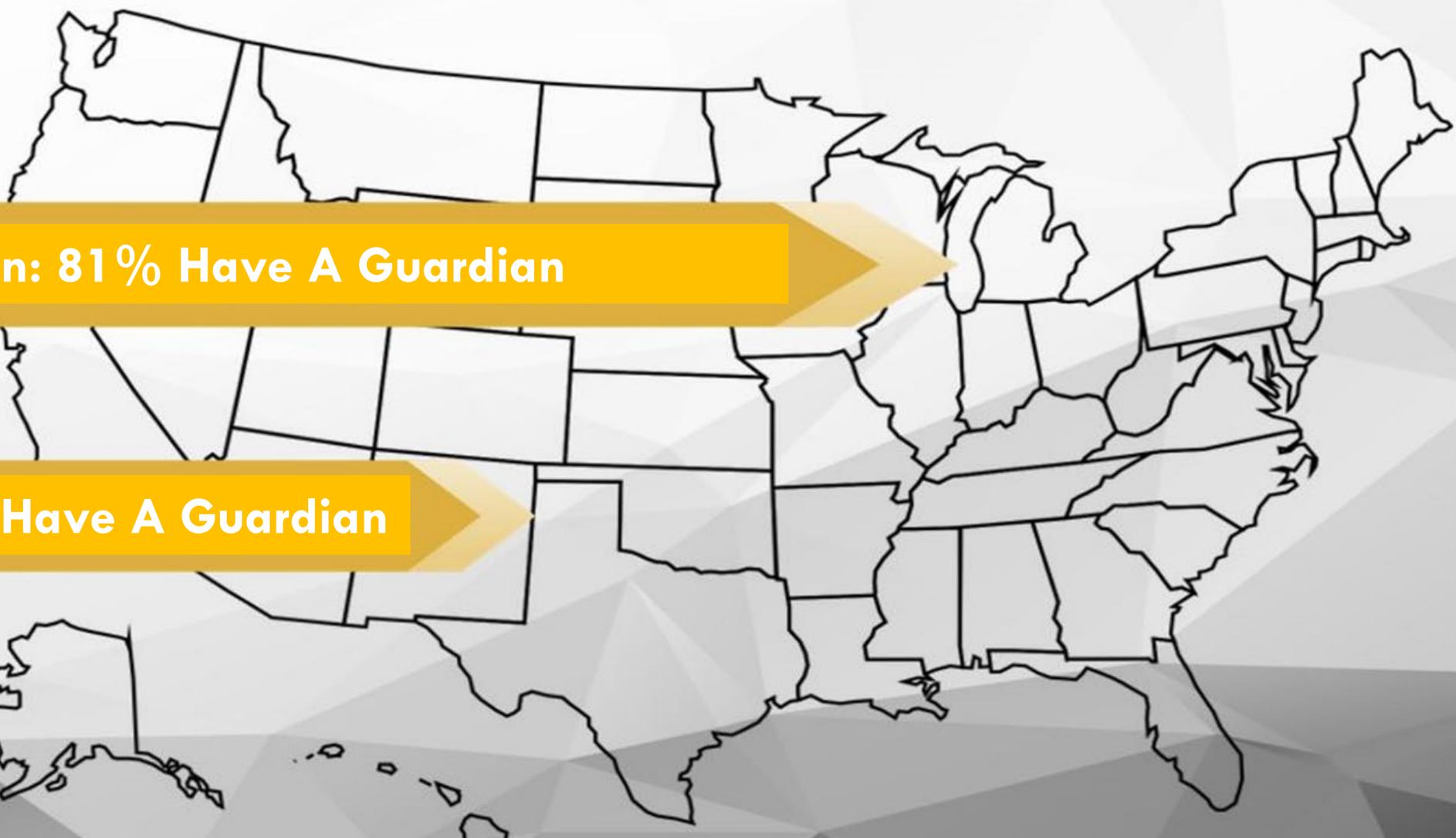


National Core Indicators (2017-2018)

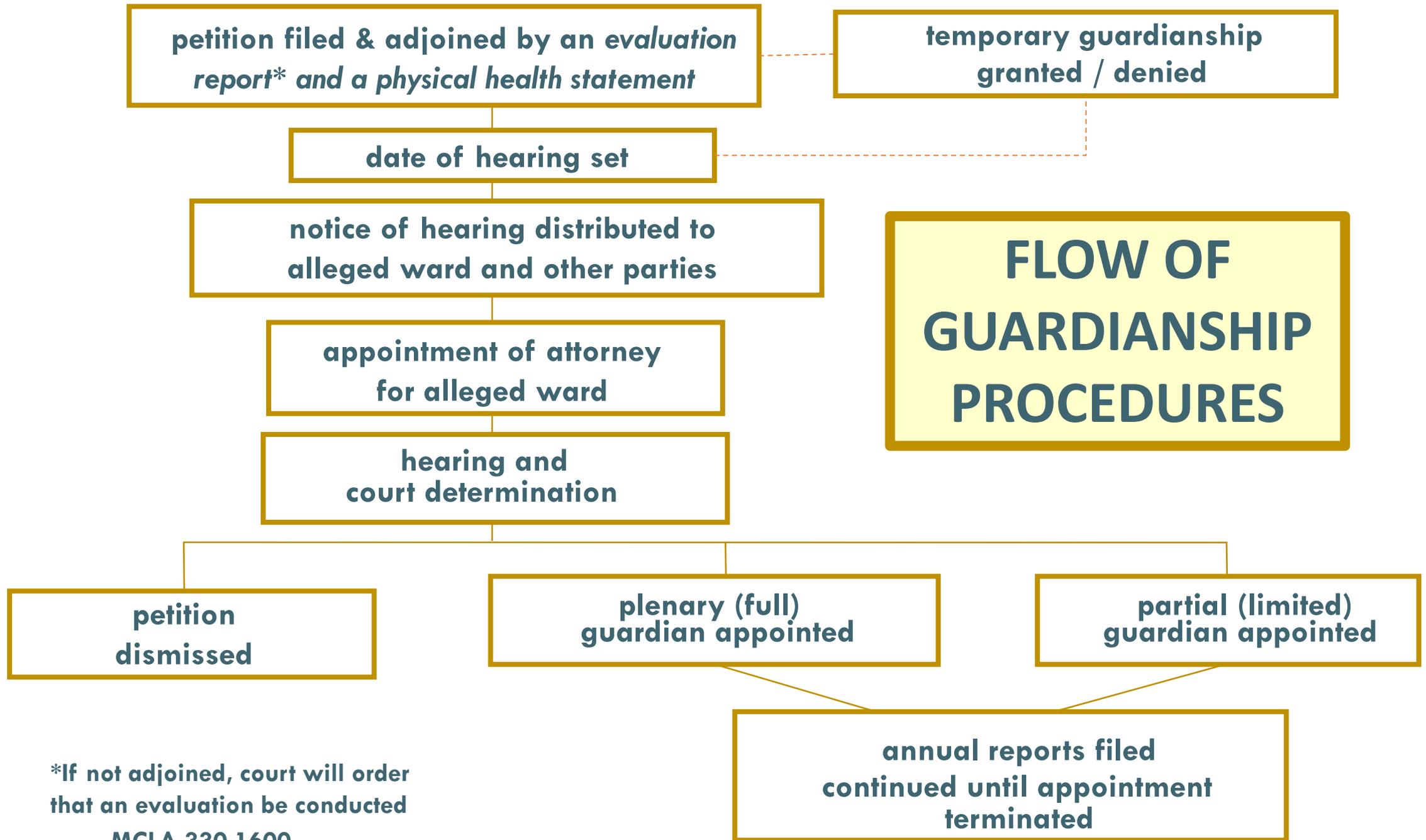
Adults with developmental disabilities served:



Michigan: 81% Have A Guardian



Nationally: 43% Have A Guardian



FLOW OF GUARDIANSHIP PROCEDURES

*If not adjoined, court will order that an evaluation be conducted
MCLA 330.1600

Types of Guardianships

Types of Guardianship

- **Guardianship of the person**
- **Guardianship of the estate**
- **Conservatorship**

Scope of Guardianship

- **Plenary (full or total)**
- **Partial (limited)**
- **Combination of plenary and limited**

How Do You Feel When Your Rights Are In Jeopardy

- Deciding where to live
- Consenting to or preventing any medical and health care or treatment
- Determining when and how to travel
- How you spend your money
- Making changes in educational or vocational programs
- Determining if and with whom you can date
- What personal property you can own
- If and where, you worship

National Guardianship Association/2015

“Supported decision-making should be considered before guardianship, and the supported decision-making process should be incorporated as a part of the guardianship if guardianship is necessary.”

What is Supported Decision-Making anyway?

We all need supporters, helpers and consultants in our lives in order to make good decisions, whether we have a disability or not.

Supported Decision-Making

- ***Substituted* decision-making = guardianship, which limits rights, choices and freedom**
- ***Supported* decision-making = a process that enables people with disabilities to retain and exercise their rights and make and communicate choices in regard to personal and legal matters**

Getting Started with Supported Decision-Making

Step 1) Start the conversation

Step 2) Identifying who is willing and able to assist

Step 3) Plan and communicate

Step 4) Set up agreement

Step 5) Let everyone know

What are the main concerns people express?

Concerns involving:

- **Education**
- **Safety**
- **Medical Decisions**
- **Finances**
- **Communication**
- **Sexuality**
- **Legal**

Circles of Support

Made up of family and friends, and can also include teachers, employers, caregivers, co-workers, community members and organizations and sometimes, paid staff.

How do people in our circles help us succeed in life?

Person-Centered Planning

Person-centered planning is a way for people with I/DD to plan their lives. It builds on their strengths and honors their choices, preferences and abilities.

It's required by state and federal law, for people who receive behavioral health care services.

(42 CFR 441.700 et. seq.)

Assistive Technology (AT)

AT can make decision-making easier and help people live more interdependently in their communities.

A few examples:

- **Medication management devices**
- **GPS technology**
- **Virtual assistants, like Alexa**
- **Remote monitoring and control of environment**

Release of Information Forms

When signed by an adult with a disability, ROI forms authorize parents (and other allies) access to student records, medical information and legal proceedings. This helps to ensure quality and continuity of services and care and enhances the supported decision-making process.

Power of Attorney

Power of Attorney is a legal document that can be used to give another person the authority to make financial transactions, enter into contracts, make legal decisions and sign legal documents on your behalf.

Medical Power of Attorney

A medical power of attorney is a legal document in which you appoint an agent to make health care decisions on your behalf when you cannot make them for yourself.

Representative Payees

A representative payee is a person, agency, organization or institution the Social Security Administration selects to manage your benefits when it determines that you are unable to do so yourself or direct others to do it for you.

Other Financial Supports

- **Joint accounts**
- **Bill-paying services**
- **Automatic payment withdrawals**
- **Fiscal intermediaries**

Trusts and Other Savings Accounts

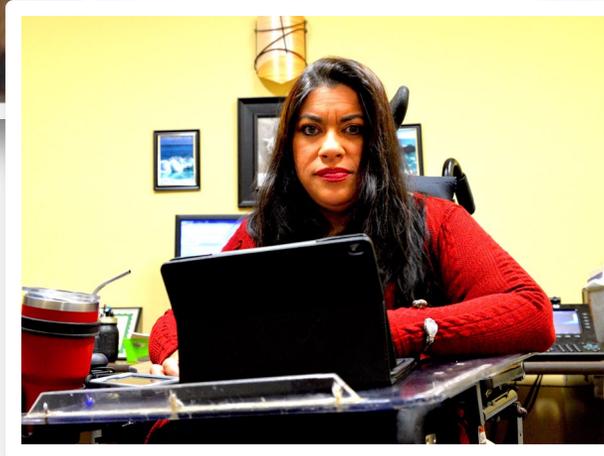
- **Special Needs Trusts**
 - Individual
 - Pooled
- **ABLE Accounts**



Self-Determination

Self-determination means making your own choices, learning to solve problems, and taking control and responsibility for your own life. People who are self-determined make things happen in their own lives. They know what they want and how to get it. They choose and set goals, then work to reach them. They advocate on their own behalf and are involved in solving problems and making decisions about their lives.

What tools fit the topic of Decision-Making?



When Using a tool is new to you, doing one about your own life is helpful.

Here's an example of how Jake took this LifeCourse tool and completed it about his own life.



Integrated Support Stars can be used for many purposes

Here's an example of how
you can work through a
problem with it in a Peer
and mentee situation.



Schedules can be used to address many situations

Here's an example of how Jake took a person's star and developed a schedule with it.



INTEGRATED RESPITE SCHEDULE

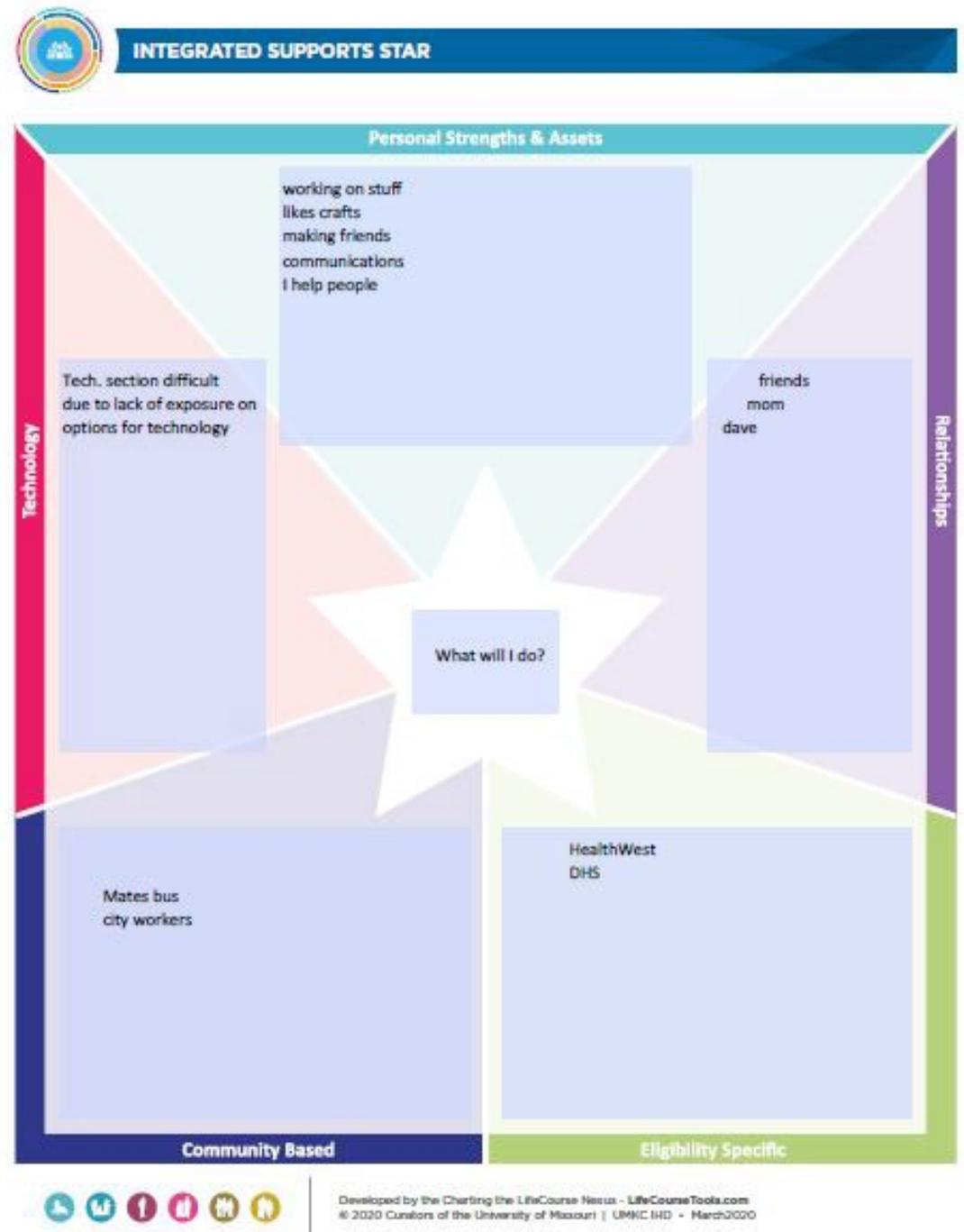
TIME	MON	TUES	WED	THURS	FRI	SAT	SUN
6:00-6:30 AM							
6:30-7:00 AM							
7:00-7:30 AM	✓ Wake up			✓ Wake up	✓ Wake up	✓ Wake up	
7:30-8:00 AM	✓ Shower		✓ Shower	✓ Shower	✓ Shower	✓ Shower	
8:00-8:30 AM	✓ feed the dog		✓ feed the dog	✓ feed the dog	✓ feed the dog	✓ feed the dog	
8:30-9:00 AM	✓ breakfast		✓ breakfast	✓ breakfast	✓ breakfast	✓ breakfast	
9:00-9:30 AM	✓ Check in			✓ Check in	✓ Check in		
9:30-10:00 AM	✓ Chores	✓ Chores	✓ Chores	✓ Chores	✓ Chores	✓ Chores	
10:00-10:30 AM							
10:30-11:00 AM							
11:00-11:30 AM							Help with dishes
11:30-12:00 PM							
12:00-12:30 PM							
12:30-1:00 PM							
1:00-1:30 PM							
1:30-2:00 PM			Help with/ garbage/Recycle				
2:00-2:30 PM	Set table help with it				laundry (1 & 3 sheets)	vacuum	
2:30-3:00 PM			Sweep kitchen entry way				
3:00-3:30 PM		vacuum					
3:30-4:00 PM	Help with dinner				Help with dinner		
4:00-4:30 PM				Vaccum			
4:30-5:00 PM	Dishes	Help with dinner		Dishes	Clean downstairs bathroom		
5:00-5:30 PM							
5:30-6:00 PM							
6:00-6:30 PM						Sweep hall + Downstairs	
6:30-7:00 PM							
7:00-7:30 PM						Clean + Vac Room	
7:30-8:00 PM							
8:00-8:30 PM							
8:30-9:00 PM							
9:00-9:30 PM							
9:30-10:00 PM							
10:00-6:00 AM							



Developed by the Charting the LifeCourse Nexus - LifeCourseTools.com
 In partnership with Arch National Respite Network and Resource Center
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Integrated Support Stars can be used for many purposes

Here's an example of how one person used the integrated star to help focus on problem solving.



Supported Decision-Making Tools

Homework

Go to the Lifecourse Website

Review: Tools for Exploring Decision-Making Supports

www.lifecoursetools.com

www.michigan.gov/ddcouncil

CHARTING the LifeCourse



LifeCourse Integrated STAR: Supported Decision-Making

When a person turns 18, they are presumed competent to make decisions about their life. Sometimes, a person might need help making decisions and staying safe. This star shows some of the ways people can be supported to be safe and secure while living an inclusive community life.



Access the LifeCourse framework and tools at lifecoursetools.com

Developed by the UMKC Institute for Human Development, UCEDD. More tools and materials at lifecoursetools.com.

SEPTEMBER 2016

CHARTING the LifeCourse

Tool for Exploring Decision Making Supports

This tool was designed to assist individuals and supporters with exploring decision making support needs for each life domain.

Name of Individual: _____
 Name of person completing this form: _____
 Relationship to individual (circle one): Self Family Friend Guardian Other: _____
 How long have you known the individual? _____

For each question below, mark the level of support you need when making and communicating decisions and choices in the Charting the LifeCourse life domains.

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DAILY LIFE & EMPLOYMENT			
Can I decide if or where I want to work?			
Can I look for and find a job (read ads, apply, use personal contacts)?			
Do I plan what my day will look like?			
Do I decide if I want to learn something new and how to best go about that?			
Can I make big decisions about money? (open bank account, make big purchases)			
Do I make everyday purchases? (food, personal items, recreation)			
Do I pay my bills on time (rent, cell, electric, internet)			
Do I keep a budget so I know how much money I have to spend?			
Am I able to manage the eligibility benefits I receive?			
Do I make sure no one is taking my money or using it for themselves?			
HEALTHY LIVING			
Do I choose when to go to the doctor or dentist?			
Do I decide/direct what doctors, medical/health clinics, hospitals, specialists or other health care providers I use?			
Can I make health/medical choices for my day-to-day well-being? (check-ups, routine screening, working out, vitamins)			
Can I make medical choices in serious situations? (surgery, big injury)			
Can I make medical choices in an emergency?			
Can I take medications as directed or follow a prescribed diet?			
Do I know the reasons why I take my medication?			
Do I understand the consequences if I refuse medical treatment?			
Can I alert others and seek medical help for serious health problems?			
Do I make choices about birth control or pregnancy?			
Do I make choices about drugs or alcohol?			
Do I understand health consequences associated with choosing high risk behaviors (substance abuse, overeating, high-risk sexual activities, etc.)?			
Do I decide where, when, and what to eat?			
Do I understand the need for personal hygiene and dental care?			

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What Does the Law Say About Guardianships...

Shall be utilized only as necessary to promote and protect the well-being of the individual...

And shall be designed to encourage the development of maximum self-reliance and autonomy in the individual.

MCLA, Chapter 6



EXPLORING OPTIONS FOR DECISION-MAKING ASSISTANCE

LEAST RESTRICTIVE

Making Own Decisions

Person-Centered Planning

Banking Services

Supported Decision-Making
Arrangements

Representative Payee

Power of Attorney

Advanced Directives

Guardianship

MOST RESTRICTIVE



Individuals with Disabilities Education Act (IDEA)

§300.320(b) Transition services. Beginning not later than the first IEP to be in effect when the child turns 16, or younger if determined appropriate by the IEP Team, and updated annually, thereafter, the IEP must include—

- Appropriate measurable postsecondary goals based upon age appropriate, transition assessments related to training, education, employment, and, where appropriate, independent living skills; and
- (2) The transition services (including courses of study) needed to assist the child in reaching those goals.

Meaningful Connections

Clear and meaningful connections must be established between what the student is learning in high school and what he or she will be doing after leaving high school.

- **Postsecondary goals are outcomes. They are age-appropriate and measurable.**
- **Align annual goals with adult outcomes (postsecondary goals)**
- **Transition Services are activities. They assist the student in reaching the goal.**

IEP Goals

Post-Secondary Goal: After graduation from high school, Leo will live with roommates of his choosing and pay his bills with money from integrated employment in the community working with animals.

Focus of Annual Goal: Independently requesting assistance to complete a task or problem solve a situation in the expected manner for the environment

The Wrap-up

- **Being a strong advocate, be involved in your own life, communicate what you want and don't want**
- **Plan using tools that work for the person (Be Person Centered)**
- **Explore the supports that the person will need to continue to be in charge, of their own life**
- **Tie back into the ALL**
- **Don't freeze people in time**
- **How Peer Mentors could be involved**

Resources

- **SSA Resources**

<https://www.ssa.gov/benefits/disability/>

<https://www.ssa.gov/redbook/>

<https://www.ssa.gov/payee/>

- **Work Incentives Planning and Assistance**

<https://miwipa.org>

- **MiABLE**

miable.org

- **State Bar of Michigan**

<https://www.zeekbeek.com/SBM>

- **The Arc US**

https://thearc.org/find-resources/?search_resource=&audience=searchAudience&type=searchtype&topic=family-support-and-future-planning



Resources

- **Michigan Alliance for Families**
<https://www.michiganallianceforfamilies.org/transition/>
- **Michigan Developmental Disabilities Council**
<http://www.Michigan.gov/ddcouncil>
- **Special Needs Trust Information**
<https://www.nolo.com/legal-encyclopedia/special-needs-trusts-30315.html>
- **Joint Banking Information**
<https://finance.zacks.com/put-restrictions-joint-bank-account-11439.html>
- **Power of Attorney Information**
<https://michiganlegalhelp.org/>
- **WIPA Projects (See Handout)**

Contact Information

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Questions

**Thank you for your time and
attention!**

What questions do you have?



We are here to support you!

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 /MichiganAlliance

For more information visit:

<https://www.michiganallianceforfamilies.org>

Call: 800-552-4821

En Español 313-217-1060

Statewide Email: info@michiganallianceforfamilies.org



Michigan Alliance for Families

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