

SUPPORTED DECISION-MAKING



Kaiden Tolbert-CYVYC Supported Decision-Making Youth Ambassador

Mary Shehan-Community Inclusion Coordinator, Michigan Developmental Disabilities Council

ADULT LEADERS

PROGRAMS

Outcomes for Today

- **A brief explanation of the differences between SD-M and Guardianship**
- **A beginning look at tools to address decision-making concerns**
- **See 'real life' examples on how to use the tools to support the life each young adult wants**
- **See where this information like this can show up on an IEP**

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!”

My Experience With Guardianship

- **My first exposure to thinking about guardianship was when I applied to be a Youth Ambassador**
- **I had never spoken to my family about it before that**
- **Now as an adult, I have lots of decisions to make just like everyone when they turn eighteen**
- **Just because I make decision, doesn't mean I don't get support. I can ask the people I trust for help**
- **I applied to be a Youth Ambassador because I really enjoy helping people with disabilities like me**



My Experience With Guardianship

- I now, live with my parents, but am making decisions about where to live in the future
- I plan to live with a roommate during college
- I am planning to get my own house someday
- After I finish College, I want to teach



My Experience With Guardianship

- I like to spend the money I earn from summer work at a market on things important to me
- I dream about getting a drivers license and buying a car
- I enjoy helping other in many ways like being a summer camp counselor
- I hope to do a speech again at my college graduation



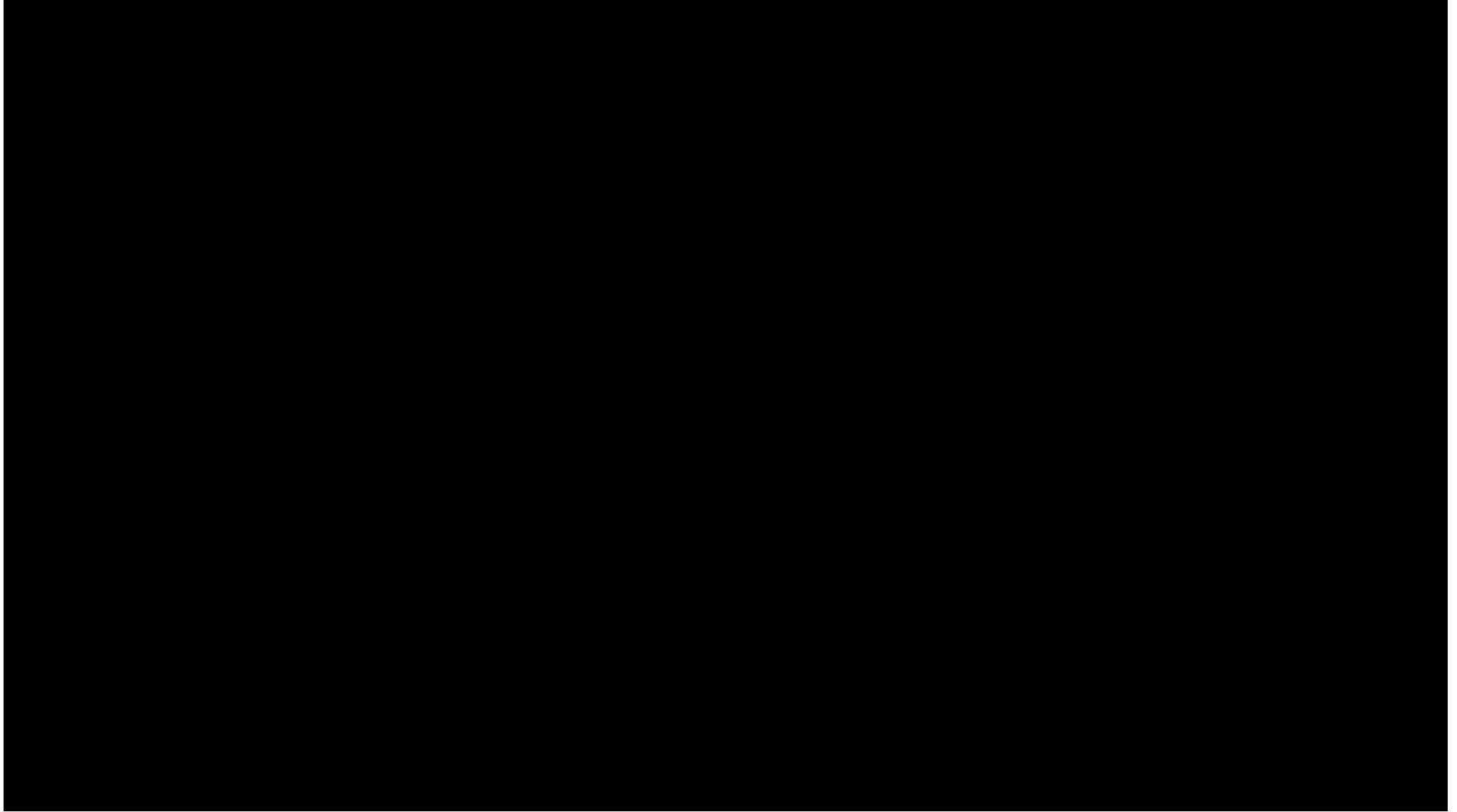
Tash Connection, 2017

“We all make decisions-big and small-every day. We may take for granted that we have the right to exercise such power 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.”

National Guardianship Association/2015

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

Video



What Does the Law Say About Guardianships...

Shall be used 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



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.**

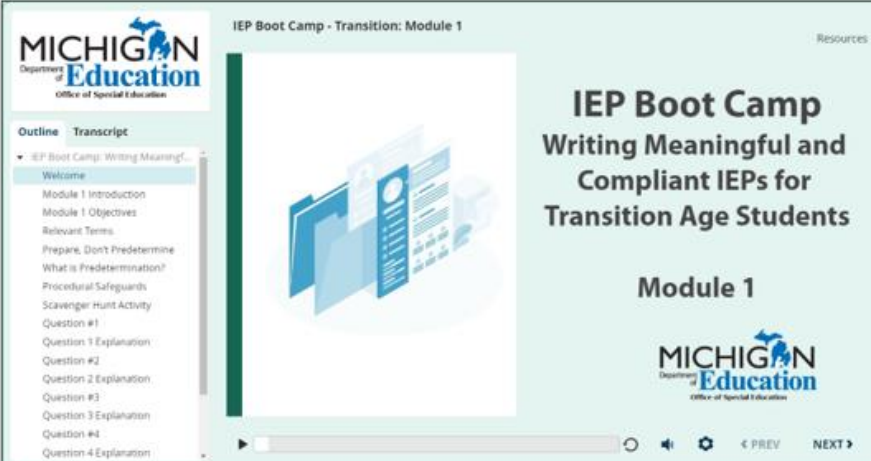
Individuals with Disabilities Education Act (IDEA)

§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.**

Office of Special Education Training

- **The student is presumed to be competent to act on their own behalf**
- **The district is presumed to have been, and is continuing to, educate the student to live a self-determined life**
- **School personnel should NOT try to persuade the parents to obtain legal guardianship over the student**



The screenshot displays a training module interface for "IEP Boot Camp - Transition: Module 1". The interface includes a navigation sidebar on the left with a table of contents, a central content area with a graphic of documents, and a right-hand panel with the module title and Michigan Department of Education logo. The sidebar lists the following items:

Outline	Transcript
IEP Boot Camp: Writing Meaningful...	
Welcome	
Module 1 Introduction	
Module 1 Objectives	
Relevant Terms	
Prepare, Don't Predetermine	
What is Predetermination?	
Procedural Safeguards	
Scavenger Hunt Activity	
Question #1	
Question 1 Explanation	
Question #2	
Question 2 Explanation	
Question #3	
Question 3 Explanation	
Question #4	
Question 4 Explanation	

The main content area features the title "IEP Boot Camp Writing Meaningful and Compliant IEPs for Transition Age Students" and "Module 1" below it. The Michigan Department of Education logo is at the bottom. The right-hand panel includes a "Resources" link and a "PREV NEXT" navigation bar.

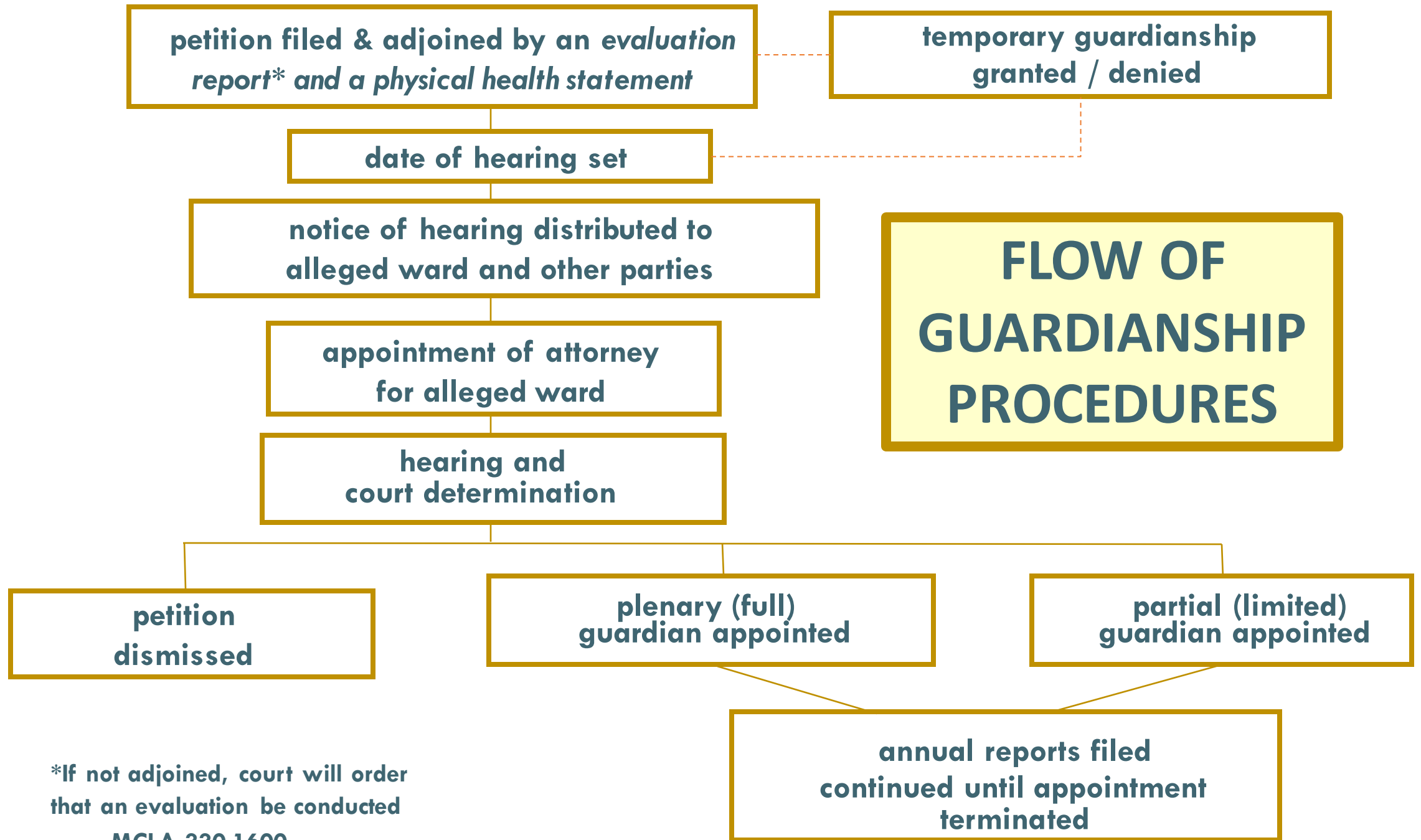
Types of Guardianships

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**



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

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 whom you can date
- What personal property you can own
- If and where, you worship

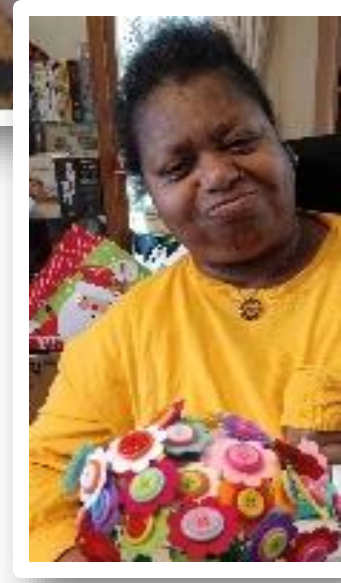
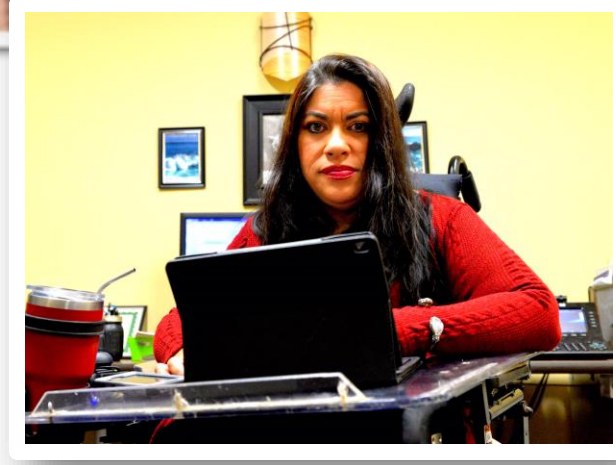
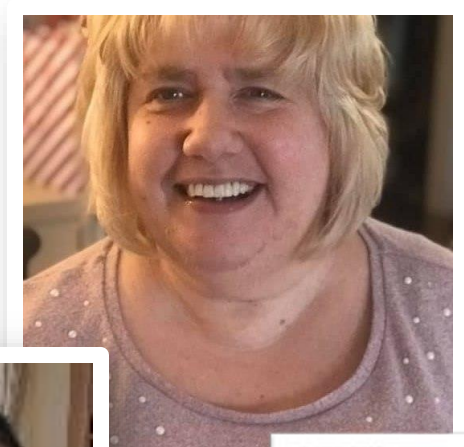
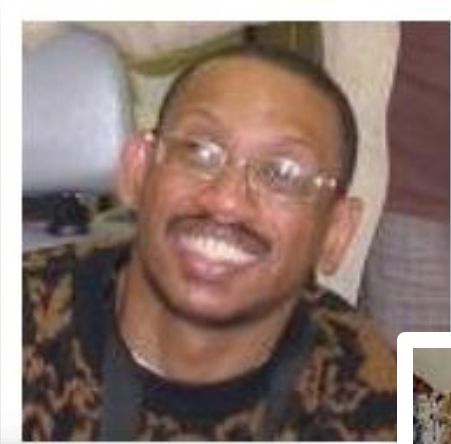
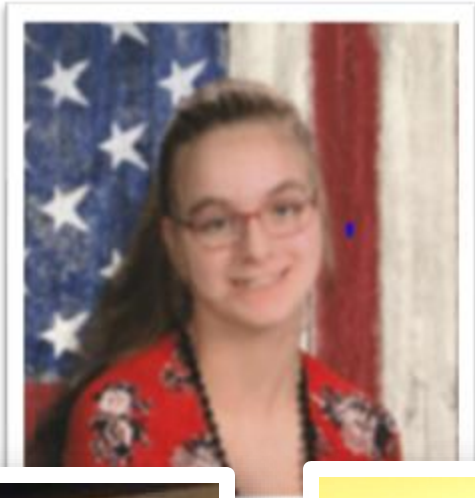
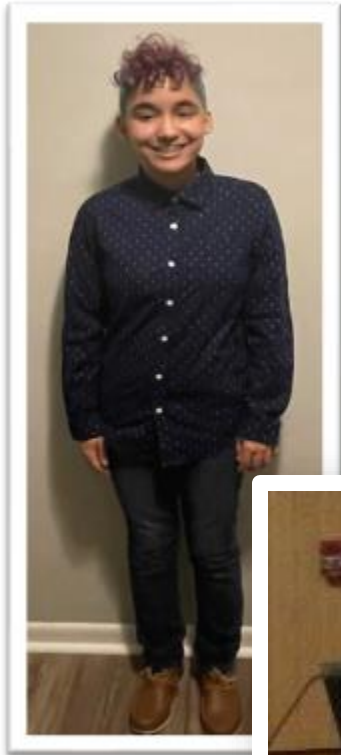
What is Supported Decision-Making anyway?

We all need supporters, helpers and people to talk to about 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**

Remember, Supported Decision Making Is Used by ALL People



Getting Started with Supported Decision-Making

Step 1) Start the conversation

Step 2) Identifying who is willing and able to assist

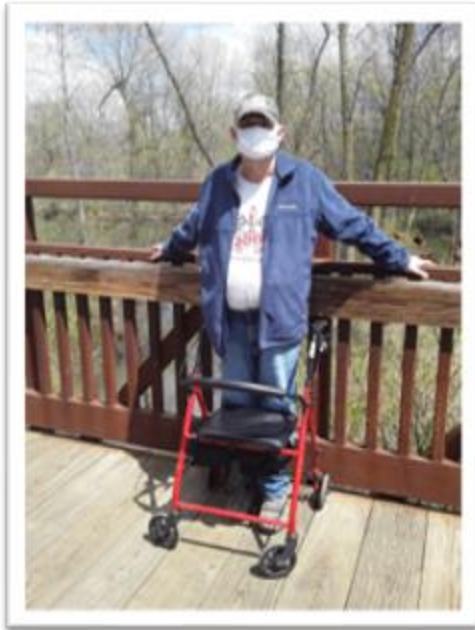
Step 3) Plan and communicate

Step 4) Set up agreement

Step 5) Let everyone know

Tools to Start the SD-M Conversation

Work you can do
on your own



KEVIN **Life Trajectory Worksheet**

<p style="text-align: center;"><u>Past Life Experiences</u> LIST past life experiences and events that supported your vision for a good life.</p> <p>Inclusive education Manager of sports teams Special Olympics Church sports teams Men's group Adopting the Shehan's Holidays with Shehan's Payees that listen Vacations with Shehan's Lived in community Worked in the community Worked at Peckham Trips with Rainbow Homes Preplanning for PCP's Makes friends easily</p>	<p style="text-align: center;"><u>Future Life Experiences</u> LIST current/ future life experiences that continue supporting your good life vision.</p> <p>Covid Vaccine Rides to church Walking weekly (PT) Planning trip to see Ty Being in Ty's wedding Family Payee (Tom B.) Dinners at Mary's Holidays at Patty's ABLE Account</p>
<p style="text-align: center;"><u>What I DON'T Want</u> LIST the things you don't want in your life...</p> <p>don't want roommates changing all the time don't want to be in pain don't want to get the COVID don't want to be alone don't want to be without family don't want to be treated like a baby</p>	<p style="text-align: center;"><u>VISION for a GOOD LIFE</u> LIST what you want your "good life" to look like ...</p> <p>I want to go back to work I want to go to church I want to be healthy I want to see Ty I want to have friends I want to do sports I want to watch sports I want to drink fizzy drinks I want to do "guy," things. (outdoor things, like camping, fishing, hunting) I want money in my pocket I want my bills paid I want to go on trips I want to say goodbye to people before they die. I want to eat football food. (nachos, real beer or, rootbeer in a brown bottle," guy," snacks) I want to walk every week I want to live in my own apartment again. (in the community, with a friend) I want big holidays. (overnights with family) I want people to let me make my own decisions I want people to explain my options</p>

Write current age here: **60**

Tools to Start the SDM Conversation

Work you can do
on your own



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.

	I can decide with no extra support	I need support with my decision	I need someone to decide for me
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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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: AMIE KUPOVITS
 Name of person completing this form: AMIE KUPOVITS
 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.

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

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Tools to Start the SDM Conversation

Work you can do
on your own

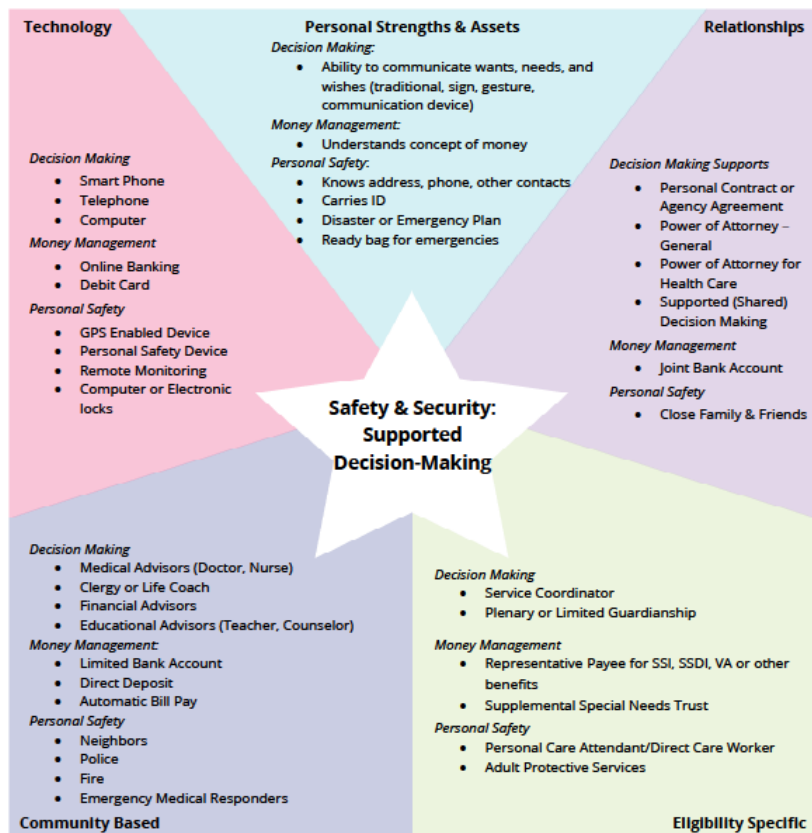


CHARTING the LifeCourse



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.



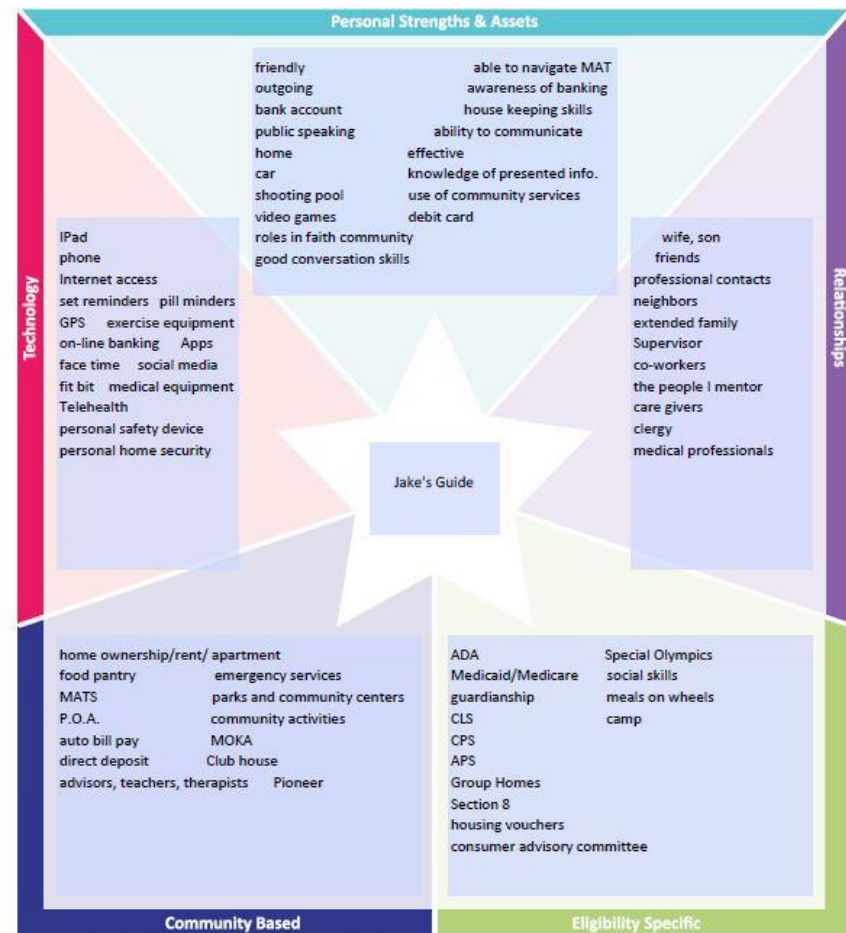
Access the LifeCourse framework and tools at lifecoursetools.com

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

SEPTEMBER 2016



INTEGRATED SUPPORTS STAR



Developed by the Charting the LifeCourse Nexus - LifeCourseTools.com
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What are the main concerns people express?

Concerns involving:

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

When the Main Concerns are Educational Decisions

- Like ALL people, it is likely that young people with disabilities will at some point want to leave their parents household
- Like ALL young adults, youth with disabilities are learning to weigh options and make choices that lead them to the adult life they want
- Like ALL young adults, youth with disabilities need time to take on successively more responsibilities in steps

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.

When the Main Concern are Safety Decisions

- Like ALL people, it is likely that young people with disabilities will at some point take risks, there is a certain dignity that comes with that.
- Like ALL young adults, youth with disabilities are learning to weigh options about levels of risk.
- Like ALL young adults, youth with disabilities need time to experience low risks, while family is still around to support and can help put in place future needs.

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**

When the Main Concern are Medical Decisions

- Like ALL people, it is likely that young people with disabilities will experience the need for medical care at some point in their lives.
- Like ALL young adults, youth with disabilities should learn to seek accurate information and weigh options
- Like ALL young adults, youth with disabilities need time to take on successively more responsibilities and when needed, have support to make these decisions

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.

Patient Advocates

A patient advocate is the name given to a health care power of attorney in Michigan. Other names include health care power of attorney, health care proxy and durable power of attorney for health care.

Advanced Directives

A Michigan advance directive is a document that lets a person select their end-of-life treatment options in the chance they cannot speak for themselves. This includes an agent that can be nominated to make health care decisions on the person's behalf in addition to treatment options and organ donation selections.

When the Main Concern are Financial Decisions

- Like ALL people, it is likely that young people with disabilities will at some point have income, either through public benefits or employment.
- Like ALL young adults, youth with disabilities should seek good information, weigh options and make decision about their money.
- Like ALL young adults, youth with disabilities need time to learn and when needed, have support to make these decisions

Other Financial Supports

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

Representative Payees

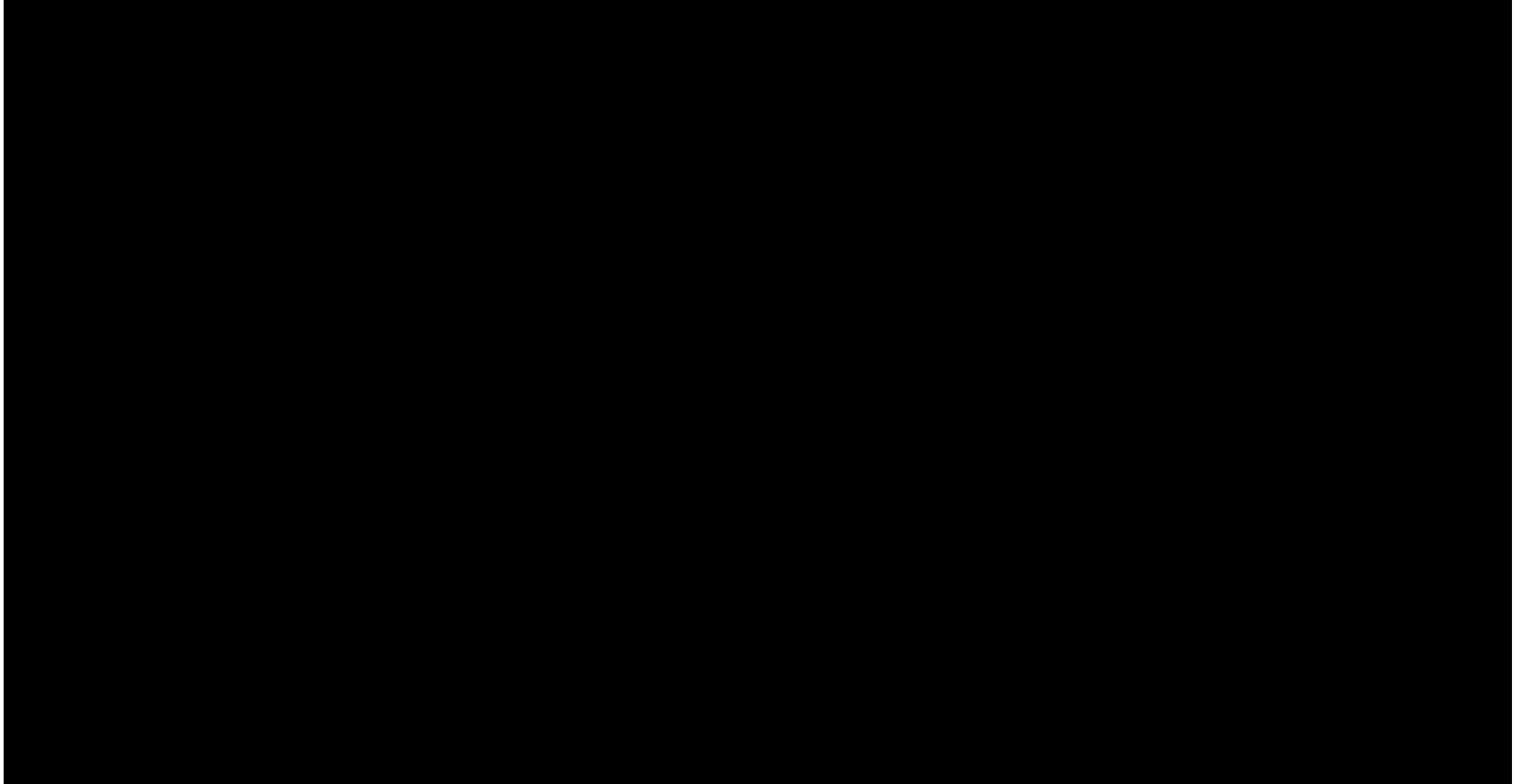
A representative payee is a person, agency, organization or institution the Social Security Administration selects to manage your benefits when it determines that you are unable to do so yourself or direct others to do it for you.

Trusts and Other Savings Accounts

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



The Intersection of Employment and Public Benefits



When the Main Concern is Their Ability to Communicate

- Like ALL people, young people with disabilities will communicate, though that may be in ways different than their peers.
- Like ALL young adults, youth with disabilities should learn to communicate with others
- Families need to assure that everyone involved in their loved one's life, understand their communication style.

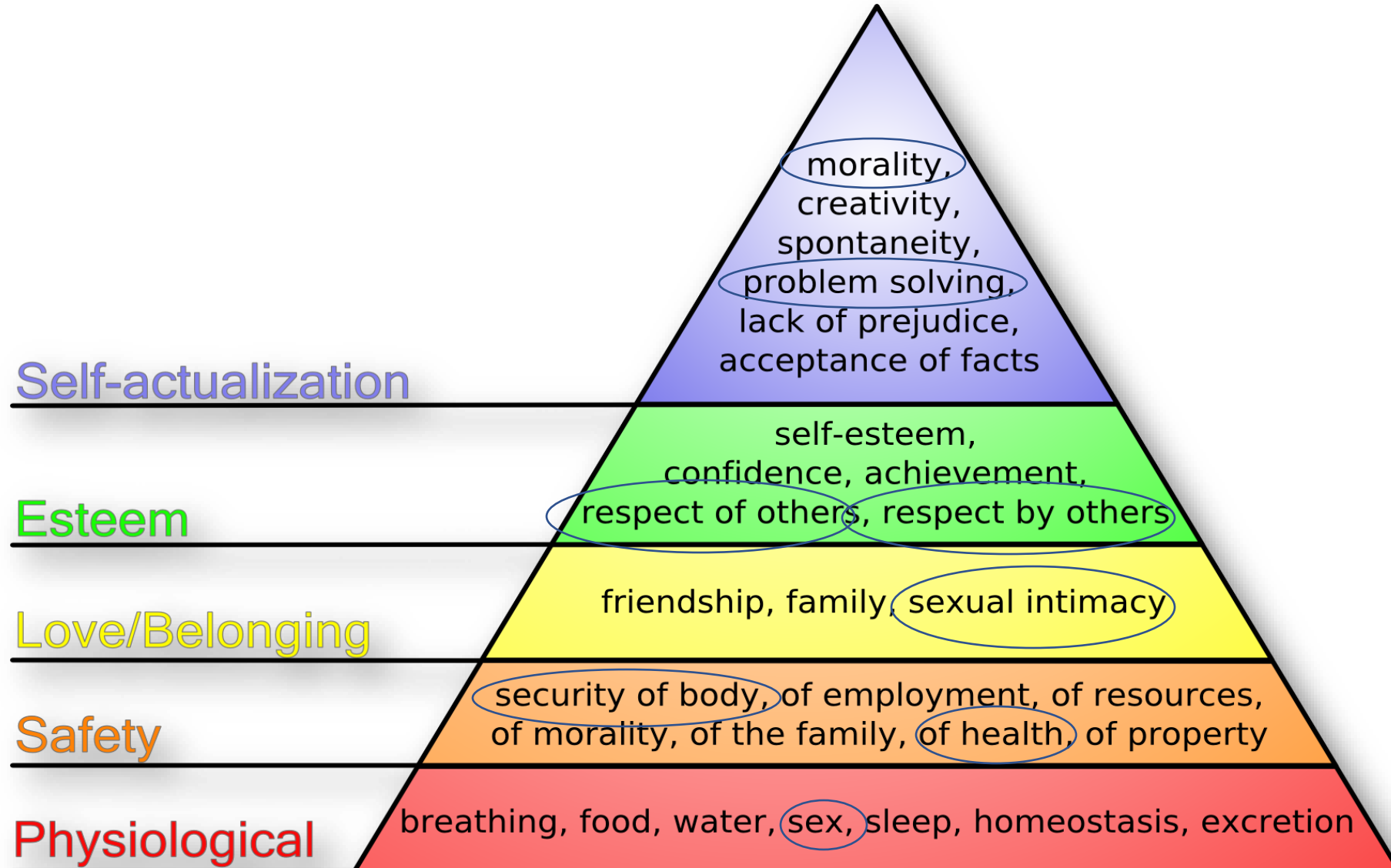
Types of Communication

There are many different ways we share information with one another. For example, you might use verbal communication when sharing a presentation with a group. You might use written communication when applying for a job or sending an email. You may also use non-verbal communication to get a point across

When the Main Concern is Relationship

- **ALL people, are sexual human beings.**
- **It is even more important for youth with disabilities to learn about sexuality because they are abused at much higher rates.**
- **There are many resources available to support families in explaining hard concepts, like consent to youth with disabilities.**

We are all human beings, so we are all sexual beings



Alarming Statistics

People with intellectual disabilities are sexually assaulted at a rate more than seven times higher than people without disabilities

(Department of Justice as cited by NPR 2018)

Alarming Statistics

70%

of people **without a learning disability** live with a partner / are in a relationship



3%

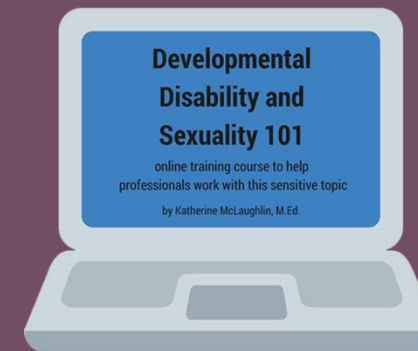
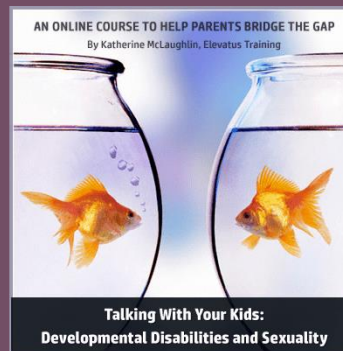
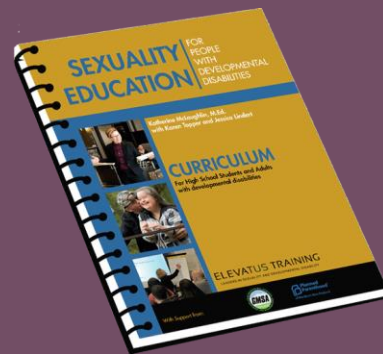
of people **with a learning disability** live with a partner / are in a relationship



Elevatus Products and Workshops

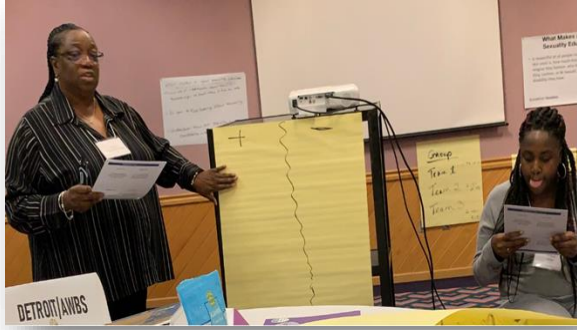
Becoming a Sexuality Educator

- 3-day Training
- Online workshops and trainings
- Trauma informed
- Evidences based
- Co-lead by Peer Educators



For more information visit: www.elevatustraining.com

Comprehensive Curriculum



1. Getting Started
2. Gender Identity and Gender Expression
3. Different types of Relationships
4. Public and Private
5. Friendship
6. Communication
7. Decision-Making
8. Moving from Friend to Relationship
9. Internet, Social Media and Communications
10. Many roads to Relationships
11. Being in a Relationship
12. Has Your Relationship Gone Bad?
13. Body Parts
14. Caring for Your Body
15. Sexual feelings, Attraction and Acts
16. Communicating About Sex
17. Decision-Making About Sex
18. Challenges or Things That Can Go Wrong
19. Do You Want to Have Child?
20. Avoiding Pregnancy
21. Getting a Sexually Transmitted Infection
22. Final Class

Pre-and Post Evaluation

Free to participants

Participant should attend all 22 weeks

When the Main Concern is Legal Matters

- **ALL people, must deal with legal matters throughout their lives**
- **It is even more important for youth with disabilities to learn about decision making in legal matters like signing a lease, a PCP or an IEP**
- **There are many resources available to support families in explaining complex ideas. Contracts can and should be explained in plain language.**

Power of Attorney and Durable Power of Attorneys

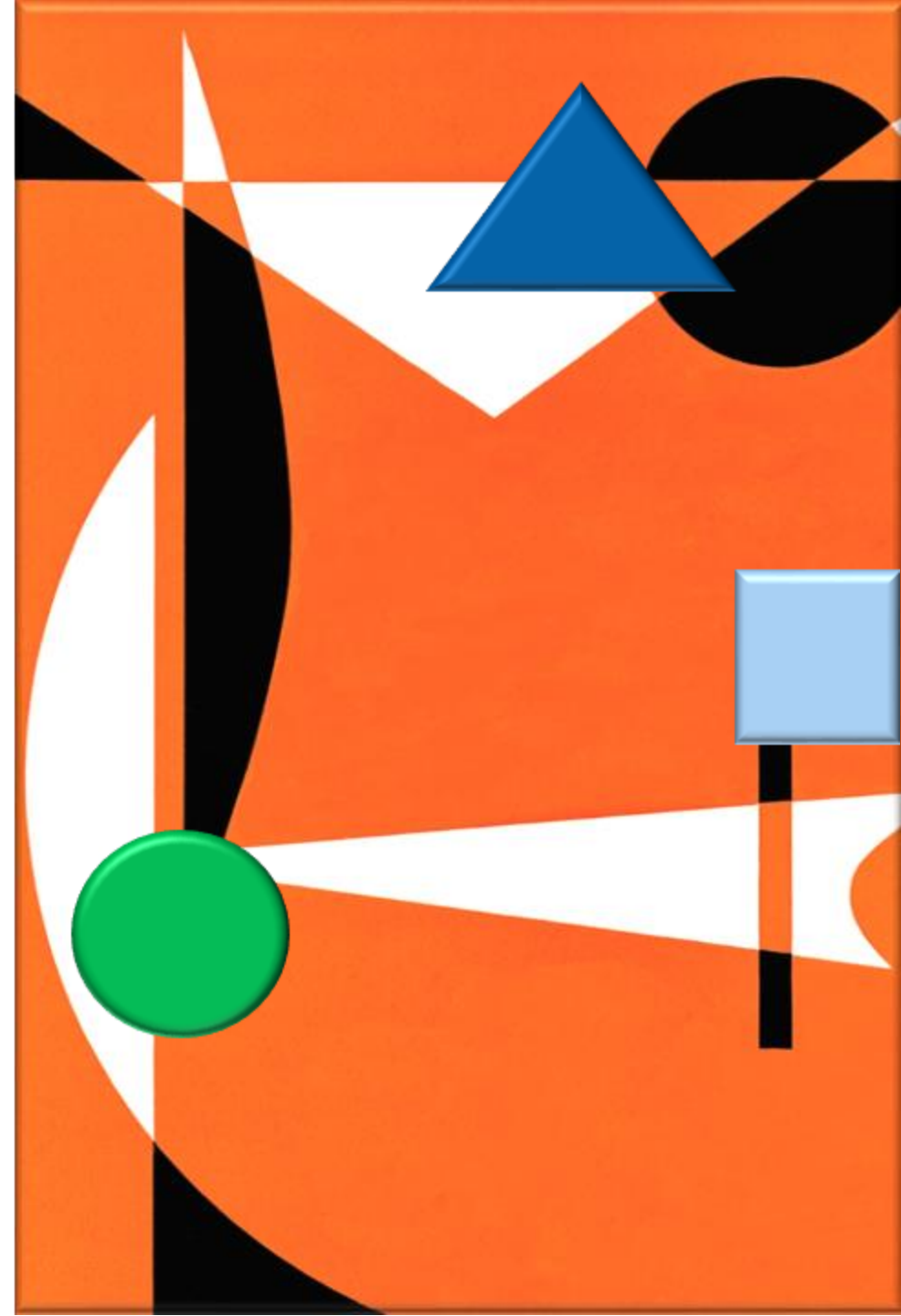
A power of attorney is a legal document in which you appoint an agent to make health care decisions on your behalf when you cannot make them for yourself.

The Wrap-up

- **Being a strong advocate**
- **Be person centered**
- **Begin young and continue throughout life**
- **Tie back into the ALL**
- **Don't freeze people in time**
- **Recognize what guardianship can and, can not do.**

CYVYC Youth Ambassador Initiative

Michigan



Ambassador Selection

Intentionally Seeking Diversity:

- **Regions around our state**
- **Culture**
- **Type of disability**
- **Gender and gender identity**



MICHIGAN'S SUPPORTED DECISION-MAKING YOUTH AMBASSADORS



Corissa Pitman-Age 14, pronouns they, them, from Ingham County Michigan

Corissa is a kind and happy student from Lansing in Michigan's, Ingham County. Corissa is 14 years old and in the 8th grade. Favorite things for Corissa are science and reading, and they very much enjoy advocating individually, and for others. Corissa has presented information on women's education and enjoys public speaking. As one of the youngest, supported decision-making Ambassadors in training, Corissa is looking forward to increasing individual advocacy skills as well as helping others to achieve their dreams for their adult lives. When asked why they applied to be an Ambassador, Corissa stated, "This is a great new opportunity for me to learn and give back to my community".



Jenna Lee-Age 16, pronouns she, her, hers, Ottawa County Michigan.

Jenna Lee is 16 years old and lives in Hudsonville MI. She attends Hudsonville High School and will be a Junior this fall. She has a Black Belt in Tae Kwon Do. Jenna volunteers at the Critter Barn in Zeeland, MI, caring for animals. She also helps with activities at the Laurels Nursing Home and helps at her church with food distributions. In her free time, Jenna enjoys watching YouTube, as well as acting, singing, and public speaking. She loves helping all people, including those with disabilities and is always ready to offer encouragement and a smile. Jenna is excited to be part of the Youth Choice project helping to spread the word on supported decision-making and alternatives to guardianship.



Kaiden Tolbert-Age 18, he his, from Wayne County Michigan.

Kaiden is a proud 2022 graduate of Redford Union High School in Michigan. He will be attending a local community college in the fall to study Education and Human Services. As a young adult with an Asperger's diagnosis, Kaiden found advocating for himself as well as others allowed him to participate in activities that may not have been available to him otherwise. Several years with The Boys Theater of Detroit gave Kaiden the confidence of public speaking and tackling his stage fright. He has been honored to work with the Detroit Chapter of the NAACP and the Living and Learning Enrichment Center of Northville, shadowing a Camp Counselor. Kaiden also worked in the Center's Mod Market where they employ and train individuals with special needs. In his free time Kaiden enjoys bike riding, going to the movies, out to eat and spending time with family and friends.



Jeanie Rowe-Age 20, she, her, from Cass County Michigan.

Jeanie Rowe is a 20-year-old student in the Heritage Southwest Intermediate School District in Cass County, Michigan. Jeanie has always had a desire to help others reach their full potential and wants them to know that they are not alone. She is currently training as a Peer Mentor at Woodlands Behavioral Health, where she will provide support to peers who also receive services there. "I am a strong advocate for all people with disabilities in all aspects of their lives". Helping people understand their right to make their own choices, was very appealing to her and what drew her to become a Supported Decision-Making Youth Ambassador as well.

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.zeebeek.com/SBM>

- **The Arc US**

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



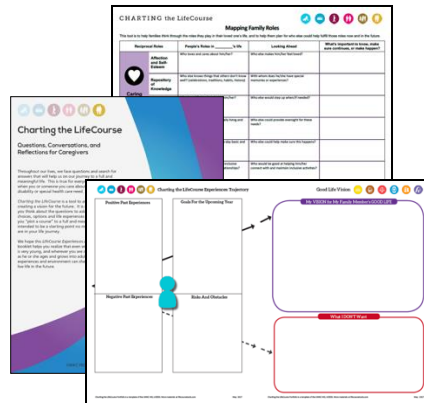
Resources

- **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)**

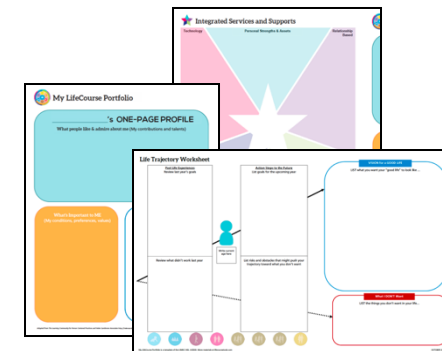
Planning for Life Outcomes and/or Service Planning



Self-Advocate
Tools & Resources



Family Perspective
Tools



Formal Planning
Tools and Forms

Questions

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

What questions do you have?



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