

# SUPPORTED DECISION-MAKING

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**Jeanie Rowe, Peer Mentor Intern and CYVYC Supported Decision-Making Youth Ambassador**

**Mary Shehan, Community Inclusion Coordinator, Michigan Developmental Disabilities Council**



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# YOUR LIFE OUR CHOICE

# Outcomes for Today

- **A brief explanation of the differences between SD-M and Guardianship**
- **More in depth 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 can show up on an IEP**

# 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.”**

# National Guardianship Association/2015

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**“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 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.**

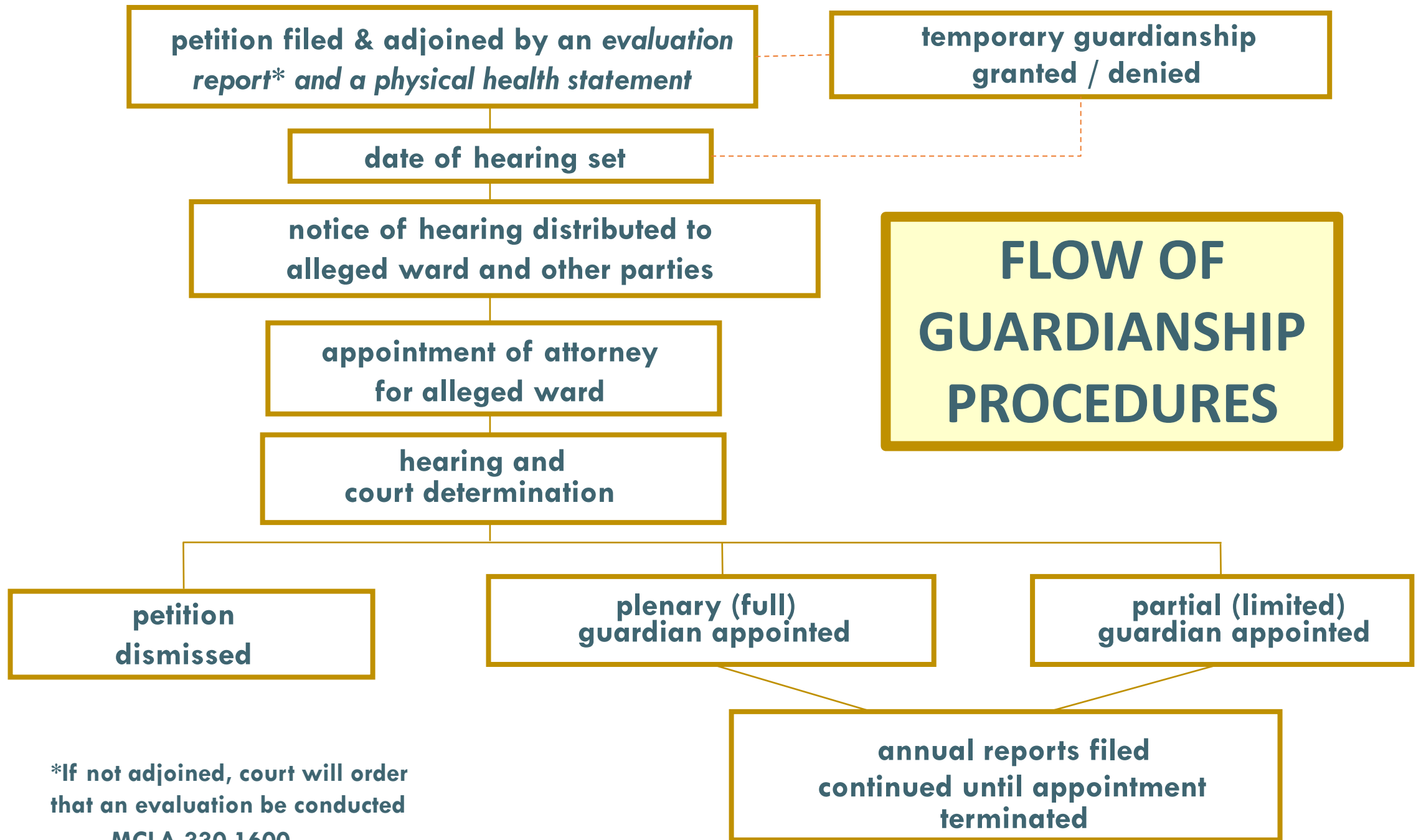
**MCLA, Chapter 6**



# My Experience with Guardianship

- My first exposure to thinking about guardianship was when I was about to turn eighteen and it was mentioned at my IEP
- I had never spoken to my family about it before that
- It made me really start thinking about how I want to make decisions about my life as an adult
- Then I saw a presentation and told my teacher I wanted to get involved in advocacy.
- She put me in touch with Mary, and the rest is advocacy history







# 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

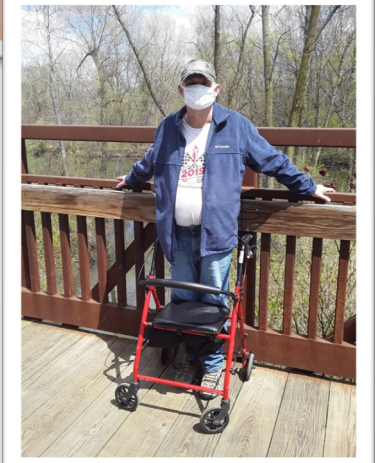
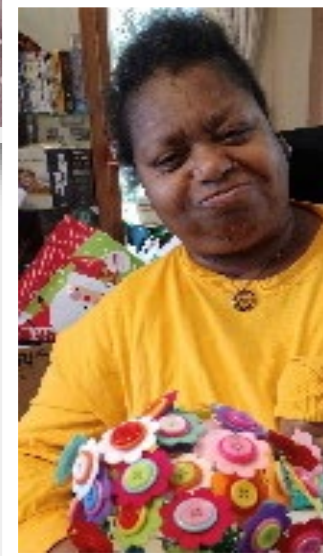
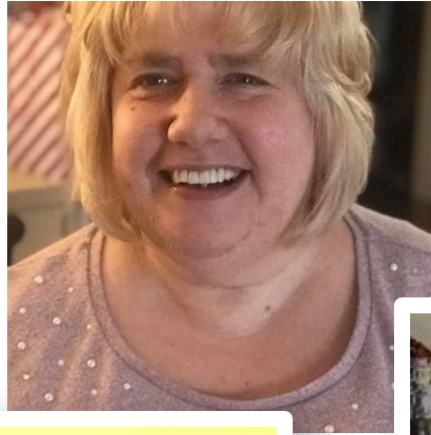
# What is Supported Decision-Making anyway?

**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**

# Remember, Supported Decision Making Is Used by ALL People



# Getting Started with Supported Decision-Making

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**Step 1) Start the conversation**

**Step 2) Identifying who is willing and able to assist**

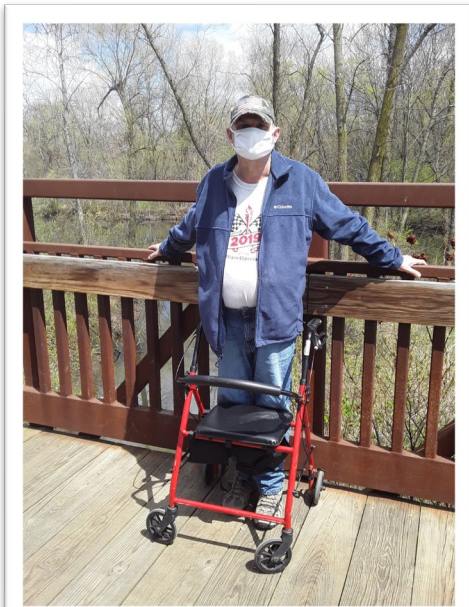
**Step 3) Plan and communicate**

**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

**Past Life Experiences**

LIST past life experiences and events that supported your vision for a good life.

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

**Future Life Experiences**

LIST current/ future life experiences that continue supporting your good life vision.

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

Write current age here:  
60

LIST past life experiences that pushed the arrow toward things you don't want.

Only child from first marriage  
Father's death  
Mother remarrying (six stepbrothers)  
Mother passing away  
Very infrequent contact with biological sibs  
Biological sibs passing away  
Never learned to drive  
Low paying job

LIST life experiences to avoid because they push you toward things you don't want.

Poor communication between family and professionals  
Cable being cut  
COVID Shut downs  
Peckham closing  
Fall (back an dhip injury)  
Poor Health  
Swallowing issues

VISION for a GOOD LIFE

LIST what you want your "good life" to look like ...

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

What I DON'T Want

LIST the things you don't want in your life...

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

My LifeCourse Portfolio is a template of the UMKC IHD, UCEDD. More materials at [lifecoursetools.com](http://lifecoursetools.com)

OCTOBER 2016



# 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.



#### 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

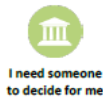
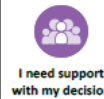
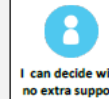


### Tool for Exploring Decision Making Supports

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.



#### 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

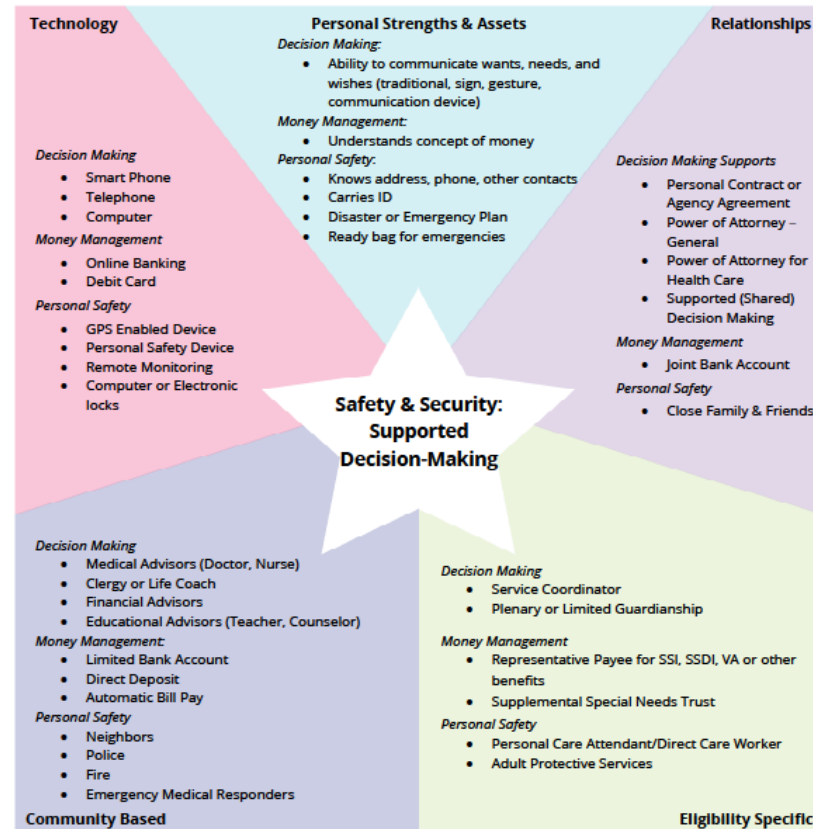


## CHARTING the LifeCourse



### 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](http://lifecoursetools.com)

Developed by the UMKC Institute for Human Development, UCEDD. More tools and materials at [lifecoursetools.com](http://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**
- **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 emancipate themselves from their parents.
- 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 over successively more responsibilities

# 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.**

# 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—

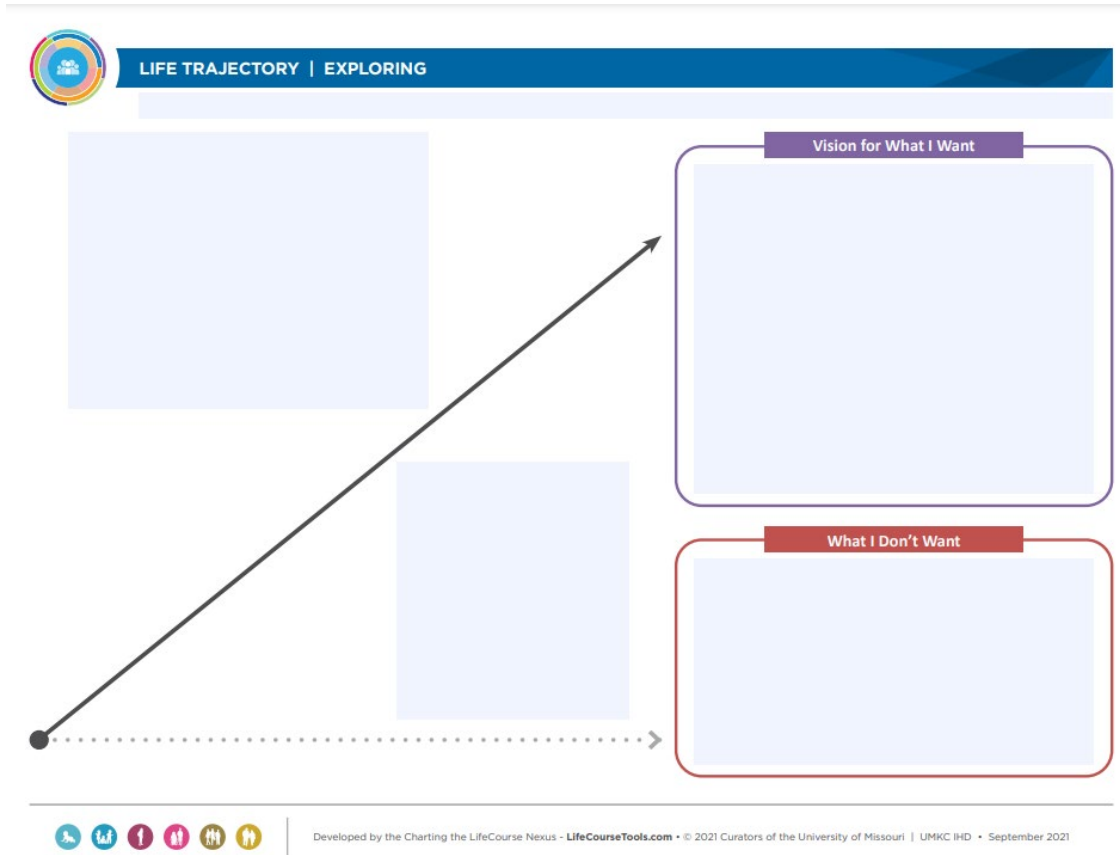
- Appropriate measurable postsecondary goals based upon age appropriate, transition assessments related to training, education, employment, and, where appropriate, independent living skills; and
- (2) The transition services (including courses of study) needed to assist the child in reaching those goals.

# 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.

# Tool: Life Trajectory: Exploring



The image shows a digital tool interface titled "LIFE TRAJECTORY | EXPLORING". It features a blue header bar with a circular logo on the left. Below the header, there are three light blue rectangular boxes. A solid black arrow starts from a black dot on the left and points diagonally upwards to the top-right box. A dotted black arrow starts from the same black dot and points horizontally to the right, ending at the bottom-right box. The top-right box is labeled "Vision for What I Want" and the bottom-right box is labeled "What I Don't Want". At the bottom of the interface, there is a row of six small circular icons and a line of text: "Developed by the Charting the LifeCourse Nexus - LifeCourseTools.com • © 2021 Curators of the University of Missouri | UMKC IHD • September 2021".

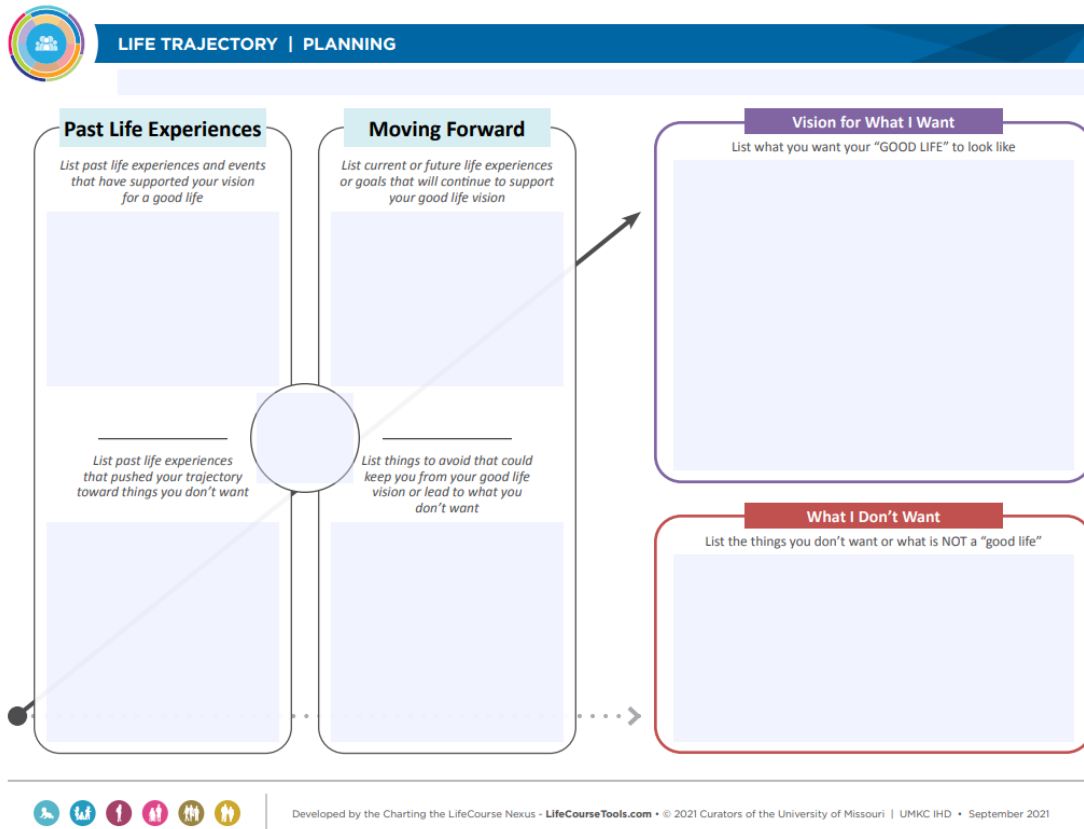
What is your vision for the life you want?

What do you not want?

Share with other members of your IEP team.

Think about if goals or activities take you to the life you want or the life you don't want.

# Tool: Life Trajectory: Planning



The Trajectory Planning Tool highlights your past life experiences that are leading or moving you away from your vision and then provides space for current goals and activities to focus on or avoid moving forward.



# 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 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 accurate 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

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# 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 neurotypical peers.
- Like ALL young adults, youth with disabilities should learn to communicate with other
- Families need to assure that everyone involved in their loved one's life, understand their communication style.

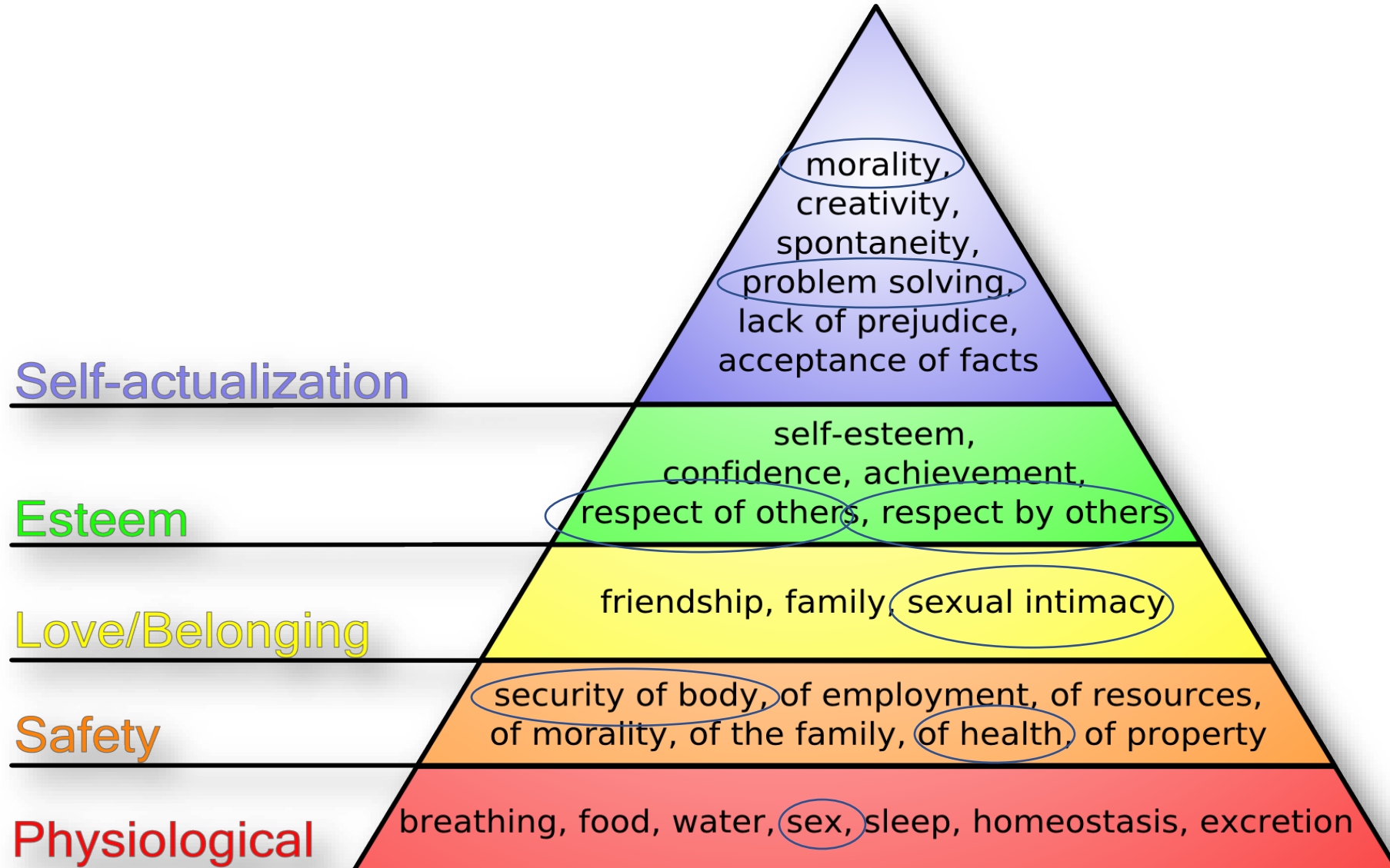
# Types of Communication

**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. Here's a more in-depth look at the four main categories of communication.**

# When the Main Concern is Sexuality

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

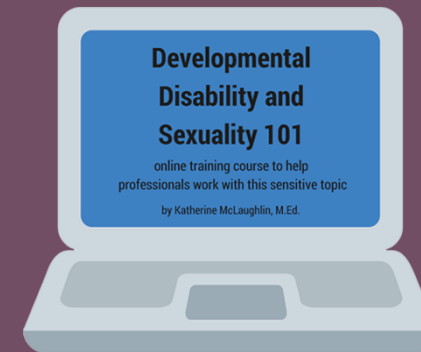
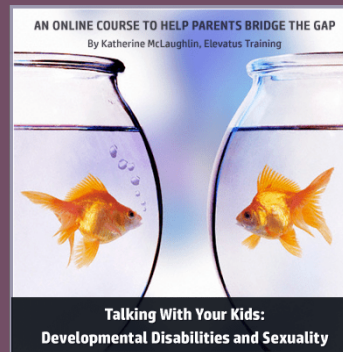
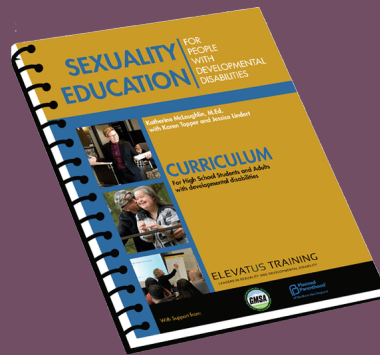
of people **with  
a learning  
disability** live with  
a partner / are in a  
relationship



# Elevatus Products and Workshops

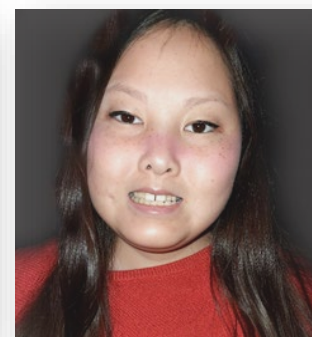
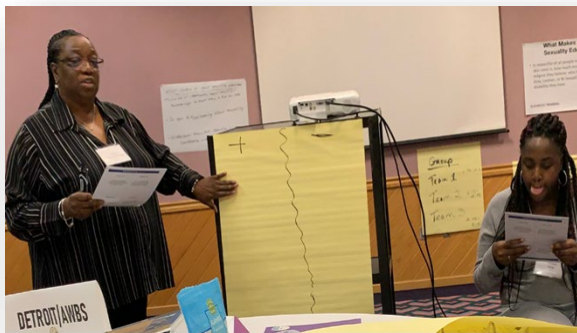
## Becoming a Sexuality Educator

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



For more information visit: [www.elevatustraining.com](http://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, have to deal with legal matter throughout their lives**
- **It is even more important for youth with disabilities to learn about decision making in legal matter like signing a lease, a PCP or an IEP**
- **There many resources available to support families in explaining complex ideas. Contracts can and should be explained in plain language.**

# 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.**

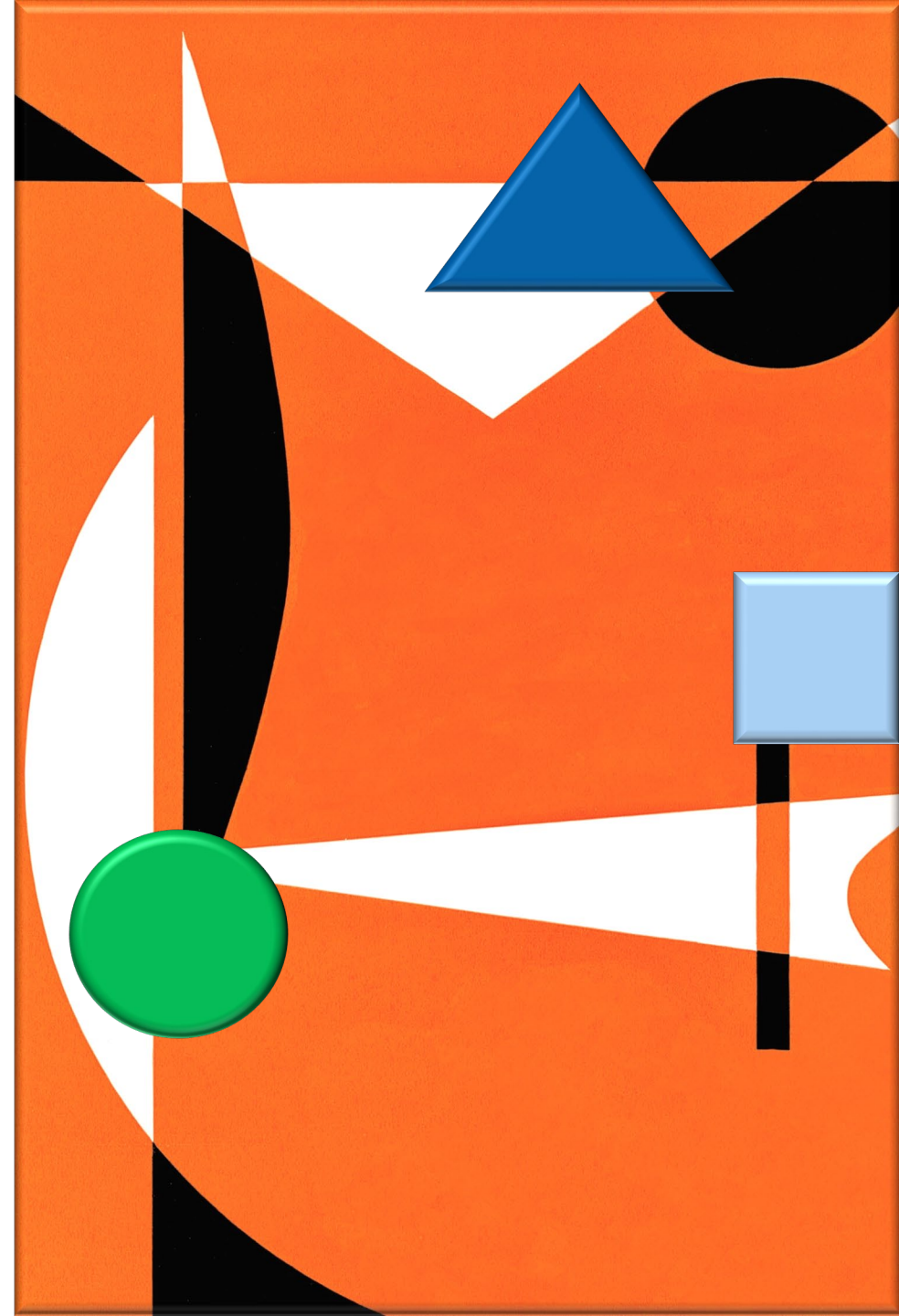
# The Wrap-up

- **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

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Michigan

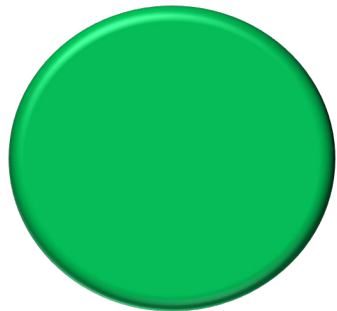




# Ambassador Selection

## 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](http://miable.org)

- **State Bar of Michigan**

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

- **The Arc US**

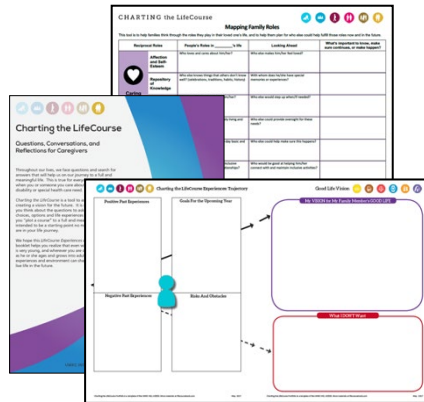
[https://thearc.org/find-resources/?search\\_resource=&audience=searchAudience&type=searchtype&topic=family-support-and-future-planning](https://thearc.org/find-resources/?search_resource=&audience=searchAudience&type=searchtype&topic=family-support-and-future-planning)



# 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)**

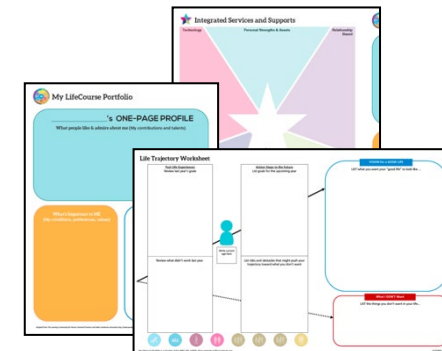
## Planning for Life Outcomes and/or Service Planning



Family Perspective  
Tools



Self-Advocate  
Tools & Resources



Formal Planning  
Tools and Forms

# Questions

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

**What questions do you have?**



# Presenter Contact Information

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# 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

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# Michigan Alliance for Families

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