

Self-Determination & Supported Decision-Making

Amie Kupovits, Peer Mentor and Rights Educator, Oakland County Health Network

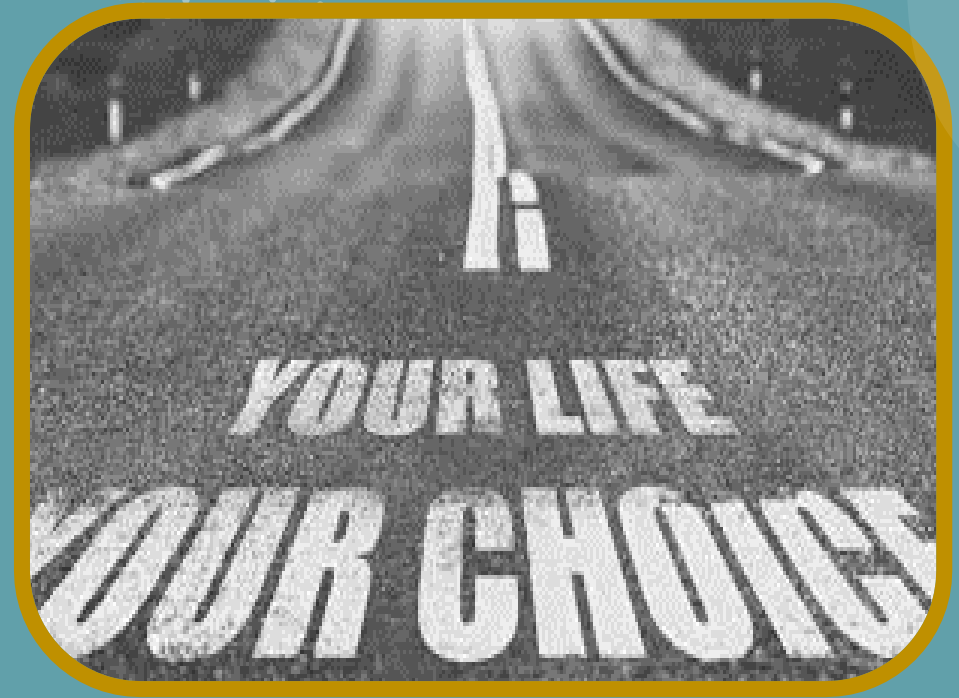
Mary Shehan, Community Inclusion Coordinator, Michigan Developmental Disabilities Council



Self-Determination & Supported Decision- Making

**Amie Kupovits: Self-Advocate and
OCHN Rights Staff**

**Mary Shehan: Community Inclusion
Coordinator-MiDDC**



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
- Practice examples of how to use the tools to support the life each student wants
- See where this information can show up on an IEP or a PCP

Disability Scoop, 8.26.21



Young adults with disabilities and their parents argue that health care officials, regional centers, and school districts need to foster more awareness about what it's like for youth with disabilities to transition to adulthood. Far too many families don't know what to expect, they said, or how to advocate for the services they need.

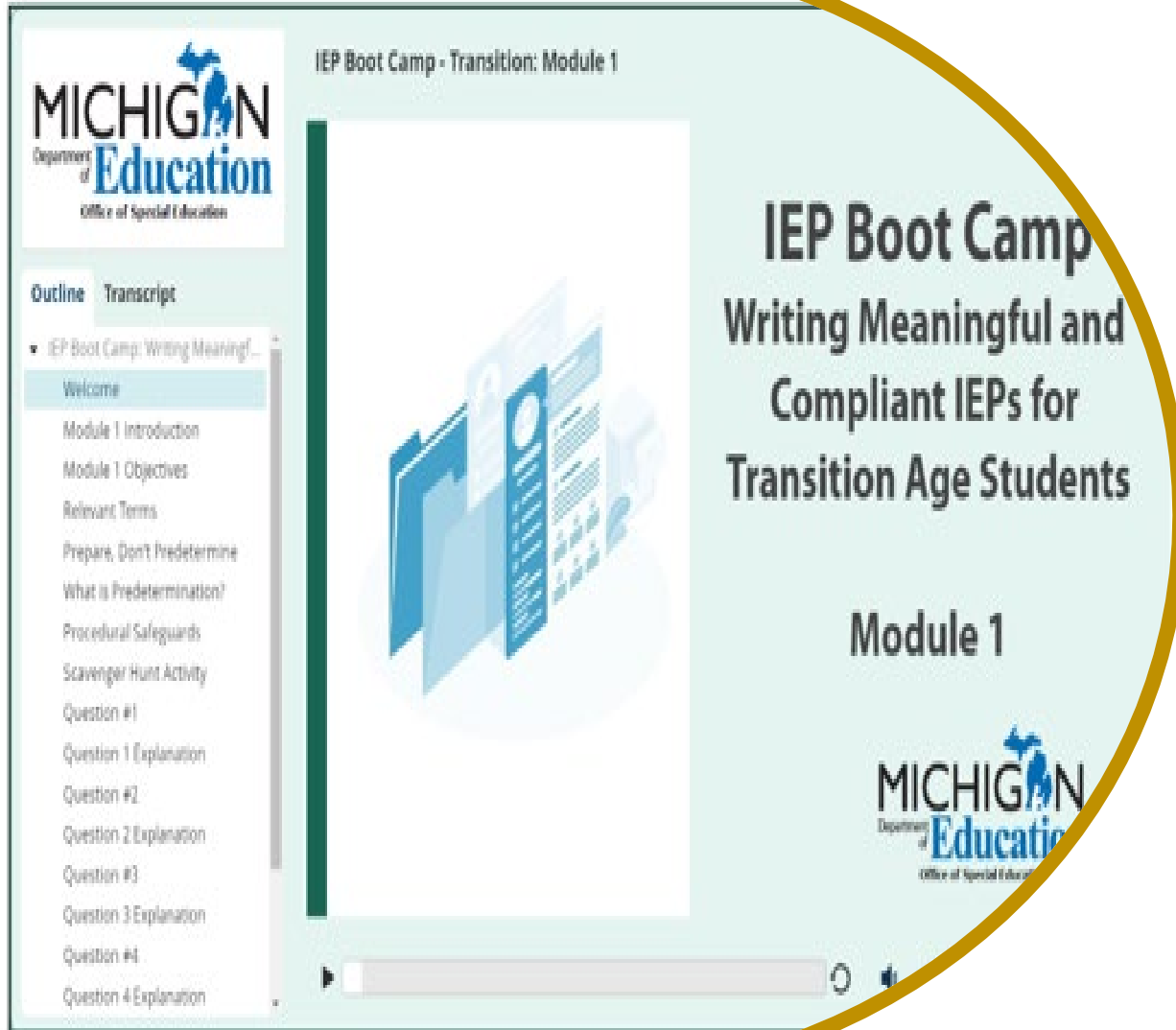
What Does the Law Say About Guardianships...

- 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.

~Mental Health Code-Chapter 6



Office of Special Education Training



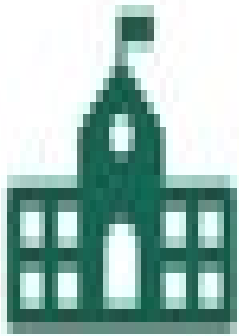
- **Michigan department of Education's IEP Boot Camp**
- **The student is presumed to be competent to act on their own behalf**
- **The district is presumed to have been, and is continuing to, educate the student to live a self-determined life**

Office of Special Education Training Continued

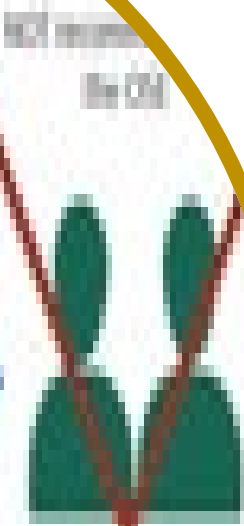
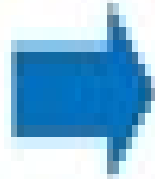
Age of Majority



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

- Self-determination goes hand and hand with Supported Decision-Making
- School personnel should NOT try to persuade the parents to obtain legal guardianship over the student

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 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 that goal**





One Adult's Experience: Part 1

- As a child, I lived with my parents, and sister and got the usual school supports
- I was placed in a separate Special Education building in Farmington though, I expressed that I wanted to graduate from the same school as my sister.
- In my junior year I attended Walled Lake Western
- I graduated with a high school diploma at age seventeen, then went to Oakland Community College
- I got an Associates Degree in Liberal Arts and an Associates Degree in Business and Management



One Adult's Experience: Part 2

- I was an autonomous, decision-making adult at that time and lived life as I wanted
- After my parents, and my sister passed away people thought I needed a guardian
- He sent someone over to the group home where I lived to interview me person said I did not need a guardian, but I could use help with finances
- Someone, I never did find out who, petitioned for me to get a public guardian and the court hearing happened without me
- I met them when they called me and announced themselves as my new guardian. I was told it was to help me settle my mom's estate
- Around this time, I started an Avon business, without telling anyone and I handled all that money



One Adult's Experience: Part 3

- My social worker found out, and then I had to tell my guardian
- One of the ladies I met through my Avon business said she thought I didn't need a guardian, and she knew a judge
- So, she helped me meet the judge who agreed that I didn't need a guardian
- Now, I just have a person that helps me with finances-I am free again to live my life as I choose

My final thoughts are: Don't just assume that every person with a disability needs a guardian. Get to know the person before you make a judgement. With an active circle of supporters, community resources, and assistive technology many people with disabilities can live safely in the communities they chose.

How Would You Feel If Your Decision-Making Rights Were 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



Kinds of choices students need to make

- Who they want at their IEP
- Telling what they need in terms of supports
- Telling their supporters when they like or, don't like something



Using your voice where it matters – examples:

- **Organizing their own meetings**
- **Being included on making medical decisions**
- **Making decisions about money with the help they need**



SELF-DETERMINATION VIDEO

<https://vimeo.com/256473639>

Person-centered planning is part self-determination

- **Everything is individualized**
- **There is a requirement that PCP's can be adjusted when it is needed**
- **If a person has a PCP, and thinks it needs to be changed, they can request a review**



Adult choices to make

- Choose who they want at a PCP
- Not be pressured to invite someone they do not want there
- Telling what they need in terms of supports
- Telling people when they like or, don't like something



How is supported decision-making connected to self-determination?

- When someone is under guardianship, there is another person making decision for them
- This is the opposite of being self-determined
- Supported decision-making is when a person has a circle of supporters who help them make difficult decisions
- It helps to keep the decision-making power in the hands of the person but, they get support when they need it



What is Supported Decision-Making anyway?

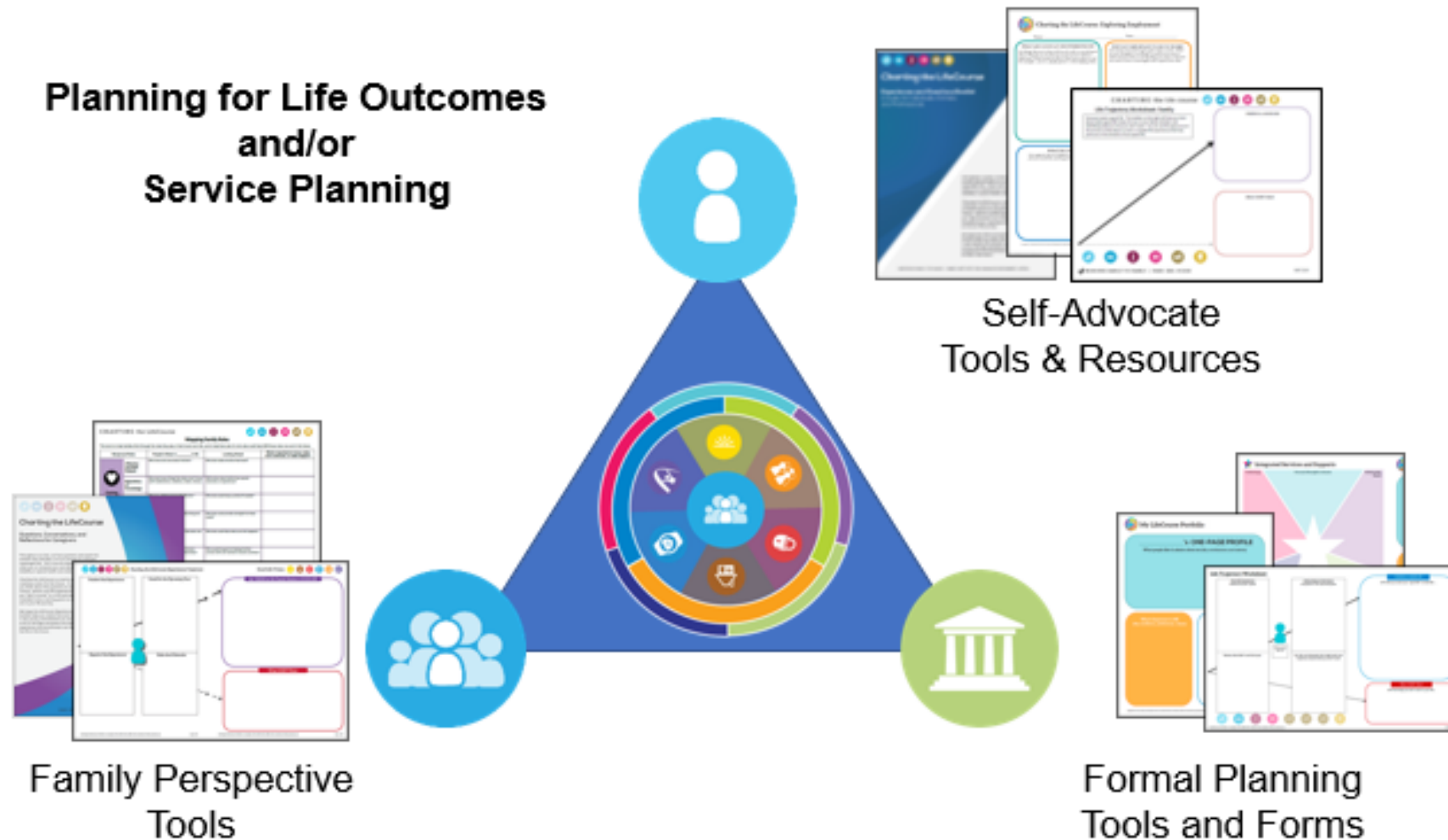


**We all need supporters,
helpers and consultants in
our lives to make good
decisions, whether we have
a disability or not.**


Tools For Your SDM Toolkit



- Every toolkit needs to be tailored to that person's life
- It should reflect their culture, race and religion as well as those they choose for their circle of supporters
- It should reflect the person's skills talents and needs
- Above all else, it should reflect that person's trajectory for their own life



Tools to get to the dream

**LIFE TRAJECTORY | SUPPORTED DECISION-MAKING**

Past Life Experiences

What helps me UNDERSTAND the issues and my options?

What has helped me COMMUNICATE my preferences, choices, and decisions?

What has helped me FOLLOW THROUGH on my choices and decisions?

What were past barriers that made it hard for me to understand, communicate, or follow through with my choices and decisions?

Moving Forward

What do I need now to help me UNDERSTAND the issues and my options?

What do I need now to help me COMMUNICATE my preferences, choices, and decisions?

What do I need to help me FOLLOW THROUGH on my choices and decisions?

What needs to happen to avoid barriers that make it hard for me to understand, communicate, or follow through with my choices and decisions?

Vision for What I Want


What decisions and choices do I want to make myself or with help from my supporters?

My vision for a good life

What I Don't Want

What decisions and choices do I NOT want someone else making for me or without my input or approval?

Not a good life



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Tools to
determine
who's in their
circle, or who
might need
to be added



MAPPING RELATIONSHIPS

 CARING ABOUT	Who serves in this role now?	Looking Ahead	Next Steps
Shares Love, Affection and Trust			
Spends Time and Creates Memories Together			
Knows about Personal Interest, Traditions, Cultures			

 CARING FOR	Who serves in this role now?	Looking Ahead	Next Steps
Supports Day-to-Day Needs			
Ensures Material and Financial Needs are Met			
Connects to Meaningful Relationships and Roles			
Advocates and Supports Life Decisions			



Tools to figure out where exactly they need support

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

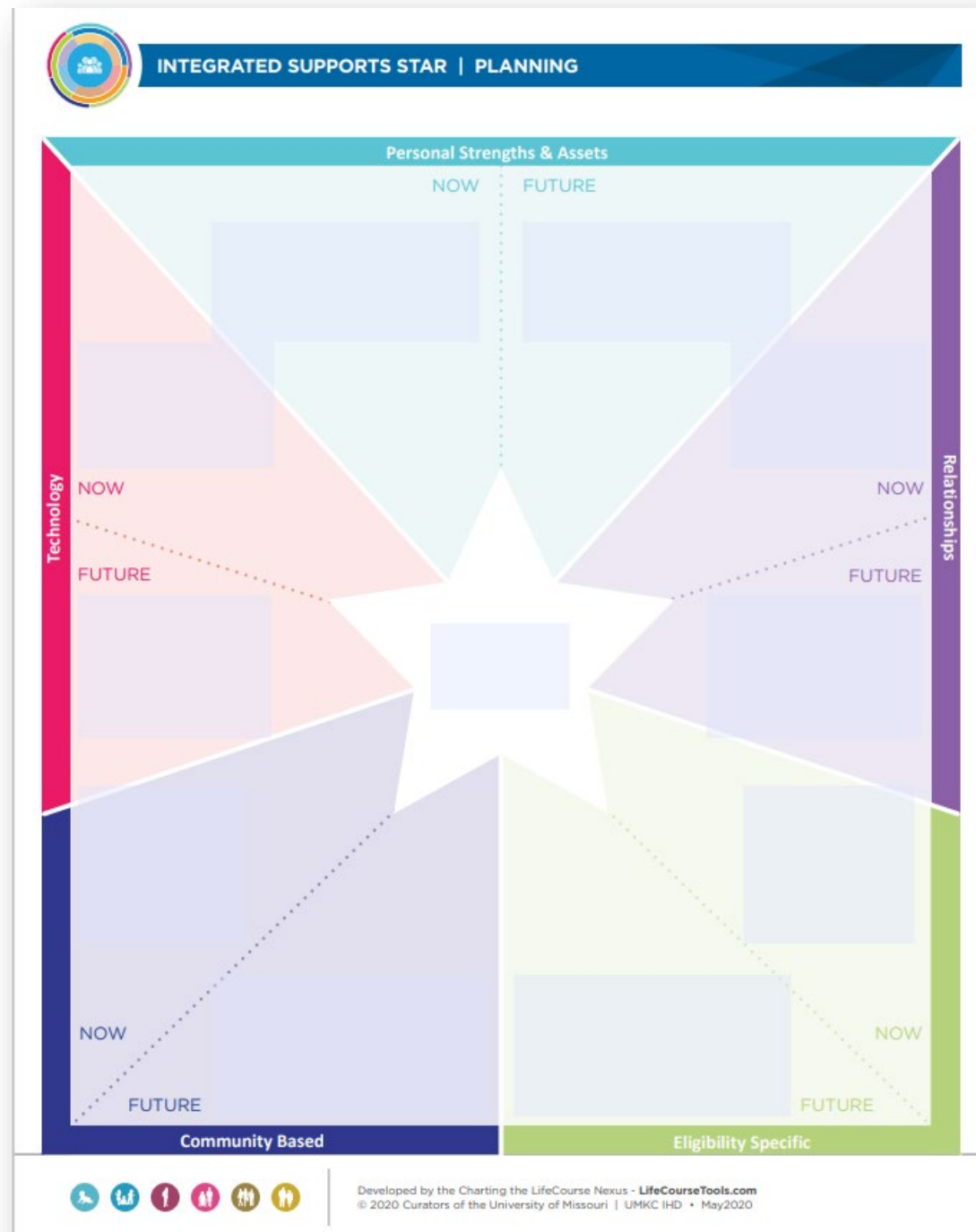
DAILY LIFE & EMPLOYMENT

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?			

**Tools to
figure out
where
possible
supports can
come from**



Tools to
show how
live are
becoming:
more
colorful!



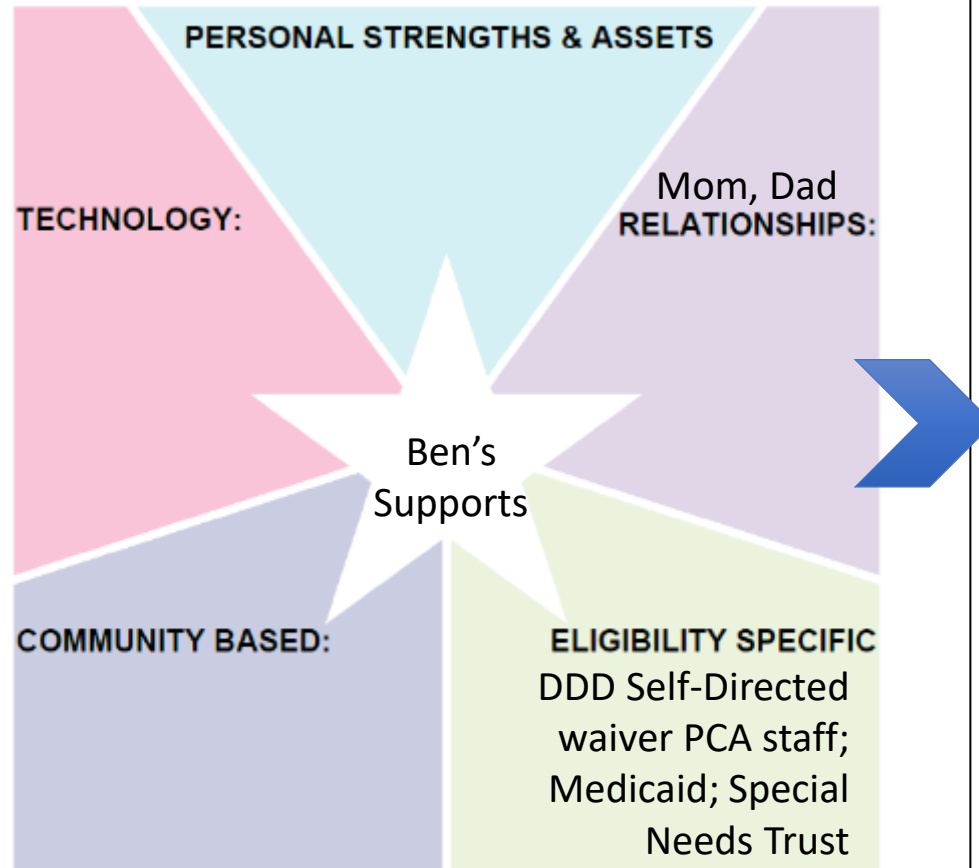
Integrated Schedule

My Name is: _____

Time	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
6:00-6:30 a.m.							
6:30-7:00 a.m.							
7:00-7:30 a.m.							
7:30-8:00 a.m.							
8:00-8:30 a.m.							
8:30-9:00 a.m.							
9:00-9:30 a.m.							
9:30-10:00 a.m.							
10:00-10:30 a.m.							
10:30-11:00 a.m.							
11:00-11:30 a.m.							
11:30-12:00 p.m.							
12:00-12:30 p.m.							
12:30-1:00 p.m.							
1:00-1:30 p.m.							
1:30-2:00 p.m.							
2:00-2:30 p.m.							
2:30-3:00 p.m.							
3:00-3:30 p.m.							
3:30-4:00 p.m.							
4:00-4:30 p.m.							
4:30-5:00 p.m.							
5:00-5:30 p.m.							
5:30-6:00 p.m.							
6:00-6:30 p.m.							
6:30-7:00 p.m.							
7:00-7:30 p.m.							
7:30-8:00 p.m.							
8:00-8:30 p.m.							
8:30-9:00 p.m.							
9:00-9:30 p.m.							
9:30-10:00 p.m.							
10:00-6:00 a.m.							



Ben - BEFORE Integrated Supports

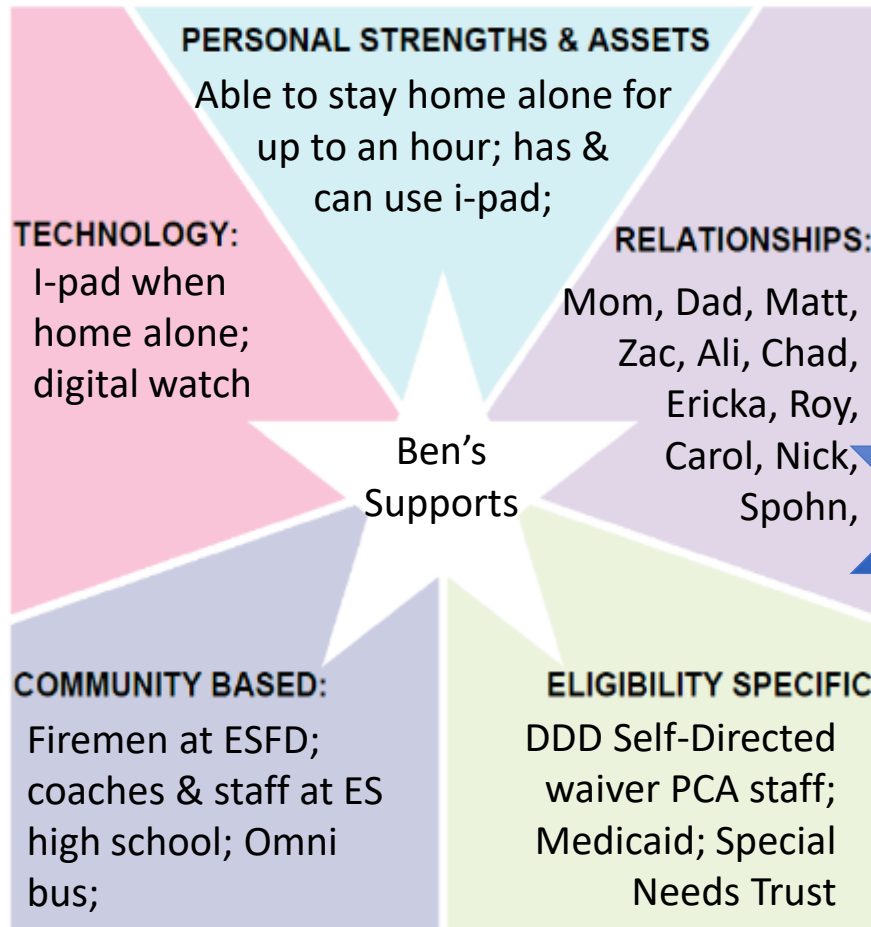


Time	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
6:4:30 AM	Parents get Ben out of bed, assist with breakfast, shower, getting dressed and ready for his day						
6:30-7 AM							
7:7:30 AM							
7:30-8 AM							
8:8:30 AM	Waiver Self-Directed PCA					Parents are weekend support	
8:30-9 AM							
9:9:30 AM							
9:30-10 AM							
10:10:30 AM							
10:30-11 AM							
11:11:30 AM							
11:30-12 PM							
12:12:30 PM							
12:30-1 PM							
1-1:30 PM							
1:30-2 PM							
2-2:30 PM							
2:30-3 PM							
3-3:30 PM							
3:30-4 PM							
4-4:30 PM	Mom and Dad provide all support, including meals, transportation and support for activities, etc.						
4:30-5 PM							
5-5:30 PM							
5:30-6 PM							
6-6:30 PM							
6:30-7 PM							
7-7:30 PM							
7:30-8 PM							
8-8:30 PM							
8:30-9 PM							
9-9:30 PM							
9:30-10 PM							
10 PM-6 AM	Mom and Dad are overnight staff						

Template by Missouri Family to Family @ UMHC-HQ, UCEDD

December 2014

Ben - AFTER Integrating Supports



Time	Mon	Tues	Wed	Thurs	Fri	Sat	Sun						
6-6:30 AM	Parents get Ben out of bed, assist with breakfast, shower, getting dressed and ready for his day												
6:30-7 AM													
7-7:30 AM	Parents support Ben												
7:30-8 AM													
8-8:30 AM	Waiver Self-Directed PCA	Volunteers Fire Dept Supported as needed by firemen	Waiver Self-Directed PCA	Volunteers Fire Dept Supported as needed by firemen	Waiver Self-Directed PCA								
8:30-9 AM													
9-9:30 AM													
9:30-10 AM													
10-10:30 AM	Waiver Self-Directed PCA						St. Ann's w/ mom						
10:30-11 AM													
11-11:30 AM													
11:30-12 PM	Home alone while Mom walks												
12-12:30 PM	Waiver Self-Directed PCA												
12:30-1 PM													
1-1:30 PM	Waiver Self-Directed PCA												
1:30-2 PM													
2-2:30 PM													
2:30-3 PM	Volunteer at high school, supported by coaches and friends												
3-3:30 PM													
3:30-4 PM													
4-4:30 PM													
4:30-5 PM													
5-5:30 PM													
5:30-6 PM	WWE With Matt	Mom and/or Dad prepare meal and assist as needed				Dinner w/ Roy & Carol & family							
6-6:30 PM													
6:30-7 PM		Home alone while Mom walks											
7-7:30 PM													
7:30-8 PM		Horseback Therapy w/ Dad					Nick's Birthday Party with Matt and friends						
8-8:30 PM													
8:30-9 PM													
9-9:30 PM													
9:30-10 PM													
10 PM-6 AM	Mom and Dad are overnight staff												

Template by Missouri Family to Family @ UMKC-HHD, UCEDD

January 2015

What are the main concerns people express?

Concerns involving:

1. Education
2. Safety
3. Medical Decisions
4. Finances
5. Communication
6. Sexuality
7. Legal



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.

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**

Legal Power of Attorney and Springing Power of Attorney

A power of attorney is a legal document in which you appoint an agent to make legal decisions 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.

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.

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

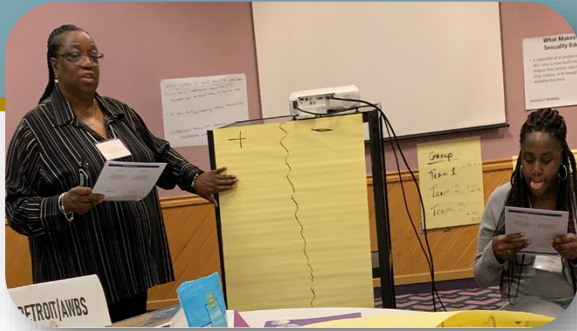
- **Special Needs Trusts**
 - Individual
 - Pooled
- **ABLE Accounts**



Types of Communication

There are many ways we share information with one another. For some people with IDD, they share information in no traditional ways. They are communicating, we just need to get better at listening with our whole selves to what they are saying.

Sexuality Education is Important for All



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

Resources

Michigan Developmental Disabilities Council

<http://www.Michigan.gov/ddcouncil>

<https://www.michigan.gov/mdhhs/keep-mi-healthy/mentalhealth/developmentaldisability/supported-decision-making/sdm-toolkit>

Michigan Alliance for Families

<https://www.michiganallianceforfamilies.org/transition/>

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/>

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



The Wrap-up

- Help your students develop strong advocacy skills
- Promote person centeredness in all you do; each student is unique
- Teach decision-making throughout the student's life
- Tie people with IDD back into the ALL, be connected to your communities
- Don't freeze people in time: we all learn and grow throughout life
- Recognize what guardianship can and, can not do, it is not the only answer

Presenter Contact Information

спасибо 谢谢
GRACIAS
THANK YOU
ありがとうございました MERCI
DANKE धन्यवाद
شُكراً OBRIGADO



Amie Kupovits
Peer Mentor and Rights Educator
Oakland County Health Network
amiejoy223@yahoo.com



Mary Shehan
Michigan Developmental
Disabilities Council
Phone: (517) 243-0618
shehanm@michigan.gov

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Call 800-552-4821

En Español 313-217-1060

لغة العربية 248-963-0607

info@michiganallianceforfamilies.org



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In collaboration with



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1-800-552-4821

info@michiganallianceforfamilies.org

