

Promoting Autonomy for Older Adults and Adults with Disabilities through Decisional and Other Supports

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Housekeeping

- All on mute. Use Questions function for substantive questions and for technical concerns.
- Problems getting on the webinar? Send an e-mail to NCLER@acl.hhs.gov.
- Written materials and a recording will be available at NCLER.acl.gov. See also the chat box for this web address.

About NCLER

The National Center on Law and Elder Rights (NCLER) provides the legal services and aging and disability communities with the tools and resources they need to serve older adults with the greatest economic and social needs. A centralized, one-stop shop for legal assistance, NCLER provides Legal Training, Case Consultations, and Technical Assistance on Legal Systems Development. Justice in Aging administers the NCLER through a contract with the Administration for Community Living's Administration on Aging.

About Institute for Community Inclusion

The Institute for Community Inclusion at UMass Boston supports the rights of children and adults with disabilities to participate in all aspects of society. As practitioners, researchers, and teachers, we form partnerships with individuals, families, and service agencies. Together we advocate for personal choice, self-determination, and social and economic justice.

We are dedicated to advancing the full inclusion of people with disabilities in all aspects of life. Our work encompasses research, program evaluation, training, consultation, education, policy analysis, and service delivery across four main areas of emphasis: Employment, Education, Community Life, and Health Care.

About Justice in Aging

Justice in Aging is a national organization that uses the power of law to fight senior poverty by securing access to affordable health care, economic security, and the courts for older adults with limited resources.

Since 1972 we've focused our efforts primarily on populations that have traditionally lacked legal protection such as women, people of color, LGBT individuals, and people with limited English proficiency.

Welcome

- Vicki Gottlich, Deputy Administrator for Policy and Evaluation at the Administration for Community Living

What We'll Cover

1. Introduction to Decisional Supports
2. Supported Decision-Making
3. The Wonderful World of Supports
 - Informal, social, lifestyle
 - Financial
 - Health care
4. Supports in Action

Part 1: Introduction to Decisional Supports

The “Why?”

- The ability to make decisions about one’s life is a fundamental human right and one of the hallmarks of adulthood/personhood.
 - **Autonomy:** the quality or state of being self-governing, self-directing, free, and independent.
- At times, we all need support making and implementing decisions, both big and small.
 - Think about the various support mechanisms you utilize in your own life every day.
- Some people need more support than others – and that’s okay – in fact...

The Goal

- *Celebrate supports!*
- *Celebrate supporters!*
- *Normalize utilizing supports!*
- *Destigmatize needing those supports!*
 - Understand the spectrum of support mechanisms available to you and those you support to preserve autonomy and independence.

Some Basics

- “Decisional supports” encompasses all means of support, from formal practices to informal interactions.
 - Informal supports
 - Social supports
 - Financial supports
 - Healthcare supports
- Methods are person-centered and person-directed.
 - Decision-making is driven by the person and their values, priorities, and wishes, as well as their circumstances, preferences, abilities, resources, and life experience.
- Tools in your toolbox, arrows in your quiver, pick your metaphor.
 - Remember: It’s not just a menu, it’s a process.

Part 2: Supported Decision-Making

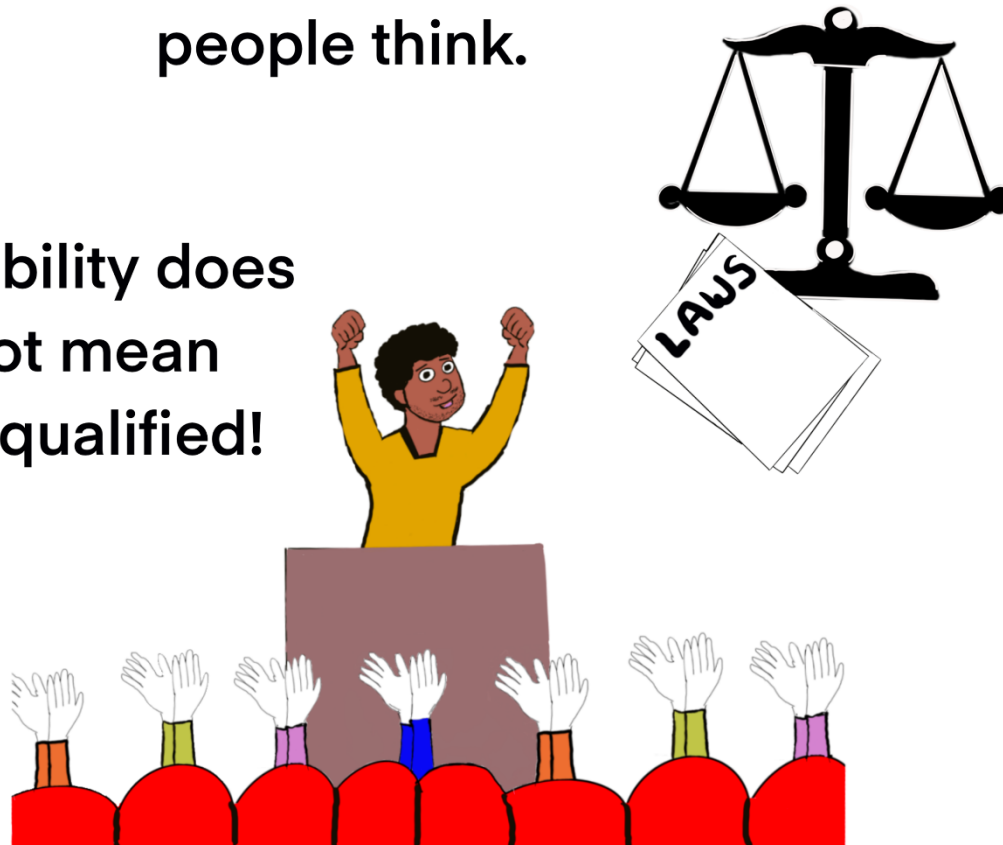
Self-Determination

- Getting support with making decisions is really about promoting **self-determination**

Disability Does Not Mean Disqualified

I want to change laws and how
people think.

Disability does
not mean
Disqualified!



Supported Decision-Making



What is Supported Decision-Making?

- People with disabilities retaining their rights
- Supporters provide guidance and assistance
- The person with the disability gets the support of trusted people to make **THEIR OWN DECISIONS** about the direction of their lives
- Can be formal or informal, and can be practiced in any state, regardless of legislation

Who are Supporters?

- Supporters are people who help with making decisions. They could be:
 - Family
 - Personal and family friends
 - Teachers and counselors
 - Religious or faith leaders
 - Employment specialists and/or employers
 - Financial and legal advisors
 - Medical professionals (medical, dental, psychological/psychiatric)
 - Really, any trusted individual



What is a Supported Decision-Making Agreement?

- Includes a description of responsibilities
- Explanation of the rights of the person being supported
- Protects the privacy of a person with a disability by defining what info a supporter can receive or see
- Clarifies expectations!
- A document that helps to inform others that a formal relationship exists (e.g. service coordinators, doctors, lawyers)
- Can be changed or terminated by the person with a disability at any time

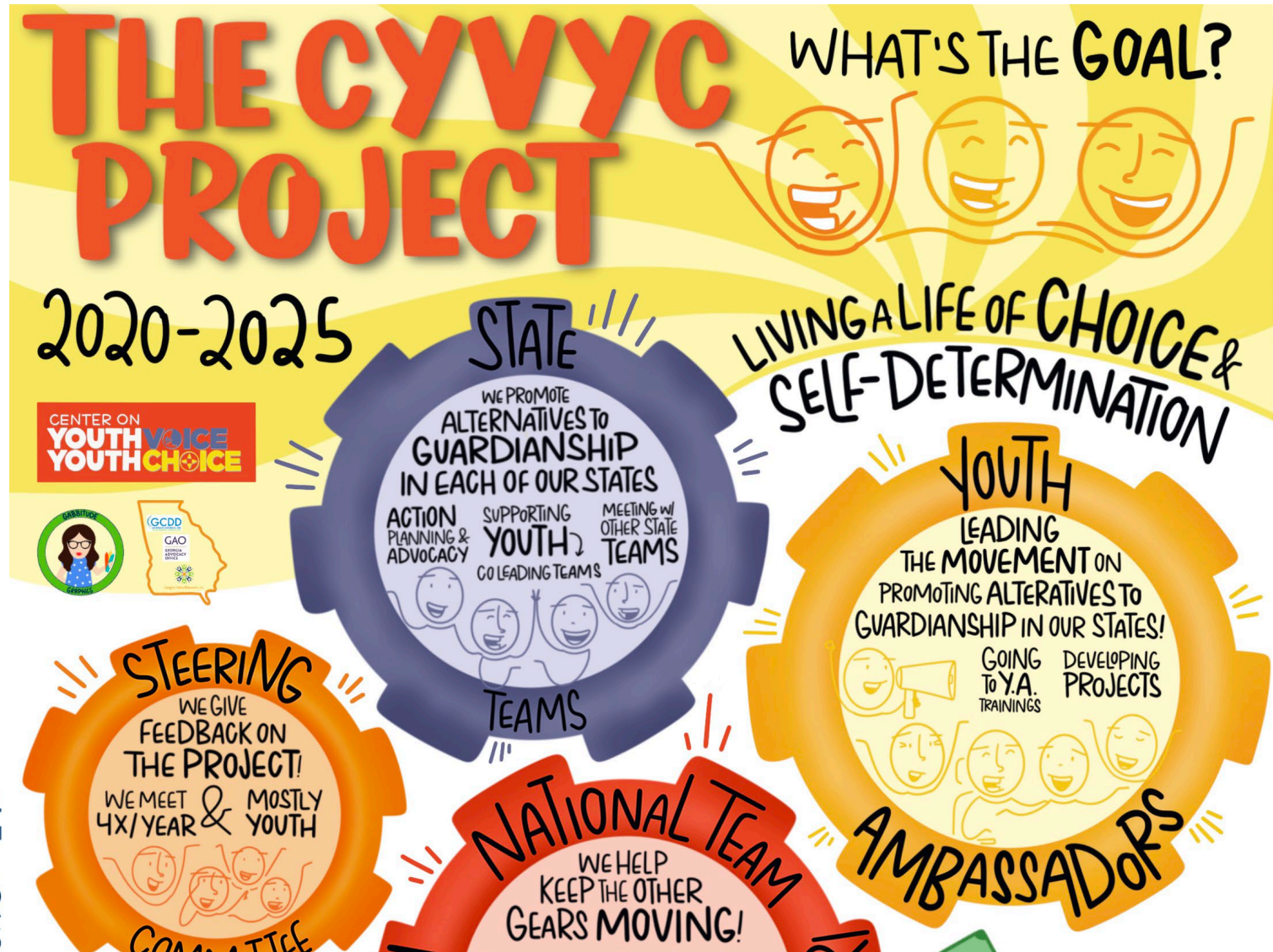


Center on Youth Voice, Youth Choice

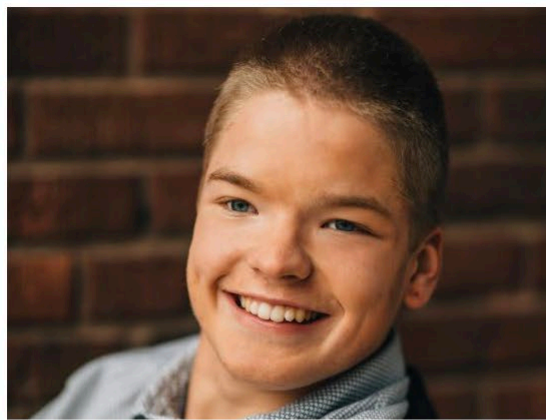
- The Center on Youth Voice, Youth Choice is a resource center for youth with disabilities.
- <https://youth-voice.org>



The CYVYC Project



Youth Stories



Meet Jordan

Jordan Anderson is a high school graduate who loves sports, politics, and journalism. He enjoys living in a small town in Auburndale, WI where there is always someone to stop and talk to.

[Read Jordan's Story](#)



Meet Houston

Houston is a college student studying Forensic Psychology. He is a strong advocate for voice and choice and believes that every person should have the opportunity to speak for themselves and explore their dreams.

[Read Houston's Story](#)



Meet Derek

Derek is a 21-year-old self-advocate and Youth Ambassador from Georgia. He is also an artist who enjoys graphic design, painting, drawing, food and playing video games.

[Read Derek's Story](#)



Meet Trina

Ketrina is a 27-year-old disability and "everything" advocate, a motivational speaker, and a blogger from Brooklyn, New York. She also serves on the CVVYC Advisory Board.

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[Read Trina's Story](#)

Part 3: The Wonderful World of Supports

The Broad Spectrum of Supports

- Wide variety of supports
 - Informal, social, lifestyle
 - Financial supports
 - Health care supports
- Supports fall on a spectrum of formality:
 - From very informal
 - Advice from a friend, an occasional ride, etc.
 - To very formal
 - Power of attorney, a trust, etc.

Informal, Social, Lifestyle Supports

- Family, friends, neighbors, community, and religious organizations
- Congregate and home-delivered meals
- Housekeeping services
- Day programs
- Transportation services
- Delivery services and online shopping
- Remember that SDM can (and should) be incorporated into other support mechanisms

Financial Supports

- Trusted person designations
- Accounts with read-only access, shared statements/notices
- Debit/credit cards with agreed limits
- Direct deposit/automatic banking
- Joint bank accounts and authorized signers
 - Presumption of ownership, maybe inheritance rights, judgment liability
- Money management and bill pay services
 - Possibly free or low cost, maybe monthly or hourly

Financial Supports (cont.)

- Representative payees
 - Administrative thru agency (Social Security, SSI, SSD, VA)
 - Could be voluntary or involuntary (“unable to manage benefits” because of mental or physical disability)
 - You can designate a rep payee in advance
- Financial power of attorney
 - Immediately effective or springing
 - Authority limited to grant in documents, can be tailored
 - Very powerful and very useful
 - Requirements vary by state
 - Note: Financial institution might require specific form
- Trusts
 - Asset management and probate avoidance

Health Care Supports

- Telehealth and remote medical monitoring
- GPS tracking
- Remote video monitoring
- Electronic medication management devices
- Care managers and coordinators
 - Professionals who identify needs, create care plans, implement services
 - Patient coordinators/navigators—organize health care and treatment, facilitate communication/info sharing
- Living will directive with agent/supporter designation
 - Varies by state

Health Care Supports (cont.)

- Health care surrogate, proxy, agent
 - Short form/oral
 - Document and state law control scope of authority
 - If no surrogate designated, state law might designate default surrogate
- Power of attorney for health care
 - Requirements vary by state
 - Immediately effective or springing
 - Authority limited to grant in documents, can be tailored

Selecting and Implementing Supports

- It's not just a menu, it's a process.
 - Identify the specific issue and familiarize yourself with all of the circumstances.
 - Get to know
 - Background, history, life experience
 - Goals and values
 - Abilities and limitations
 - Target supports to specific issues
 - Start with most informal supports first
 - Use creative combinations, trial and error
 - Always a person-directed and person-centered process!
 - Remember that everything evolves and changes.

Part 4: Decisional Supports in Action

Who am I?

- I'm a 23 year-old with autism, furthering disability rights and justice through providing direct services to youth with disabilities.
- I work as a Youth Independent Living Specialist for Able South Carolina.
- In my free time, I enjoy chess and strategy video games and spending time with friends and my significant other.
- I am also an advocate for Supported Decision Making, and independent living.



Holden Roberts

My Training as a Youth Ambassador with the Center on Youth Voice, Youth Choice

Over the course of several months, we learned about different ways people can get help with making decisions. We also learned about the negative effects of having people make decisions for you without your input. I also helped to lead the South Carolina State Team that promotes supported decision-making.

Our CYVYC Youth Ambassador Projects

- Every youth ambassador works on their own project. My project involves making a resource for young adults and teens in South Carolina. This resource provides specific information about decisional supports in our state. Many youth are not aware of what decisional supports can help them.
- Another resource in development is geared towards parents of younger children with disabilities. It helps parents prepare early for supported decision-making, so that they can have high expectations for their children and help them practice decision-making skills.

Benefits of the CYVYC Youth Ambassador Training

- Applying it to my own life, and knowing that it's okay to ask for help sometimes.
- Encouraging the principles of it to friends and family.
- Teaching about decisional supports at the Equip Summer Series and the Youth Leadership Forum.
- Being a resource for our peers who seek our services at Able South Carolina.
- During our training, we learned a lot about the fight for disability justice nationwide and how important it is to promote autonomy for everyone.
- We made meaningful partnerships and built greater community across states for people with disabilities.

Questions for Holden

- What kinds of conversations did you have with your family about making your own decisions, and getting help with making decisions?
- What are some examples of how you've used supported decision-making?
- How have you chosen your supporters?
- What would you tell someone who is just learning about supported decision-making? What advice would you give them?

Example

- Mary is an older adult who lives alone in her own home. She is married but separated from her husband. Mary has a daughter who lives in another state and a son who lives nearby. Mary receives Social Security and a support check from her husband every month.
- Mary's daughter has become concerned after learning that some of Mary's bills have gone unpaid, she has missed a number of doctor appointments, and her neighbors are complaining that her house is falling into disrepair/hoarding.

Conclusion

- Hilary Dalin, Office of Elder Justice and Adult Protective Services at the Administration for Community Living

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ELDER
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Case Consultations

Case consultation assistance is available for attorneys and professionals seeking more information to help older adults. Contact NCLER at ConsultNCLER@acl.hhs.gov.