

**The Culture of Coordinated
Support:
Health Care and Life
Planning**

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ARTICLE OF FAITH

“[P]hysical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society”

The Americans with Disabilities Act,
42 U.S.C. 12101

AND YET

People with Disabilities have more medical conditions, yet are more often poorly diagnosed [and] over/under treated

- Office of the Surgeon General "The surgeon general's call to action to improve the health and wellness of persons with disabilities." (2005)

MAYBE THAT'S BECAUSE...

In a recent survey, 10% of people under guardianship or who sought guardianship for someone identified a medical professional as the person who first recommended it.

- Jameson, et al 2015

THE SITUATION OUT THERE

- In DC....
 - 70% of people served by Department on Disability Services have a guardian or substitute decision-maker.

- Nationally....
 - According to the CQL database, only one-half or fewer of the over 8,100 people reviewed were exercising choices about home, work, goals or services in a way that was meaningful to them.

KEY CONCEPT: “INFORMED CONSENT”

- The Heart of the Dr/Patient relationship
- Three Key Parts:
 - Information from Dr to person
 - Understanding by the person
 - Choice by the person and communication to Dr
- American Medical Association

AS WITH EVERY DECISION

- Assistance can be provided to help individual make medical decisions:

“Explain that to me in English”

- Ability to make decisions is a continuum. A person may be able to make some but not others

Capacity to Consent to Surgery is NOT the Same as Capacity to Perform Surgery

THEREFORE

There is a need to empower and enable Informed Consent in ways that are

- Flexible
- Immediate
- Improve Dr-Patient communication and collaboration
- Increase the role of family, friends, and people close to the patient

DOESN'T THAT SOUND LIKE SUPPORTED DECISION-MAKING?

People working with friends, family members, and professionals to help them understand the situations and choices they face so they can make their own decisions

- Blanck & Martinis, 2015

“The solutions also are different for each person. Some people need one-on-one support and discussion about the issue at hand. For others, a team approach works best. Some people may benefit from situations being explained pictorially. With Supported decision-making the possibilities are endless.”

- Administration for Community Living, “Preserving the Right to Self-determination: Supported Decision-Making”

MAYBE THAT'S WHY ...

Supported Decision-Making has been endorsed by:

- US Department on Health and Human Services
- American Bar Association
- National Guardianship Association
- ASAN
- The Arc
- NAMI

MAKING IT HAPPEN

- Easy as adding language “and for decision-making purposes” in HIPAA release
- Or make up your own form.
- Or use models, like those found at www.SupportedDecisionMaking.Org

POA WITH SUPPORTED DECISION- MAKING

Power of Attorney giving agent decision-making authority:

“It is my and my agent’s intent that we will work together to implement this Power of Attorney. That means that I should retain as much control over my life and make my own decisions, with my agents support, to the maximum of my abilities. **I am giving my agent the power to make certain decisions on my behalf, but my agent agrees to give primary consideration to my express wishes in the way she makes those decisions.**”

MEDICAL ADVANCED DIRECTIVE WITH SUPPORTED DECISION-MAKING

“My agent will work with me to make decisions and give me the support I need and want to make my own health care decisions. This means my agent will help me understand the situations I face and the decisions I have to make. Therefore, at times when my agent does not have full power to make health care decisions for me, my agent will provide support to make sure I am able to make health care decisions to the maximum of my ability, with me being the final decision maker.”

“PERSON CENTERED PLANNING”

Person Centered Plan MUST:

- Address “health and long-term services and support needs in a manner that reflects individual preferences and goals.”
- Result “in a person-centered plan with individually identified goals and preferences, including those related community participation, employment, income and savings, health care and wellness, education and others.”
- <https://www.medicaid.gov/medicaid/hcbs/downloads/1915c-fact-sheet.pdf>

Culture of Coordinated Support: Doesn't That Sound Like:

Special Education Transition services are “a coordinated set of activities”

- To “facilitate the child’s movement from school to post-school activities, including post-secondary **education**, vocational education, integrated **employment** (including supported employment), continuing and adult education, adult services, **independent living**, or community participation;”
- Are “based on the individual child’s needs, taking into account the child’s strengths, preferences, and interests; and
- Include “instruction, related services, community experiences, the development of employment and other **post-school adult living objectives**, and, when appropriate, **acquisition of daily living skills** and functional vocational evaluation.”

20 USC 1401(34)

CULTURE OF COORDINATED SUPPORT: DOESN'T THAT SOUND LIKE

VR Supports and Services include:

- Assessments
- Counseling
- Job search and retention services
- Assistive technology
- Medical and mental health care
- Education Expenses (including College)
- On the job training
- Job coaches
- Transportation
- “Maintenance” payments
- Interpreters
- Services to family members (like Day Care!)

34 CFR 361.48

PERSON CENTERED PLANNING FOCUSES ON

What is:

- Important TO the Person
- Important FOR the Person

Where the Person is and where the Person wants to be

- What needs to change and what needs to stay the same to get there

**CULTURE OF COORDINATED SUPPORT:
DOESN'T THAT SOUND LIKE...**

Supported Decision-Making?
The Student Led IEP?
Informed Choice in VR?
Informed Consent in
Medical Care?

PLANNING THROUGHOUT THE LIFE COURSE

Supported Decision-Making can work in a number of contexts – if it requires a decisions, Supported Decision-Making can help the person exercise the Right to Make Choices

EXAMPLE: FINANCIAL AUTHORITY

I will not buy, sell, manage, or otherwise take or exercise any interest in any tangible property or item costing or worth more than \$X without my agent's agreement. For example, if I want to buy or sell a car for \$20,000, I would need my agent to agree or the sale could not go through.

In making decisions whether or not to buy, sell, manage, or otherwise take or exercise any interest in any tangible property or item costing or worth more than X, **my agent and I will discuss the situation and give consideration to my express wishes before my agent decides whether or not to agree.**

EXAMPLE: BANKING

I agree that my agent will be listed as a joint account holder on all bank or other financial institution accounts – including checking and savings accounts, as well as credit and debit cards – that I have or open while this power of attorney is in effect.

I agree that I will not withdraw more than \$X from any account, write a check for more than \$X, or otherwise cause more than \$X to be withdrawn from or charged to any account unless my agent agrees.

In making decisions whether or not to agree to write checks, withdraw money from my accounts or charge money to my accounts, my agent and I will discuss the situation and **give consideration to my express wishes before my agent decides whether or not to agree.**

WHAT DOES THAT ALL ADD UP TO?

“[P]eople with disabilities cannot have a decent quality of life with limited financial resources and modest government support.”

- Forbes Magazine, “Are Tax-Free ABLE Accounts The Right Financial Solution for People with Disabilities,” 12/4/14

WHEN YOU RECEIVE PUBLIC BENEFITS

- To live independently, many people rely on public benefits like Medicaid, SSI, and SSDI
- To qualify for Medicaid/SSI, you generally may not have more than \$2,000 of countable assets. Earnings of more than the substantial gainful activity (SGA) level can also affect eligibility for these programs.
- If families provide financial or “in-kind” support, the person may be disqualified or have benefits reduced.

ENTER ABLE

Achieving a

Better

Life

Experience

WHAT IT IS

- Like 529 Accounts for Education
- Family, friends can contribute up to \$14,000 per year into an ABLE account
- ABLE account money can be withdrawn, tax free, to pay for housing, transportation, healthcare and other expenses
- Money in an ABLE account **does not** affect eligibility for Social Security or Medicaid/Medicare (if there is more than \$100,000 in account, SSI benefits will be suspended, but still receive Medicaid).

ELIGIBILITY FOR ABLE

An ABLE Account can be established for or by any individual with a disability, including:

- An individual eligible for SSI or SSDI due to blindness or disability.
- An individual who WOULD be eligible under disability criteria for SSI/SSDI, even if
 - S/he has not been found eligible
 - S/he WOULD NOT be found eligible due to income.

ESTABLISHING ELIGIBILITY

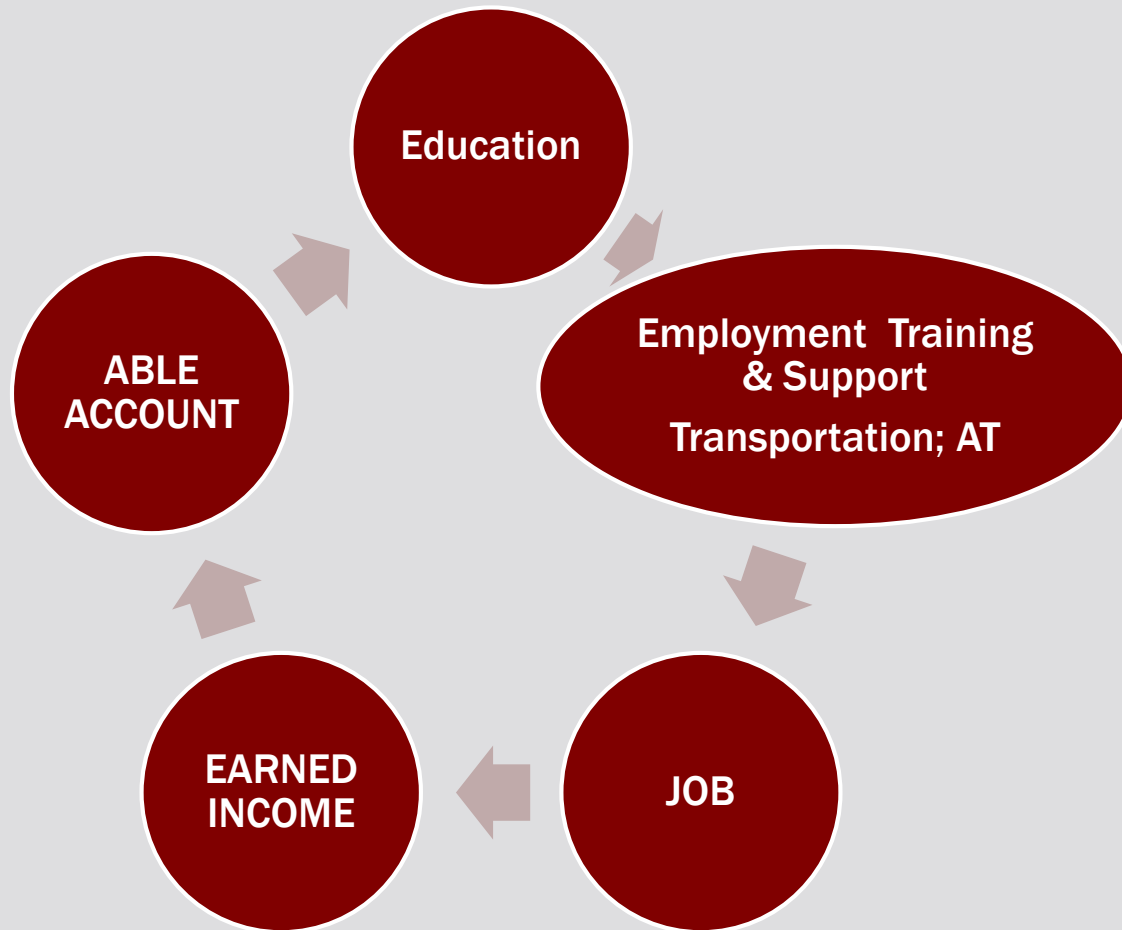
- Is designed to be done by filling out a tax form with a Dr certification saying the person has a disability that would make him or her eligible for SSI or SSDI
- States can set up their own ABLE accounts but you don't have to live in the state to open an account
- Missouri ABLE account is the STABLE account:
www.MoABLE.Com

SPECIFICALLY

ABLE Account funds can be used for:

- **Education**—including tuition for preschool thru post-secondary education, books, supplies, and educational materials related to such education, tutors, and special education services.
- **Housing**—including rent, mortgage payments, home improvements and modifications, maintenance and repairs, real property taxes, and utility charges.
- **Employment Support**—including expenses related to obtaining and maintaining employment, including job-related training, assistive technology, and personal assistance supports.
- **Health**—including premiums for health insurance, medical, vision, and dental expenses, habilitation and rehabilitation services, durable medical equipment, therapy, respite care, long term services and supports, and nutritional management.
- **Transportation**—including the use of mass transit, the purchase or modification of vehicles, and moving expenses.
- **Other Life Necessities**—including clothing, activities which are religious, cultural, or recreational, supplies and equipment for personal care, community-based supports, communication services and devices, adaptive equipment, assistive technology, personal assistance supports, financial management and administrative services, expenses for oversight, monitoring, or advocacy, funeral and burial expenses.

A PATH OUT OF POVERTY



ABLE ACCOUNTS AND SELF- DETERMINATION

In ABLE Accounts, the person with disabilities decides how the money is spent

THE WHOLE POINT

Purpose of the ABLE Act is:

“supporting individuals with disabilities to maintain health, independence, and quality of life.”

MAKING IT ACHIEVE-ABLE

If Increased Self-Determination=Improved Health, Increased Independence, and Better Quality of Life . . .

**Shouldn't ABLE Accounts
Increase Self-Determination?**

BRINGING IT TOGETHER: A COORDINATED SUPPORT PLAN

- **Review!** Go through each area of the individual's life.
 - Example: Financial, Medical, Social, Employment
- **Brainstorm!** Does the person need support in these areas?
 - If so, talk about what support could help, who could provide it, and how
- **Write!** As you develop support solutions, create a written plan for the person and team to use
- **Attach!** Include it as part of the person's IEP, ISP, IPE, and other plans

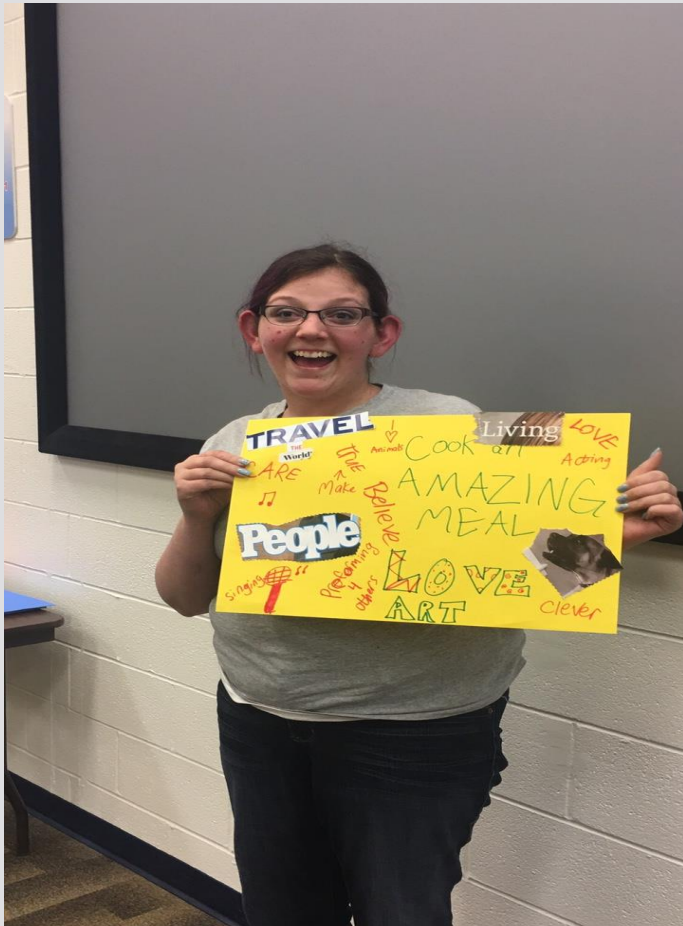
MAKING IT HAPPEN: DREAM-INSPIRED PLANNING

- Coordinating and collaborating to create support plans that build on the person's dreams.
- Goals and Objectives are created by working with the person to identify their dreams, the values that make them up, and the education, employment, independent living, and other goals that match up to them

DREAM-INSPIRED PLANNING: THREE STEPS

- **Dream:** The person identifies and communicates his/her dreams
- **Dig:** Conversations between the person and the support coordinator about his/her dreams, the values and visions that make them up, and the implications of them
- **Develop:** The person and support coordinator develop program goals and objectives that are consistent with and move the person toward their dreams

DREAMING



IT CAN HAPPEN: PROJECT RENEW

Provided young adults with coordinated services including employment planning and training as well as education in independent living skills and social skills- Malloy, 2013.

- First year of program
 - 93% of participants found employment
 - 69% maintained employment for more than 6 months

 - 2 years after program
 - 94% either completed high school or were involved in a high school program
 - 75% were enrolled in post-secondary education
 - 83% found employment
- Hagner, Cheney, & Malloy, 1998

IT IS HAPPENING

- Laws in Texas, Delaware, Wisconsin, Tennessee, and the District of Columbia increasing access to Supported Decision-Making
- National Resource Center for Supported Decision-Making – www.SupportedDecisionMaking.Org
- Projects in South Carolina, Tennessee, New York, Kentucky, California, Nevada, North Carolina, Maine, Massachusetts, Florida, Georgia, and others focused on increasing access to Supported Decision-Making

IT IS HAPPENING: RUTLAND, VERMONT AND PICKAWAY OHIO

- Partnerships between High School, Vocational Rehabilitation, and I/DD agency
- Identifying HS Students with I/DD who are at risk of guardianship
- HS, VR, and I/DD Agency creating joint plans with unified goals and complimentary supports to maximize independence

THE ELEPHANT IN THE ROOM: SAFETY

NOTHING: Not Guardianship, Not Supported Decision-Making is 100% "Safe."

HOWEVER: Supported Decision-Making Increases Self-Determination (Blanck & Martinis, 2015), which is correlated with increased Safety (Khemka, Hickson, & Reynolds, 2005).

SIGNS AND SIGNALS –ABUSE, NEGLECT, EXPLOITATION

- Injuries
- Unusual bruising or abrasions
- Fear or nervousness
- Withdrawal Basic needs not being met
- Bills not being paid
- Living below means
- Unexplained changes in lifestyle

REMEMBER: PROTECTION IS AVAILABLE

If you see Abuse, Neglect or Exploitation:

Neglect

- Police
- APS
- CPS
- Attorney General's Fraud Unit
- Protection and Advocacy System

BUT REMEMBER: ADULTS ARE ALLOWED TO MAKE BAD DECISIONS

- Health
- Money
- Love
- Living Conditions

CHANGE THE CULTURE, CHANGE THE WORLD!

“Long after the schools, Vocational Rehabilitation, early interventionist, behavioral consultants, and para-educators have gone. the students will be adults. . . We [are] ethically, morally, and fiscally responsible for supporting their lives of success and meaning. . . . We have the tools, we have the means . . . we have the vision.”

Gustin, 2015

JOIN THE CONVERSATION

**National Resource Center for
Supported Decision-Making:
SupportedDecisionMaking.Org**

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