Options for Decision-Making Support When My Child Turns 18

Quality Trust
for Individuals with Disabilities

November 18, 2020

1

1

Quality Trust
for Individuals with Disabilities

- **Independent advocacy and monitoring**
  - Children and adults with disabilities
- **Dignity, respect, and autonomy**
  - Rights protection and decision-making supports
- **Personal Support Services**
- **Jenny Hatch Justice Project** (2013 to present)
  - www.JennyHatchJusticeProject.org
  - JHJP Health Care Decision-Making Initiative (2019 to 2021)
- **National Resource Center for Supported Decision-Making** (2014 to present)
  - www.SupportedDecisionMaking.org

2

2

Jenny Hatch Justice Project's
Health Care Decision-Making Initiative

▸ JHJP is dedicated to protecting and advancing people with disabilities' **"Right to Make Choices"**
▸ We provide **free legal services** to qualifying **Maryland residents with developmental disabilities** who need assistance with **less restrictive legal options for health care decision-making**
  - Supported Decision-Making
  - Advance Directives
  - Other Legal Options

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3

3

Today's Topics

▸ **What Happens at Age 18?**

▸ **What is Adult Guardianship?**

▸ **Why Think About Other Options First?**

▸ **What is Supported Decision-Making?**
  ◦ **What?**
  ◦ **Why?**
  ◦ **How?**
    • **Example**: Health Care

TO DO LIST

4

4

What Happens When My Child Turns 18?

▸ In Maryland, people become **legal adults** when they turn 18.

▸ They get to **make their own decisions**, regardless of whether or not they have a disability
  ◦ <u>Maryland Exception</u>: Special Education

5

Continuum of Main Legal Tools for Decision-Making in Maryland

▸ **Supported Decision-Making**
▸ **Advance Directive &/or Power of Attorney**
▸ **Exception for Special Education Students,** by operation of Maryland Law
▸ **Surrogate Decision-Maker in Healthcare,** by operation of Maryland law.
▸ **Representative payee**, appointed by SSA
▸ **Court-appointed Guardian**
  ◦ Guardian of Person
  ◦ Guardian of Property
  ◦ Both

These are examples of less-restrictive options

There are many more, like Trusts, MOLST Forms, ABLE Accounts, etc.

Call QT to learn more!

6

What is "Guardianship" for Adults?
Rate Your Familiarity

Poll 2

7

7

What is "Guardianship" for Adults?

▸ A **formal legal process** where a **court** determines whether an adult is **"incapacitated"** and, if so, **whether someone else** (a "guardian") **must be appointed** to make all or some decisions for them.

▸ Guardianship = **Court + Court Order + Court Oversight**

8

What are Some Myths about Guardianship?

- ⊘ Parents are automatically guardians of their adult children with disabilities. ➡️ <u>FALSE</u>
- ⊘ Individuals appointed guardian of a minor child with a disability remain guardian when the child becomes an adult ➡️ <u>FALSE</u>
- ⊘ Parents need guardianship to review their adult child's records ➡️ <u>FALSE</u>
- ⊘ Parents need guardianship to go to their adult children's planning meetings and appointments ➡️ <u>FALSE</u>
- ⊘ Guardianship always protects adults with disabilities from abuse. ➡️ <u>FALSE</u>

9

Why Think About Other Options First?

- ‣ Guardianship **takes away** some or all of a person's rights to make important decisions about his or her life.
- ‣ The **court** will become part of both the guardian's and the person's lives going forward.
- ‣ Guardianship can **change relationships**.
- ‣ Guardianship can take **time** and cost **money**.
- ‣ Guardianships are **difficult to modify or terminate**.
- ‣ For many people with disabilities, **decision-making is a learned skill** – people need the opportunity to practice!
- ‣ **Self-Determination = Better Life Outcomes**

10

Explore Alternatives First

‣ **<u>Finding the Right Support:</u>**
   ◦ What **kind of decision** needs to be made?
   ◦ How much **risk** is involved?
   ◦ How hard would it be to **undo** the decision?
   ◦ Has the person made a **decision like this** before?
   ◦ Is the decision likely to be **challenged**?
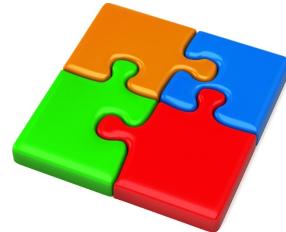
‣ **<u>Ask</u>**: What is the **least restrictive** support that might work?

‣ **<u>Remember:</u>** Use the Right **Tool**, for the Right **Decision**, at and for the Right **Time**

11

Rethink "Capacity"

‣ Capacity is **<u>not</u>**
   ◦ **"all or nothing"**
   ◦ Based solely on **IQ or diagnosis.**

‣ People **may have "capacity" to**:
   ◦ Make **some decisions** but not others.
   ◦ Make **decisions some times** but not others.
   ◦ **Make decisions if they get help understanding** the decision to be made.

‣ A **lack of opportunity** to make decisions can **prevent** people from **developing capacity** or **further decrease capacity**

12

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13

What is "Supported Decision-Making"?
Rate Your Familiarity

Poll 3

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14

14

Supported Decision-Making: What?

‣ **Supports and services** that help an adult with a disability make his or her own decisions, by using friends, family members, and other people he or she trusts:
  ‣ to **help understand** the issues and choices
  ‣ **ask questions**
  ‣ **receive explanations** in language he or she understands, and
  ‣ **communicate** his or her own decisions to others.
‣ Now formally recognized in **D.C. Law 22-93** (May 2018)

15

15

Myths of Supported Decision-Making

⊘ Supported Decision-Making isn't available in my state because we don't have a Supported Decision-Making law. ➡ <u>FALSE</u>

⊘ People with intellectual disabilities don't have the capacity to use Supported Decision-Making. ➡ <u>FALSE</u>

16

16

Supported Decision-Making: Why?

▸ **Self-Determination**
  ▸ **Life control** — People's ability and opportunity to be "causal agents . . . Actors in their lives instead of being acted upon" (Wehmeyer et. al, 2000)

▸ **Studies have shown people with disabilities with greater self-determination are**:
  ▸ More **independent**
  ▸ More **integrated** into their communities
  ▸ **Healthier**
  ▸ Better able to **recognize and resist abuse** (see reference list)
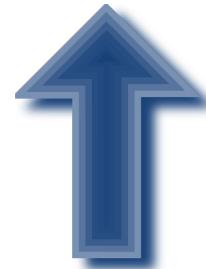
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17

More evidence

▸ **When denied self-determination**, people can:
  ▸ "[F]eel **helpless, hopeless, and self-critical**" (Deci, 1975).
  ▸ Experience "**low self-esteem, passivity, and feelings of inadequacy and incompetency**," decreasing their ability to function (Winick, 1995)
▸ **Decreased Life Outcomes**
  ▸ Overbroad or undue guardianship can cause a "significant negative impact on . . . physical and mental health, longevity, ability to function, and reports of subjective well-being" (Wright, 2010)

18

More evidence

▸ Students who have self-determination skills are **more likely to successfully make the transition to adulthood**, including improved education, employment, and independent living outcomes (Wehmeyer & Schwartz, 1997)

▸ **People with intellectual and developmental disabilities** who do not have a guardian are more likely to:
  ◦ **Live in their own homes or apartments**
  ◦ Be **included in the community**
  ◦ Have their **rights respected**
  ◦ Have **community jobs or service plans** with that goal
  ◦ Be **supported to communicate** with friends
  ◦ Be **involved in making choices** about their own lives.
  (Bradley et al., National Core Indicator Data Brief, 2019)

19

19

Supported Decision-Making: How?

▸ There is **no one method** of Supported Decision-Making
  • SDM **looks different** for everyone

▸ **Supporters work with the person to find out:**
  ▸ What are their **goals**?
  ▸ What **help** do they need?
  ▸ **Who** do they want to give them that help?
  ▸ **How** do they want the help to be given?
  ▸ **What will it take** to make their own decisions with support?

ONE SIZE DOES NOT FIT ALL

20

20

"Tool Box" for Supported Decision-Making

‣ **Effective Communication**

‣ **Informal** or **Formal** Supports

‣ **Peer Support**

‣ **Practical Experiences**

‣ **Role Play** and **Practice**

‣ **Life Coaching**

‣ **Technology**

‣ **Welcoming and Respectful Environments**

21

21

More Tools for SDM

‣ **Written Documents**
  ◦ Release of Information forms – "HIPAA" or "FERPA"
  ◦ Other Written Plans
  ◦ Advance Planning Tools
‣ **Supported Decision-Making Guides**
  ◦ See Resource List
‣ **Law, Regulations, and Policy**
  ◦ Americans with Disabilities Act
  ◦ Maryland Statute on Nondiscrimination in Access to Anatomical Gifts and Organ Transplantation, Md. Code Ann., Health-Gen. §§ 20-1601 to 20-1606

22

22

Example: Less Restrictive Options in Health Care

➡ **Supported Decision-Making**
  ‣ **Maryland Advanced Directive**, for health care and/or mental health decisions
  ‣ **Surrogate Decision Making**, under the Maryland "Health Care Decisions Act"

23

Supported Decision-Making in Health Care

  ‣ **HIPAA Release Forms**

  ‣ **Americans with Disabilities Act**
    ‣ **Reasonable accommodations** of disability when medical professionals obtain informed consent
    ‣ **Assistance** can be provided to help the person make and participate in medical decisions:
    ‣ **"Support person"** (not "visitor") in hospital and/or ambulance during time of COVID-19 visitor bans
    ‣ Maryland's law on "**Nondiscrimination in Access to Anatomical Gifts and Organ Transplantation**"

  ‣ **Not all medical decisions are the same**
    ‣ Blood draw vs. Surgery

24

24

Health Care SDM Guides & Resources

▸ **Autistic Self Advocacy Network:** "Transition to Adulthood: A Health Care Guide for Youth and Families

▸ **My Choice Kentucky:** "Blood Draw Tool"

▸ **The Arc of the U.S.:** "A Letter for My Doctors"

▸ **VIDEOS!**
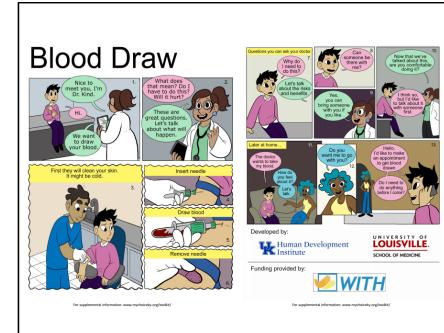
25

Everyone Has the "Right to Make Choices"

▸ **Support your child in building capacity** to make decisions over time.

▸ **Explore less restrictive alternatives** to decision-making support before thinking about guardianship.

26

Ask Questions Tonight or Later

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27