

“Transfer of Rights” & Supported Decision-Making

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Topics We Will Cover

- ▶ What happens when students with a disability turn 18?
- ▶ What is adult guardianship?
- ▶ Why should families and IEP teams think about other options first?
- ▶ What are some other options in school?
 - What is “Supported Decision-Making” and how does it work?

What Happens When A Student Turns 18?

- ▶ Under D.C. law, students become legal adults when they turn 18 years old.
- ▶ They generally get to make their own school decisions – even if they have an IEP.
- ▶ This is called “transfer of rights.”
 - Written notices
 - Evaluations
 - IEP meetings
 - Complaints and due process hearings

Why do families think about getting guardianship?



Why do families think about getting guardianship?

Family members may:

- ▶ Have been told by their child's school to do so.
- ▶ Be worried about access to their child's doctor.
- ▶ Want to help their child handle money.
- ▶ Be concerned that they will not be able to connect their child with adult services.

What is “Guardianship” for Adults?

- ▶ Guardianship is a formal court proceeding that removes a person’s right to make some or all of his or her own decisions and gives that right to someone else, called a “**guardian.**”
- ▶ Guardianship = Going to **court** + court **order**
- ▶ A judge decides if the person with a disability is “**incapacitated**” and, if so, whether guardianship is “**necessary.**”
- ▶ It can vary in **scope** -- time-limited vs. permanent; general vs. limited.

Why should families 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 life going forward.
- ▶ Guardianship may **change relationships**.
- ▶ Guardianship may take **time** and cost **money**.
- ▶ **Decision-making is a learned skill** – people need the opportunity to practice!

And it also makes sense!

▶ **Self-Determination**

- ▶ Life control — People's ability and opportunity to be actors in their lives, rather than being acted upon

▶ **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

Studies Show:

- ▶ Students who have self-determination skills are **more likely to successfully make the transition to adulthood**, including improved education, employment, and independent living outcomes
- ▶ Promoting self-determination is a “**best practice**” in special education
- ▶ **Schools should focus on improving students’ ability** to set goals, solve problems, make decisions and advocate for themselves and, just as importantly, to give students the opportunity to exercise these skills

AND

- ▶ **When denied self-determination**, people can:
 - ▶ “[F]eel **helpless, hopeless, and self-critical**” (Deci, 1975, p. 208).
 - ▶ Experience “**low self-esteem**, passivity, and feelings of inadequacy and incompetency,” decreasing their ability to function (Winick 1995, p. 21).
- ▶ **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, p. 354)

AND

People with intellectual and developmental disabilities who **do not have a guardian** are more likely to:

- ▶ Have a **paid job**
- ▶ **Live independently**
- ▶ **Have friends** other than staff or family
- ▶ Go on dates and **socialize** in the community

2013-2014 National Core Indicators

Or, As the National Guardianship Association Says

“Alternatives to guardianship, **including supported decision making**, should always be identified and considered whenever possible **prior to the commencement of guardianship proceedings.**”

- National Guardianship Association, “Position Statement on Guardianship, Surrogate Decision Making and Supported Decision Making” (2015)

And Yet....

▶ Research shows:

- **Guardianship** is treated like the **default option** for students with intellectual disabilities.
- **School personnel** are the **most frequent source** of recommendations that parents seek guardianship.
- Estimated number of adults under guardianship has **tripled** since 1995.

Guardianship May Be Needed

▶ In emergency situations when

- The person is incapacitated and cannot give consent
- The person did not previously identify how decisions should be made in that situation
- There is no one else available in the person's life to provide consent through a Power of Attorney, Advanced Directive, or other means

▶ To support people:

- Who face critical decisions and have no interest in or ability to make decisions
- Who need immediate protection from exploitation or abuse

Guardianship is never needed just:

- ▶ “Because he has an IQ of ____”
- ▶ “Because she has ____ diagnosis”
- ▶ “Because they need help”
- ▶ “Because that’s the way its always been”

That is not enough!

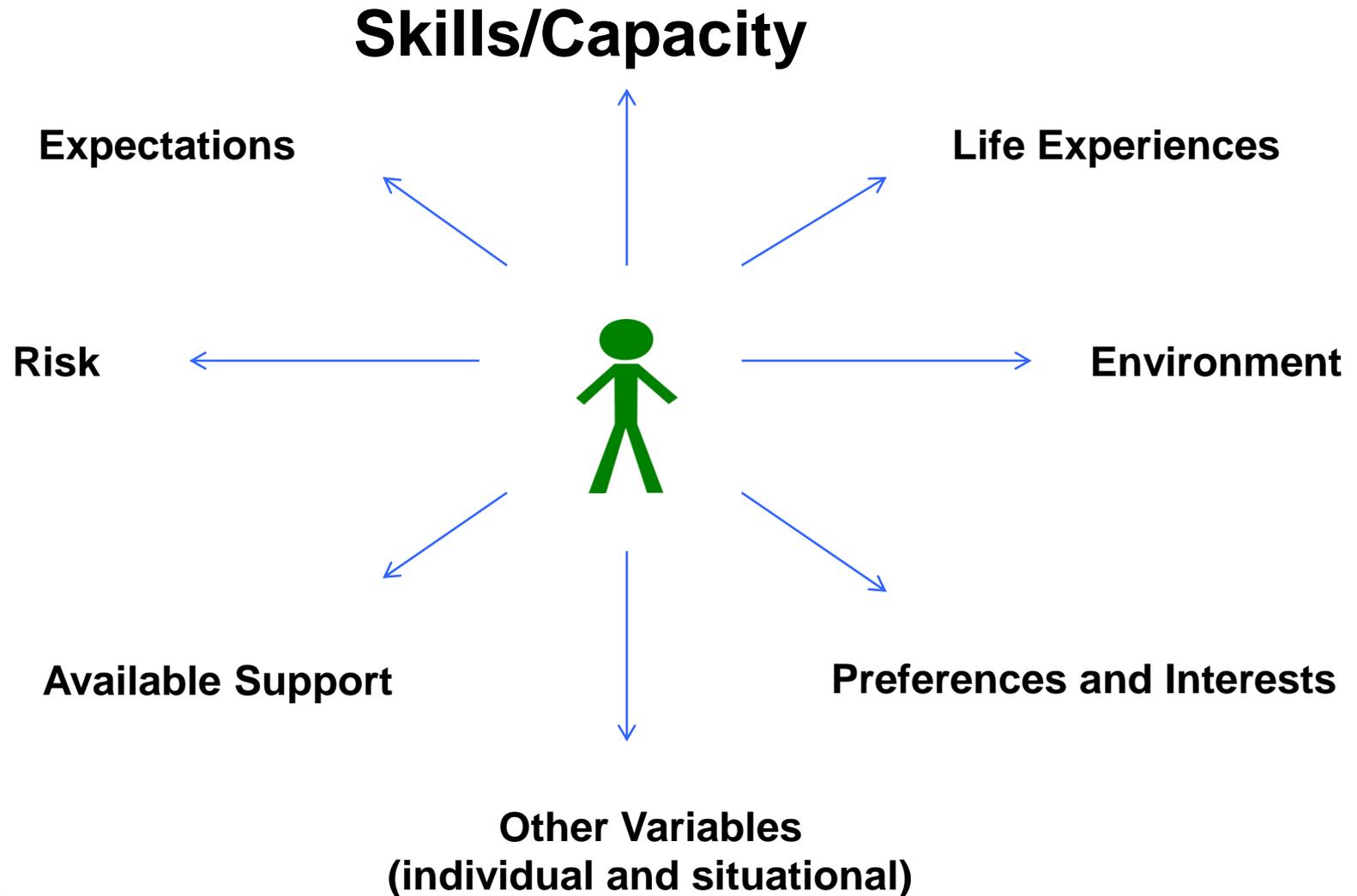
Explore Alternatives First

- ▶ Finding the Right Support: Considerations
 - 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**?
- ▶ Ask: What is the **least restrictive** support that might work?

Remember: Capacity is NOT “all or nothing”

- ▶ It is not based solely on IQ or diagnosis
- ▶ A person may be able to:
 - Make some decisions and not others
 - Make decisions at some times, but not others

Rethink “Assessment”



Decision-Making Supports in Education



U.S. Dept. of Education, Office of Special Education & Rehabilitative Services

- In January 2017, DOE OSERS issued “A **Transition Guide** to Postsecondary Education and Employment for Students and Youth with Disabilities” that included second on “**Parental Consent, Age of Majority, Supported Decision-Making and Guardianship**”
 - <https://www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-2017.pdf>
- ▶ “A student **need not be placed under guardianship** in order for his or her family to remain involved in educational decisions. **Guardianship places significant restrictions on the rights** of an individual. Students and parents are urged to **consider information about less restrictive alternatives.**”

More from U.S. DOE

- ▶ “If State law permits parental rights under the IDEA to transfer to a student who has reached the age of majority, that **student can become the educational rights holder** who invites family members to participate in the IEP meeting.”
- ▶ “If the adult student does not want to have that role, he or she can **execute a power of attorney** authorizing a family member to be the educational decision-maker.”
- ▶ “Alternatively, . . . a **supported decision-making arrangement** can be established consistent with applicable State procedures, in which the parents (or other representatives) assist the student in making decisions, if the student has not been determined to be incompetent but does not have the ability to provide informed consent with respect to his or her educational programs.”
 - “**Unlike under guardianship, the student remains an autonomous decision-maker in all aspects of his or her life.** To learn more about supported decision-making visit: www.supporteddecisionmaking.org.”

D.C. Options for School Decisions

1. **Supported Decision-Making**
2. **Educational Power of Attorney**
3. **Educational Representative**, appointed by OSSE

1. “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, professionals, 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.

SDM is Already in D.C. Law & Policy

- ▶ **Special Education Student Rights Act of 2014**
 - ▶ “[S]tudent[s] who ha[ve] reached 18 years of age may receive support from another competent and willing adult to aid them in their decision-making”
 - ▶ See D.C. Act 20-486, Sec. 104(b)(1) & (2) (March 2015)
- ▶ **Office of the State Superintendent of Education Regulations (July 2016)**
 - ▶ Includes a definition of Supported Decision-Making and a section to implement it.
 - ▶ See D.C. Mun. Regs. Title 5-E, Secs. 3001.1, 3034.1-3034.3
 - ▶ Available at <https://osse.dc.gov/service/education-decision-making>

SDM is Already in D.C. Law & Policy

- ▶ **D.C. Public Schools, *Transfer of Rights Guidelines***
(Aug. 2013)
 - ▶ Recognizes supported decision-making as an alternative to guardianship for adult students with disabilities in D.C.
 - ▶ Available at: <https://transitioncentral.files.wordpress.com/2011/12/transfer-of-rights-guidelines.pdf>
- ▶ **DCPS Supported Decision-Making Form**
 - ▶ Available at http://supporteddecisionmaking.org/sites/default/files/dcps_supported_decision_making_form.pdf
- ▶ **OSSE Supported Decision-Making Model Form**
 - ▶ Available at <https://osse.dc.gov/service/education-decision-making>

Supported Decision-Making: Why? Ryan's Story



“Ryan is a whole person. We want him to be whole. **The decision process is part of being whole . . .** If I try to force Ryan to do something, I am destroying his selfness and being whole. **He is a whole person and he is making decisions and I encourage him.**”

– Herbert King

For more on Ryan's story, visit
[http://www.supporteddecisionmaking.org/
impact-stories/ryan-king](http://www.supporteddecisionmaking.org/impact-stories/ryan-king)

Supported Decision-Making: How?

- ▶ There is **no “one size fits all” method** of Supported Decision-Making
- ▶ It can include, as needed and appropriate,
 - ▶ Informal support
 - ▶ Written agreements
 - ▶ Formal Micro-Boards and Circles of Support(Martinis, Blanck, & Gonzalez 2015)

Common Considerations

- ▶ All forms of SDM recognize:
 - ▶ The person's autonomy, presumption of capacity, and **right to make decisions** on an equal basis with others;
 - ▶ That **a person can take part in a decision-making process** that does not remove his or her decision-making rights; and
 - ▶ **People will often need assistance in decision-making** through such means as interpreter assistance, facilitated communication, assistive technologies, and plain language.

SDM in Education: How?

- ▶ Help the adult student sign an OSSE or DCPS **SDM Form**
- ▶ **Help the student get ready** for meetings ahead of time.
- ▶ Make sure IEP team meetings are **student-friendly**.
- ▶ Slow the conversation down – **No rushing decisions.**
- ▶ Support the student in **leading** or **participating** his or her own IEP meeting.
- ▶ **Start Early!**

Supported Decision Making Form

Adult Student: _____

Address: _____

Cell Phone _____ Home Phone _____

Washington, DC _____

Street

Zip Code

I understand that I may create a network of individuals to help me inform my educational decisions related to my Individualized Education Program (IEP) once I reach the age of majority. I would like the following individual(s) to assist me with making educational decisions. I understand that my parent or other individuals may support me in the decision making process and may have access to the documents listed below.

NAME	RELATIONSHIP	HOME ADDRESS	EMAIL ADDRESS	PHONE NUMBER
1.				
2.				

Members in my network may have access to the following educational documents if I have checked the box next to it:

DOCUMENT	ACCESS
IEP meeting invitations, and agendas	
Requests for assessments	
Requests for changes in placement	
Requests for changes in services	
Exit requests	
Progress reports	
Report cards	
Attendance information	
Assessment results	
Other	

It is my understanding that I make the final decisions about my educational future after communicating with members in my network, and can remove a member from my network, or their access to my educational documents at any time.

Adult Student Signature Date

Network Member Signature Date

Network Member Signature Date



DISTRICT OF COLUMBIA
OFFICE OF THE STATE SUPERINTENDENT OF

EDUCATION

Supported Decision-Making Model Form

This is a model form intended to provide assistance to local education agencies (LEAs) and adult students to document supported decision-making decisions described in Title 5-E, Section 3034 of the District of Columbia Municipal Regulations (DCMR). Supported decision-making is supports, services, and accommodations that help a student with disability under the Individuals with Disabilities Education Act (IDEA), who has reached age 18 and to whom all IDEA rights have transferred, make his or her own decisions, by using adult friends, family members, professionals, 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. LEAs are encouraged to use this form or create an alternative process for meeting the documentation requirements in 5-E DCMR § 3034.3.

Adult Student Name: _____
(Last) (First) (Middle)

Date of Birth: ____/____/____ Unique Student Identifier (USI): _____
MM DD YYYY

Address: _____

City: _____ State: _____ Zip: _____

Telephone Number(s): _____

Email address: _____

I understand that I may create a network of individuals to help me make educational decisions related to my Individualized Education Program (IEP) once I reach the age of eighteen (18). I would like the following individual(s) to assist me with making educational decisions. I understand that my parent or other individuals may support me in the decision making process and may have access to my educational records if I grant them access.

Name:	Relationship to me:
Address:	Phone number(s):
	Email address, if applicable:

Name:	Relationship to me:
Address:	Phone number(s):
	Email address, if applicable:

If there are additional people you would like in your network, please list all of their information on a separate piece of paper.

Members in my network may have access to the following educational documents if I have checked the box next to it:

DOCUMENTS	✓	DOCUMENTS	✓
IEP meeting invitations and agendas		Progress reports	
Requests for assessments		Report cards	
Requests for changes in placement		Attendance information	
Requests for changes in services		Assessment results	
Exit requests		Other	

I understand that I make the final decisions about my educational future and I can remove a member from my network or revoke their access to my educational documents at any time.

Adult Student Signature _____
(Date)

I understand that the student makes all final decisions about his or her educational future and the student may remove me as a member of his or her network or revoke my access to his or her educational documents at any time.

Network Member Signature _____
(Date)

Network Member Signature _____
(Date)

SDM in Education

- ▶ **Include the student in IEP meetings**, starting in elementary school.
- ▶ **Support IEP goals and objectives** related to self-determination and decision-making.
 - For every goal, there should be an application of self-determination to get there. Use “I statements”
 - Promote student involvement and accountability.

2. “Power of Attorney”

▶ What is a “Power of Attorney” or “POA”?

- A legal paper where an adult agrees that someone else will make decisions for him/her under certain circumstances and in certain areas of his/her life.

▶ How’s a POA different from guardianship?

- The person decides what power to give away and who gets it, not a court.
- The person can cancel or change the POA.

Educational Power of Attorney

Compare . . .

Educational Decision

- ▶ Deciding whether or not to file a Due Process Hearing Request to fight a change in school placement.

Educational Power of Attorney

- ▶ Deciding who you would trust to make that school decision for you.

3. “Educational Representative”

- ▶ This option is for when an adult student: (1) **cannot** make his or her **own educational decisions, even with support**, and (2) **cannot sign a power of attorney**.
- ▶ This option requires the **submission of forms to OSSE**, including two signed professional certifications.
- ▶ If the student **challenges** the appointment of an educational representative, this **option cannot be used**.
- ▶ See <https://osse.dc.gov/service/education-decision-making>

What about Medical Decisions?

There are Other Options Too!



1. Supported Decision-Making

- ▶ “HIPAA” Release Forms
- ▶ Reasonable Accommodations under American with Disabilities Act.
- ▶ Not all medical decisions are the same! (flu shot vs. open heart surgery)

2. Durable Power of Attorney for Health Care

- ▶ **Model DC Form** with SDM Principles (for informational purposes only): <http://www.supporteddecisionmaking.org/node/390>

3. Substitute Health Care Decision-Maker, under D.C. Code § 21-2210

What about Financial Decisions?

There are Other Options Too!

- ▶ **Supported Decision-Making**
- ▶ **Direct deposit and payment**
- ▶ **Joint bank accounts**
- ▶ **Financial Power of Attorney**
- ▶ **Representative payee**
 - Manages a person's social security benefits and is appointed by the Social Security Administration, not a court.
- ▶ **Trusts**
- ▶ **Conservatorship**



SDM: More on How

- ▶ **Quality Trust for Individuals with Disabilities**
 - ▶ www.DCQualityTrust.org
- ▶ **National Resource Center for Supported Decision-Making**
 - ▶ www.SupportedDecisionMaking.org
- ▶ **NRC-SDM 2016 “From Theory to Practice” Webinar Series**
 - ▶ Archived webinar topics include implementing SDM in education, community based supports, and with financial decisions.
 - ▶ Available at: <http://www.supporteddecisionmaking.org/events>
- ▶ **“Supported Decision-Making Teams: Setting the Wheels in Motion”**
 - ▶ Parents guide available at: <http://www.supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf>

Everyone Has the “Right to Make Choices”

- ▶ Support students in **building capacity** to make decisions over time.
- ▶ Encourage families to **explore less restrictive alternatives to decision-making** support before thinking about guardianship.
 - Example of **tools** that can be used to explore alternatives like Supported Decision-Making can be found at www.SupportedDecisionMaking.org.

Quality Trust is here to help!

- ▶ Quality Trust for Individuals with Disabilities:
 - Is a **legal and lay advocacy resource** for students planning transition from school-to-adult services.
 - Can help students with disabilities, in collaboration with their families, **explore alternatives to adult guardianship.**
 - Can provide **free training** for parent groups, students with disabilities, educators, and school transition coordinators on available decision-making supports.



Ask Questions – Now or Later

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