




Marilyn Stata


*“I am starting to get self-direction services and I feel really proud of myself.”*


## What’s Inside...

This issue of *Bridges* highlights

### **Guardianship and Supported Decision-Making**

 **Guardianship and Supported Decision-Making**  
page 2-5

 **Anxiety and School Avoidance Workshop**  
page 6

 **Functional Behavior Assessments and Behavior Intervention Plans Workshop and Webinar**  
page 6

## Personal Perspectives

### Interview with *Marilyn Stata*

#### What do you do for fun?

What I do for fun is hanging out with friends at movies or mall.

#### Do you work? If yes, tell us about your work.

I currently work for Sam’s club in Henrietta as a door Greeter checking receipts, welcoming members, helping them figure out which aisle has certain items they’re looking for.

#### Do you volunteer? Where do you volunteer?

I volunteer for SANYS, Self-Advocacy of NYS.

#### What is an important decision you have made in your life? How do you feel about this decision?

I am starting to get self-direction services and I feel really proud of myself.

#### Who helps you with problems or helps you make important decisions?

My parents help me when I’m concerned and frustrated about issues pertaining to me, especially financial issues. I would rather have help and respect the decision than do something wrong and be in a bind.

#### How does it make you feel if someone close to you tries to make a decision for you?

When others make decisions for me instead of with me I get frustrated because I don’t have a say in what I want to do. If I need assistance with judgment I will let someone know.

*“I would rather work together than just have someone else do it for me.”*

#### What is your dream for the future?

I will be starting a job with the state that’s my dream job. I love meeting new people. I will help with the conferences, helping the individuals with some advocacy projects and new groups just starting. I will be advocating for people in the group homes and doing some meetings.

#### What does “self-advocacy” mean to you?

Self-advocacy means how to speak up for my needs and things I need to do.

# Guardianship and Supported Decision-Making

How do we make decisions? Who do we turn to? Most of us consult with family, friends, or trusted professionals to decide. This process of consulting with others describes supported decision-making. From where to go for lunch to important financial and health care options, decision-making touches every aspect of our lives. Is decision-making different for adults who have disabilities? It may be a guardian who makes the decisions; or it may be the person working with a trusted group of supporters who make decisions together. In this issue of *Bridges*, we explore two different decision-making options. Which one is right for your family? Only the adult who has a disability together with their circle of support can decide.

## What is Guardianship?

### Article 17A

In New York State, when a person becomes 18 years old they are assumed to be legally able to make decision for themselves. This means no other person is allowed to make a personal, medical or financial decisions for that person. If a person is “intellectually disabled or developmentally disabled (I/DD),” has difficulty making decisions for themselves and over 18 years old, you can ask the Surrogate’s Court to appoint a guardian for them.

### Guardianship Basics

- Families have traditionally been advised to pursue guardianship as a way of protecting their children; today this notion is being challenged
- Requires only certification from one physician and one psychologist or two physicians
- A guardian is appointed by the court
- Very broad in scope of decision-making – a guardian legally can make all healthcare, financial, housing, education, employment, and every other decision for the person
- Most restrictive type of decision-making – takes away a person’s civil rights and gives them to the guardian

An Article 17-A Guardianship is available only for people who are I/DD. These are the legal terms used in Article 17-A of the Surrogate’s Court Procedures Act.

A certification from one physician and one psychologist or two physicians must be filed with the petition certifying that the person has a disability and is not able to manage their affairs because of intellectual disability, developmental disability or a traumatic head injury. The Surrogate’s Court can appoint a guardian of the person, the property, or both.

An Article 17-A Guardianship is very broad and covers most decisions that are usually made by a family for a child such as financial and healthcare decisions.

Adapted from <https://www.nycourts.gov/courthelp/Guardianship/17A.shtml>

Guardianship is the means by which the state (through a court proceeding) takes the right and power to make choices away from a person (often called the “ward”) and gives the power to another, the guardian. In New York, the ward loses all legal ability to make decisions about healthcare, finances, where to live, who to associate with, what kind of education or work they will have, and every other aspect of their life.



### What is the purpose of guardianship?

Historically, guardianship has been seen as a way of protecting vulnerable persons, including persons with I/DD. Changes in the way that we understand disability today challenge this view. For example, research shows that promoting self-determination and inclusion in the community is often the best protection. Even if guardianship may have made sense in the past when no one expected persons with I/DD to strive for greater independence, today self-determined and inclusive lives are the goal.

The current law in New York allows families to obtain guardianship, often without even a hearing, based entirely on affirmations by healthcare professionals attesting to their child’s I/DD and the conclusion that it would be in the child’s best interest to have a guardian appointed. This law has been widely criticized by scholars and practitioners and new versions of the law with more procedural protections are being considered by the legislature.

# Guardianship and Supported Decision-Making

## What is Guardianship? *continued from page 2*

### Why do people seek guardianship for their children?

Families are often told that they need to obtain guardianship when their child with I/DD turns 18 in order to participate in their child's educational planning or to seek benefits from the Office for Persons with Developmental Disabilities (OPWDD). This misinformation often leads families to seek guardianship without realizing that guardianship entails the total deprivation of their child's rights and without considering available alternatives.

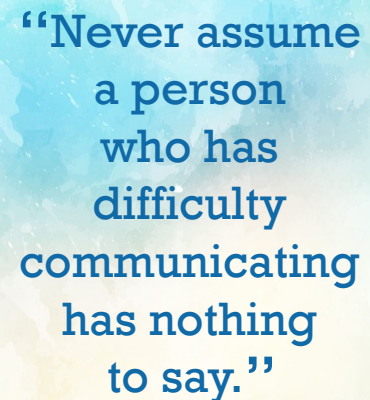
For further information, please see <http://sdmny.org/wp-content/uploads/2017/04/170509-Guardianship-and-Alternatives-FAQs.pdf>

### Article 81 of the Mental Hygiene Law

Appointment of a Guardian for Personal Needs and/or Property Management, authorizes a proceeding based on the concept of the least restrictive alternative - one that authorizes the appointment of a guardian whose authority is appropriate to satisfy the needs of an incapacitated person, either personal or financial, while at the same time tailored and limited to only those activities for which a person needs assistance. The standard for appointment under this procedure focuses on the decisional capacity and functional limitations of the person for whom the appointment is sought rather

than on some underlying mental or physical condition of the person.

For further information, please see <http://ocfs.ny.gov/ohrd/materials/151670.pdf>



**“Never assume a person who has difficulty communicating has nothing to say.”**

## What is Supported Decision-Making?

Supported decision-making (SDM) is an alternative to guardianship that allows a person with a disability to work with a team and make their own choices about their own life. Under this model, the person designates people to be part of a support network to help with decision-making.

SDM promotes self-determination, control and autonomy. It fosters independence. Unlike *substituted* decision-making, where guardians or family members or caregivers make decisions for the individual, *supported* decision-making enables the person to make

their own decisions with assistance from a trusted network of supporters.

Likewise, people with disabilities may need assistance making decisions about living arrangements, health care, lifestyles and financial matters, but they don't necessarily need a guardian to make those decisions for them. What they might need instead is a trusted network of supporters to field questions and review options so they too can confer and consult, and then reach their own decisions. Supporters can be family members, co-workers, friends, and past or

present providers (though many SDM models discourage paid staff on support networks). It is critical that the individual select supporters who know and respect their will and preferences, and will honor the choices and decisions they make.

For further information, please see <http://supporteddecisions.org/about-sdm/>

Often the arrangement will be reduced to writing in a contract called a “supported decision-making agreement.” Some institutions, like schools, may agree to accept such agreements instead of guardianship as is the

*continued on page 4*

# Guardianship and Supported Decision-Making

## What is Supported Decision-Making? *continued from page 3*

case in Washington, DC. Some states, like Texas and Delaware, now have laws requiring private third parties (like doctors, financial institutions, or landlords) to accept supported decision-making agreements. While New York does not yet have such a law, Supported Decision-Making New York hopes to develop evidence that will support legislation, regulations, and policies that will make supported decision-making a more readily available alternative to guardianship in the future.

For further information, please see <http://sdmny.org/for-parents/alternatives-to-guardianship/>

### How to Provide Support

A supporter is someone who a decision-maker knows and trusts. Generally, good supporters have an understanding of the decision-maker's abilities, learning styles,

and personality, and are aware of how the decision-maker's strengths and weaknesses may affect her decision-making process.

When supporting a decision-maker, a skilled supporter:

- listens more than talks
- repeats, reviews and simplifies information for a decision-maker
- observes the decision-maker's body language
- encourages purposeful conversations led by the decision-maker
- asks open-ended questions
- helps the decision-maker to give authentic responses instead of those that a supporter prefers
- focuses on the decision-maker's strengths rather than weaknesses.

### How Not to Provide Support

Importantly, supporters do NOT rescue. A "rescuer" gives advice, controls, knows best, disempowers, jumps to conclusions, doesn't listen, and

talks a lot. A "rescuer" might try to complete a task for a decision-maker, instead of allowing her to assume the responsibility for completing that task, despite the possibility that she might not do it successfully—or at least as well as the would-be "rescuer"—and that the decision-maker might face unwanted consequences. Instead, a supporter believes in the "dignity of risk."

### What is Dignity of Risk?

Sometimes a decision-maker's decisions will not go in the way that decision-maker or supporters prefer. However, every "poor" decision may present a valuable learning opportunity that will help the decision-maker in the long run. In the words of Robert Peske,

***"To deny the right to make choices in an effort to protect the person with disabilities from risk is to diminish their human dignity."***

For further information, please see <http://sdmny.org/for-parents/how-to-provide-support/>

## Supported Decision-Making Basics

- An alternative to guardianship
- Allows people who have disabilities to choose family, friends, or trusted others to support them in making their own decisions
- Often the arrangement will be documented in a contract called a "supported decision-making agreement"
- A person retains their civil rights
- A person-centered approach to decision-making

## Alternatives to Guardianship and SDM in New York State

There are many alternatives, depending on why people think guardianship may be desirable in the first instance. For example, if the issue is financial, there are alternatives including representative payeeships for SSI payments, authorized representation for Medicaid benefits, joint or limited bank accounts, credit or bank cards with predetermined limits, and powers of attorney. For healthcare, the persons with I/DD may execute a healthcare proxy. Also, New York's Family Healthcare Decisions Act permits involved family members to make decisions on behalf of persons with I/DD without guardianship.

# Guardianship and Supported Decision-Making

## Interview with Desiree Loucks-Baer

Desiree Loucks-Baer is the Director of Program and Member Services, NYS Association of Community and Residential Agencies (NYSACRA). Most recently, she has been working with CUNY/Hunter College on a DDPC grant developing and piloting a model for Supported Decision-Making for people with intellectual and developmental disabilities in NYS.

### How can parents and family members help persons with disabilities to be decision-makers?

Practicing decision-making is huge. Assist decision-makers to select supporters and to vocalize how and when to make decisions. Then make sure those choices are honored. Teach decision-makers to extend decision-making beyond family and friends to direct support personnel and to community members.

It's important to remember that decision-making for any of us involves risk. Give people who have disabilities opportunities to experience something different beyond the predictable choices in any given situation. They need the opportunity to take risks and to learn from them.

### Who can be a decision-maker? Is it inappropriate for persons who have significant disabilities?

Anyone can be a decision-maker. People who are non-verbal, for example, still communicate choices. They communicate to people in their support networks what they prefer or don't prefer. Decision-making is very person-specific.

We know through research that supported decision-makers are safer, more empowered, and develop better relationships. People in a guardianship situation are more vulnerable because they are less empowered.

I want parents and family members to understand that supported decision-making is another tool in the toolbox. The decision ultimately comes down to the person and the family.

***“There is no greater disability in society, than the inability to see a person as more.”***

— Robert M. Hensel



## Resources

### American Association on Intellectual and Developmental Disabilities webinar, Education Archive, *Guardianship and Supported Decision-Making*

<http://aaidd.org/education/education-archive/2017/09/28/default-calendar/guardianship-and-supported-decision-making#.WeD2Vk2WxLO>

### Supported Decision-Making New York <http://sdmny.org/>

### Texas Council for Developmental Disabilities, *Supported Decision-Making*

<http://www.t added decision-making/>

### ASAN, Autistic Self Advocacy Network

<http://autisticadvocacy.org/2016/02/the-right-to-make-choices-new-resource-on-supported-decision-making/>

### National Resource for Supported Decision-Making

<http://www.supporteddecisionmaking.org/about>

### Delaware DDC, Supported Decision Making: Your Support, My Decisions

<https://www.youtube.com/watch?v=dGJe5KyflxM>

### Impact Stories: Jenny Hatch

<http://www.supporteddecisionmaking.org/impact-stories/jenny-hatch>

Check out Starbridge webinar recordings

### Guardianship and Supported Decision Making: *Planning for the Future - A Webinar Series to Explore Legal and Financial Options*



<http://www.starbridgeinc.org/resources/webinar-recordings>

# Starbridge Workshops, Conferences & Special Events

Check our website event calendar for updates! [www.starbridgeinc.org/events](http://www.starbridgeinc.org/events)

## Anxiety and School Avoidance

**January 16, 6:00-7:30pm**

Randolph Free Library  
26 Jamestown Street  
Randolph, NY 14772

(Workshop will be held in library basement, which is accessible by elevator)

Anxiety is a natural part of childhood, but when anxiety impedes on your child's ability to learn, you may need support and services through the Committee on Special Education. Learn how to collaborate with your child's school and what supports and services are available through school when your child has anxiety.

### Registration is required.

This workshop is FREE to family members of children who have disabilities or suspected disabilities.

**To register**, please go to the event calendar on our website at [www.starbridgeinc.org](http://www.starbridgeinc.org) or call Registration at 585-224-7399.

*Please request special accommodations at least two weeks before the event.*

## Functional Behavior Assessments and Behavior Intervention Plans

*Join us in-person or online!*

**January 25, 2018 | 12:00-1:30pm at Starbridge  
OR  
6:00-7:00pm via Webinar**

When a child's behaviors interfere with learning, students and teachers need strategies to minimize those behaviors. Join us either in person or online to explore the nature of a child's behavior and when a Functional Behavior Assessment (FBA) should be requested. Whether you are a family member or an educator, learn tools and strategies to support student success.



**Registration is required.** This workshop and webinar are FREE to family members of children and youth who have disabilities or suspected disabilities.

**To register for the workshop**, please go to the event calendar on our website at [www.starbridgeinc.org](http://www.starbridgeinc.org) or call Registration at 585-224-7399.

**To register for the webinar**, please go to <https://attendee.gotowebinar.com/register/4297936364463388417>

**Registration deadline: January 24**

*Please request special accommodations at least two weeks before the event.*

## Free Webinar! Creating a Path to Positive Behaviors

**January 16, 6:00-8:00pm**

### You will learn:

- When and why a Functional Behavior Assessment (FBA) is conducted
- When, why and how to develop a Behavior Intervention Plan (BIP)
- How the BIP leads to goals that can be built into a child's Individualized Education Program (IEP) & 504 Accommodations

**To register**, email: [info@parentnetworkwny.org](mailto:info@parentnetworkwny.org)  
call: 716.332.4170  
online: [www.parentnetworkwny.org/events](http://www.parentnetworkwny.org/events)

## Free Workshop! Preparing for a Meeting at Your Child's School

**March 13, 6:00-8:00pm**

Dibble Family & Event Center  
4110 West Main St Road, Batavia, NY 14020

### You will learn:

- Tips on how to prepare for the various meetings with professionals throughout the school year, including the Annual Committee on Special Education
- Tips on how to stay organized
- Learn how to be a powerful advocate

**To register**, email: [info@parentnetworkwny.org](mailto:info@parentnetworkwny.org)  
call: 716.332.4170  
online: [www.parentnetworkwny.org/events](http://www.parentnetworkwny.org/events)

*Please let us know if you need assistance with childcare or transportation when you register.*

*Presented by Starbridge in partnership with Parent Network of Western New York*



## Discipline and Suspension: Understanding the Rights of Students with Disabilities

**January 25, 12:00-2:00pm**

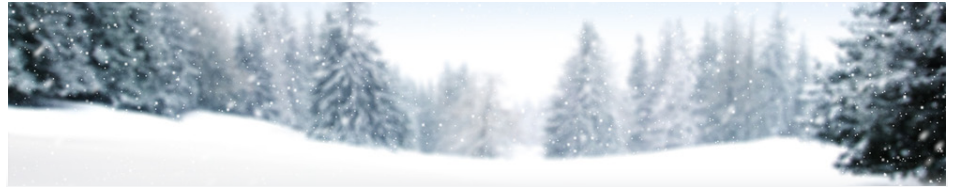
Exceptional Family Resources  
1820 Lemoyne Ave, Syracuse, NY 13208

Did you know there is a difference between general discipline procedures and discipline procedures for students with disabilities? Children with disabilities have specific rights under state and federal laws when it comes to suspensions and school discipline. This workshop will provide an overview of these rights and the process used for discipline and suspensions. Participants will learn about Functional Behavioral Assessments and how to create a proactive behavior management plan to help avoid future conflict.

**Registration is required.** This workshop is FREE to family members of children who have disabilities. **To register**, please contact Karen Adams at 315-478-1462, ext. 337.

*Please request special accommodations at least two weeks before the event.*

**OPWDD Family Education and Training Credit is available.**



## From the Editor:



This issue certainly challenges our ideas around guardianship and who makes decisions for our kids. Many of us pursued guardianship with all good intentions, to protect our children for example, in a critical health emergency. If my child was ill and couldn't speak for himself, would I want the medical staff making decisions for him or do we, his loving parents and guardians, make decisions? Among other scenarios, that's the way guardianship was presented to me a few years ago. My husband and I considered it a partnership much more than a dictatorship. We give Nick choices all the time and honor his decisions in every aspect of his life. Is being a guardian, even a very person-centered guardian, serving our son's best interests?

I have to admit my stomach turned when I considered that guardianship legally strips people of their civil rights and gives the power to make all decisions to the guardian. No one should have that much influence on another human being. So what do guardians do now who are considering changing this critical relationship? We can petition the court to reverse guardianship and the decision to do so would be decided by the court. It certainly is something to think about and possibly pursue in 2018.

\*\*\*\*\*

Wishing all of our readers happy holidays and a happy, peaceful 2018!

*Maria Schaertel*

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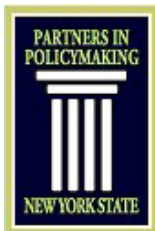
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