Supported Decision Making: Setting the Wheels in Motion

Connecting
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Raising Special Kids
As a father of a son who has autism and moderate intellectual disability, I often think of what his future will look like. I remind myself the realization I had 10 years ago when he was diagnosed at age two, ‘my job is to teach and support, to the best of my ability, so that he achieves his dreams.’ Some days the ‘best of my ability’ is just getting out of the way and allowing my now 12 year old to make mistakes and fail – allowing him the dignity of risk without shirking my duty of care as a parent is not always an easy balance. My wife and I have about five more years of practicing this balance, teaching and supporting to the best of our ability, until we will likely begin exploring legal options as our son approaches adulthood at 18 years of age.

Our lead article in this issue of Connecting discusses Supported Decision Making, and our family story highlights Janna, Mark and Tucker Murrell who decided as team that Supported Decision Making was the right option for them, rather than petitioning the court for guardianship when Tucker turned 18. Janna explains how it works for their family, “[Tucker’s Support Decision Making Team] all understand that Tucker is a part of every conversation,” and also that Supported Decision Making may not be appropriate for everyone.

If you have or are caring for a child who has a disability, the thought and process of transition to adulthood, specifically turning 18 years old, can come with a range of emotions. As Arizona’s Parent Training and Information Center, one of our responsibilities is to provide families the information they need to make fully informed decisions in the education and health care of their child who has a disability. One of the most powerful, and effective, methods of support is connecting families who have traveled the same path. If you would like to speak to a parent or family member about this, or any issue relating to raising a child of any age who has a disability, please know that Raising Special Kids is here.

Christopher Tiffany, MEd

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Supporting Decision-Making Teams: Setting the Wheels in Motion
By Suzanne M. Francisco with Jonathan G. Martinis, Esq. (used with permission)

Introduction:
For thousands of years – going back to Ancient Rome – society treated people with intellectual disabilities as if they were unable to take care of or make decisions for themselves. Today, it is still expected that someone else – usually called a guardian, but in California, a conservator – will be appointed to make decisions for them. In fact, that is often the advice parents get when their children with disabilities turn 18: become their guardian/conservator as soon as possible. It doesn’t have to be that way. This paper is about your options and actions you can take to help your children make their own decisions and direct their own lives to the maximum of their abilities.

I share this from my own experience. I am the proud mother of three children with disabilities. We have navigated our way through many systems, advocating for the tools, methods and resources they need to lead their best lives. I am the sister to a person with physical and mental illness. I watched with sadness when she was placed in a group home against her will, then shared her joy after she successfully fought to be released to her own supported apartment.

I carry their experiences, their strength, and their values with me as contributing author and an educational advocate, where I help children and young adults receive the support and services they need to transition to adulthood.

In this paper, I will present ways to help your children Set the Wheels in Motion toward lives of independence. The journey starts with a question.

WHY NOT Guardianship/Conservatorship?
The difficulty with guardianship/conservatorship is that it takes away the person’s Right to Make Choices, the basic right we all have to direct our lives to the maximum of our abilities. When people lose the right to control their lives, it’s like they don’t exist – someone else has the power to make decisions like where they live, what they do, who they see, and whether they work.

In the last forty years, study after study has found that when people with disabilities have more control over their lives, when they make decisions for themselves – when they have more self determination – they have better lives. People with disabilities who have more self-determination are more likely to be employed, independent, healthier, and safer.

Because of this, we should empower people to exercise their Right to Make Choices rather than to take it away. There are many less restrictive alternatives to guardianship/conservatorship that can do that. One of the most popular is Supported Decision-Making or SDM.

WHAT is Supported Decision-Making?
SDM can be defined as follows:
when we need to make decisions. We may ask our brother, the accountant, for financial advice or our sister, the doctor, to help us understand medical jargon. So, if we can do it, shouldn’t we give people with disabilities a chance to do it, too?

**HOW CAN I KNOW that a Person can use Supported Decision-Making?**

There are assessments that can examine a person’s ability to make decisions and manage key areas of life with and without supports. For example, the Missouri Stoplight Tool examines a person’s everyday abilities like managing money, working, and taking care of him or herself. However, no instrument is definitive or intended to provide a final determination of a person’s abilities.

Therefore, the best answer to the question “How can I know if a person can use SDM?” is this: You never know until you try. We should presume that everyone – including people with intellectual disabilities - has the right to make choices and everyone needs support until proven otherwise. So why not give the person the chance to use SDM: support him or her like you’d want to be supported or, even better, like he or she asks to be supported? That’s the advice the National Guardianship Association – an organization made up of guardians and conservators – gives: try SDM before seeking guardianship/conservatorship.

**SETTING THE WHEELS IN MOTION**

**Part 1: HOW can I help my Friend or Family Member use SDM?**

When individuals, families and their supporters hear and think about using SDM, there is often a pause. Then the question: “What do we do now?” As you think about that question, it is very important to stress the “WE.” By its very nature, SDM is a process and a journey where no one can, should, or needs to “go it alone.” The whole point of SDM is that it encourages people to seek out and work with others to help them. I use the term “Supported Decision-Making Team” to describe the individual and people who support him or her to make decisions. That’s because SDM is truly a Team Effort with the person as the “captain” or “coach.” When the team is working well together – when the wheels are in motion – the person is able to make his or her own decisions to the best of their abilities with the support of the team.

Because SDM will be a new concept to many people with exceptional abilities and their families, the entire process and the path can seem difficult or overwhelming. How can we discover what a person needs or wants help with? Or who the person wants help from? The most important thing to do is to begin. Set the wheels in motion! A free-form brainstorming session can help the person think about and specify his or her wants, needs, and abilities. Because, after all, the individual with exceptional abilities should “drive” the process. So, don’t over-think it. Listen to the person.

**Part 2: WHO should be on the SDM Team?**

To find the answer to this question, ask the person. And ask yourself: Who shares the joys of this person and is driven by a like purpose? Who does the person connect with? Who is the person motivated by? AND, who can also meet the person’s needs and wants? This may require people to stretch and reach for life’s possibilities. You may need to look to people who are not currently participating in the individual’s life. In our case, a long-time speech therapist, who we were unable to continue seeing, was the absolute clincher to connecting my daughter to the SDM journey. This “Gal Pal” of a therapist took my daughter shopping, into the community, and just “got” her. My daughter lit up with the mention of her favorite person who she had missed so much.

Here is a guide that may be able to help you as you think about who might be appropriate members of a SDM Team:

**A good SDM Team member is:**

1. Someone the person trusts and who is willing to go on the journey implementing SDM.
2. Someone who accepts and supports the individual/family.
3. Someone who has knowledge in a particular area we are seeking to include in the SDM agreement.
4. Someone that can be available long term (although changes to the Team should be anticipated over time).
5. Someone who is open to novel ideas, flexible and can make the individual “the agenda”.

**Part 3: WHAT are the Goals of an SDM Team? HOW do we Know What to Work On?**

Experience has taught us to think big picture at this stage rather
than getting stuck “in the weeds.” So think about the “big things” like:
- What are the person’s goals?
- What does the person need to reach those goals?
- What’s in the person’s way from reaching his or her goals?
- Who can help and how?

You may want to consider asking those questions for several “life areas” like:
- Finances
- Medical
- Housing
- Employment
- Education
- Speech and Language
- Interpersonal/Social Behavior
- Self-Care/ADL (Activities of Daily Living)
- Organization
- Recreation and Leisure

In seeking SDM Team members, consider where these areas overlap. For instance, social skills may fall under the life areas of speech, behavior and community integration. Remember, we want to keep it simple - we don’t need to know all the answers right now. It is important to start by having a conversation and setting goals. Think about what the person needs to reach those goals and who can help him or her do it. Generate a strategy that enables you to **Set the Wheels in Motion.**

**Part 4: HOW do we Schedule SDM Team meetings? HOW OFTEN should the Team Meet?**

The schedule should be based upon the needs of the person, as well as the needs of any potential SDM Team members. What is manageable for everyone on the team and will help the person reach a successful outcome? In other words, what works? Our advice is, at least in the beginning: meeting frequently is better. That way, the team can get to know each other and learn the best way to work together. Over time, and through trial and error, you’ll come up with a meeting schedule and style that works best for the person.

**How can we Keep Team Members Engaged and Interested in this Process?**

Once we have an idea of WHO the Team Members are and an initial schedule, **nurturing and fostering Team relationships is key.** In approaching potential team members, it is important not to overwhelm them - as a parent of three exceptional children, I have found this can often occur. Always remember and focus on the goal: helping the person make connections and develop decision-making skills. As you begin working with the Team, you should make sure that all members are “up to speed” on the person’s current supports and services. That will help the Team understand what is available to help the person and identify “missing” supports to seek out. We have found the SDM Parent Group - Individual Implementation Intake Form to be very helpful. [See resource list at the end of this article.]

It can be hard work. People may get frustrated. But there is a sense of joy and relief when it “clicks!” I had an epiphany, a “light bulb moment” if you will, waking up at 4am with an idea about how to help my non-verbal, teenage daughter work with an SDM Team. I realized that she already had people in her life who she loved and trusted: an Educational Psychologist, Advocate and family friend; a Speech Therapist; some neighbors. By getting the team together, we could (and still are) able to focus on goals and resources that fit what she wants to do.

**ALWAYS REMEMBER TO ASK: WHAT does our Unique, Exceptional Person Want?**

It is tempting for family members and SDM Team members to play the lead role. But, remember, the person is the “captain” of the Team. So, if you have not already done so, STOP and ask the person what he or she wants and who the person wants help from. Remember: just because people
need help in an area, it doesn’t mean they can’t make decisions about that area, or shouldn’t be given the chance to learn to do so.

Ask the person and yourself: What decisions does the person already make? How does he or she make them? Who does he or she connect with to help facilitate these decisions? That can give you a clue to his or her preferred way to make decisions. Another important question to ask is: What decisions are important to the person? What motivates him or her? Reinforcement surveys along with behavioral assessments and tools may be insightful for supporters and individuals who are non-verbal or who have intellectual disabilities. For my children, these interventions have been a key to understanding their thoughts and desires, so that we can support them to make decisions. The use of visuals along with daily, routine or ritualized practice of decision-making skills can be effective teaching tools. These abilities can be effectively captured and substantiated through data collection and video.

Once you know what is important to the person, and know how the person likes to make decisions, and who the person wants help from to make decisions, you can make a formal or informal SDM agreement that includes which decisions the person wants help with, who the person wants help from, and what type of help the person wants. This can be done through informal agreements or legal documents like a Power of Attorney.

Part 5: LET’S GET TO WORK
So much is possible even when the path is not clear. Now that you’ve set the wheels in motion, keep going! The ride may get bumpy. Keep going! There may be disagreements. Some Team members may not be a “good fit.” Difficult or “bad” choices may be made. Keep going! Every Supported Decision-Making Team paves the way to a future where everyone has the Right to Make Choices, can direct their own lives, and truly has the rights to life, liberty and the pursuit of happiness.

Set the Wheels in Motion!

RESOURCES

National Resource Center for Supported Decision Making
supporteddecisionmaking.org

Identifying Alternatives to Guardianship Worksheet "The Stoplight Tool" 2nd Edition

Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination

Alternatives to Guardianship: Supported Decision-Making Agreements

Supported Decision Making & the Problems of Guardianship
http://bit.ly/2XDkm8T

Supported Decision-Making: A User’s Guide for People with Disabilities and Their Supporters

Raising Special Kids Workshops & Training
Register online at www.raisingspecialkids.org or call 602-242-4366 | 800-237-3006

IEP Training
Gain a better understanding of the special education process and the Individualized Education Program (IEP).

Turning 18 - Legal Options
Learn about the different legal options families will need consider when their child becomes an adult at the age of 18.

Positive Behavior Support
Learn how to reduce unwanted behavior and increase preferred behavior by using Positive Behavior Supports in your home and in the community.
Janna Murrell first heard the term Supported Decision Making at a self-advocacy conference in Washington, DC about six months before her son Tucker was to turn 18. At the time, she and her husband Mark were planning to petition the court for full guardianship for Tucker; something they’d always assumed they’d do.

“I remember going to the conference hearing self-advocates say they were their own guardian and using the term ‘supported decision making,’ and thinking that’s not an option I would choose for Tucker and I just shoved it out of my head.”

Julie Ann Petty, a member of President Obama’s Committee for People with Intellectual Disabilities, was at the same conference. During a conversation with Janna, Julie talked about her own experiences with SDM and questioned why Janna would not consider it for Tucker. Janna remembers being offended and thinking, “You don’t understand! You’re not the parent! You don’t know him! We know how vulnerable he is! This is our personal choice!”

Weeks later, as Janna began filling out the guardianship paperwork, she would find herself putting it off, remembering Ms. Petty’s challenge. She started looking into at SDM beginning with the supporteddecisionmaking.org website.

As Tucker’s 18th birthday grew closer, Janna began having serious misgivings about standing before a judge claiming that Tucker is incapacitated. She thought of all the intelligent, insightful conversations they have and knew she couldn’t do it.

Janna, Mark and Tucker had a serious conversation. They considered the reality of their situation and discussed ways to address concerns. Together, they decided to try SDM and use some of the tools recommended. They started with a healthcare power of attorney. Janna explained the form to Tucker and took it to the notary at the bank who knows Tucker. He asked, “Do you want your mom to be your health care power of attorney?” Tucker told him “Pfft! Yeah!” And, the notary said, “That’s good enough for me.”

Supported decision making isn’t just about not petitioning the court for guardianship. Janna explained, “For us, it was all about using his existing network and explicitly talking about SDM with them. It’s no longer us making decisions for Tucker. Now it’s Tucker’s decision. If he needs help, he asks for help from his team. They all understand that Tucker is a part of every conversation.”

Janna is quick to point out that she does not think that SDM is right for everyone. “It’s not a one-size fits all. Right now, this works for us.” She continued, “There may come a time when that changes.”

Read about Arizona’s plan for establishing a SDM information and training pilot project at bit.ly/AzSDM.
Introducción
Durante miles de años—podemos remontarnos hasta la antigua Roma—la sociedad ha tratado a las personas con discapacidades intelectuales como si no pudieran cuidarse o tomar decisiones por sí mismas. En la actualidad, todavía se espera que se asigne a alguien más—que por lo general se denomina tutor o, en California, custodio—para que tome decisiones por ellas. De hecho, eso es lo que con frecuencia se aconseja a los padres cuando su hijo o hija con discapacidad cumple 18 años: vuélvase su tutor lo más pronto posible. No tiene que ser así. Este artículo habla de las opciones que tiene y las acciones que puede emprender para ayudar a su hijo o hija a tomar sus propias decisiones y dirigir su propia vida al máximo de su capacidad.

Comparto esto desde mi propia experiencia. Estoy orgullosa de ser madre de tres niños con discapacidad. Nos hemos abierto camino por muchos sistemas, abogando por las herramientas, los métodos y los recursos que necesitan para que vivan la mejor vida posible. Soy hermana de una persona con una enfermedad física y mental. Vi con tristeza cuando la enviaron a un hogar grupal contra su voluntad, y después compartí su alegría una vez que luchó con éxito para que le permitieran estar en su propio departamento respaldado. Llevo sus experiencias, su fortaleza y sus valores conmigo en calidad de autora colaboradora y defensora educativa, con lo que ayudo a niños y adultos jóvenes a recibir el apoyo y los servicios que necesitan para hacer la transición a la edad adulta. En este artículo, presentaré maneras de ayudar a sus hijos a ponerse en marcha hacia vidas independientes. El camino inicia con una pregunta.

¿POR QUÉ NO la tutela/custodia?
La dificultad de la tutela/custodia es que despoja a la persona de su derecho a efectuar elecciones propias, el derecho básico que todos tenemos a dirigir nuestras vidas al máximo de nuestra capacidad. Cuando las personas pierden el derecho a controlar sus
vidas, es como si no existieran; alguien más tiene el poder de tomar decisiones como dónde viven, qué hacen, a quién ven y si trabajan. En los últimos cuarenta años, estudio tras estudio, se ha encontrado que cuando las personas con discapacidad tienen mayor control de sus vidas, cuando ellas mismas toman decisiones—cuando tienen más autodeterminación—viven mejor. Es más probable que las personas con discapacidad que tienen mayor autodeterminación tengan un empleo, sean independientes, más saludables y estén más seguras. Debido a ello, debemos empoderarlas para que ejerzan su derecho a efectuar elecciones propias en lugar de quitárselo. Hay muchas alternativas menos restrictivas para la tutela/custodia que pueden hacerlo. Una de las más populares es la toma de decisiones con apoyo.

¿QUÉ ES LA TOMA DE DECISIONES CON APOYO?

Se puede definir de la siguiente manera:
Si lo piensa, lo anterior no es más que una forma rebuscada de describir cómo todos tomamos decisiones. Todos recibimos ayuda de amigos o familiares cuando necesitamos tomar decisiones. Podemos pedirle asesoría financiera a nuestro hermano contador, o a nuestra hermana doctora que nos ayude a entender la jerga médica. Entonces, si nosotros podemos hacerlo, ¿no deberíamos darles la oportunidad a las personas con discapacidad de hacerlo también?

Si quiere saber más sobre la toma de decisiones con apoyo, contacte acérquese a un especialista de apoyo familiar en Raising Special Kids, llamando al 602-242-4366 o enviando un correo electrónico a info@raisingspecialkids.org.

RECURSOS:
Alternativas a la tutela:
Los convenios sobre decisiones asesoradas
Convenio sobre decisiones asesoradas
Toma de Decisiones con Apoyo

Talleres y entrenamientos
Por favor vea nuestra página de web para el horario y los lugares más actuales, www.raisingspecialkids.org, o llame al 800-237-3007

El Comportamiento Positivo

Aprenda cómo reducir el mal comportamiento y aumentar el bueno. Comprenda el papel que usted tiene con respecto al comportamiento de su hijo, y como trabajar en conjunto con la escuela para que el mal comportamiento no interrumpa el aprendizaje.

Cumpliendo los 18 años - Opciones Legales

Aprenda sobre las diferentes opciones legales que las familias deben considerar cuando sus hijos se convierten en adultos a la edad de 18 años. Familiarícese con los pasos del proceso de la Tutela

Entrenamiento del IEP

Aprender acerca del propósito del IEP a través de una visión general del documento y reunión.
Recently, Dr. Ahmed Agha attended one of the two-part trainings provided for medical residents at Raising Special Kids. During the presentation portion, as she was sharing the story of her daughter’s prenatal diagnosis, the presenter could tell that the story was emotionally affecting Dr. Agha. He then shared with her that, before he and his wife began medical school, they, too, had received unexpected news during a prenatal ultrasound; their baby boy would be born with an orthopedic impairment. He described the emotional roller coaster they went through and how helpless he felt. He expressed that he wished he had known about Raising Special Kids at the time and noted what a difference it would have made for him and his wife.

The second part of the resident training is a visit at the home of one of our parent leaders. Imagine the mutual surprise when the door opened at his assigned family's home and he came face-to-face with Laurie Shook, the mother of a former patient. Dr. Agha had just begun his residency when he first met Laurie's daughter Adilyn. He had treated 4-year-old Adi during two separate weeks-long hospital admissions. Laurie shared, "Dr. Agha remembered how sick she had been and was shocked to see how far she has come. He just smiled in amazement because she is doing so well! We got to thank him for how much he helped us, and he got an update and an amazing story to share!"

Thank you to the doctors, nurses, therapists and all medical professionals. We are often reminded of how much your job means to so many families and how you can help move mountains!

Dr. Ahmed Agha and Adilyn Shook
Parent Leaders
Thank you! Parent Leaders are the heart of our mission.

Avondale
Belinda Johnson
Jennifer Priddy
Buckeye
Angie Jeffreys
Brittany Retsinas
Audre Slusher
Cave Creek
Cheryl Gilroy
Saritina Siebenaler
Chandler
Humaira Ahmed
Dawn Bailey
Marti Baio
Amanda Steele
Kara Szwier
Cathy Turner
Chino Valley
Johny Valley
Jody Brigham
Flagstaff
May Shepherd-Ketchner
Gilbert
Sherrine Hayward
Sonya Kanidis
Elisina Matthie

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Cheri Skiba
Tucson
Jaclyn Larson
Wendy Swartz
Kimberly Williams
Yuma
Maria Avina
Jennifer Delgado
Claudia Gamez
Nora Adriania Viayra Ramierz
Cynthia Yee

The Parent Leaders listed above participated in leadership activities from February 1 through May 31, 2019. We appreciate each of our 300 Parent Leaders, but we do not have room to list all of their names.

Thank You for Referring Families

A New Leaf
Ability360
Adelante Healthcare
Allum Health
All About Kids Pediatrics
Arizona Assocation for Gifted and Talented
Arizona Autism Society
Arizona Autism United
Arizona Charter Academy
Arizona Children's Academy
Arizona Cooperative Therapies
Arizona Department of Child Safety
Arizona Department of Economic Security
Arizona Early Intervention Program
Division of Aging and Adult Services
Division of Developmental Disabilities
Division of Employment and Rehabilitation Services/Rehabilitation Services Administration
Arizona Department of Education
Arizona Department of Education/ASPIRE
Arizona Developmental Disabilities Planning Council
Arizona Early Head Start
Arizona Hands & Voices
Arizona Healthcare Cost Containment System ALTPS
Arizona Pediatrics
Arizona Statewide Independent Living Council
Arizona's Children Association
Ash Fork Unified School District
ASU Preparatory Academy
Avondale Elementary School District
Banner University Family Care
Banner University Medical Center Tucson
Barrow Neurological Institute
BAYADA Pediatrics
Bayless Integrated Healthcare
Care1st Avondale Resource and Housing Center
Carol McLean, PhD
Catholic Charities Westside Head Start
Chandler Regional Medical Center
Child Crisis Arizona
Child & Family Support Services
Children's Clinics-Tucson CCRS
Christian Family Care
City of Phoenix Head Start
Clinica Hispana of West Valley
Community Legal Services
Desert Choice Schools
Desert Heights Academy
Desert Shores Pediatrics
Devereaux Advanced Behavioral Health
Diana's Tax & Document Services, LLC
Dignity Health-St. Joseph's Pediatrics
DMG Children's Rehabilitation Services
Down Syndrome Network
Dynamite Therapy
Eastersons Blake Foundation
Emily Center
EM Pact
Epilepsy Foundation of Arizona
Ethos Academy
Family Connections of SC
Family Partners
Family TIES of Massachusetts
Family Voices of Tennessee
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Flagstaff Medical Center
Florence Unified School District
Fort Huachuca EFMP
Foundation For Blind Children
Fun Van by First Things First
Gadsden School District
Gila River Health Care Behavioral Health Services
Gilbert Public Schools
Glendale Union High School District
Gompers School
Healing Hearts Pediatrics
Highlands Church
Honor Health Medical Group - Bethany Home
Hualapai Health Education & Wellness
Jewish Family & Children's Service
Joni and Friends International Disability Center
Juvenile Probation
Keogh Health Connection
Kyrene Elementary School District
La Frontera- EM PACT
Life Development Institute
Litchfield Elementary School District
Luke Air Force Base
Marana Unified School District
Maricopa Integrated Health System
Maricopa Medical Center
Mayo Clinic
MIKID
Mountain Park Health Center - Gateway
Mountain Park Medical Center
NAMI
New Hope of Arizona
New Leaf West Valley
New Life Center
NOAH — Neighborhood Outreach Access to Health
Northern Arizona Healthcare
Northland Family Help Center
Nuestra Salud/Our Health Foundation
Office of Councilwoman Laura Pastor
Painted Desert Montessori Academy
Paradise Valley Unified School District
Parent to Parent of Georgia
Parent to Parent of New York State
Pediatric Dialysis Center of Phoenix
Pendleton Pediatrics
Peoria Unified School District
Phoenix Children's Hospital
Phoenix Indian Medical Center
Phoenix Day School for the Deaf
Phoenix Union High School District
Pilot Parents of Southern Arizona
Roosevelt Elementary School District
SAGE Counseling
Sahuarita Unified Schools
Sojourner Center
Sonoran Sky Pediatrics
Southwest Behavioral & Health Services
Southwest Human Development
Southwest Network
Special Olympics
St. Joseph’s Hospital
Teen Outreach Pregnancy Services
Tornos Health
Touchstone Health Services
Tourette Association Arizona
Tuba City Boarding School
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