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WHO MAKES THE DECISIONS: A LOOK AT SUPPORTED DECISION MAKING

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hat is autonomy and do I have it? For most, having autonomy means the right for each person to make his or her own decisions on their own terms. It means having the right to live your life without undue interference from someone else. It means having the final say over decisions that affect your life, without anyone else having control to override those decisions. Conversely, losing autonomy could mean a restriction of the ability to control one's circumstances. For many others, it may mean a total loss of the ability to make decisions and determine how to live their lives. This total loss of decision-making authority is seen in many interdictions in Louisiana.

Imagine being served with court papers informing you that someone you may know, possibly a family member, is seeking a court order to take away your right to make your own decisions and gives that power to the family member. What follows may feel like an impossible battle to make your voice heard so you can prove that you do not need anyone else to make decisions for you. In this process, you are fully exposed. Personal and intimate details of your life, including sensitive medical information, become public record and are put on display to justify the need to restrict your rights. Despite pleas and evidence to the contrary, a court may determine that the person filing the request has proven enough to restrict or remove your rights. Suddenly, the life that once was yours is now under the control of someone else.

Think of all the rights you have as a bundle of sticks. Each one of the rights you have is a separate stick. These rights include the ability to make your own medical decisions, to choose where you live, to sue or be sued, to accept or renounce a succession, to enter into a contract such as a lease, to choose how you spend your money, or to choose who you associate with in your personal life. The rights at stake include everyday decisions that most people take for granted such as what you eat, what shows you watch, whether you can have sex, have a job, get married, have children, have friends, go on vacation . . .

the list goes on. With a full interdiction, the entire bundle of sticks is often taken from you and given to another person. In many cases, the person appointed by the court may not consider what you want or what might provide you quality of life and may unnecessarily restrict you when alternative options could have sufficed.

For decades, this restrictive, rights-revoking process was the only option available for individuals who need some assistance with decision making. However, that is no longer the case. With the passage of the Dustin Gary Act in Louisiana,¹ a new rights-affirming alternative became legally recognized: Supported Decision Making.

Supported Decision Making (SDM) has been available in some parts of the United States since 2006 after it was endorsed by the United Nations' Convention on the Rights of Persons with Disabilities² with the adoption of Article 12 which states: "persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life" and that "[all] parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity." This paradigm shift away from guardianship, or interdiction, and toward supported decision making is evident with SDM legislation that has been adopted throughout the United States.

What is SDM?

SDM is the process nearly everyone uses on a daily basis when making decisions. Every time you seek the advice of a close friend or colleague about a decision you are going to make, that is supported decision making. SDM legislation is simply the formalization of a process that all individuals rely upon when making decisions, and a recognition that individuals with disabilities are entitled to the same rights. While some may perceive this to be a revolutionary idea, SDM is simply an attempt to change the way society and the law view and treat people with disabilities or other neuro-divergent issues.

The most important aspect to remember about SDM is the individual with a disability is the decision maker. The individual chooses people who he/she knows and trusts to be part of the decision-making support network. The support network does not supplant decision making authority; they offer guidance and support to ensure all the necessary information is available in an understandable manner. This trusted network can field questions and review options to help the person with the disability make his/her own decisions.

A SDM agreement identifies who the individual would like to have as supporters, or the people he/she will rely upon when making decisions about various issues. An individual may choose as many or as few supporters as makes sense. For instance, an individual may choose a parent to assist with medical or financial decisions, but may choose a close friend to help with nutritional or general health decisions. The agreement identifies the decision area for which each supporter is responsible for providing assistance or advice.

The agreement also can be changed as the individual's needs change. Supporters can be added or removed and the agreement may be amended to reflect life changes. The identified supporters commit to providing information and guidance to the individual in the areas they are identified for. Supporters commit to honoring the individual's decisions, even if they disagree.

How Does SDM Benefit the Individual?

Where SDM has been implemented and utilized as a less restrictive alternative to guardianship, individuals report an increase in confidence and independence in expressing their opinions, increased willingness to try new things, and a greater desire to engage in social interactions. Individuals who utilize SDM are also more likely to maintain gainful employment and report feeling safer and more secure.

In Louisiana, the catalyst and namesake

of the SDM legislation is Dustin Gary. At the time the legislation finally passed, Dustin, who has a developmental disability, was turning 18 years old. His mother, Liz Gary, feared that under Louisiana law it was quite possible that her son would lose his decision-making rights. Prior to this legislation, there were no formally recognized less restrictive alternatives to interdiction. The lack of meaningful alternatives convinced many individuals associated with the provision of care and services for individuals with disabilities that it was necessary to change the law. Liz Gary, the ever-fierce advocate and mother, fought for an alternative for her son. She pushed for an option that would allow her son to have the same rights and opportunities as his older siblings and other persons without disabilities.

From the time that Dustin was very young, Liz Gary was passionate about affording Dustin the opportunity to be part of decisions that impact his life. From choosing what snacks to eat to what activities he participates in during the week, she made sure he understood the pros and cons for each decision, as well as the potential consequences. As with her other children, she educated Dustin about his decisions to ensure that he understood the consequences of each decision and how he can make better decisions in the future. These lifelong efforts set the stage for Dustin to utilize SDM as he transitions into adulthood because he has been making decisions in an informal SDM

model his entire life.

While the formalized SDM agreement is in progress of being developed, it is still too new for Dustin to reap the full benefits of having this less restrictive option in place as he traverses the many challenges in life as an adult. Dustin is currently finishing his final year of high school and, while he has expressed interests for what post-high school may hold for him, he has not made any final plans.

What is significant is the impact the informal SDM usage has had on Dustin. Dustin's teachers and peers have watched Dustin grow into an independent and confident young man over the years. He has excelled at developing social skills and taking initiatives to try new things that he observes his peers involved in. In the process, he has been able to make decisions with input from his family and friends as needed. For instance, Dustin is prediabetic so he has to be cautious about his diet and the food choices he makes. As a result of the lifelong support and guidance from his parents, Dustin is often able to make decisions about food and snacks that he wants, while balancing it with his health needs.

It is this lifelong reliance on a SDM model that has fostered Dustin's independence and confidence. Far too often children with disabilities are not provided adequate opportunities to learn and develop decision-making skills. Without those skills, they will lack the confidence in themselves or situations and will have difficulty socializing, taking



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NEW RESOURCE:

LSBA REFERENCE CARD ON INTERDICTION PROCEDURES & LESS RESTRICTIVE ALTERNATIVES

The LSBA recently published a reference card to educate the bench and the bar on the interdiction process and less restrictive alternatives, such as Supported Decision Making. An electronic version of the Reference Card can be accessed through the QR Code. Physical copies can be obtained at the Bar Center.



FOOTNOTES

1. La. R.S. 13:4261.101 through 4261.302 (enacted August 2020).

2. [https://www.centerforpublicrep.org/initiative/supported-decision-making/#:~:text=Supported%20decision%2Dmaking%20\(SDM\),the%20United%20States%20as%20well](https://www.centerforpublicrep.org/initiative/supported-decision-making/#:~:text=Supported%20decision%2Dmaking%20(SDM),the%20United%20States%20as%20well).

3. <https://legis.la.gov/legis/ViewDocument.aspx?d=1370243>.

4. Access the Bench/Reference Card for Interdiction Procedure & Less Restrictive Alternatives: www.lsba.org/documents/LSPD/RefCardInterdictionLessRestAlts.pdf.

initiative, or trying new things.

Dustin and his family have also benefitted from the guidance and support they have received in going through the process to develop a SDM agreement. It is often difficult to take a step back from the day-to-day decisions and look at the bigger picture, which can be overwhelming. Dustin and his family have been part of the Arc of Louisiana's SDM mentoring program to guide them through the process. This program has provided them with the tools and resources they need to make SDM a great success.

How Can the Legal Community Help?

Lawyers and judges play a key role in protecting the rights of individuals with disabilities and other neuro-divergent issues. The legal community is the front line for education and advocacy for the least restrictive option for individuals with disabilities. When families seek legal counsel to guide them when they are considering changing the legal status of a loved one, attorneys need to be able to present all the available options, including SDM.

In Louisiana, the passage of the SDM legislation included an amendment to interdiction law that specifies all less restrictive options must be considered or tried before seeking an interdiction. If a less restrictive option is not considered or tried, the reasons must be specifically detailed in the petition for an interdiction. The intention behind the amendment was to add a layer of protection to avoid unnecessarily restrictions on individual

rights. It is incumbent upon attorneys to provide information about SDM and encourage families to try it when appropriate for the individual.

The 2024 legislative session passed House Concurrent Resolution 38, which urges the Louisiana State Bar Association (LSBA) to "raise awareness about all legal options including but not limited to supported decision-making, power of attorney, continuing and permanent tutorship, and limited and full interdiction, and to assist parents and guardians of children with disabilities to obtain the best legal option that best suits their families."³ This resolution reinforces the idea that all options must be considered, including less restrictive alternatives, to find the best option to meet the needs of the individual. The national push for SDM has resulted in a plethora of resources, trainings, studies and articles available to both the legal community and the general public. In response, the LSBA has published a bench card to educate the bench and bar on SDM.⁴

Individuals with disabilities and other neuro-divergent issues deserve the same opportunities and dignity of risk to make decisions and learn from their experiences as individuals without disabilities. Supported decision making can have an immense positive impact on someone's life by fostering independence and avoiding a potentially catastrophic loss of rights as an alternative. In many cases, it should be the first step for individuals with disabilities before a more restrictive alternative is sought.

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