

You Have One Life to Live But Infinite Choices to Make...

With Supported Decision Making You Can Decide For Yourself Autonomy, Agency, Advocacy

By
Otto Lana

On January 1, 2023, Assembly Bill 1663, Supported Decision Making (SDM), became law in California,

which provides adults with disabilities alternatives to conservatorship. A

conservatorship is a court proceeding where a judge assigns a person (conservator) to take charge of another adult's (conservatee's) entire life, to make decisions for them, and to act on their behalf. A conservatee is stripped of their rights, plain and simple.

What is CYVYC?

According to their website, <https://youth-voice.org/> the Center on Youth Voice, Youth Choice (CYVYC...pronounced civic like the car) is a national resource for youth with disabilities. The Center teaches about alternatives to guardianship and conservatorship. You have the right to make your own decisions about your life.

What is a CYVYC State Youth Ambassador?

We are the face of the self advocates leading the charge to inform disabled individuals and their families and allies that they have rights, they have choices, and they can decide for themselves the lives they wish to lead. I have the honor

and privilege for the next two years of being a youth ambassador. There are only twelve states that have laws supporting Supported Decision Making. We, as youth ambassadors, are leading by example. With this informational campaign, I am demonstrating, in real time, a real-life example of a disabled adult who is living an amazing interdependent life with agency and autonomy through self advocacy.

Why did you apply for CYVYC?

William Leiner, managing attorney for Disability Rights California, and Judy Mark, founder and president of Disability Voices United, contacted me and my two best friends, William Del Rosario and Bella Santoyo. We were part of the inaugural class of the DVU Self Advocates Speakers Bureau, so Will and Judy thought this was the perfect opportunity to put the rubber to the road and drive the change that DRC and DVU fought so hard for with the California law AB 1663, Supported Decision Making.

Empowered self advocates speak out for alternatives to conservatorship. There's no better way to empower those who are traditionally powerless. We are the sparks that ignite change.

What was it like to apply?

It was so much fun to apply. We have a great working relationship, an excellent camaraderie, and tons of support from heavy hitters in the disability rights network. It was a team effort—a dream team in fact. The California State team consists of the State Council on Developmental Disability, the University of California at Davis' MIND Institute, and, of course, the folks at Disability Rights California and Disability Voices United. The application was long, and the Zoom interview was intense. But, of course, we crushed it. In fact, the selection committee asked our permission to use our interviews in training sessions to demonstrate what a well-prepared team looks like.



The California State Team Youth Ambassadors for the Center on Youth Voice, Youth Choice. William Del Rosario, Bella Santoyo, and, Otto Lana.

What is Supported Decision Making (SDM)?

Here's an official answer:

Supported decision making is a collaborative and inclusive approach that empowers individuals, particularly those with disabilities or cognitive challenges, to actively participate in making choices about their own lives. Unlike traditional models that may rely on guardianship/conservatorship or substitute decision-making, supported decision making emphasizes the importance of providing assistance and resources to enable individuals to express their preferences, understand information, and communicate their decisions effectively. This approach recognizes and respects the autonomy and dignity of the person involved, promoting their independence and self-determination. Support can take various forms, such as the provision of information, communication aids, and assistance from trusted friends, family members, or professionals. By fostering a supportive environment, supported decision making seeks to enhance the individual's ability to make choices that align with their values and aspirations, thereby promoting a more inclusive and person centered approach to decision making.

Here's the plain language version...

Supported decision making is all about collaborating with people, especially those with disabilities or challenges in understanding things, to have a say in their own lives and to give them the opportunity to have skin in the game. Instead of having someone else make all the decisions for them, this approach is about giving them support so they can make choices on their own. It respects their right to make decisions about their own lives and values their independence. Support can come in different ways, like

giving information, using tools to help them communicate, or getting help from trusted friends and family. The goal is to create an environment where people can make decisions that matter to them and make their own choices in a way that works for them. It's all about being inclusive and making decisions that truly reflect the person's wishes and dreams.

When you stop to think about it, this is how we all make decisions. For decisions and small decisions alike, we ask family and friends for their advice. We check out the internet for recommendations, we log onto YouTube, and watch countless videos of John Q. Public telling us the pros and cons of anything you can imagine. We download the Yelp app and check out Consumer Reports. We seek out information and second opinions from experts. Supported decision making gives a name to what we do all the time. We reach out to trusted individuals to assist us in deciding the choices to make and the paths to take.

What do you want people to learn from your informational campaign?

Despite the level of support you need in your life, you have rights, and your opinions matter. You don't have to be the smartest person in the world when you know you can get decision making support from the smartest people in your world. Conservatorship strips you of these rights, and people need to know there are alternatives. Supported Decision Making is an excellent alternative. Information gives you power. Independence is having the freedom to choose the type of support you want and where and when you want it. As someone who uses alternative and augmentative communication (AAC), I can tell you firsthand that supported decision making begins with access to and support for a robust system of communication. An

exchange of information is imperative to being a supportive ally and truly being able to express your desires. You are not alone; whether you are a disabled individual or a person in a supportive role, there are scores of knowledgeable people to support you on your decision making journey. I have learned families have the most questions about health care, finances, education, and housing decisions. The beauty is that there are infinite combinations of the level of support or independence you choose. You have the right to decide.

Here are some really knowledgeable people who can support you and your family to learn more, ask questions, and get informed!

Disability Voices United

<https://disabilityvoicesunited.org/supported-decision-making/>

Center on Youth Voice Youth Choice

<https://youth-voice.org/a2g-in-your-state/>

Disability Rights California

<https://www.disabilityrightsca.org/publications/limited-conservatorships-alternatives>

California State Council on Developmental Disabilities

<https://scdd.ca.gov/> ■



Otto Lana, a high school senior living in San Diego. He is a poet, film maker, actor, lyricist, and self-advocate. He won the Harry

Servidio Memorial Leadership Award for his work in advocacy and inclusion. He also won the first inaugural Heumann-Armstrong Award for Excellence in overcoming ableism in academia. He is an entrepreneur, designing and selling waterproof letterboards and apparel on his website www.ottosmottos.com.

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