



## ***Voices of Change: Youth Ambassadors from the Center on Youth Voice, Youth Choice (CYVYC) Promote Alternatives to Guardianship***

### **Background**

The Center on Youth Voice, Youth Choice (CYVYC) promotes alternatives to guardianship for youth with intellectual and/or developmental disabilities (IDD) by advancing youth self-advocacy and leadership. CYVYC also works with 11 states to develop and implement state action plans that intentionally place youth at the helm of systems change. Research shows that youth with IDD under guardianship experience fewer positive transition outcomes, such as employment, than those without guardianship (Bonardi et al., 2022). CYVYC's objective is to promote the adoption of alternatives to guardianship that prioritize self-determination and autonomy among youth with IDD.

To achieve its goal, CYVYC works to support youth with IDD to be catalysts for state-level systems change, so that:

- » more youth will have less restrictive decisional support options
- » states will implement policy and practice changes
- » fewer youth will be subject to guardianship

Lastly, CYVYC works with a Community of Practice that is composed of three cohorts of State Teams and Youth Ambassadors. Prioritizing and promoting youth leadership has proven to be an effective strategy for reducing overbroad and unnecessary guardianships, as evidenced by the three Youth Ambassador stories described next.

### **Impact Stories**

#### ***Derek, Georgia***

[Derek Heard](#) is a Youth Ambassador with the [Georgia State Team](#), one of the first three states to join CYVYC. Derek, an advocate and artist in his early twenties, uses graphic design to advocate for the rights of people with disabilities. As Derek puts it, *"I want to change laws and how people think. Disability does not mean disqualified!"*



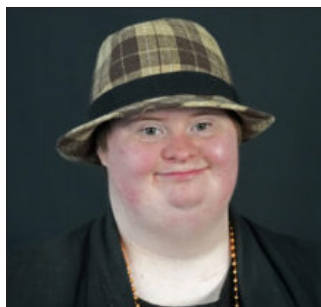
Derek presents at numerous webinars, conferences, and legislative forums. In a webinar with his supporter and mother in January 2023, [Derek shared his supported decision-making journey](#), comparing it to driving a car. He described how he started as a baby in a rear-facing car seat in the back of the car, with his mother driving, and how his position changed as he grew and started making more choices for himself. Ultimately, Derek ended up in the driver's seat, directing his own life. The impactful analogy resonated with the audience, prompting a participant to reconsider initiating a full guardianship process for their son. The participant commented:

***"While I thought I included my son in his journey to make decisions and really share his thoughts / ideas, this presentation opened my eyes wider. I just began [the] full guardianship process and now will take a pause and rethink how this will impact and forever shape my son's independence. Thank you."***

Derek's metaphorical journey from the backseat of a car to the driver's seat effectively communicates the essence of supported decision-making. His advocacy, both through graphic design and engaging presentations, has not only showcased his leadership but has also changed minds.

## Jenna, Michigan

[Jenna Lee](#) is a Youth Ambassador with the [Michigan State Team](#), which is part of CYVYC's second cohort. When Jenna was 17 years old, she shared her turning-18 journey through a [series of short videos](#) on social media. Jenna noted in one of her videos, *"Because I have Down syndrome, some people think I can't be independent. But I think I can make my own decisions. It's my life, so it should be my choice!"* In her videos, Jenna shares information about alternatives to guardianship, including supported decision-making, and how she is working with her family and other trusted supporters to plan for her future.



Jenna's story contributed to diverting a fellow Michigander from guardianship. A Michigan lawyer had been asked by his family to set up a guardianship for a relative with a developmental disability who was about to turn 18. This lawyer contacted the state team co-lead from the Michigan Developmental Disabilities Council. During their meeting, the co-lead shared one of Jenna's videos with the lawyer. After his first viewing, he paused the Zoom conversation and called in other legal professionals in his law firm to crowd around his computer and watch the video with him. Impressed by Jenna's story, the lawyer opted against recommending guardianship for his relative. The Michigan state team co-lead celebrated this saying:

**"There is now one person we know in Michigan who is probably not going to end up under guardianship because of [Jenna] and that video."**

Jenna's videos about her turning 18 journey challenged stereotypes and provided valuable information about alternatives to guardianship. Her impact resonated beyond social media, diverting a lawyer from recommending guardianship. The ripple effect of Jenna's story showcases the influence of youth-led advocacy.

## Otto, California

[Otto Lana](#) is a Youth Ambassador and co-lead of the [California State Team](#), which is part of CYVYC's third cohort. He is a recent high school graduate who champions the right to communicate. As Otto says, *"I am a self-advocate and motivational speaker using augmentative and alternative communication (AAC), giving a voice to those in silence and in the margins. I am living my best life in the limelight and shining a light on those in the shadows."*



Otto's advocacy extends to presenting on alternatives to guardianship<sup>1</sup> (called "conservatorship" in California), and he is changing the minds of people in the Golden State and beyond. In the summer of 2023, Otto joined Disability Voices United with a fellow state team member, to present on alternatives to conservatorship at an event sponsored by the Autism Community in Action (TACA). The presentation influenced a family that was in the process of conservatorship to reconsider their decision. A family member commented:

**"We were in the process of conservatorship and have now halted it (luckily, we were in the early stages). I have to say the lawyer did not mention this alternative...and also did not point out any issues with a conservatorship [for us] to consider."**

Otto's presentations on alternatives to guardianship influenced a family in the process of conservatorship to reassess their decision.

<sup>1</sup>Guardianship is a legal term. Guardianship is when a court decides that an adult cannot make their own decisions. The court then gives someone else (a guardian) the power to make decisions for the person. Some states use other terms, like "conservatorship," to refer to guardianship.

## Conclusion

Derek, Jenna, and Otto's impactful stories illustrate the transformative power of youth voices in promoting alternatives to guardianship for youth with IDD. These narratives showcase the remarkable outcomes achieved through CYVYC's commitment to supporting youth self-advocacy and leadership as well as its collaborative efforts with states to promote systems change.

## Reference

Bonardi, A., Bradley, V. & Timmons, J. (2022). Exploring Alternatives to Guardianship: A Brief for Youth with Intellectual and/or Developmental Disabilities and Their Supporters. Center on Youth Voice, Youth Choice Brief #1. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.



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## What is the Center on Youth Voice, Youth Choice?

At the Center on Youth Voice, Youth Choice, we work with youth with IDD, families, and supporters. We share information about alternatives to guardianship. Youth with IDD lead projects about alternatives to guardianship. We believe that you have the right to make your own decisions about your life!

[Visit the Center on Youth Voice, Youth Choice website](#) to learn more about *alternatives to guardianship* and what these words mean.

[Visit the Center for Public Representation's website](#) to learn more about *supported decision-making*.

## Do you have more questions about this fact sheet and guardianship?

Please email the Center on Youth Voice, Youth Choice team at [youthvoice@umb.edu](mailto:youthvoice@umb.edu)