



State-level Strategies That Promote Alternatives to Guardianship for Youth with Intellectual and/or Developmental Disabilities: Lessons Learned from Georgia, Vermont, and Wisconsin

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Introduction

Promoting alternatives to guardianship has emerged as a critical issue affecting youth with intellectual and/or developmental disabilities (IDD). While guardianship is often used in the United States to protect these youth, research has shown it can limit their rights and decision-making, including decisions about where they live, who they live with, what they choose to buy, and how they spend their time ([Bonardi, Bradley, & Timmons, 2022](#)).

[The Center for Youth Voice, Youth Choice](#) is a national center that promotes the use of alternatives to guardianship for youth with IDD. Among the Center's goals are to conduct research, training, advocacy, and systems change initiatives with people interested in cultivating stakeholder capacity to promote alternatives. Through the provision of focused technical assistance to three multi-stakeholder state teams during this project's first year, staff from the Center have learned about and supported successful state-level strategies that promote the diversion of youth with IDD away from guardianship and into less restrictive options. The following brief will share key strategies to promote creativity and encourage replication among other state-level projects seeking change in this area.

Methods

In February 2021, following a Request for Proposal process and comprehensive multi-stakeholder review, the Center selected state teams from Georgia, Vermont, and Wisconsin to be the first cohort to join its Community of Practice. This Community of Practice (CoP) is a learning community that supports state-level systems change, innovation, and identification of best practices through cross-state

knowledge exchange and access to the Center's individualized technical assistance. The selected state teams are composed of leaders representing youth with IDD, family members, special education and school personnel, healthcare professionals, attorneys, and disability policymakers. [For more on the composition of each state team, read *CYVYC State Teams*.](#)

Upon selection, Center staff scheduled a 90-minute listening session with members of each of these state team using Zoom video conferencing. We asked state team members four questions:

1. What are the key initiatives and/or activities that have proven useful in efforts to promote alternatives to guardianship in your state?
2. What has been the impact of those activities?
3. What barriers have you encountered and how did you overcome those barriers?
4. How do you envision moving your state's agenda forward?

We transcribed each listening session conversation. Then, we coded and analyzed transcripts for themes using Atlas.ti qualitative software.

We also used listening sessions to begin building relationships with individual members of each state's team and to launch the technical assistance. For the state team's first year, technical assistance activities included:

- » customized action planning
- » monthly individualized, video-based coaching and support, and
- » the opportunity to engage with each other in a Community of Practice (CoP) that met quarterly and provided a platform for information sharing and problem solving to address obstacles and promote solutions.

Findings

State team members across the three states shared strategies that have proven successful in promoting alternatives to guardianship. The following four key themes emerged:

1. **Engaging the full range of stakeholders**
2. **Implementing an array of outreach strategies to increase awareness**
3. **Developing the expertise of interested stakeholders**
4. **Using affirmative, values-based messaging**

1. Engaging the full range of stakeholders

All three states understood the importance of engaging the full range of stakeholders to promote alternatives to guardianship. This included youth with IDD and their parents, school personnel and special educators, courts, judges, attorneys, and the medical community.

States worked with:

- » **Youth with IDD and their parents** to ensure they knew what questions to ask, what concerns to raise, and how to articulate specific questions to ensure they received accurate information. States noted that the provision of training in this area had been useful in steering the conversation away from guardianship and toward alternatives. This included outreach to youth and parents representing culturally and ethnically diverse backgrounds.
- » **School personnel and special education teachers** to ensure they had information on alternatives to guardianship to share with parents. One state held regular webinars on supported decision-making and the early development of decision-making skills. They provided resources to assist educators in sharing information and guidance about the various options during Individual Education Program (IEP) meetings and transfer-of-rights discussions. One state team partnered with their state Department of Education and a parent advocacy group to develop and share related educational materials.
- » **Courts, judges, and attorneys** to promote the use of alternatives to guardianship, given many judges and attorneys lacked adequate information. States reported creating

informational packets and working face-to-face to educate. Each year in both Georgia and Vermont, a state representative was invited to the judicial college to inform the probate bench and the judges about alternatives, including supported decision-making.

- » **The medical community**, because they were perceived as another source of guardianship information for parents and youth. Training them on alternatives will ensure that families and youth with IDD *“are getting a unified message on alternatives to guardianship and supported decision-making so families don’t hear conflicting messages from different professionals that support them.”*

2. Implementing an array of outreach strategies to increase awareness

- » **Story telling** from youth with IDD who co-created training materials, such as videos for workshops. Sharing their journeys about maintaining autonomy or seeking ways to regain their rights elevated the importance of youth leadership in advancing alternatives to guardianship and decision-making rights.
- » **Conferences and webinars** such as Vermont’s Voices and Choices conference, organized by self-advocates. The conference included a training on guardianship termination that was open to self-advocates, family members, and provider staff. During that training, self-advocates were also invited to a legal clinic, where they could get one-on-one legal advice from a lawyer about their rights.
- » **Informational packets** targeted to different audiences, including courts, attorneys, judges, educators, families, and individuals. Each packet includes useful tools on using alternatives to guardianship and supported decision-making.
- » **Legal guidance bulletins** on alternatives to guardianship, including supported decision-making, for special education staff/teachers, so they have information to share with parents. The bulletin includes links to disability rights and advocacy organizations.
- » **Transition fairs** to engage with families on alternatives to guardianship. Georgia partnered with parent mentors and invited them to transition fairs to speak to families.

- » **Holding strategic outreach sessions** in locations that had high numbers of parents who represented culturally and ethnically diverse backgrounds. Specific sessions incorporated an identification and exploration of the cultural factors that may lead to guardianships for certain groups or impede access to alternatives.

3. Developing the expertise of interested stakeholders

State teams did this by:

- » **Starting with those who already had interest and knowledge in the subject.** This included families and individuals and others who were already participating in supported decision-making activities, had shown interest in participating, or had reached out for support. This started the process of creating a broader coalition of invested stakeholders, creating momentum for larger, statewide change efforts.
- » **Forming a [Community of Practice](#) for different stakeholders.** For example, Wisconsin's state team formed a CoP specifically to build support for legislative change in their state. Georgia proposed using a CoP to build the capacity of youth with IDD and their parents on alternatives to guardianship, so they can share this information with their peers. Georgia also proposed forming a CoP for attorneys to promote the use of alternatives to guardianship.
- » **Seeking outside expertise.** One state invited a national expert in supported decision-making to help them engage in stakeholder conversations to promote the use of alternatives to guardianship. Reputable experts added to the expertise of stakeholders by providing strategies to allow them to advance their state's efforts and support them to address guardianship assumptions embedded in the education system.

4. Using affirmative, values-based messaging

By using positive communication strategies that were embedded in a set of core beliefs, state teams were able to promote alternatives rather

than condemn the use of guardianship. These core beliefs included:

- » **Promoting the benefits of alternatives to guardianship.** States had better results when they made the transfer-of-rights discussions about opportunities, choices, growth, and self-determination, as opposed to solely focusing on the harm that can come with guardianship. This approach opened opportunities for more meaningful conversations, and audiences were more receptive.
- » **Presuming youth competence.** The three state teams agreed that, to create a path toward alternatives to guardianship for youth with IDD, they needed to emphasize the need for parents and educators to presume competence, as it “creates conditions where people are able to make their own decisions.” This decision-making competence needed to be assumed as early as possible to provide the space for youth to acquire decision-making skills. This presumption also fosters student self-determination.
- » **Introducing early opportunities for youth to practice decision-making.** States underscored the importance of introducing decision-making early and providing opportunities to practice, putting youth and families on a path toward alternatives. To this end, states worked with educators to include decision-making and self-determination skills in curriculums and equipped families with tools to provide space and support to children and youth to practice early decision-making. This enabled youth to build skills and confidence in decision-making prior to transfer-of-rights conversations.
- » **Focusing on the connection to inclusion.** States found it productive to connect conversations about alternatives to guardianship, including supported decision-making, to the wider conversations about the importance of inclusion. They did this by advancing the idea that everyone can benefit from and be a good candidate for supported decision-making, and that people do not need to obtain a benchmark to use the strategy. States found it important to create awareness and educate parents, educators, and other stakeholders to know that, with necessary support and when started early, everyone can be a candidate for supported decision-making.

Considerations

All three state teams implemented a set of collective approaches to foster alternatives to guardianship. The following section offers key lessons learned from these states that others can contemplate as they expand efforts and promote alternatives to guardianship.

Creating a shared responsibility for changing the paradigm. These three state teams understood that engaging the broadest group of stakeholders increases the likelihood of creating a shared responsibility for changing their state's current paradigm. To maximize engagement from the widest group, these state teams implemented a broad range of informational and communication strategies. Varying the modes of educational awareness acknowledges that what works for one group may not work for another and increases the likelihood of appealing to everyone. Also, with many different modes of communication, stakeholders are likely to see the message in multiple places, ultimately reinforcing the effort. Other states need to recognize that, when promoting alternatives to guardianship for youth with IDD, the youth themselves must be at the center of the statewide initiative, as well as intentional outreach efforts to engage those representing culturally and ethnically diverse backgrounds.

Establishing an invested cadre of champions. As these three state teams engaged stakeholders, they actively worked to develop the expertise of these groups to build a coalition that champions the promotion of alternatives to guardianship. By prioritizing the individuals and groups already interested in promoting alternatives, they created a foundation of experts that could grow. In this way, they established a statewide coalition with a mutual interest and investment in promoting alternatives to guardianship. They did this across systems (legal, educational, and medical) and across stakeholder groups. Other states must recognize that efforts to build a cadre of experts does not mean professionals, but rather

more importantly, youth and people with IDD themselves. Investing in efforts to train youth with IDD on the range of alternatives will ultimately reinforce their voices as leaders among these champions.

For more information on how to train youth with IDD on content related to self-advocacy, self-determination, supported decision-making, alternatives to guardianship, and leadership, see the [Center for Youth Voice, Youth Choice's Youth Ambassador Curriculum](#). The goal of this curriculum is to train youth leaders to create systems change in their states!

Ensuring consistent and constructive messaging. Grounded in values around individual strengths, promoting self-determination, and maximizing independence of individuals with disabilities, these three state teams created a positive messaging campaign whereby decision-making is a recognized as a viable activity for people with IDD, especially if given the opportunity to start early and practice often. These state teams use this messaging consistently across an array of modes of communication and across the range of systems. These include schools, doctors, courts, and attorneys so that youth and parents are hearing the same message everywhere. Other states can consider constructing a messaging campaign that celebrates the many benefits of the range of alternatives to guardianship, such as supported decision-making.

Other resources from the Center for Youth Voice Youth Choice

Learn more about [our work with State Teams](#)

See who is part of our [National Coalition](#)

[Read the stories of youth](#) who chose supported decision-making

[Use our interactive map](#) to understand your state's laws as they relate to alternatives to guardianship.



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