



Youth Ambassador Call to Action on Alternatives to Guardianship

Background

In this **[Call to Action](#)**, Youth Ambassadors from the Center on Youth Voice, Youth Choice (CYVYC), a national resource center for youth with intellectual and developmental disabilities, share their perspectives and make recommendations about:

- » why alternatives to guardianship, like supported decision-making, are important
- » who needs to hear about alternatives to guardianship
- » who needs to act to make sure that alternatives to guardianship are the first option for youth with disabilities

The Youth Ambassadors identified what people need to know about alternatives to guardianship to:

- » promote independence and [dignity of risk](#)
- » raise expectations for youth with disabilities
- » help youth know and exercise their rights and autonomy

The Youth Ambassadors also made recommendations for what legal professionals and policymakers, education professionals, parents and families, medical professionals, direct support professionals, advocates and allies, and others can do to make alternatives to guardianship the first option for youth with disabilities.

If you know that youth with intellectual and developmental disabilities need more access to alternatives to guardianship, like supported decision-making, we encourage you to read and share this Call to Action.



Self-Determination

Why are alternatives to guardianship, like supported decision-making, important, and what do people need to know about them?

[Alternatives to guardianship](#), like supported decision-making, are important because they can promote good outcomes and prevent bad outcomes for youth with disabilities. For example, alternatives to guardianship can:

- » **Help youth keep their rights:** [Guardianship](#) takes away a person's [rights](#), like the right to vote, the right to marry, and the right to manage their own money. How would non-disabled people feel if they were no longer allowed to make decisions for themselves? Guardianship can also be hard to remove once it is in place. Youth with disabilities want to make their own decisions. Alternatives to guardianship help youth keep their rights and make their own decisions, with support.

» **Promote independence, dignity, and informed decision-making:**

Alternatives to guardianship can help youth practice and improve decision-making skills and maintain independence.

» **Increase trust, communication, and collaboration:**

Alternatives to guardianship, like supported decision-making, are about relationships and trust. Youth pick supporters, build trust, and create a structure to talk through decisions they face, so that they can make informed choices and pursue their dreams.

» **Allow for dignity of risk:** Youth with disabilities often have their mistakes held against them. To live their authentic lives and be independent, youth with disabilities need to be allowed to make mistakes and to grow. Alternatives to guardianship, like supported decision-making, can make that happen.

» **Create higher expectations for youth with disabilities and hold all youth to the same standard:** Often youth with disabilities are held to a different standard than youth without disabilities. Often people have low expectations for youth with disabilities. For example, when youth with disabilities “act out,” they may experience rights restrictions in their behavior plans, but when youth without disabilities do the same thing, it is just considered a mistake that can be learned from. People use words like “incapacitated” to refer to people under guardianship. That says a lot about how people with disabilities under guardianship are viewed—as being unable to make decisions and speak up for themselves or control their lives. Words matter and say a lot about how people with disabilities are regarded and judged by others.

» **Benefit everyone:** Alternatives to guardianship, like supported decision-making, can be used by people with and without disabilities who have different abilities or needs. Everyone uses support from people they know and trust to make decisions. How people use supported decision-making may look different for each person, but it should be considered an option for everyone.

» **Offer more options:** Alternatives to guardianship give people with disabilities and their loved ones options besides guardianship. Alternatives to guardianship can also be used alongside each other. For example, a person who uses supported decision-making can also have an [advanced health care directive](#) or [power of attorney](#). Guardianship is a big decision that takes away people’s rights. It is important for youth with disabilities and their families to know and explore all their options, so that they can choose the best option for them.

» **Empower youth with disabilities:** Youth Ambassadors have shared that guardianship can feel “debilitating,” and like they are “less than.” Alternatives to guardianship [empower](#) youth because they promote respect for their voices and decisions.



Dignity of Risk

What can everyone do to help promote alternatives to guardianship?

Raise awareness about alternatives to guardianship and their benefits.

- » **Everyone can do their part to spread the word about alternatives to guardianship.** All people can help advance the decision-making rights of youth with disabilities, no matter who they are or what role they play in the community.
- » **Everyone should become a knowledgeable messenger.** It's not just about telling people that alternatives to guardianship exist. It's also about helping people understand the benefits of using alternatives to guardianship, and confidently answering the questions that other people ask.
- » **Everyone is different and will spread the word differently.** Some people are leaders in their communities. Some people have specific perspectives because of groups they belong to. Some people communicate or express themselves in different languages or styles. Some people can speak up in public but other people might spread the word behind the scenes. That's okay!
- » **Everyone should try and use personal stories in their message.** When people have a personal story that they want to share, it can help explain the benefits of alternatives to guardianship. The CYVYC Youth Ambassadors have done just that. They have used their stories and their special talents/skills to create apps, comic books, art, videos, presentations, and other ways to do their part to help spread the word.

Help youth in making their voices heard.

- » **Everyone should respect youth for who they are.** Youth with disabilities have a lot to say that other people need to hear. But youth don't always have opportunities to share what they know and what they think. Often that is because of low expectations. Everyone should know that youth with disabilities are capable and competent. Everyone should be willing to give youth with disabilities the support they need to reach their potential.
- » **Everyone needs to listen to youth.** Sometimes youth also need support from allies to speak up. Everyone should ask youth how to help them do that. Everyone should also think about how to make space for youth to share their perspectives and experiences.
- » **Everyone should include youth in all the awareness raising and training activities described previously.** When a parent tells another parent about their story or experiences with alternatives to guardianship, it is important for that parent to share not only their views but the views of the youth.
- » **Everyone should recognize youth as the true leaders on projects that promote alternatives to guardianship.** The CYVYC project, with its youth advisors and Youth Ambassadors, is a great example of how youth can and should help lead the way.

There are also specific groups of people who can play specific roles in promoting alternatives to guardianship. Many individuals from these groups were part of the CYVYC team. ***The Youth Ambassadors had recommendations about what people from these groups needed to do to make alternatives to guardianship the first option for youth with disabilities:***

Legal professionals & policymakers, like judges, attorneys, and elected representatives should:

- » **Adopt new laws and policies and strengthen existing ones** to make sure that alternatives are the *first option* that youth with intellectual and developmental disabilities and their supporters try.
- » **Consult the real experts—youth!** While legal professionals and policymakers know about good laws and policies, they should also talk to youth leaders to make sure they address youth needs and priorities.

Education professionals, like teachers, transition coordinators, paraprofessionals, and school counselors should:

- » **Change Individual Education Program (IEP) forms and other school-related paperwork that youth and parents receive as part of their education planning.** It is important that these forms clearly state that *youth with disabilities have options* for how they can make decisions with support, especially when they become adults.
- » **Go over informational materials and procedures for discussing alternatives to guardianship.** Start talking about alternatives to guardianship early, in pre-K or sooner, so that youth and parents can make informed choices before youth reach adulthood and continue to have access to easy-to-understand information.
- » **Find strategies to empower youth to express themselves and build their decision-making muscles in the classroom.** This is especially important for students who use augmentative and alternative communication (AAC) and other supports to communicate.



Presume Competence

Parents and families should:

- » **Form or join peer support groups to share information about alternatives to guardianship.** Some people might not know that certain alternatives are out there or what those options mean. Other people, need to learn to “let go” and give youth opportunities to learn from mistakes, so they can become independent and live authentic lives.
- » **Be cross-cultural ambassadors.** For some parents and families, alternatives to guardianship may seem like a foreign concept. Parents and families who are part of specific cultural or language groups can play an important role in describing alternatives to guardianship in ways that their peers can easily relate to.
- » **Start early when exploring alternatives to guardianship.** Parents and families should not just wait until youth are close to becoming adults. Start as soon as possible, like in pre-K. It’s important for parents to understand what youth can do with the right tools and support.
- » **Remember that it is easier to start with less restrictive alternatives and then make a change if needed.** It is very hard to remove guardianship once it is in place, and so it should be the last—not the first—option.

Medical professionals, like doctors and therapists should:

- » **Get training on alternatives to guardianship and not just recommend guardianship.** Medical professionals need be trained on what alternatives to guardianship are and why they are important. They need to learn how to explain all the options to people they serve. Youth with disabilities can help provide those trainings when medical professionals are in school or practicing in their field.
- » **Presume competence.** Medical professionals should start from a place that assumes people with disabilities can make their own medical decisions, even if support is needed. Medical professionals should include youth in medical decisions and support their autonomy. Medical professionals need to make sure that they are listening to what the youth are saying, not just what their supporters or parents think.
- » **“Flip the script” when serving youth with disabilities.** Medical professionals should focus on the abilities of youth, rather than on their disabilities. Medical professionals should not just document what they think youth with disabilities can’t do. They should document what youth with disabilities can do, with or without support. They should be willing to provide documentation that supports the capacity of youth to make their own decisions and use alternatives to guardianship, like supported decision-making, to exercise their rights.

Direct support professionals and service providers should:

- » **Help youth explore options and make their own informed decisions in person-centered planning processes.** Direct support professionals and service providers should push boundaries and help youth and parents and families understand that decision-making and risk-taking can be fun and exciting, and not just something to worry about.
- » **Listen to the youth voice.** Service providers and other direct support professionals should provide individualized support to understand what youth with disabilities want and help them grow in their decision-making.

Advocates and allies should:

- » **Help form support groups or networks for youth and their parents and families on topics relating to alternatives to guardianship.** Advocates and allies can encourage peer connections and access to reliable information that youth and their families can use in their lives.
- » **Help make sure that informational materials are accessible and easy to understand.** Advocates and allies should tailor informational materials for both youth and their parents and families with specific needs or from specific backgrounds. Advocates and allies should work closely with youth leaders to make sure they get their informational materials right.

People with disabilities are capable and competent. Society may have low expectations for youth with disabilities, but youth with disabilities are brilliant! People may have different abilities and support needs, but alternatives to guardianship, like supported decision-making, can benefit everyone.

Presume Competence.

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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!

For more information about CYVYC, contact:

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