



After the Law: Guiding the I/DD Community to Supported Decision-Making

Start Date: January 2024

System Gap Addressed

- Critical issues related to healthcare decision-making arose during the COVID-19 pandemic for individuals with I/DD.
- Individuals with I/DD have historically been prevented from making many critical life decisions because their rights have been unnecessarily taken from them through guardianship when some type of other supported decision-making or independent decision-making was possible.

Initiative Goals and Timeline

- Build on the work of NCCDD's previous initiatives that focused on rethinking North Carolina's guardianship system and promoting alternatives to full guardianship.
- Educate individuals with I/DD, family members, the legal community, and other key stakeholders about the new Guardianship Rights law titled "[An Act to . . . promote the rights and independence of persons subject to the guardianship process.](#)"
- Educate community members on how these rights may specifically offer more independence in healthcare decision-making in preparation for or in light of any future pandemic.

Description of Activities

- Identify and assemble subject matter experts and advisory council members, including people with I/DD, family members, and professionals.
- Develop a Decision Tree for people in guardianship proceedings, particularly people with I/DD, family members, and professionals in the I/DD community.
- Complete the Guardianship Alternatives Step-By-Step Guide, incorporation the Decision Tree as well as previously produced materials on the [Rethinking Guardianship website](#).

Achievements and Outcomes to Date

- Identified and assembled an Advisory Committee consisting of 17 people who include people with I/DD, family members and professionals who are all people with lived experience and/or subject matter experts.
- Convened four Advisory Council meetings.
- Consulted with 14 subject matter experts during the first quarter through establishing checkpoints with them to provide written content and feedback on the Step-By-Step guide, including the Decision Tree.
- Reviewed the North Carolina Guardianship Capacity Questionnaire, an Administrative Office of the Courts (AOC) form, and differentiated between decision-making, communication and skill-based items appearing on the form.
- Expanded the original list of 12 options for supported decision-making, only three of which related to health. New options include the use of assistive and adaptive technologies.

Expected System Change as Result

- More people with I/DD will be aware of supported decision-making and other alternatives to full guardianship, especially regarding healthcare decision-making.
- More individuals with I/DD, family members, member of the legal community, and other stakeholders will be aware of the new Guardianship Rights Law in North Carolina.