



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 tool to assist in identifying less restrictive alternatives (LRAs) for people considering guardianship proceedings, particularly people with I/DD, family members, and professionals in the I/DD community.
- Complete the LRA Planning Guide and incorporate it into the [Rethinking Guardianship website](#).

Achievements and Outcomes to Date

- Drafted 3 new LRA Resource Guides – Transitioning to Adult Healthcare, Health Education, and Monitoring and Communicating About Your Health.
- Drafted content and layout for health domain LRA guide.
- Numerous presentations to groups across the state, including the Money Follows the Person (MFP) Community Transitions Institute and the Exceptional Children's Assistance Center.
- Presented a poster about the forthcoming website for less restrictive alternatives (LRAs) planning at the 2024 North Carolina Guardianship Association meeting.
- 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 18+ subject matter experts, including 3 self-advocates and 5 families, who have provided feedback on the website content and format.
- 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 less restrictive alternatives (LRA) resource guides to 22. New options in the health domain include health education, transitioning to adult healthcare, monitoring and communicating about your health, and 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, members of the legal community, and other stakeholders will be aware of the new Guardianship Rights Law in North Carolina.