



# **Report on Rethinking Guardianship: A Person-Centered Approach**

July 1, 2018 – December 31, 2019

*Prepared by*

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## Introduction

The North Carolina Council on Developmental Disabilities (NCCDD) funded *Rethinking Guardianship*, an initiative from 2015-2017 through a contract with the North Carolina Division of Aging and Adult Services (DAAS), which subcontracted with the Jordan Institute for Families at the School of Social Work, University of North Carolina at Chapel Hill. The initiative, subtitled *Building a Case for Less Restrictive Alternatives*, built on their 2013 public guardianship efforts by creating a sustainable infrastructure that effects long-term changes to North Carolina's guardianship system by promoting less restrictive alternatives to guardianship, with a particular focus on people with intellectual and other developmental disabilities.

The initiative, benefiting from the Collective Impact model, convened a workgroup consisting of diverse stakeholders representing individuals under guardianship, family members, human service organizations, Disability Rights North Carolina (DRNC), the Carolina Institute on Developmental Disabilities (CIDD), and county court systems. Over the course of the initiative, the workgroup accomplished several important outcomes, including:

- Use of data from the North Carolina Administrative Office of the Courts (AOC), Catawba County, and individual stories to build a baseline for shared measurement toward a goal of systemic improvements in North Carolina's guardianship system and the promotion of less restrictive alternatives to guardianship.
- The passage of NC General Statute (G.S.) 35B – the Uniform Adult Guardianship Protective Proceedings Jurisdiction Act (UAGPPJA).
- Recognition of North Carolina by the American Bar Association as a Working Interdisciplinary Network of Guardianship Stakeholders (WINGS) state.
- Creation of a Rethinking Guardianship website: <http://rethinkingguardianshipnc.org>.
- Completion of the video *Understanding Guardianship*, which is available through the Rethinking Guardianship website (<http://www.nccourts.org/Training/Guardianship.asp>).
- Creation of "Restoration to Competence" forms through AOC in May 2017; these forms may be used in restoration of competency proceedings under NC General Statute 35A-1130.
- Additional funding from the North Carolina Division of Social Services (DSS) through June 30, 2018 allowed the workgroup to continue its work toward comprehensive reform on NC G.S. 35A during the 2019 legislative session.

A second phase of Rethinking Guardianship, subtitled *A Person-Centered Approach*, was supported by an 18-month grant from the North Carolina Council on Developmental Disabilities (NCCDD), which was awarded to the Jordan Institute for Families (now the Center for Aging Research and Education Services, CARES) at the UNC School of Social Work.

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*This report describes the achievements of the latest phase of Rethinking Guardianship and recommends ways to expand the reach of the initiative.*

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This phase of Rethinking Guardianship (July 1, 2018–Dec. 31, 2019) built on the outcomes and recommendations from phase 1. This involved developing and adapting strategies to move the work forward, while creating the structure and processes to support effective and efficient group work and decision-making.

Specifically, the goals of the *Person-Centered Approach* phase were the following:

- Further the work and extend the reach of Rethinking Guardianship so all stakeholders in the guardianship system are educated about guardianship, less restrictive alternatives to guardianship, best practices, and current and emerging statutory language;
- Encourage more guardians to support individuals living in long-term residential facilities to transition into a less restrictive setting with less restrictive decision-making constraints; and
- Achieve successful legislative reform and help individuals understand the details of the legislative bill so that they might engage in advocacy and self-advocacy and address guardianship practice changes and implications.

The *Person-Centered Approach* phase of Rethinking Guardianship accomplished the following objectives:

- Establish Sustainability for Rethinking Guardianship. Promote the ongoing work and sustainability of a steering group and the statewide workgroup.
- Expand the Reach through a Summit. Fold the lessons learned from *Rethinking Guardianship: Building a Case for Less Restrictive Alternatives* into a two-part summit for Clerks of Superior Court, guardians, and all other stakeholders to bring more attention to guardianship and the rights of people with disabilities to self-direct their lives.
- Educate about Guardianship Legislative Reform and Less Restrictive Options. Provide education around proposed legislative reforms in the 2019 long session, including plain-language materials to help people understand the bill and the need for reforming guardianship practices in North Carolina. The initiative also continued the work to make people aware of the guardianship process and less restrictive options to guardianship.
- Engage with Guardians of Individuals in Long-term Residential Facilities. Convene listening sessions with guardians specifically focused on individuals living in long-term residential facilities to understand guardians' practices and how they make decisions for and with individuals under guardianship, and to educate them about guardianship resources, guardianship statutes, and proposed policy, practice, and statutory changes.

This report describes the processes and outcomes associated with each of the above objectives and recommends next steps to further the work and expand the reach of Rethinking Guardianship.

# 1. Establishing Sustainability for Rethinking Guardianship

A new Steering Committee was established in August 2018 to set Statewide Workgroup agendas and assist in strategic and tactical decision-making for Rethinking Guardianship (RG). This committee has 27 members and includes representation from UNC Center for Aging Research and Education Services (CARES), the NC Council on Developmental Disabilities (NCCDD), the NC Division of Aging and Adult Services (DAAS), Money Follow the Person (MFP), the Transitions to Community Living Initiative (TCLI), the Administrative Office of the Courts (AOC), the Conference of Clerks, the North Carolina Guardianship Association (NCGA), Disability Rights NC (DRNC), and designated advocates/self-advocates. The Steering Committee met monthly throughout the grant period via teleconference.

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*In this phase, a Steering Committee was established, the Statewide Workgroup was maintained, and new funding sources and other strategies were identified to sustain RG in the future.*

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Throughout the grant period, the Steering Committee’s work focused on the three objectives: (1) listening sessions with guardians of individuals in long-term residential facilities; (2) a two-part summit for clerks, guardians, and stakeholders to bring more attention to the issues; and (3) education around proposed legislative reforms. Meetings regularly involved discussion of progress to date, strategies and next steps, and a continual effort to identify and recruit diverse statewide stakeholders to participate in the Statewide Workgroup. This last objective resulted in three self-advocates joining the workgroup and the creation of a sample invitation letter for Steering Committee members to use in recruiting new members.

Parentetically, individuals, families, and professionals regularly come forward through direct emails and telephone calls, as well as through the Rethinking Guardianship website, to share frustrations and seek information and guidance about guardianship. On April 24, 2019, a small representative group from the RG Steering Committee met with members of CEAR (Center for Estate Administration Reform). The group raises important issues around the guardianship process for individuals and families, but unfortunately they are not willing or able to discuss these issues in a collaborative way with Rethinking Guardianship, choosing instead to see all organizations as part of the problem. Nevertheless, one family member attending the meeting from CEAR is eager to be part of Rethinking Guardianship, and experiences shared by North Carolinians like her, impacted by adult guardianship, continue to shape the discussions and actions of the initiative.

Members of the Steering Committee also participated in planning and facilitating the summits and listening sessions, as well as in the writing of possible legislative reforms, each of which is discussed in greater detail below.

The RG Statewide Workgroup met quarterly through the 18-month period.

## STATEWIDE WORKGROUP MEETINGS AND KEY TOPICS

*July 1, 2018—December 31, 2019*

August 21, 2018	Innovations in Catawba County court practices and “Promoting Greater Self-Determination through NC ABLE Accounts”
November 30, 2018	The Rethinking Guardianship/NC Conference of Clerks of Superior Court Summit Part I, with group discussion and special presentations on the Uniform Law (UGCOPPA)
December 18, 2018	U.S. Senate Special Committee on Aging Report on “Strengthening State Efforts to Overhaul the Guardianship Process...” and “Innovations in the NC Exceptional Children’s Program at DPI”
February 25, 2019	The Rethinking Guardianship Summit Part II, featuring national speaker, Erica Wood, WINGS Coordinator from the American Bar Association, Washington, D.C.
May 21, 2019	Highlights from the NC Guardianship Association Conference and the WINGS Forum in D.C. as well as “NC Guardian Survey Findings” and plans for Study Bills H.B. 619 & S.B. 337
August 27, 2019	Next steps on G.S. 35A, input on “Making Less Restrictive Alternatives a Reality in NC,” and “The Journey to Supported Decision-Making in Indiana”
November 19, 2019	Findings from the Guardian Focus Groups and Oregon WINGS and Guardian Partners; Wrapping up 2019 and Looking Ahead to 2020

In addition to establishing a functioning Steering Committee and maintaining the Statewide Workgroup, this period included identifying funding sources and other strategies to sustain the RG effort beyond the current funding.

AARP, which has great interest in realizing guardianship reform for its constituency, was identified as a key partner to Rethinking Guardianship, both in terms of strategy and future funding. AARP assisted in supporting the November 30, 2018 summit part I and the February 25, 2019 summit part II. Furthermore, Charmaine Fuller-Cooper from the NC AARP office and Diana Noel from the AARP office in Washington, D.C. each provided invaluable guidance with the Rethinking Guardianship study bills to amend G.S. 35A and will undoubtedly offer continued assistance in the future as the goals of the initiative continue to align with the priorities of AARP.

Also, a concept proposal titled "Making Less Restrictive Alternatives a Reality in North Carolina" was developed by UNC CARES staff and discussed with key stakeholders from the Family Support Network™ of North Carolina and First in Families of North Carolina. The concept was further shared with the Community Living Committee of the NC Council on Developmental Disabilities, and it was eventually released as a Request for Application (RFA) by the NCCDD in November 2019.

Finally, an agreement was established with MFP through a contract with the NC Division of Health Benefits (DHB) to bridge a gap of funding between the end of the grant on December 31, 2019 and the beginning of a new phase of RG entitled "Making Less Restrictive Alternatives and Reality in North Carolina" in July 2020.

One idea that did not come to fruition but may be a resource to consider in the future is based on conversations that took place with the elected Clerks of Court in Wake and Orange Counties and a contractor for Medical Health Homes initiatives for NCCDD about finding funding for a pilot project through Massachusetts Health Decisions (which also funds NC projects) regarding court complaints that hospitals "clog up" the courtroom with unnecessary interim guardianship requests.

## 2. Expanding the Reach through a Summit

Originally, the plan was to coordinate and integrate the guardianship reform efforts of the NC Administrative Office of the Courts and the Executive Committee of the Conference of Clerks with the Rethinking Guardianship Statewide Workgroup. The group anticipated joining a task force set up by Judge Marion Warren, Director of AOC, to look at adult guardianship legislation, policy, and practice together with representatives from the Conference of Clerks and AOC. Unfortunately, Judge Warren was unable to commit to his original intent to put a Guardianship Task Force together and recommended RG work directly with the NC Conference of Clerks of Superior Court.

The Steering Committee developed strategies and next steps in working with the Clerks of Court and planning for a two-part summit.

The first part of the summit took place in Greensboro, NC on November 30, 2018 and was jointly held by Rethinking Guardianship and the NC Conference of Clerks of Superior Court. This event focused on a facilitated dialogue between 15 members of the Conference of Clerks Executive and Legislative Committees and approximately 15 representatives of Rethinking Guardianship (primarily members of the Steering Committee) to build buy-in and consensus around important elements for statutory change. At the beginning of the meeting, Nicole Brinkley, the group's AOC representative, read a letter of support for the guardianship reform initiative from AOC Director, Judge Marion Warren. The desired outcome of the meeting was a Guardianship Legislative Common Agenda between Rethinking Guardianship and the Conference of Clerks. As a result of this successful endeavor, the group moved forward with legislative drafting for the long session of the NC General Assembly in 2019 and planning the content of the second part of the summit. In addition, at this meeting, RG shared its educational materials with the Conference of Clerks.

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*The first part of the summit, held jointly with the Conference of Clerks of Superior Court in November 2018, enabled RG to move its legislative drafting work forward.*

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The second part of the summit was held on February 25, 2019 as a pre-conference to the Clerk’s Conference, which was scheduled to begin the next day. Both legislators and clerks were invited; 25 clerks participated and, although several NC legislators signed up, most were unable to attend because the Governor scheduled a "State of the State" address on the same day. Nevertheless, Representative Jean Farmer-Butterfield attended the summit, representing the General Assembly. The summit was "opened" with a welcome by the presiding President of the Conference of Clerks with a presentation later by the Catawba County Clerk, and letters were read from U.S. Senators Thomas Tillis and Richard Burr to start the program. These decisions were strategic and vital to making sure that changes in policy, practice, training, and G.S. 35A are "owned" and instituted by the judicial branch.



*Conversation at part II of the summit in February 2019.*

The second summit drew a capacity crowd of 280. Every attendee received educational materials and resources, including a handout titled “Spotlight on Guardianship Reform,” which compared the items the Statewide Workgroup targeted for reform in NC’s General Statute 35A side-by-side with recommended changes to the 2018 Uniform Law (UGCOPAA) and the 2018 U.S. Senate Special Committee on Aging Report (*see chart below*). During this meeting, the agreed-upon Common Agenda between the Clerks and Rethinking Guardianship was highlighted, along with the continued work going on in North Carolina and across the country through a presentation by Erica Wood, WINGS Coordinator with the American Bar Association.

### SPOTLIGHT ON GUARDIANSHIP REFORM

*Comparing Rethinking Guardianship, Uniform Guardianship, Conservatorship & Other Protective Arrangements Act (UGCOPAA) and U.S. Senate Special Committee on Aging report “Ensuring Trust”*

Rethinking Guardianship	Uniform Act	U.S. Senate Special Committee on Aging
Rights of an individual under guardianship	Guaranteed visitation and communication Promotes the adult’s self-determination and encourages participation in decisions	Strengthen protections for individuals under guardianship Nationwide adoption of UGCOPAA
Change terminology	Updated person-centered terminology	Adopt UGCOPAA
Requirement for consideration of alternatives to guardianship	Prohibits courts from issuing guardianship when a less restrictive alternative is available	Promotion of alternatives to guardianship - training to understand less restrictive alternatives
Provide for counsel in addition to GAL	Right to independent legal representation	Unbiased legal representation
Regular review rather than presumption of Permanence	Courts monitor guardianship to ensure compliance and community monitoring	Thorough and frequent reviews of guardianship arrangements by court
Availability, quality, consistency of multi-disciplinary evaluations (MDEs)	Provides forms to help courts conduct thorough assessments of an individual’s capabilities & needs & craft individual orders	Adopt UGCOPAA – allow for access to resources for timely consideration by the courts



A major highlight of the event came when the Dorothy R. Crawford Award was presented to the Rethinking Guardianship Statewide Workgroup by Joyce Massey-Smith, Director of the NC Division of Aging and Adult Services. This was a thrilling moment for all members of the workgroup as the award was given "to the Rethinking Guardianship Statewide Stakeholders Group for its leadership in developing innovative strategies related to adult protective services or guardianship. With sincerest thanks for bringing positive change." (See photos below.)

One noteworthy change during this period was the departure of Judge Marion Warren (Director of AOC), with whom Rethinking Guardianship spent considerable time discussing concerns and issues. Judge Warren had initiated a process for procuring an e-court system to create electronic court records, including guardianship records (a recommendation made by RG). He had also initiated an exploratory conversation with the Minnesota courts to learn about and possibility duplicate their court oversight and monitoring system in North Carolina. With his sudden absence, it was unclear whether AOC had continued interest and time to pursue what Judge Warren had put in motion.



*Photos from the second Rethinking Guardianship summit, February 2019, where Joyce Massey-Smith, Director of the NC Division of Aging and Adult Services, presented the Dorothy R. Crawford Award to the Rethinking Guardianship Statewide Workgroup.*

## Sean's Story

Sean's story unfolded over the course of this project. In the *Rethinking Guardianship Year Two Report*, Sean was given the pseudonym "John" because he was under guardianship and unable to give consent for his story to be told. Part I is excerpted from the *Year Two Report* with his name corrected. Part II is excerpted from the *Year Three Final Report*, and Part III unfolded during 2018-2019.

### **PART I**

Sean first became known to the Rethinking Guardianship workgroup when, out of curiosity, he followed directional signs to one of the stakeholder meetings held in 2016. After revealing to a workgroup member during a break that he was himself under guardianship, he was invited and agreed to share his story with the whole group.

Sean's story is a perfect illustration of a sad irony of the guardianship system. Born in the mid-1980s, he experienced a disrupted childhood that included domestic violence. Although he may have had developmental delays—he asks, "Am I on the [autism] spectrum?"— he has graduated from high school and is enrolled in an associate's degree program at a community college to "take my life to a whole 'nother level."

Sean's father petitioned for guardianship some years ago to keep his mother from taking his Social Security check. At first, Sean was living with his father and stepmother, with whom he never saw eye-to-eye. After being granted guardianship, they moved him to a group home 40 minutes from where he was going to school.

Sean had this to say about guardianship: "Some people that have guardians may need one for the rest of their lives if they have a severe incapacity. For others, like me, it should be limited. It depends on the situation."

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### **PART II**

Sean was eager to return to court to establish his competency, especially as it related to his driving privileges, which had been suspended when he was found incompetent. Upon his first return to court, the judge told Sean that he needed to obtain a doctor's note stating that he was completely competent.

He then spent several months searching for a doctor who would take Medicaid and was willing to complete an MDE. He reported that he experienced "getting the runaround" between the mental health system and the court.

Through his connections with Rethinking Guardianship, Sean was introduced to a pair of attorneys, one of whom practiced in the county where his guardianship was established. For Sean, "having someone know what the heck is going on—knowing what the judge wants—instead of getting the runaround" made a huge difference. First, his attorneys explained to

him that he could obtain the doctor's note from his regular doctor, and it could be a short note, it didn't need to be an MDE.

Sean's rights were readily restored upon his second return to the court, this time with his lawyers and the requested doctor's note. The local lawyer took him through a series of questions at the hearing, demonstrating his capacity in each of the areas on the capacity questionnaire routinely used in NC courts. Before they reached the end of the list, the Clerk said that he had heard enough to make his ruling, restoring Sean's rights. When asked how his life has changed since, he says, "Well, it's completely different. I don't have to try to track down my guardian. I can move more quickly on the things I want to do. I got my driving rights restored and am now looking for a car." In addition, Sean is taking a class in arboriculture and plans to look for work through the Tree Industry Association.



*The RG workgroup celebrates Sean's success.*

### **PART III**

Sean has completed the Horticulture program at Alamance Community College and is excited about his new job at Lowe's. He has also obtained a driver's license and recently purchased a truck.

Regarding decision-making, Sean is putting a team together that includes a realtor and a certified accountant. He recognizes the value of connections, saying "the right counsel will make a big difference." He appreciates people's input but says, "people's opinions are just that, opinions." He relies on the Bible and on his strong faith. Looking back, Sean says he wouldn't change anything. He says he now knows how to help others and is eager to do so. He plans to remain involved with Rethinking Guardianship.

### **3. Educating about Guardianship Legislative Reform and Less Restrictive Options**

The work on this objective went in a number of different directions, including:

- A. The Long and Winding Road to Legislative Reform
- B. Participation in the National WINGS Group
- C. Presentations and Promotion of Rethinking Guardianship Materials
- D. Access and Use of the Rethinking Guardianship Website

#### **A. “The Long and Winding Road to Legislative Reform”**

##### **Study Bills HB 619 and SB 337**

Following the summit event on February 25, 2019, the Steering Committee and UNC CARES staff provided information, assistance, support, and educational materials to help create, and then obtain sponsorship for, Legislative Study Bills (SB 337, HB 619) in the NC General Assembly. In total, three drafts of an amended G.S. 35A were written before it was determined that introducing a focused study bill would be the best course of action.

Members of the Conference of Clerks and the group's representative from AOC, as well as the Steering Committee, provided input into and continued to track the study bills, requesting a few changes to them based on the input of stakeholders representing different populations and organizations (such as the NC Bar Association and The Arc). Talking points for legislators and other stakeholders were developed in plain language and individuals and advocates volunteered to testify if requested.

The bill passed the House but stalled, along with all other study bills, in the Senate Rules Committee. And so, the Steering Committee decided to discontinue waiting for the Senate to make a move and instead established an ad hoc writing team to draft a reformed G.S. 35A bill which could be introduced as a completed document during the General Assembly short session in May 2019. At the August 27 Rethinking Guardianship Statewide Workgroup, participants were asked to sign up to serve on the writing team or serve on a review committee.

##### **Draft of Reformed G.S. 35A**

Eighteen members of the Rethinking Guardianship Statewide Workgroup volunteered to take a deep dive into the language of G.S. 35A, identify strengths and weaknesses, and consider language from the Uniform Law (UCOPAA).

Much time was devoted to discussing and drafting changes to G.S. 35A in the following seven areas of interest that were identified at the November 2018 summit.

- 1) Using alternatives to guardianship first;
- 2) Eliminating the presumption of permanence;
- 3) Reinforcing individual rights within guardianship;
- 4) Updating terminology;
- 5) Providing for a spousal (or partner) exception to division of assets, at the discretion of the clerk;

- 6) Providing for counsel in addition to the guardian ad litem (GAL); and
- 7) Improving the quality and availability of multi-disciplinary evaluations (MDEs).

As of the end of the initiative and scope of this report, the writing team and review team continue to meet twice a month at the NC Judicial Center to complete revisions to 35A. When this work is completed in spring 2020, the writing team leaders will discuss the draft with the AOC Interim Director and will discuss the best way to engage the Conference of Clerks of Superior Court in piloting the revised statute. After grappling with numerous strategies to engage the judicial system in needed updates, it is considered the best option to pilot the changes within select counties to see how the changes play out in practice before attempting to go statewide.

## **B. Participation in WINGS**

Rethinking Guardianship's work in the legislative arena is supported by its membership in the Working Interdisciplinary Networks of Guardianship Stakeholders (WINGS) national network. Rethinking Guardianship receives information from the WINGS national office and participates in monthly national stakeholder phone meetings. During these meetings, representatives from WINGS states, including from RG, ask questions and share progress, challenges, and ideas on legislative initiatives. Timely and relevant pieces of legislation or best practices are forwarded as they become available. One notable example of this is the final version (July 9, 2018) of the Uniform Guardianship, Conservatorship, and Other Protective Arrangement Act (UGCOPAA), which reinforces the reform recommendations made by the RG workgroup.

Through WINGS, Rethinking Guardianship engaged the Indiana WINGS group to make a presentation on that state's Support Decision-Making statute at the August 2018 workgroup meeting. Two other WINGS calls were particularly relevant to RG during this granting period: January 28, 2019, on Guardian Education, and March 25, 2019, on Limited Orders, with RG presenting on NCAOC & Catawba County data.

Rethinking Guardianship was represented at the North Carolina at the National WINGS Forum from April 1, 2019 through April 4, 2019 at the American Bar Association in Washington, D.C. Also, an article on Rethinking Guardianship was published in the May/June 2019 edition of *BIFOCAL*, the journal of the ABA Commission on Law and Aging.

## **C. Promotion and Distribution of Educational Materials**

The Rethinking Guardianship brochure was completed, printed, and made available in both English and Spanish. The brochure, "Rethinking Guardianship: Understanding Options," continues to be an important resource for individuals and families across the state and is distributed during meetings, presentations, and in response to email inquiries.

Rethinking Guardianship has found a way to address guardianship and promote less restrictive alternatives to guardianship by completing a section about dignity of risk/experience and informed/supported decision-making within the NC Supported Living Guidebook, which is part of the NCCDD-sponsored Supported Living initiative. The following story developed for this section highlights the lives of two NC women living self-determined lives with the principles and practice of supported decision-making.



## A Story... Janie and Suvya

Janie Desmond and Suvya Carroll share an apartment in a regular neighborhood in Durham, NC. While each had lived away from family during college, neither had lived on her own as an adult. The myriad regular responsibilities, the minor and more serious emergencies that come up, and the longer-term questions about life and direction have all provided a ripe context for using supported and/or informed decision-making.

Luckily, both Janie and Suvya have bountiful networks of friends and family they tap for advice, so they have not needed to identify one single advisor for this or that type of decision. Living on one's own for two years together, they have figured out who can help most effectively with what. They have also figured out (most of the time) when something is an emergency, and if it is, who to contact: a neighbor? Family who is further away? 911?

Only through practice in real life experiences can individuals learn these nuances. And real community settings also provide access to more people that are unpaid, be they neighbors, storekeepers, family, or friends.

Sometimes the concerns around which they ask for help relate to Janie's staff. It can get pretty complex, as both women are compassionate. If someone doesn't show up, who to complain to and what might be the consequence? Is it okay to talk to that person directly? What might be the consequence? Other concerns are security, or health, or finance related. And they come up almost daily.

It is incumbent on people supporting these women to push them to make their own decisions when it is clearly in their power. In their power does not mean they will always get it right, but without stretching the muscles, there is no growth. This has clearly led to less asking, more acting, and greater self-determination.

*\*Story told by Janie's mother Betsy MacMichael, Executive Director, First in Families of NC.*

The Rethinking Guardianship Statewide Workgroup meeting in December 2018 featured Beverly Colwell, from the NC Department of Public Instruction. She discussed the requirement that parents of children with Individual Education Plans (IEPs) be informed of the changes that will occur when the child reaches majority (i.e., age 18). She has been educating school districts about this and shared both her PowerPoint presentation and some model educational materials for parents with the group. When asked if it is possible to add a line recommending that the parents seek the least restrictive solution for their child, she stated that this is not currently Division policy. However, she is willing (as a member of the Rethinking Guardianship Statewide Workgroup) to take a request to the leadership of her division within the NC Department of Public Instruction to see if they will seek a policy change that would make it possible to add this suggestion.



*Janie and Suvya at home.*

Rethinking Guardianship also generated several articles after the February 25, 2019 summit for the UNC School of Social Work, American Bar Association WINGS website, and NCCDD. Also, NC Health News published an article (with photo) about the summit and effort, entitled "Adult Guardianship Group to Propose Changes in Law, practices to NCGA."

In November 2019, Raleigh/ Durham's news channel WRAL ran a segment on guardianship, the strengths and weaknesses of the system, and where to go for help. It featured Rethinking Guardianship.

Other noteworthy informational and educational events occurred during this 18-month period, including:

- Sharing resources with ABC11 in Raleigh, which highlighted a family's story and referred to the importance of the Rethinking Guardianship initiative. *July 18, 2018*
- Compiling and submitting recommendations made by the Rethinking Guardianship Statewide Workgroup to the U.S. Senate Special Committee on Aging, which requested stakeholder input on adult guardianship. *July 20, 2018*
- Providing an "elevator speech" and sharing the Rethinking Guardianship Final Report (2017) and new grant information during the NCCDD World Cafe event in Asheville, NC. *August 8, 2018*
- Distributing 60 Rethinking Guardianship brochures at the Asheville-based Transitions to Adulthood Conference, sponsored by the Family Support Network. *October 2018*
- Speaking about guardianship and less restrictive alternatives during a Division of Aging and Adult Services conference for Options Counselors. *November 2018*
- Providing information and materials for the North Carolina Guardianship Association Meeting in Kannapolis, NC. *November 2018*
- Presenting to the MFP Roundtable in Cary, NC on the Rethinking Guardianship initiative, educational resources, and information about reaching out to guardians of individuals living in long-term care facilities. *November 16, 2018*
- Presenting to parents and youth at the ImaginAbility Conference in Raleigh; activities included distributing approximately 80 "Introduction to Options" brochures and making people aware of the Rethinking Guardianship website. *February 23, 2019*
- Educating and distributing materials to over 30 Cardinal Innovations Care Coordinators in Chapel Hill and Winston-Salem. *July 2019*
- Facilitating a webinar on the Rethinking Guardianship initiative for 208 members of the Money Follows the Person Roundtable. Several individuals reached out for discussions and further clarification on guardianship/less restrictive details after the webinar. Also following the webinar, FIRST's newsletter promoted the website and resources. *September 2019*
- Providing English and Spanish brochures to the NC Statewide Independent Living Council (SILC) meeting in Burlington. *September 2019*
- Distributing brochures during "From Planning to Action: Integrated, Collaborative Care for People with I/DD," a meeting of the Community-Academic-Provider Consortium at The Arc of North Carolina's office in Raleigh. *September 2019*

- Discussing guardianship and less restrictive options with 9 staff and volunteers at DisAbility Partners, a Center for Independent Living in Asheville. *October 2019*
- Providing information and resources to 9 IDD Parent Partners in Wilmington. *October 2019*
- Providing information and resources to an IDD Parent Group in Johnston County. *November 2019*
- Offering education about Oregon WINGS and Portland’s Guardianship Partner’s monitoring and oversight service to the RG Statewide Workgroup. *November 2019*
- Providing information about Rethinking Guardianship (specifically about the guardian survey and focus groups) to 90 stakeholders of the Money Follows the Person Roundtable. *November 2019*

## D. Access and Use of the Rethinking Guardianship Website

UNC CARES and the Rethinking Guardianship webmaster maintain the RG website, periodically changing and updating educational materials. During the grant period, important resources were uploaded to the website, including a free, online course about Supported Decision-Making, the "Spotlight on North Carolina: Rethinking Guardianship" article published by the ABA publication *BIFOCAL*, and news reports and meeting schedules.

Usage of the website has consistently grown, from 54 users and 65 sessions in September 2018 to an average of 123 users and 158 sessions in each subsequent month through December 2019.

Month/ Year	Number of Users	Number of Sessions
September 2018	54	65
October 2018	83	105
November 2018	75	97
December 2018	92	106
January 2019	119	226
February 2019	191	223
March 2019	162	217
April 2019	95	118
May 2019	114	137
June 2019	97	116
July 2019	126	165
August 2019	108	144
September 2019	169	207
October 2019	120	170
November 2019	182	218
December 2019	108	127



## 4. Engaging with Guardians of Individuals in Long-term Residential Facilities

Together, the UNC CARES staff, the Rethinking Guardianship Steering Committee, and representatives from DAAS/DHHS developed the following goals associated with this objective:

1. To understand gaps (in service community) and barriers that interfere with moving individuals from institutions into community settings; and
2. To promote resources about less restrictive alternatives – website, brochure, national materials, etc.

As a precursor to the listening sessions, two surveys were developed to capture information from larger numbers of people and to form the basis of group discussions and listening sessions. One was designed for attorneys who handle adult guardianship cases for DSS; the other was for both family and professional guardians of people living in facilities. The guardianship survey included a link guardians could use to express interest in participating in a listening session or one-on-one interview. Several groups and organizations were enlisted to distribute the guardian survey to their members and the NC Division of Aging and Adult Services distributed the survey to county DSS directors and staff with adult guardianship responsibilities.

Preliminary responses to the two surveys were discussed at the Steering Committee. At the May 2019 meeting of the RG Statewide Workgroup there was a presentation of key results from the two surveys, which included a perceived lack of community services and safety concerns as major barriers.

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*In this phase, surveys and listening sessions increased our understanding of guardians' needs and the barriers they face.*

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Results from the surveys were instrumental in forming more in-depth questions for the listening sessions. As these questions were developed, input and editing were sought from members of the workgroup, as well as leaders at MFP and TCLI.

Ultimately, listening sessions for professional guardians were held in Durham and Wilmington in September 2019. Guardians from surrounding counties were also invited to these sessions. Following is a summary of the comments made by the 31 professional guardians who participated in these sessions.

- Guardianship professionals balance a sincere belief in honoring the individual client's preferences and providing the least restrictive environment with a statutory obligation to keep people under their guardianship safe.
- They struggle with large gaps in service availability and funding, as well as serious workforce shortages and turnover in the lower-paid end of the service sector.
- Listening session participants provided valuable input to the Transitions to Community Living Initiative (TCLI), stressing the needs and challenges of people with chronic, persistent mental health disabilities in the aftermath of a transition to the community.
- They would like for transition coordinators to communicate and work with the guardians or other members of the professional care team. This is to assure that the best possible array of services is in place to improve the chances of success, rather than approaching facility residents with no contact with the current guardian or service providers outside of the facility.

- They would like to see the community and the justice system better educated on an adult’s right to choose and on the inability of guardianship to compensate for the absence of services or “fix” people whose behavior is dangerous or annoying.

These findings were shared with TCLI and MFP leadership in November 2019, with follow-up in early January 2020.

## **Recommendations**

Based upon the *Person-Centered Approach* phase of Rethinking Guardianship, the following recommendations are intended to inform continued work on furthering long-term changes in NC’s guardianship system.

1. Continue writing statute changes and engaging in dialogue with the courts.
2. Consider piloting statutory changes within select counties to work out details, gather lessons learned, and build momentum toward state adoption.
3. Continue to collect stories and add them to the RG website.
4. Revisit AOC data to see if there is discernable change from the data collected in 2015.
5. Utilize the e-court system and collect demographic data on guardianship.
6. Continue to educate stakeholders across the state and impact the culture around guardianship.
7. Investigate the possible overuse of guardianship by hospitals.
8. Develop tools to help adult protective services resolve emergency situations so that vulnerable adults are safe but do not enter the pipeline to guardianship unnecessarily.
9. Develop strategies for oversight using models such as “Guardianship Partners,” a volunteer nonprofit program in Oregon.
10. Continue to promote less restrictive alternatives to guardianship, including promoting powers of attorney, supported decision-making as an overall approach and practice, as well as Foster Care 18-21 as an alternative for youth transitioning to adulthood.

## Conclusion

During the 18-month Rethinking Guardianship: A Person-Centered Approach initiative, individuals with disabilities, their families, guardians, and other stakeholders across North Carolina were increasingly exposed to new ways of thinking about and practicing guardianship and were encouraged to consider less restrictive ways to support individual decision-making rights.

As demonstrated by the numerous activities and accomplishments of the Rethinking Guardianship Steering Committee and Statewide Workgroup during this grant period, the work was indeed furthered and the reach was unquestionably extended to increasing numbers of individuals and organizations across the state and even across the country.

Yet, there is still much left to do. Remarkably, Rethinking Guardianship is attracting growing interest among stakeholders and the initiative's momentum continues to push forward towards greater systems change.

While the challenge remains to enact legislative changes to G.S. 35A, clear and significant progress has been made in informing and educating stakeholders and the general public about widely recognized and needed reforms. Rethinking Guardianship has also made headway in establishing collaborative relationships with the Conference of Clerks of Superior Court, AOC, and members of the General Assembly — all of whom will be essential to realizing statutory change.

While the initiative will stay vigilant to the purpose of creating positive long-term change within the current adult guardianship system, it will also place greater emphasis in the coming years on the development of supported decision-making principles and tools. Undoubtedly, there will continue to be a need to address the policies and practice of guardianship but there is also an imperative to learn about and practice new ways of honoring the decision-making rights of adults, regardless of age, disability type, and level of support needed.

And so Rethinking Guardianship, grounded by five tenacious years of hard work and experience and the collection of data, stories, and best practices, stands ready to take on the next challenge in service to the greater good of all North Carolina citizens.

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*The Rethinking Guardianship initiative has made important strides in helping North Carolina embrace less restrictive ways to support individual decision-making rights. But there is still much left to do.*

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