



Building a Case for Less Restrictive Alternatives Second Year Report

Jordan Institute for Families
School of Social Work
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Executive Summary

In January 2015, *Rethinking Guardianship: Building a Case for Less Restrictive Alternatives* was launched as an initiative of the North Carolina Division of Aging and Adult Services (DAAS), through funding from the North Carolina Council on Developmental Disabilities, and in partnership with the Jordan Institute for Families, of the School of Social Work at The University of North Carolina Chapel Hill.

The *Rethinking Guardianship* project in North Carolina follows the Collective Impact framework used by WINGS (Working Interdisciplinary Networks of Guardianship Stakeholders) projects nationwide. In Year 1, the initiative successfully brought together a diverse and committed statewide work group, began building a knowledge base of best practices, and began collecting relevant data to support a deeper understanding of guardianship and its alternatives, as well as the state of guardianship in North Carolina today.

In 2016 (Year 2 of *Rethinking Guardianship*), the statewide group met five times and established three subgroups (Legislation, Policy, and Practice; Education, Awareness, and Training; and New Information: Data and Stories). The project was advanced by the creation of a Common Agenda (i.e., one of five essential elements of a Collective Impact initiative); the collection of statewide and county-specific data (for Catawba County); and the selection of a county-specific project to go deeper into a particular locale (also Catawba County) in order to better understand the guardianship system, as well as to more deeply effect change within that system over time.

The Common Agenda was forged from the collective views of the statewide workgroup that also established core concepts, basic principles (in the form of a preamble), and long-term outcomes.

The core concepts and basic principles are:

- autonomy, liberty, freedom, dignity
- presumption of competence
- right to life-time decision-making support.

The Common Agenda consists of:

- a guardianship system that is less restrictive and based on best practices
- a guardianship process in which all stakeholders are identified and engaged
- options and pathways toward guardianship, and alternatives to guardianship, that are communicated to and understood by all stakeholders
- a public and private guardianship system that is held accountable
- information about guardianship and its alternatives that is easily available and accessible.

Goals for *Rethinking Guardianship* Year 2 were developed by the workgroup, and results were achieved through subcommittee activities. During the year, the initiative accomplished the following:

- identified desired North Carolina statutory changes
- developed learning objectives and compared curricula for private guardians
- established a functional, user-friendly website
- engaged in guardianship story collection
- analyzed Administrative Office of the Courts (AOC) data
- conducted guardianship case reviews within Catawba County
- supported the passage of the Uniform Adult Guardianship Protection and Proceedings Jurisdiction Act (UAGPPJA)
- joined the national dialogue about guardianship and alternatives with other WINGS states.

Building upon these accomplishments, the goals for Year 3 (2017) include:

- establishing a more central leadership role for the NC AOC
- sustaining the initiative's work when present funding is completed by exploring potential grant funding through organizations such as the American Bar Association and the Administration for Community Living
- identifying legislative champions to introduce Statute 35A revisions
- mobilizing stakeholders to support reform efforts
- promoting the new *Rethinking Guardianship* website
- creating training opportunities for guardians using a new curriculum

- using data and stories to build a case for system improvements and less restrictive alternatives
- evaluating the pilot initiative in Catawba County as a step toward informing the system on changes that should be made at the county level
- interfacing with the child welfare system and the educational system to promote less restrictive alternatives to guardianship as children transition to adulthood.

Introduction

“When people go to file a petition, they should be given information—perhaps a brochure—that makes it clear what guardianship is and what alternatives exist. Guardianship is SO serious and legally binding.”

—Mother of an adult son currently under 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.”

—30-year old man seeking restoration

Statements like these are shining a light on the importance of understanding guardianship in North Carolina and the need to improve the present system. Guardianship essentially removes an adult’s rights to manage his or her life decisions and places those decision-making responsibilities with a court-appointed guardian.

Recent information about public¹ guardianship cases reveals that frail elders, although still a significant segment of the guardianship population, no longer make up the majority of people under guardianship in North Carolina. Out of more than 5,000 adults in the state who are served by a public guardian, nearly 3,000 (56%) are younger adults ages 18 to 59, the majority of whom (86%) have a primary diagnosis of intellectual and other developmental disabilities (I/DD) or mental illness.

With this information, the North Carolina Division of Aging and Adult Services (DAAS), together with other key stakeholders, determined that the state's guardianship

¹ Year 1 of *Rethinking Guardianship* found that private (i.e., typically family and friends) guardianship cases comprise the majority of cases brought before the Clerks of Superior Courts in North Carolina. However, data on public guardianships is much more readily available.

system, including statutes and their interpretation, as well as data collection capacity, have the opportunity to respond more fully to the needs of this younger demographic. Stakeholders were also concerned that current policies and procedures are not always interpreted uniformly throughout the state.

The Rethinking Guardianship: Building a Case for Less Restrictive Alternatives initiative began in January 2015 amidst a growing call to action around the state, and throughout the country, to rethink the statutes and systems of guardianship. With a three-year grant from the North Carolina Council on Developmental Disabilities, DAAS launched this initiative to (1) create long-term changes in the state's guardianship system, (2) promote less restrictive alternatives to guardianship, and (3) use the process of Collective Impact to create change in the guardianship system of a pilot community in North Carolina.

DAAS contracted with the Jordan Institute for Families, at the School of Social Work, The University of North Carolina Chapel Hill, to implement this initiative. The Jordan Institute was charged with addressing these goals by facilitating a diverse statewide workgroup using the Collective Impact model (see Appendix A for more detail). The initiative is modeled on WINGS, a national model that employs the Collective Impact framework to address the myriad of complex issues related to state guardianship reform.

This report describes the activities and results of Year 2 (2016) of the *Rethinking Guardianship* initiative. Further, it shows how these results build upon the Year 1 findings and continue to take root as the initiative moves into Year 3.

Rethinking Guardianship: Year 1 Summary

During the first year of the initiative, the Jordan Institute research team discovered that, in fact, private (i.e., typically family and friends) guardianship cases comprise the majority of cases brought before the Clerks of Superior Courts in North Carolina, but there are no annual reporting requirements of private guardians as there are for public guardians.

Other important outcomes from Year 1 include the following:²

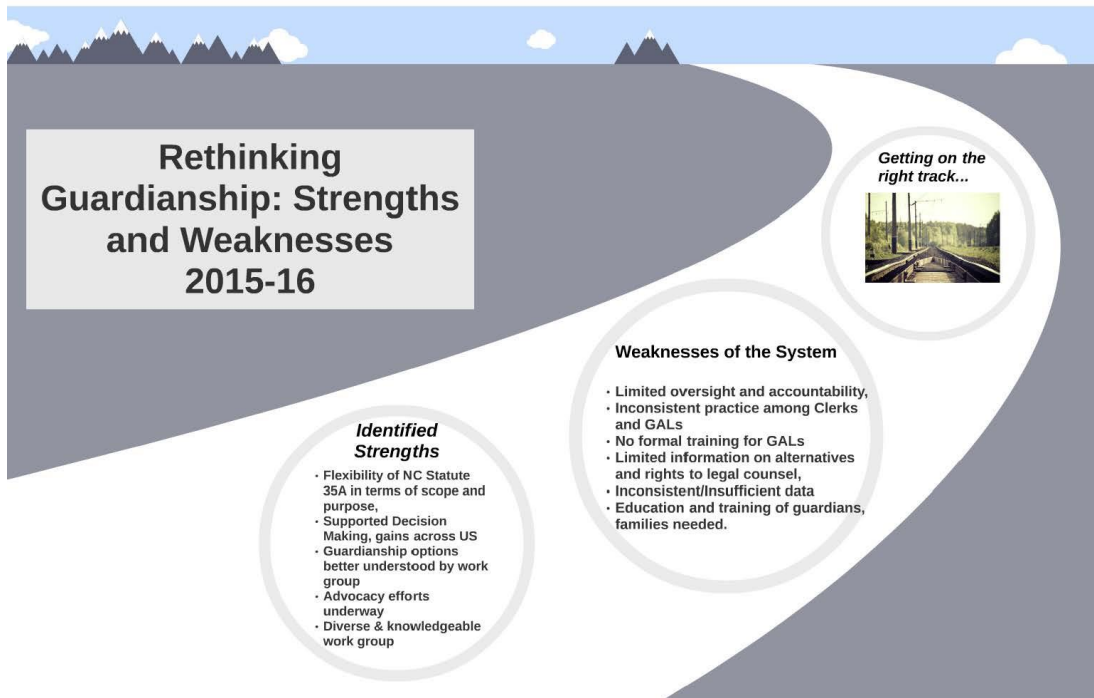
1. Establishment of a diverse and broad-based, statewide working group. Representation included individuals and families directly impacted by guardianship; Clerks of Superior Courts and other court officials, attorneys and guardians ad litem (GALs); academic experts on the subject of guardianship; legislators and state Department of Health and Human Services (DHHS) employees; as well as many other providers and advocates for older adults and people with disabilities.
2. Understanding that families and individuals who are considering guardianship need more information about
 - alternative options and courses of action to avoid filing for guardianship
 - how to file and present evidence in a guardianship proceeding
 - the duties and obligations of being a guardian (including how to maximize decision making for the individual under guardianship).
3. Awareness that Clerks making guardianship decisions rely on varying and inconsistent sources of information. Here are three examples.
 - They rely heavily on the testimony of guardians ad litem, who have a specific role of recommending a professional opinion that may conflict with the wishes and desires of the respondent.
 - Multidisciplinary evaluations are not done consistently and vary in quality and availability.
 - Fewer than half of Clerks view the testimony of the person whose competency is questioned as “very important.”
4. Understanding that, unlike public guardianship cases, the monitoring of private guardianship of the person is optional, not mandated.³

² The complete Year 1 report is available at <http://bitly/1RvF5T9>

³ Please refer to the Glossary of Guardians in Appendix B for a description of guardians in North Carolina.

The Bridge between Years 1 and 2

At the start of Year 2, the *Rethinking Guardianship* statewide workgroup took stock of the findings in Year 1 and began a process of envisioning desired outcomes and offering strategies to move the initiative forward. The following illustration was used early in 2016 as a bridge between the two years.



Rethinking Guardianship Results, Year 2

Common Agenda

As a preamble to the Common Agenda (i.e., one of five essential elements of a Collective Impact project) for the *Rethinking Guardianship* initiative, the statewide workgroup considered and adopted *core concepts* and *basic principles* set forth by Rud Turnbull, a member of the workgroup and an author, educator, and leader in the field of special education policy and law.

Rooted in federal law and the UN Convention on the Rights of Persons with Disabilities, these concepts and principles recognize that the rights of individuals with disabilities are equal to those of persons without disabilities under the law (UNCRPD, Americans with Disabilities Act, and other federal and state laws).

Core concepts and basic principles

- autonomy, liberty, freedom, dignity
 - *Autonomy* refers to the psychological instinct of a person to have control over his/her life; the legal right to do so; and the duty of family, friends, and providers to support the person to have autonomy.
 - *Liberty* refers to the right of a person with a disability not to be physically and/or emotionally restricted in autonomy, physical movement, and emotional well-being. The term includes without limitation the person's claim to exercise all his/her constitutional rights.
 - *Freedom* refers to the same right and is a synonym for liberty.
 - *Dignity* refers to the right of the person to be respected, and to the duty of family, friends, and providers to accord the person respect, where respect means valuing the person as a person with rights; presumptions of competence, status/standing in law and community, and all activities within both; and esteem, that is, being valued as a worthy human being, free from the status as a commodity whose value is a benefit of any kind to another person or entity.
- presumption of competence
- right to life-time decision-making support.

Outcomes of these core concepts and basic principles [ADA Sec. 12101(a)(7)] and other federal laws include

- equal opportunity and equal standing in law
- independent living and autonomy (choice)
- full participation in all of life's domains, activities, and communities
- economic self-sufficiency, including support for economic opportunities and security.

Informed by these core concepts and basic principles plus findings gathered in the first year, the statewide *Rethinking Guardianship* work group developed a set of desired long-term outcomes for the initiative and agreed to a prioritized

set of strategies to achieve them. These long-term outcome statements, forged from the collective views of the statewide workgroup, establish the Common Agenda for the effort. The process seeks to develop

1. a guardianship system that is less restrictive and based on best practices
2. a guardianship process in which all stakeholders are identified and engaged
3. options and pathways toward guardianship, and alternatives to guardianship, that are communicated to and understood by all stakeholders
4. a public and private guardianship system that is held accountable
5. information about guardianship and its alternatives that is easily available and accessible.

In addition to statewide efforts in Year 2, the initiative selected Catawba County as a pilot site for more extensive data collection and action. Following a kick-off event in summer 2016, Catawba County partners, including the county Department of Social Services and Partners Behavioral Health, prioritized a set of action steps, which will be discussed later in this report.

An Engaged and Diverse Work Group

Building on Year 1's momentum, the *Rethinking Guardianship* Statewide Workgroup, now 118 members strong, met five times in 2016 with attendance at any given meeting ranging from 40 to 60 participants (see Appendix C for a list of workgroup members). The group also established three subcommittees, each assigned specific work on behalf of the initiative in between the large stakeholder gatherings. Here is a summary of the results of the meetings of the whole workgroup.

January 28, 2016

- articulated a Common Agenda and determined next steps
- established workgroup subcommittees.

March 31, 2016

- introduced the recently selected Catawba County *Rethinking Guardianship* Pilot Project
- continued to articulate the initiative's Common Agenda by revising and clarifying the objectives and action steps of each subcommittee and selecting a logo for the initiative

- determined actionable steps to accomplish by December 31, 2016.

May 19, 2016

- gained greater understanding of the NC Guardianship Statute 35A & the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act (UAGPPJA), as well as the UN Convention on the Rights of People with Disabilities.

July 21, 2016

- gained greater understanding of what other states are doing to promote the use of less-restrictive alternatives and improve the guardianship process.

September 29, 2016

- gained greater understanding of what Minnesota and Missouri are doing to promote the use of less restrictive alternatives and improve the guardianship process
- determined “next steps” for 2017, Year 3 of the initiative.

Subcommittee Goals and Results

Three subcommittees, created during the first meeting of the year, set goals with steps to be achieved by December 31, 2016. The subcommittees are named (1) Legislation, Policy, and Practice, (2) Education, Awareness, and Training, and (3) New Information: Stories and Data. These are the results of actions taken by these subcommittees with support from the Jordan Institute for Families.

Legislation, Policy, and Practice

GOAL 1: Identify desired North Carolina statutory changes

- STEP 1: Review NC statutes; identify barriers and gaps, impracticality, terminology
- STEP 2: Identify which states/countries (including model states) to compare
- STEP 3: Analysis/recommendations

GOAL 1 RESULTS: Statute 35A and policy recommendations identified

- The Legislation, Policy, and Practice Subcommittee met throughout the year to name and consider the best approaches to effecting legislative, policy, and practice changes in alignment with the *Rethinking Guardianship* goals. During the final meeting in December, the subgroup met to make recommendations for moving forward with legislative and policy changes in 2017.

These recommendations will be shared with the large *Rethinking Guardianship* workgroup in January 2017.

- The group strategically created the following short-term and long-term recommendations.

Short term

- Work together with legislators to draft and introduce a Supported Decision Making Bill
 - Review, consider, modify language from Texas and Delaware.
 - Consider a pilot community for implementation.
- Introduce a North Carolina Guardianship Bill of Rights.
 - Consider documents from Minnesota and Texas and other states.
 - Draft a high-quality North Carolina Guardianship “Bill of Rights” to introduce to the legislature.
- Recommend a “spousal solution” to the guardianship statute, based on widespread acknowledgment that separating finances between spouses in a guardianship arrangement is often unnecessarily onerous.
 - Follow up with Clerks and Assistant Clerks to get ideas for solutions.
 - Investigate what other states have done to address/solve this issue.
- Meet with key leaders at the AOC to invite engagement and buy-in with the goals of the *Rethinking Guardianship* initiative.
- Create and introduce a restoration form in partnership with the AOC and determine how to make it available to people inside and outside of the court system.

Longer term

The group is committed to researching these changes to Statute 35A.

- Give respondents the right to counsel as one solution to address the conflict of interest within the guardian ad litem role.
- End the presumption of permanence in guardianship, that is, how guardianship can be revisited on a regular basis without the individual needing to initiate the review.
- Modernize the language contained in the statute with person-centered language (e.g., replace “ward” and “incompetence,” etc.).

Education, Awareness, and Training

GOAL 2: Develop a draft training curriculum for private guardians (this goal was ultimately addressed by an ad hoc committee comprised of members from both the Legislative and Education subcommittees).

- STEP 1: Survey existing curricula.
- STEP 2: Identify learning objectives.

GOAL 2 RESULTS: Learning objectives for guardianship training have been created and curriculum development is under way.

The Education, Awareness, and Training Subcommittee met throughout the year. During the final meetings, in August and November, the subgroup met at the Wake County Justice Center and set about two tasks: (1) to review other state trainings with the intention of incorporating best practices (both content and form/modality) into a new training product, and (2) to create a set of learning objectives for private guardianship training.

Here is a summary of the results achieved by this group in Year 2, which will guide the work of the subcommittee in Year 3.

Survey Existing Curricula. Members of the subcommittee reviewed guardianship training curricula, websites, and other on-line resources from four states (North Dakota, Missouri, Arizona, and Idaho). The criteria used to evaluate these curricula included to what degree they

- were visual, used adult learning principles, were simply organized and explained
- used clear language
- were interactive/engaging
- used examples
- were thorough/comprehensive
- targeted private guardians—families/interested persons (kept the audience in mind)
- were ADA-compliant
- had one focus on young adults in addition to other age groups
- provided a contact available for support
- provided/included sample documents such as medical directives and other forms.

In addition, members attended a Clerk of Court guardianship training, which is held monthly in Wake County.

A representative from the AOC was present during this meeting and expressed interest in videotaping the Wake County training for use by other counties in North Carolina.

The group determined that the standout among other state trainings was North Dakota, which has developed training that is user-friendly, professional, visually appealing, and easy to read and understand. It is more comprehensive in providing both pre- and post-guardianship information. It also provides guidance in identifying alternatives to guardianship and understanding when guardianship is appropriate. There is information that explains what to expect if guardianship is the only option and what a guardian's responsibilities are, including court-reporting requirements.

The group also liked materials from Missouri for identifying alternatives to guardianship and understanding when guardianship is appropriate. The group will proceed with this information in Year 3 and will work together with the AOC to fully develop North Carolina's private guardianship training, which can be used throughout the state's 100 counties. Out of this work at the end of Year 2, the subcommittee has identified these learning objectives and training materials/content.

Learning objectives

Private Guardians will

1. understand what guardianship is, including its limitations, whom it is intended for, and what it means to be appointed someone's guardian
2. identify and consider alternatives to guardianship prior to applying for guardianship
3. engage in ongoing self-reflection and informal assessment before, during, and after adjudication of incompetence
4. understand how to determine when it may be appropriate to modify the guardianship or petition for restoration of competence (partial or full)
5. utilize person-centered tools to assess individuals' situations and elicit from them what they want in their own words
6. understand the diversity of planning tools they have available to them, and use them appropriately and as needed, including
 - training and resources that are specific to 'disability/condition

- caregiver support (support groups) and other community resources.

The subcommittee also identified two opportunities for training and the specific materials and content that would be most appropriate at each stage.

Training Prior to Filing a Petition

- materials on alternatives to guardianship (e.g., supported decision making) and limited guardianship
- video on what to expect in a hearing (AOC video/ Disability Rights video)
- Forsyth County DSS assessment of who can best serve, in order of priority
- what to expect in a competency hearing
- description of the role of the guardian ad litem attorney

Training Following Appointment as Guardian

- communication and conflict resolution (between family members)
 - family meeting with DSS
 - mediation
- financial responsibilities of guardianship
 - Money management/practices
 - Culture of money
 - Other materials/content TBD

GOAL 3: Establish a functional, user-friendly website

- STEP 1: Identify the stakeholders who will use the website
- STEP 2: Invite and include missing stakeholders on the Education Subcommittee
- STEP 3: Determine the design, layout, and sections of the website
- STEP 4: Create a fact sheet that can be printed
- STEP 5: Establish a comprehensive list of information tailored for each stakeholder

GOAL 3 RESULTS: Website completed:
<http://ssw.unc.edu/rethinking/>



HOME

OUR MISSION

WHO WE ARE

RESOURCES

PILOT PROJECTS

STORIES

CONTACT US

Welcome



The Jordan Institute developed a comprehensive website with input from the Education Subcommittee. It provides information about the *Rethinking Guardianship* Initiative, FAQs (Frequently Asked Questions) about guardianship and alternatives, stories of those who have lived experience with guardianship and restoration, pilot projects, and an extensive store of resources and links to information and services related to guardianship. The website assists guardians, individuals under guardianship, family members, policymakers, and others to find accurate and timely information about guardianship and alternatives in North Carolina.

RETHINKING GUARDIANSHIP

RETHINKING GUARDIANSHIP: BUILDING THE CASE FOR LESS RESTRICTIVE ALTERNATIVES

Year 1 (2015) Activities

- Brought together a diverse and committed work group
- Began building a knowledge base of best practices
- Began building a collection of relevant data

PROJECT GOALS

- Promote less restrictive alternatives to guardianship in North Carolina
- Create long-term changes in North Carolina's guardianship system
- Create a process of Collective Impact for one or two pilot projects

Year 2 (2016) Activities

FORMED THREE WORKING SUBCOMMITTEES FOCUSED ON

- Legislation, Policy, and Practice
- Education and Awareness
- Data and Stories

PLANNED ACTIVITIES FOR 2016

- Identify desired North Carolina statutory changes
- Develop draft of training curriculum for guardians
- Establish a user-friendly website
- Support and launch a pilot project in Catawba County
- Conduct guardianship case reviews within Catawba County
- Engage in guardianship story collection
- Analyze Administrative Office of the Courts (AOC) data

Administrative Offices of the Court Data Example

Fiscal Year	Total Cases	Judicial District	Clerk of Superior Court	County Clerk
FY 2010-11	1,800	1,200	400	200
FY 2011-12	1,900	1,300	450	150
FY 2012-13	2,000	1,400	500	100
FY 2013-14	2,100	1,500	550	50
FY 2014-15	2,200	1,600	600	50

Survey of Clerks of Superior Court Data Example

Response Category	Percentage
Need for reform	75%
No need for reform	15%
Don't know	10%

Why Rethink Guardianship?

Of the 10,000+ adults served by ODS annually:

- ~1,000 are under 18 years old
- ~1,000 are over 65 years old
- ~1,000 are in nursing homes
- ~1,000 are in assisted living facilities
- ~1,000 are in residential care facilities
- ~1,000 are in community-based settings

Of Adults age 18-64 Of Adults age 65+

"There are many alternatives to guardianship that enable and empower individuals while still providing the appropriate level of support for a healthy, happy and successful life." - Rachel

"I like your house a little, I like my house a lot!" - Jeremy, 33 year-old self-advocate, apartment owner and decision maker

"We chose not to take guardianship of our son. This has given him a great deal of confidence. He tells me regularly: 'Mom, I can do that.' I am my own guardian you know!" - Rachel

"It has been devastating to me to have false statements written and made to say I was incompetent. I read all those lies and wondered how I could fight this injustice!" - Anonymous

SPONSORS

New Information: Stories and Data

GOAL 4: Engage in guardianship story collection in order to foster understanding of the lived experience and need for changes within the system.

GOAL 4 RESULTS: Sixteen stories were gathered from individuals impacted by guardianship, and additional stories will be collected in Year 3.

The stories contained in this report reflect the experiences of individuals and family members affected directly by guardianship, collected through interviews during Year 2. Additional stories were gathered from professionals working within the guardianship system, and more personal and professional stories will be collected throughout Year 3. These will be shared in future reports and on the *Rethinking Guardianship* website.

In reading the stories of individuals and family affected by guardianship, one can acknowledge that there is a range of experiences and reactions to the guardianship system and to guardianship itself. However, one may also notice consistent responses and/or themes woven throughout the stories.

- desire to do what is best for one's family member
- expressions of individuals' hope and desire for autonomy and choice
- surprise or shock about what was unknown before, during, and after guardianship
- disillusionment over the role of the guardian ad litem because of a seeming "disconnect" between what is expected of that person and what is experienced
- feelings of outrage or despair when the court appointed guardian takes control of an adult's life and, in some cases, abuses this power
- empowerment and pride at the prospect (and realization) of restoration.

Here are some of the stories that were gathered. Some of the tellers permitted us to show their photograph. Readers should be aware that the stories recorded here are told from the perspective of the individual, and the accuracy of the remarks cannot be fully substantiated by the authors of this report and reflects the experiences of some individuals involved in the guardianship process.

John's Story

John 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. His story was compelling and this earnest, likeable young man drew in the group.

John's story is a perfect illustration of a sad irony of the guardianship system. Born in the mid-1980s, he is very high functioning and yet is under full guardianship. His childhood included domestic violence, and he may have had developmental delays (he asks, "Am I on the 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."

John's father petitioned for guardianship a couple years ago to keep his mother from taking his social security check. At first, John was living with his dad and stepmother, with whom he never saw eye-to-eye, and after guardianship, his family moved him to a group home 40 minutes from where he is going to school. "This situation has been difficult for me because I can't drive, and I can't get a job because I can't drive."

Recalling his court hearing, John said that at first he was looking forward to working with the guardian ad litem. However, the person who was appointed "never really protected me—just showed up to make it official—didn't give me the papers, didn't give me information. It was kind of like a 'one and done' thing."

Now John is trying to complete the restoration form given to him during his serendipitous visit to the *Rethinking Guardianship* workgroup meeting, as well as the past paperwork from the GAL. His immediate goals are to restore his competency, get a driver's license, and get a job so he can make some income.

"I'm working on putting my team together—getting to the point where I can be my own boss. One day, I hope to be an employer instead of an employee—changing the economy around me one person at a time—like a pebble in water."

John 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. Still, I don't think I'd change anything—if this guardianship hadn't happened, I

wouldn't have known about this and what to do in the future. Regrets are lessons."



Nora and Josh's Story

After college, Nora joined the Army Reserve where she learned to navigate the complicated military system. She had no idea that she would have to learn and navigate several more complicated systems later in life. After marrying and having three biological children, Nora adopted Josh, now 18 years old, from the Ukraine when he was 3-and-a-half years old.

Josh needed medical and dental care when Nora adopted him. Although he created amazingly detailed drawings, Nora was overwhelmed by his repetitive behaviors and lack of eye contact.

As he got older, Josh's challenging behaviors continued, and he was diagnosed with reactive attachment disorder, Asperger's Syndrome, and anxiety. At age 14 he had a major "meltdown" which required hospitalization, followed by a move to a psychiatric residential treatment facility. Nora came to the hard realization that her artistic little boy had grown into a teenager who couldn't safely live at home anymore. When he was 17-and-a-half years old, she was advised to seek guardianship.

Nora didn't realize that she could represent herself to seek guardianship for Josh. When she discovered that she could file for guardianship without an attorney, she dropped the attorney and got the paperwork together herself because she said, "There is no one on this earth that knows this boy better than me."

Nora was dismayed that the guardian ad litem assigned to Josh met with him only a few minutes before the hearing. The guardianship process moved quickly, and Nora was granted guardianship of the person for Josh. For a person who once navigated a career in the military, navigating the world of mental health care, hospitals, group homes, and treatment centers for her son has been tough. Fortunately, Josh is currently thriving in a therapeutic foster home.

Nora believes that improvements in the guardianship system should include educating people on the process of applying for guardianship, preparing for filing and court, and collecting the documents needed for evidence. She also believes people need to better understand what being declared incompetent means, as she realizes that Josh *isn't*

incompetent in many ways. Nora would like to see the guardians ad litem work more closely with the individual and their current guardian/parent. Lastly, she would like to see training afterwards on how to be a guardian. As Nora remarked, “Whew! Having to learn the WHOLE SYSTEM is tough. If this can be made a little simpler, it would be a big help!”

Scott and Aidan’s Story

Aidan is 20 and loves spending time with his family and friends. He works a summer job when school is out and volunteers at his church. Aidan also has Fragile X syndrome, which causes social anxiety and communication delays, and is the most common known genetic cause of autism spectrum disorders.

To support Aidan in pursuing his dreams, his parents, Scott and Terry, decided to seek guardianship when he turned 18. Scott said, “No one can or will love him like I do, but I want to prepare him to be his own person.” Aidan retains decision making over money, which can make his parents nervous sometimes, but they want him to have the chance to learn about handling money. Aidan understands that it takes money to buy things, even though he doesn’t always understand the value of a bill or an item.

In addition to being Aidan’s father and guardian, Scott has had a long career working and volunteering on behalf of individuals and families with disabilities. If he could change anything about the systems that support people with disabilities it would be to give them more options. He said that individuals with disabilities need “more decisions and more options, the chance to try something, change their mind, and try another option” (such as trying multiple living arrangements, different jobs, etc.). Young adults with disabilities are supposed to make a plan, but “the system doesn’t include plan B and C— it doesn’t have that many options.”

Scott also remains open to modifying Aidan’s guardianship as Aidan has more real-life experiences and demonstrates good decision-making capacity in different areas. He hopes that someday Aidan will live independently, and wants him to try sooner rather than later. He doesn’t want Aidan’s first experience of living independently to be in middle age when his parents are elderly. Although future planning can be a hard concept for Aidan to understand, Scott talks with him about different living options, using picture cards to

help illustrate. Scott hopes that by Aidan trying different living settings in early adulthood that it will allow Scott, Terry, other caregivers, and friends to support Aidan to adapt, learn new habits, or change detrimental habits so he can be successful.



Maureen and Lukas's Story

"When I was told that I should petition for guardianship, the first thing I thought of was 'Guardian Angel'—someone to protect you and guide you. It had no negative connotation attached to it."

And now? "I think guardianship should be used only if someone is comatose. The reality is that many people are not advanced enough as human beings to put someone else's needs ahead of their own."

These are the reflections of Maureen, the mother of Lukas, now in his 30s, who has recently moved in with his father after going through a challenging guardianship process and living in group homes for the past two years.

Lukas, a creative and sensitive young man who writes poetry to this day, has congenitally malformed ear canals as well as a CMT neuromuscular disorder, (similar to Muscular Dystrophy) which required special medical attention and surgical procedures in his youth. At 19, he was diagnosed as having Schizoaffective and Bipolar Disorders.

At 30, Lukas had a mental health crisis, and Maureen was told by a social worker "If I were you, I would petition for guardianship so he doesn't go back to his father."

When Maureen expressed concern about the permanency of guardianship, the Assistant Clerk told her it "could always be reversed." There was no information given at the Court on guardianship and its responsibilities and consequences.

The Assistant Clerk assigned Lukas a guardian ad litem, who visited Lukas while he was in a psychotic episode in the hospital and then met with the two parents' attorneys to determine "best interest," which resulted in a recommendation to the Clerk that Lukas be assigned a third-party guardian. Maureen received the guardian ad litem's two-page report halfway through the hearing.

Eventually, Lukas was taken from the hospital and placed in a group home. Maureen was ordered not to contact Lukas

and was unable to see him for three months. She was repeatedly told, “Lukas doesn’t want to talk to you.” However, as soon as he was moved to another group home, she had sudden access him and they were back in touch with each other.

In the past month, Lukas has moved back in with his father while retaining his third-party guardian. Although it is still early, he is fairly stabilized on his medication. Ultimately, together with Lukas’ father and stepfather, Maureen envisions a restoration of Lukas’ rights.

What important change would she make to the guardianship system in North Carolina? “When people go to file a petition, they should be given information—perhaps a brochure—that makes it clear what guardianship is and what alternatives exist. I think there should a 24-hour waiting period given to read this information. Guardianship is SO serious and legally binding.”

Tyler’s Story

“My name is Tyler. I was born in 1990 and grew up in Hickory NC with my adoptive parents. I am single and have never been married, nor do I have children. I am very active in my church and recently started a new job in my community.

“I know from my adoptive father that my biological mother struggled with drug addiction and mental health problems. I struggled with depression and anger throughout my teenage years.

“I was engaged to be married this past year but found that I needed to be free of my last relationship, as I felt I was taking on her problems. I have been living in my own apartment for three years, and I was able to become my own guardian in September of 2014.

“I continue to get help from DSS for my social security money and bills, and for case management to link me to resources that might help. I asked for help with restoring my guardianship in 2012, and it was a long hard journey. Today I love studying history, I like reading, watching television, gaming, and bowling. My church is very important to me. My faith is most important to me. The spiritual love and guidance I have received at my church means so much.

“I started counseling when I was young, I had lots of diagnoses and medications by the time I was an adult. I



went to the hospital often. I know now that I feel best on a low dose of medication, monitored by my psychiatrist, and that I don't feel good if I take too many medications, but I also don't feel well without any medications. I have learned some ways to deal with myself and others, but I also know I have to continue to work on this.

"Having my rights restored was very important to me. I can go anywhere I want without permission. I have family in other states, and I like going to see them. I also really enjoy hanging with my friends and playing with my gaming system, having my own apartment, and having my own paying job. I continue to use some community resources to assist me, but I am more in charge of taking care of those things for myself."

Peggy and Jean's Story

Despite a court order explicitly stating that she had the right to see her twin sister Jean, and after three years of being blocked from seeing her, the Clerk told Peggy, "It is not our job to enforce orders concerning the guardian of the person; it's just our job to review the accounting of the guardian of the estate."

When Peggy asked, "So whose responsibility is it to enforce the orders of the guardian of the person?" the Clerk answered, "Nobody's." Peggy's reply: "What should I do to be able to see my sister?" The Clerk's answer: "You need to file a petition for another hearing." Peggy said, "If the orders aren't enforced from the hearing, what good would this do?" The Clerk did not answer.

In the early 1970s, when Jean was 17 or 18, she had a mental health crisis and was diagnosed with Paranoid Schizophrenia and Delusional Schizophrenia.

Peggy's challenging journey with guardianship and the court system began in the late 1990s when her sister stopped taking her medication and was in and out of psychiatric hospitals.

In 1999, Peggy was told that her sister needed a guardian; Jean didn't have insight into her illness and wouldn't accept that she was sick. An attorney told Peggy that she was "too close" to be the guardian. Peggy listened and believed her.

At the time, the two sisters were attending NAMI (National Alliance on Mental Illness) meetings and shared experiences with others there. A charismatic and persuasive woman attending the meetings took an interest

in them. Peggy shared that her sister had a large trust from her father, which she believed was a major factor in this woman's interest in Jean. Peggy trusted her at the time.

When Peggy petitioned for guardianship in 2001—"I just wanted to do what was best for her"—and testified in court on Jean's incapacity (e.g., jumping out of the car and almost getting hit), Jean heard this testimony and was upset. The woman attending the NAMI meeting was in the courtroom and having gained the confidence of the sisters, was named Jean's general guardian.

At first, even after the guardianship was assigned, Peggy still took care of her sister and the guardian rarely saw her. In 2002, after an inpatient stay, the guardian placed Jean in a home by herself and didn't consult Peggy about it. Eventually, Jean was living in an unlicensed family care home, operated by the guardian, and she had run away several times.

In 2006, Peggy petitioned for a hearing to become guardian of the person and estate upon suspicion that the guardian was comingling Jean's trust funds to benefit her businesses. Although a neighboring county's Department of Social Services investigated and recommended removal of guardian of person and estate, according to Peggy, the Clerk of Court of the county in which Jean had been assigned guardianship ignored the investigation. This Clerk found that the guardian had indeed comingled funds, yet allowed her to retain the role of guardian of the person while guardian of the estate was reassigned to a public guardian.

After the public guardian spent all of Jean's trust money (over \$500,000 in five years), Peggy was contracted to pay for her sister's expenses, which she can no longer afford to do. Except for a three-year period, during which Peggy paid over \$3,000 a month for Jean's care, Peggy has been blocked by the guardian from seeing her sister.

Here are Peggy's comments about her experience:

"There is no accountability or oversight of the guardians or the local court system that is supposed to govern the guardians. With this lack of accountability, the guardian system allows for financial exploitation, fraud, and abuse at several levels.

"The mentally ill are not able to help themselves or to speak for themselves, in many cases, because social workers are

told by the guardian that they are unreliable and too sick to be taken seriously.”

Peggy concludes:

“When a system such as this allows such unlimited and ungoverned power of the guardians over their incompetent wards, this system attracts unscrupulous guardians and others who are supposed to monitor the guardians. Especially when large amounts of money are available from federal and state funding and from their ward’s own funds, this provides a very lucrative incentive to become guardian or family care owner.”



Robyn’s Story

“When my mom died when I was just 15 years old, my mom was everything to me. I’m the youngest of five. My mom made it her mission to make sure that if anything ever happened to her, I would be taken care of.

“Rhonda is the oldest, older than me. Mom wanted to find a lawyer but wound up finding two. I didn’t know this information until I went to a conference to get information about how to get my guardianship restored. That’s when I learned I had two lawyers: Deborah Greenblatt and Sheila Benninger. Deborah Greenblatt made it her mission to have my guardianship restored back to me in 2002. If it hadn’t been for her, I would never have gotten my guardianship.

“Till this day, I still talk about how I got my guardianship. I always get questions from parents that want their child to have their own guardianship and from adults who have guardians, but want their guardianship restored.

“But what makes me the proudest is when I know Deborah Greenblatt gave me my confidence to tell other people about guardianship.”

Robyn Dorton is a self-advocate trainer who has presented interactive training sessions with Project STIR since 1999. She received the 2006 NC Self-Advocate of the Year Award from the Association of Self-Advocates and was president of her local self-advocacy group. She became her own guardian in 2002.

GOAL 5: Analyze Administration Office of the Courts data to discover what we do and do not know about people who have had guardianship filings, identify gaps in reporting and record keeping, and make suggestions for systemic

data/record-keeping changes that will increase accountability within guardianship.

GOAL 6: Conduct guardianship case reviews within Catawba County to gain an understanding of who is currently experiencing guardianship and why, and to understand ways in which data collection can be systemically changed to provide greater oversight and accountability.

GOALS 5 and 6 RESULTS: Refined Data Collection Findings Reported

As the *Rethinking Guardianship* Workgroup has delved into guardianship in North Carolina, one pressing concern has been the question of who is being served by the guardianship system and what their experiences look like. Story gathering interviewing, which allows people to describe their first-hand experiences with how they understand the circumstances of their guardianship, has been one way to get at this information. Another approach is to look more closely at the limited administrative data that the courts do collect.

The findings in this report are based on individual-level records from the North Carolina Administrative Office of the Courts. At the request of the NC Division of Aging and Adult Services, the AOC provided all records for people who had had at least one guardianship-related activity between July 1, 2012, and December 31, 2015. For people who had records of activity during this time period and *also* from before July 1, 2012, the AOC provided complete information about earlier activity, which is included in this analysis. Records were provided for both Special Proceedings (SP), which include rulings of incompetence and restoration, and Estate (E) filings, which include appointment of guardians of the estate and reports from guardians. Only the SP cases are included in this report. Records from the E file will be analyzed in Year 3 of this project.

Caveats Regarding Data from the Administrative Office of the Courts Data. Administrative personnel from the 100 County Clerks' offices receive uniform training from the AOC in how to enter guardianship case data. However, many real events and aspects of a case may not fit well or be easily captured by the established database categories. Furthermore, both counties and individuals within counties may have their own styles of entry, so that records may not

be coded consistently.⁴ Additionally, there is no mechanism for routinely checking data accuracy and quality. Thus, readers should be aware that findings here are the work of *Rethinking Guardianship* Data and Stories Committee and *neither the accuracy of the analysis nor any conclusions are accepted as accurate or endorsed by the Administrative Office of the Court.*

Perhaps the single most serious limitation to these data, beyond inconsistencies and potential errors, is that the AOC records do not contain any information about the alleged reason for incompetence or about the individuals, such as their age or gender. This information is only found in the paper records stored at each county court house.

Guardianship Findings from AOC Data

Rates and Numbers

In the forty-two months between July 1, 2012, and December 31, 2015, there were 15,798 individuals in North Carolina who were involved in some guardianship-related “special proceeding” activity. (See Appendix D for Guardianship and Restoration Activity by County.) This represents 21 people for every 10,000 adults in the state. The average rate for counties was 22 per 10,000, and the median was 20. The records indicate that of the 15,798 individuals, 11,927 (75.7%) were declared incompetent. Table 1 shows the dispositions of incompetence petitions during that time.

Table 1. Outcomes of Petitions to Declare the Respondent Incompetent, July 1, 2012, to December 31, 2015

Outcome	Number	%	Cumulative %
Ruled Incompetent	11,945	75.7	75.7
No Ruling	3,484	22.1	97.8
Denied Incompetence	342	2.2	100.0
Total	15,771	100.0	
Note: This table includes 15,771 of the 15,798 cases—excluding 27 people (0.17%) whose records were missing any petition/ruling on incompetence.			

⁴ For example, almost 20% of the 37,789 SP records were coded as “other,” which had to be manually recoded to more meaningful categories. Of these records, *over 30%* were found to be incorrectly labeled as “other” when an AOC code would have been appropriate, and 49% were directly related to guardianship procedure.

Length of Time

Among individuals with a ruling of incompetence, 62% received that ruling in fewer than 30 days from the date the case was initiated. Among all cases, the average length of time between the date the petition was filed to the date of the ruling was just over five weeks (37.6 days), with a median of just under one month (27 days).

Among individuals for whom incompetence was denied (i.e., did not need a guardian), the length of time between the date the petition was filed to the date of the ruling was longer. Only 34% of these decisions took less than one month, compared to 62% of those with a ruling of incompetence. Among all cases for which incompetence was denied, the average length of time between petition and ruling was 67 days, with a median of 45 days.

Finally, among the 15,798 people with guardianship activity in the target timeframe, 1,695 were assigned an interim guardian, to serve in the time between the petition and the ruling. Of these 1,695, the average length of time between petition and ruling was nearly twice that of the 10,380 individuals without an interim guardian (an average of 52 days, median 41 days, compared to 36 days and 26 days, respectively).

Explanations for this difference include the possibility that interim guardians are typically appointed for people for whom the wait is expected to be long—either from the need to gather more than the usual amount of evidence or because they may have a potentially reversible condition (e.g., a person who has had a stroke or been in an accident from which they might recover decision-making ability or for whom the evidence may become clearer after additional treatment). On the other hand, it may be that once an interim guardian is in place, the sense of urgency for a final ruling decreases. The AOC data cannot answer this question. The more in-depth material from the Catawba County record review may shed greater light on the reasons for this difference in one county, but there were only 18 cases with interim guardianship in Catawba County during the AOC data period, so findings will be suggestive at best.

Restoration of Rights

Of the 15,798 people with guardianship activity in the target timeframe, 468 (3%) experienced some activity

around restoration of their rights. Of these, 326 (69.7%) had their rights restored (2.1% of the 15,798).

The length of time between the petition for and the granting of restoration ranges from just over one month (34 days) to more than 24 years. The average length of time was more than three and a half years (3 years, 7 months), but this number is inflated by a small number of people who waited more than 10 years. The median length of time was just under two years (1 year, 10 months), which is probably more representative of the typical experience.

We would expect that the differences in time to restoration would be related to the underlying reason guardianship was granted. People's unique personal circumstances leading to guardianship, their individual abilities, motivation to seek restoration, and access to allies in the process of restoration can all contribute to the timing and success of a restoration proceeding. Because the AOC records do not include any information on the alleged reason for incompetence or even the person's age, we cannot begin to categorize people who get restoration.

Catawba County Pilot Launched

Catawba County was selected to participate in the *Rethinking Guardianship* project in early 2016. The existing Catawba County Adult Collaborative (CCAC) submitted their successful application in response to a RFI released by the Division of Aging and Adult Services in collaboration with the Jordan Institute for Families.

CCAC identified a core team made up of people from the county Department of Social Services, Partners Behavioral Health Management, the Greater Hickory Cooperative Christian Ministry, and Sipe's Orchard Home to begin to address guardianship in Catawba County. This core team developed a pilot—*"Rethinking Guardianship: Options for Independence"*—to focus on individuals ages 18 to 59 living with an intellectual and/or developmental disability or mental illness. The overarching goal is to assist this population to gain self-sufficiency skills at maximum capacity for their abilities. The team held an event mid-year to identify additional community partners and expand participation.

One of the first steps taken by the Catawba *Rethinking Guardianship* group was to establish a picture of guardianship in Catawba County. According to records at

Catawba County Department of Social Services, there are currently 96 cases of guardianship of the person; 1 limited guardianship case; 1 general guardianship case; 3 corporate guardianship cases; and an estimated 200 private guardianship cases.

These two charts show the age distribution of people under guardianship that DSS serves and the major diagnosis/reason for guardianship for those people.

Figure 1. Catawba County - Age in years of People served under Guardianship by DSS

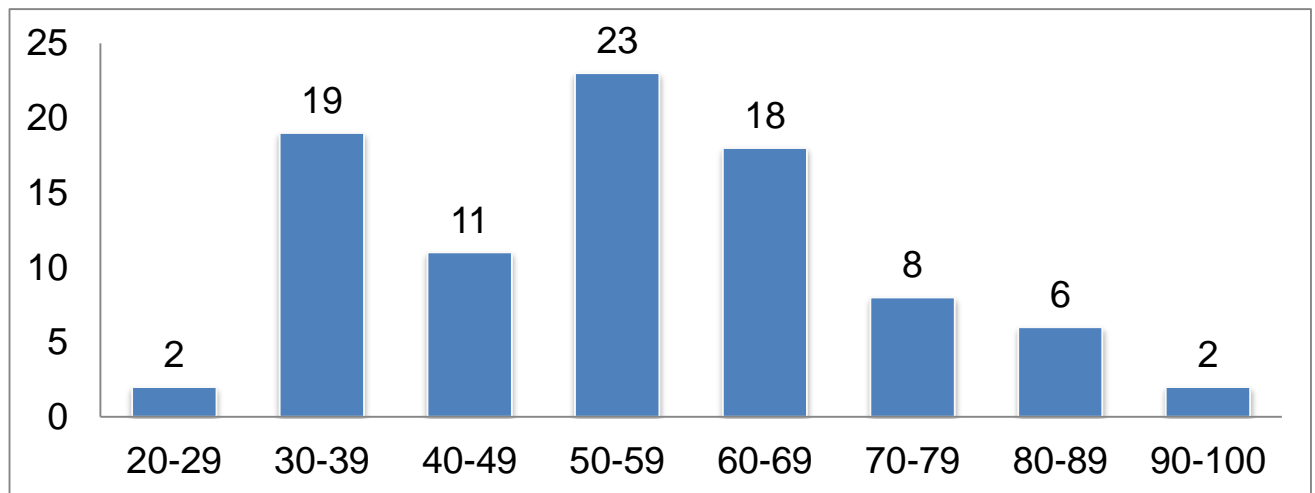
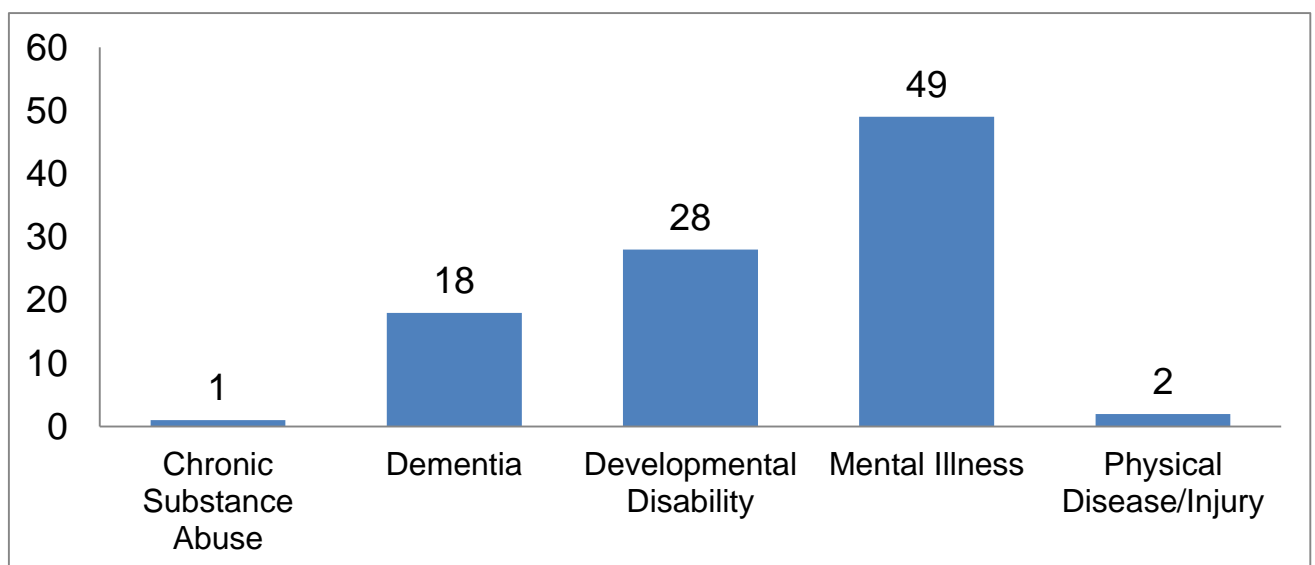


Figure 2. Catawba County - Number of People with Various Diagnoses Served by DSS Guardianship



The Catawba *Rethinking Guardianship* group then established three committees, each with a set of goals.

1. Transitioning to Adulthood
 - Focus on individuals with Intellectual and Developmental Disabilities who are turning age 18 (also includes youth aging out of foster care system).
 - Develop a training module for schools to use in educating school staff, parents, families and individuals with I/DD or aging out of the foster care system on options for independence.
 - Involve the three public school systems in Catawba County on the RTG subcommittee.
2. Supportive/Surrogate Decision Making
 - Increase knowledge and availability of alternatives to guardianship and supported decision making in the community.
 - Create a volunteer and training process that will help create a “support team” for potential persons needing guardianship (in lieu of guardianship or as an added support).
 - Partner with a provider who has the expertise to help achieve this goal.
3. Community Education and Awareness
 - Develop education/training for attorneys (GALs), Clerks of Court, and court employees on alternatives to guardianship (including limited guardianships).
 - Develop material to share with petitioners about alternatives.

These committees are currently meeting, focusing on their specific area of interest, and gathering information. The Catawba *Rethinking Guardianship* group will review all the information gathered and using the Collective Impact model, will discuss shared measurements and indicators of success for future work.

Next Steps in Catawba County

- Work with the statewide *Rethinking Guardianship* group in developing training modules for three target areas, including the school system (teens aging out of services and I/DD population); court system, Clerks of Court, attorneys, and petitioners—alternatives; and community—increasing alternatives in the community and supported decision making.

- Employ continuous communication to increase awareness and knowledge in the community to provide the best options for independent living and alternative guardianship options.
- Assure backbone support to see that progress is being made in each goal area through a local steering committee to align activities, measure outcomes, advance needed policy changes, and mobilize resources, while keeping the community engaged.
- Partner with the workgroup on suggested guardianship policy revisions.

Record Review in Catawba County

Toward the end of Year 2, team members from the Jordan Institute began visiting the Catawba County Courthouse to review the paper guardianship records in that county.

These records, though time-consuming to review, provide much more detail than the AOC data. The key information this team is hoping to identify includes

- types, rates and numbers of the most common difficulties that lead to petitions for incompetency (e.g., age-related dementias, mental illness, intellectual/developmental disabilities, substance abuse)
- rates and numbers of guardianship in the general population, to expand upon the Catawba County DSS statistics shared earlier in this report (i.e., the current record review will include private guardianships as well)
- variations in the length of time from initial filing to case ruling and from petition for restoration to successful restoration, and any insights into the reasons for these variations that the more detailed county records can provide
- the factors associated with successful restoration
- insight into the relationship between the assignment of an interim guardian and the length of time from petition to ruling.

It is too early to draw any conclusions from the small number of files reviewed thus far, but cases already reviewed have included respondents with a dual diagnosis of developmental disability and mental illness, developmental disabilities alone, physical disease or injury (e.g., stroke, head injury), dementia, and mental illness.

Other Noteworthy Accomplishments

North Carolina named a WINGS state by the American Bar Association

During 2016, the *Rethinking Guardianship* team had the opportunity to talk with several states involved in guardianship reform as well as Erica Wood at the American Bar Association, who named North Carolina as a new WINGS state. This distinction was verified during the National Guardianship Association Conference in Charleston, SC, in November 2016.

As a result of being added to the list of WINGS states, the North Carolina *Rethinking Guardianship* initiative is now able to fully engage with the national movement towards reform; swap ideas and lessons learned with other states; and trade valuable information about legislation, education, and data collection.

Passage of the NC Statue 35B – Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act (UAGPPJA)

Although not a direct initiative of *Rethinking Guardianship*, passage of the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act (UAGPPJA) was a significant legislative achievement during the second year of this initiative.

The UAGPPJA is a uniform law enacted by the NC General Assembly during the 2016 legislative session. The law applies to incompetency and adult guardianship proceedings under G.S. Chapter 35A and creates a new G.S. Chapter 35B. Effective at the end of Year 2, December 1, 2016, 35B provides a new process for transferring existing cases in and out of NC.

The UAGPPJA clarifies state jurisdiction issues, facilitates the transfer of guardianships between states, enhances interstate recognition and enforcement of guardianship orders, simplifies communication and cooperation between courts, and addresses emergency situations and other special cases.

Summary and Looking Ahead to Year 3

The *Rethinking Guardianship: Building a Case for Less Restrictive Alternatives* initiative has grown and taken root in Year 2 as diverse and engaged members of the workgroup have made it a productive year of “focused action toward desired results.”

As the group completes the activity of 2016 described in this report, it also looks to build on existing momentum to make lasting improvements to the guardianship system and increase awareness of less restrictive alternatives in 2017. Here is the preliminary “to-do list” for *Rethinking Guardianship* from January 1, 2017, through December 31, 2017.

- Support a more central leadership role for the *Rethinking Guardianship* initiative in the NC Administrative Office of the Courts.
- Sustain the initiative’s work when present funding is completed by exploring potential grant funding through organizations such as the American Bar Association and the Administration for Community Living.
- Identify legislative champions to introduce Statute 35A revisions.
- Mobilize stakeholders to support reform efforts.
- Make North Carolinians aware of the *Rethinking Guardianship* website.
- Create training opportunities for guardians, using a new curriculum.
- Use data and stories to build a case for system improvements and less restrictive alternatives.
- Evaluate pilot initiative in Catawba County as a step towards a replicable model.
- Interface with the child welfare system and the educational system to promote less restrictive alternatives to guardianship as children transition to adulthood.

Appendixes

- A. The Collective Impact Framework
- B. Glossary of Guardians
- C. Rethinking Guardianship Workgroup 2016
- D. Guardianship and Restoration Activity by County

Appendix A

The Collective Impact Framework

“Collective Impact initiatives are long-term commitments by a group of important actors from different sectors to a common agenda for solving a specific social problem. Their actions are supported by a shared measurement system, mutually reinforcing activities, and ongoing communication, and are staffed by an independent backbone organization.”⁵

Five essential elements comprise the Collective Impact framework:

Common Agenda

All participants *share a vision for change* that includes a common understanding of the problem and a joint approach to solving the problem through agreed upon actions.

Shared Measurement

All participating organizations *agree on the ways success will be measured and reported*, with a short list of common indicators identified and used for learning and improvement.

Mutually Reinforcing Activities

A diverse set of stakeholders, typically across sectors, coordinate a set of differentiated activities through a mutually reinforcing plan of action.

Continuous Communication

All players engage in frequent and structured open communication to build trust, assure mutual objectives, and create common motivation.

Backbone Support

An independent, funded staff dedicated to the initiative provides ongoing support by guiding the initiative’s vision and strategy, supporting aligned activities, establishing shared measurement practices, building public will, advancing policy, and mobilizing resources.

⁵ Kania, John, and Mark Kramer. “Collective impact.” (2011): 36-41.

http://c.ymcdn.com/sites/www.lano.org/resource/dynamic/blogs/20131007_093137_25993.pdf

Communities are ready or near-ready for Collective Impact when:

- There is a “champion” for this cause who has the ability to engage and encourage multiple sectors in the community and is willing to use that ability to help the community solve this problem.
- There is some local funding available to begin this effort or in-kind resources (protected time for selected staff members) to begin working to obtain funding.
- There is a history of other kinds of successful collaboration in the community among at least some of the relevant stakeholders.
- The general public is aware of this problem and cares about it, or can be readily made aware and will care if they are aware.

Appendix B

Glossary of Guardians

Guardian of the Person is a guardian who is appointed solely for the purpose of performing duties relating to the care, custody, and control of an individual. This includes such decisions as

- where the individual will live
- who the individual can visit and can communicate with
- the type of location of medical care the individual receives (with the exception of sterilization).

Guardian of the Estate is a guardian who is appointed solely for the purpose of managing the property, estate, and business affairs of an individual. Essentially, managing all financial aspects of the individual's life. This includes

- initiate, defend, or settle lawsuits
- lend or borrow money
- make a will for the individual
- manage or possess the property or income of the person under guardianship
- pay or collect debts.

General Guardians are guardians of the person *and* of the estate and have the decision-making authority of both of those positions.

A **Public Guardian** is assigned to a “disinterested public agent” when there is no family member or friend available or appropriate to serve as guardian. In North Carolina, Director and Assistant Director of the Department of Social Services are the only officials authorized to serve as the “disinterested public agent” guardian. When a public guardian is assigned, a worker from the local county DSS will serve as the guardian.

A **Private Guardian** is a private, individual citizen who is assigned to be the person's guardian. This type of guardian is typically a family member or friend of the person who is placed under guardianship.

A **Corporate Guardian** is a for-profit or nonprofit corporation whose corporate charter expressly authorizes it to serve as a guardian or in a similar fiduciary capacity.

Appendix C

Rethinking Guardianship Workgroup

Julie Bailey, Parent (retired; MHA-Triangle)
Erin Baluyot, North Carolina Department of Health and Human Services, Social Services, Foster Care Coordinator
Pam Barlow, North Carolina Clerk of Superior Court (Ashe County)
Tamara Barringer, North Carolina State Senator
Kelly Beauchamp, North Carolina Council on Developmental Disabilities
Lynne Berry, North Carolina Division of Aging and Adult Services
Helaine Bilos, Neuro Community Care
Erica Bing, Alliance Behavioral Healthcare (MCO)
Diane Brady, Legal Aid of North Carolina
Nicole Brinkley, Wake County Clerks of Court
Wanda Burney, Forsyth County Department of Social Services
Craig Burrus, Wake County Department of Human Services
Samantha Cabe, Orange, Chatham County Departments of Social Services
Walt Caison, North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services
Kathleen Cameron, National Alliance for the Mentally Ill North Carolina
Sam Clark, North Carolina Health Care Facilities Association
Beverly Colwell, North Carolina Department of Public Instruction
Lisa Corbett, North Carolina Department of Health and Human Services
Julie Cronin, North Carolina Department of Health and Human Services, Assistant General Counsel
B. Davis, North Carolina Center for Independent Living
Kim Dawkins Berry, Area Agency on Aging for Region G
Bill Donohue, Parent Advocate
Robyn Dorton, Self Advocate
Corye Dunn, Disability Rights North Carolina

Ken Edminster, North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services
John Eller, Catawba County Department of Social Services (Catawba Pilot)
Annette Eubanks, Mid-East Commission Area Agency on Aging
Jean Farmer-Butterfield, ARC of North Carolina, North Carolina General Assembly
Kent Flowers, Craven County Department of Social Services
Dorian Fredricksen, Corporation of Guardianship, Inc.
Charmaine Fuller Cooper, North Carolina AARP
Amy Funderburk, North Carolina Administrative Office of Courts
Gloria Garton, North Carolina Center for Independent Living
Carey Graham, Elon University, Elder Law (Intern)
Keith Greenarch, North Carolina Statewide Independent Living Council, The Adaptables-Winston Salem
Michele Haber, Geriatrics Consulting Services, Inc.
Tami Hefner, Catawba County Department of Social Services (Catawba Pilot)
Matthew Herr, Disability Rights North Carolina
Debbie Hippler, North Carolina Statewide Independent Living Council
Dean Hollandsworth, Social Services Attorneys Association
Pat Hurley, NC General Assembly, House Committee on Aging (Chair)
Kathy Jackson, Social Services Attorneys Association
Damie Jackson-Diop, NC Families United
Laura Jett, Mid-East Commission Area Agency on Aging:
Frank Johns, Booth, Harrington, & Johns, Elderlaw Firm
Nicholle Karim, National Alliance for the Mentally Ill North Carolina

Jessica Keith, North Carolina Department of Health and Human Services
 Carol Kelly, A Helping Hand
 Linda Kendall Fields, University of North Carolina, Jordan Institute
 Athena Kinch, A Helping Hand
 Joanna Kipnes, Duke University
 Gale Kirk, National Guardianship Association
 Terri Lawson, Assistant Clerk of Court, Catawba County
 Barbara Leach, University of North Carolina, Jordan Institute
 Tameka Lee, ARC of North Carolina
 Tienna Luong, Mecklenburg County Department of Social Services
 Janie MacMichael, Self Advocate
 Betsy MacMichael, First In Families North Carolina
 Seth Maid, National Alliance for the Mentally Ill North Carolina
 Regina Manly, Trillium Health Resources (MCO)
 Roger Manus, Campbell University, Senior Law Clinic
 Sarah Marsh, University of North Carolina, Jordan Institute
 Joyce Massey-Smith, North Carolina Division of Aging and Adult Services
 Suzanne Merrill, Division of Aging and Adult Services, DHHS
 Kate Mewhinney, Wake Forest University, Elderlaw Clinic
 Graig Meyer, Representative, General Assembly
 William T. Miller, North Carolina Statewide Independent Living Council Staff
 Natalie Miller, North Carolina Bar Association
 Bonnie Nelson, ARC of North Carolina
 Gary Nelson, University of North Carolina, Jordan Institute
 Tamara Norris, University of North Carolina, Jordan Institute
 Mark O'Donnell, North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services
 Michael Owen, University of North Carolina, Jordan Institute
 Mark Pegram, North Carolina Clerk of Superior Court (Rockingham County)

Richard Pender, Forsyth County Department of Social Services
 Michelle Pennell, Catawba County
 Rosalyn Pettyford, North Carolina Guardianship Association
 Belinda Pettyford, North Carolina Department of Health and Human Services
 Evelyn Pitchford, North Carolina Division of Aging and Adult Services
 Page Potter, North Carolina Central University, Elderlaw
 Raj Premakumar, North Carolina Department of Justice
 Sharnese Ransome, North Carolina Association of County Departments of Social Services Directors
 Glenda Reed, Wake County Department of Human Services
 Larry Reeves, Southwestern Commission Area Agency on Aging
 Jack Register, National Alliance for the Mentally Ill North Carolina
 Holly Riddle, North Carolina Department of Health and Human Services
 Denise Rogers, Office of the State Ombudsman
 Cynthia Ross, Pitt County Department of Social Services
 Amanda Rozycki, Duke Children's Hospital and Health Center
 Mary Anne Salmon, University of North Carolina, Jordan Institute
 Winsor Schmidt, University of North Carolina at Charlotte
 Scott Secor, First In Families North Carolina
 Elizabeth Shinar, Duke University Hospital, Clinical Social Work Department
 Kim Sigmon, North Carolina Clerk of Superior Court, Catawba County (Catawba Pilot)
 Shayna Simpson-Hall, North Carolina Department of Health and Human Services
 Stacey Skradski, Empowering Lives, Incorporated
 Meredith Smith, University of North Carolina School of Government
 Michael Smith, Partners Behavioral Health Management (MCO), Catawba Pilot
 Judy Smithmyer, Autism Society of North Carolina

Steve Strom, NC Council on Developmental
Disabilities

Peggy Terhune, Monarch North Carolina

Cynthia Trickel, North Carolina Department of
Public Safety

Rud Turnbull, Retired, Co-Founder, Beach
Center on Disability

Rena Turner, North Carolina General Assembly,
House Committee on Aging (Chair)

Hannah Vaughan, Elon University, Elder Law

Cheryl Walfall-Flag, Parent Advocate

Sunni Walker, University of North Carolina,
Jordan Institute

Aimee Wall, University of North Carolina School
of Government

Kate Walton, North Carolina Division of Aging
and Adult Services

Heather Carty Ward, Elder Law (Private
Practice), Charlotte NC

Nancy Warren, North Carolina Division of Aging
and Adult Services

Alice Watkins, Alzheimers North Carolina, Inc.

Polly Welsh, NC Health Care Facilities
Association

Carrie Whitaker, Duke University

Jeanette Wilhelm, Monarch North Carolina

Mya Williams, North Carolina Department of
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Deborah Woolard, Parent Advocate

Deborah Zuver, Carolina Institute for
Developmental Disabilities

Appendix D

Guardianship and Restoration Activity by NC County

July 1, 2012–December 31, 2015

Region	Adult Population (18+)	People with Guardianship Actions in the Courts	People with Guardianship Actions in the Courts per 10,000 adult population	People with Restoration Action	Percent with Restoration Action	People with Rights Restored	Percent of People with Restoration Action Whose Rights Were Restored	Percent of People in System Whose Rights Were Restored
State	7,369,782	15,798	21	468	3.0	326	69.7	2.1
<i>Counties</i>								
Alamance	117,037	248	21	1	0.4	1	100.0	0.4
Alexander	28,800	79	27	3	3.8	2	66.7	2.5
Alleghany	8,897	29	33	1	3.4	1	100.0	3.4
Anson	20,817	24	12	0	0.0	0	0.0	0.0
Ashe	21,974	112	51	1	0.9	1	100.0	0.9
Avery	14,769	15	10	1	6.7	1	100.0	6.7
Beaufort	37,252	86	23	2	2.3	2	100.0	2.3
Bertie	16,630	26	16	1	3.8	1	100.0	3.8
Bladen	27,066	107	40	3	2.8	3	33.3	2.8
Brunswick	90,111	108	12	1	0.9	1	100.0	0.9
Buncombe	192,977	449	23	24	5.4	15	62.5	3.3
Burke	71,069	201	28	2	1.0	2	100.0	1.0
Cabarrus	132,305	289	22	10	3.5	8	80.0	2.8
Caldwell	64,173	153	24	3	2.0	1	33.3	0.7
Camden	7,541	12	16	0	0.0	0	0.0	0.0
Carteret	54,540	94	17	3	3.2	3	100.0	3.2
Caswell	18,771	62	33	4	6.4	4	100.0	6.5
Catawba	118,097	203	17	11	5.4	6	54.5	3.0
Chatham	51,143	76	15	0	0.0	0	0.0	0.0
Cherokee	22,101	89	40	3	3.4	2	66.7	2.2
Chowan	11,462	13	11	0	0.0	0	0.0	0.0
Clay	8,577	21	24	3	14.3	3	100.0	14.3
Cleveland	75,172	173	23	0	0.0	0	0.0	0.0
Columbus	44,520	75	17	1	1.3	0	0.0	0.0
Craven	80,006	185	23	5	2.7	2	40.0	1.1
Cumberland	236,570	594	25	22	3.7	14	63.6	2.4
Currituck	18,407	30	16	0	0.0	0	0.0	0.0
Dare	27,472	55	20	1	1.8	1	100.0	1.8
Davidson	124,735	381	31	14	3.7	12	85.7	3.1
Davie	31,771	57	18	1	1.8	1	100.0	1.8
Duplin	44,280	61	14	3	4.9	2	66.7	3.3
Durham	214,977	391	18	16	4.1	15	93.8	3.8
Edgecombe	42,493	50	12	0	0.0	0	0.0	0.0
Forsyth	269,115	757	28	47	6.2	34	72.3	4.5
Franklin	46,508	119	26	1	0.8	1	100.0	0.8
Gaston	158,213	261	16	3	1.2	3	100.0	1.1
Gates	9,200	6	7	0	0.0	0	0.0	0.0
Graham	6,822	43	63	0	0.0	0	0.0	0.0
Granville	45,070	97	22	4	4.1	3	75.0	3.1
Greene	16,535	34	21	2	5.9	1	50.0	2.9

Region	Adult Population (18+)	People with Guardianship Actions in the Courts	People with Guardianship Actions in the Courts per 10,000 adult population	People with Restoration Action	Percent with Restoration Action	People with Rights Restored	Percent of People with Restoration Action Whose Rights Were Restored	Percent of People in System Whose Rights Were Restored
Guilford	380,510	715	19	21	2.9	16	76.2	2.2
Halifax	42,006	101	24	1	1.0	1	100.0	1.0
Harnett	85,922	118	14	0	0.0	0	0.0	0.0
Haywood	47,713	175	37	1	0.6	1	100.0	0.6
Henderson	85,852	300	35	14	4.7	6	42.9	2.0
Hertford	19,577	57	29	0	0.0	0	0.0	0.0
Hoke	34,323	54	16	1	1.8	1	100.0	1.9
Hyde	4,733	8	17	0	0.0	0	0.0	0.0
Iredell	121,084	184	15	4	2.2	3	75.0	1.6
Jackson	33,295	63	19	2	3.2	2	100.0	3.2
Johnston	125,136	193	15	9	4.7	8	88.9	4.1
Jones	8,077	16	20	0	0.0	0	0.0	0.0
Lee	43,642	57	13	0	0.0	0	0.0	0.0
Lenoir	45,232	60	13	5	8.3	2	40.0	3.3
Lincoln	60,573	148	24	4	2.7	0	0.0	0.0
Macon	27,544	55	20	0	0.0	0	0.0	0.0
Madison	16,717	51	31	0	0.0	0	0.0	0.0
Martin	18,931	18	10	0	0.0	0	0.0	0.0
McDowell	35,328	102	29	3	2.9	3	100.0	2.9
Mecklenburg	709,116	1246	18	32	2.6	28	87.5	2.2
Mitchell	12,520	29	23	2	6.9	0	0.0	0.0
Montgomery	21,063	36	17	1	2.8	1	100.0	2.8
Moore	70,231	104	15	1	1.0	1	100.0	1.0
Nash	73,085	99	14	1	1.0	1	100.0	1.0
New Hanover	165,453	292	18	5	1.7	3	60.0	1.0
Northampton	17,226	49	28	1	2.0	1	100.0	2.0
Onslow	134,017	155	12	2	1.3	2	100.0	1.3
Orange	107,937	127	12	2	1.6	1	50.0	0.8
Pamlico	10,813	45	42	0	0.0	0	0.0	0.0
Pasquotank	31,417	53	17	1	1.9	1	100.0	1.9
Pender	41,327	71	17	3	4.2	3	100.0	4.2
Perquimans	10,736	21	20	1	4.8	1	100.0	4.8
Person	30,345	97	32	6	6.2	2	33.3	2.1
Pitt	132,458	234	18	4	1.7	4	100.0	1.7
Polk	16,607	60	36	2	3.3	0	0.0	0.0
Randolph	107,652	113	10	3	2.6	1	33.3	0.9
Richmond	35,212	129	37	0	0.0	0	0.0	0.0
Robeson	98,775	187	19	1	0.5	1	100.0	0.5
Rockingham	72,764	220	30	9	4.1	8	88.9	3.6
Rowan	105,912	240	23	4	1.7	1	25.0	0.4
Rutherford	52,559	82	16	2	2.4	1	50.0	1.2
Sampson	47,555	64	13	2	3.1	0	0.0	0.0
Scotland	27,303	47	17	0	0.0	0	0.0	0.0
Stanly	46,992	69	15	2	2.9	1	50.0	1.4
Stokes	36,920	76	21	4	5.3	4	100.0	5.3
Surry	56,559	110	19	1	0.9	1	100.0	0.9
Swain	10,883	46	42	1	2.2	0	0.0	0.0
Transylvania	27,161	61	22	0	0.0	0	0.0	0.0

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Tyrrell	3,505	3	9	0	0.0	0	0.0	0.0
Union	144,253	246	17	6	2.4	3	50.0	1.2
Vance	33,848	25	7	2	8.0	0	0.0	0.0
Wake	690,207	2229	32	94	4.2	65	69.2	2.9
Warren	16,649	47	28	0	0.0	0	0.0	0.0
Washington	9,885	13	13	0	0.0	0	0.0	0.0
Watauga	44,497	41	9	0	0.0	0	0.0	0.0
Wayne	92,989	321	35	4	1.2	2	50.0	0.6
Wilkes	53,861	120	22	3	2.5	2	66.7	1.7
Wilson	61,557	167	27	2	1.2	1	50.0	0.6
Yadkin	29,517	47	16	1	2.1	1	100.0	2.1
Yancey	14,246	37	26	1	2.7	0	0.0	0.0

Note: Population count for adults is calculated from the American Community Survey 2013 five-year data, Table B01001--Age by Sex for All Races. All other data are calculated from individual guardianship records provided, at the request of the NC Division of Aging and Adult Services, by the Administrative Office of the Courts.

Disclaimer: No analysis of or conclusions drawn from these data may be attributed to the Administrative Office of the Courts, and any analysis or report shall include a prominent notice that the analysis is solely that of the person conducting the analysis and that neither the analysis nor any conclusions are accepted as accurate or endorsed by the Administrative Office of the Courts.