



RETHINKING GUARDIANSHIP

Building a Case for Less Restrictive Alternatives Final Report

Jordan Institute for Families

School of Social Work

The University of North Carolina at Chapel Hill

January 31, 2018

Linda Kendall Fields, MEd
Mary Anne Salmon, PhD
Sarah Marsh, MSW
Alison Climo, MSW, PhD
Tamara Norris, MSW, MPA
Gary Nelson, DSW

Contents

Executive Summary	1
Accomplishments	2
Recommendations	2
Introduction	5
A Complex Problem—A Call to Action	5
Addressing the Challenge: A Summary of Years One and Two	6
Year Three Outcomes	10
Legislation, Policy, and Practice Subcommittee	11
Education, Awareness, and Training Subcommittee	12
Data and Stories Subcommittee	13
Accomplishments, Recommendations, and Conclusion	23
Appendixes	
A. A Means to an End: Using Collective Impact	29
B. The Statewide Workgroup	33
C. Glossary of Guardians	36
D. Methods and Sources for the Data Reported	37
Guardianship and Restoration Activity by	
NC County 2012–2015	39

Funded by the North Carolina Council on Developmental Disabilities and the North Carolina Department of Health and Human Services, Division of Aging and Adult Services.
0000 copies printed at a cost of 0000 per copy.

Rethinking Guardianship

Building a Case for Less Restrictive Alternatives

Executive Summary

Rethinking Guardianship: Building a Case for Less Restrictive Alternatives, is a three-year initiative (2015–17) of the North Carolina Division of Aging and Adult Services (DAAS). It was designed to create a **sustainable infrastructure that effects long-term changes and heightens performance in North Carolina’s guardianship system and promotes less restrictive alternatives to guardianship**. The project was also designed to conduct a pilot project to create change in the guardianship system in one NC county (Catawba). *Rethinking Guardianship* was implemented 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 at Chapel Hill. This report summarizes the work and accomplishments of the *Rethinking Guardianship* initiative, and it offers recommendations toward improving North Carolina’s guardianship system and promoting less restrictive alternatives.

Rethinking Guardianship in North Carolina followed the Collective Impact framework used by Working Interdisciplinary Networks of Guardianship Stakeholders (WINGS) projects nationwide. The Collective Impact theory of change includes the following: (1) crafting a common agenda, (2) maintaining continuous communication, (3) fostering mutually reinforcing activities, (4) tracking learning and progress through shared measurement, and (5) supporting all aspects of the project through a backbone organization. (See Appendix A.)

The project’s common agenda established core concepts, basic principles, and long-term outcomes and consists of the following:

- 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 available and easily accessible.

Accomplishments

1. A website with Frequently Asked Questions (FAQs), illustrative stories of individuals and families and guardianship, and a comprehensive set of resources on guardianship and its alternatives
2. An educational video, titled “Understanding Guardianship,” available online through the Administrative Office of the Courts and distributed to all Clerks of Court across North Carolina
3. An informational brochure to inform stakeholder audiences of the available options and resources related to guardianship and its alternatives, to be distributed electronically throughout North Carolina
4. A set of shared values and experiences, which emerged from the more than twenty stories collected from individuals, family members, and professionals impacted by guardianship, and which, when paired with other data, become knowledge that drives solution-finding and change
5. Analysis of the available administrative data that courts collect to reveal what is knowable about the guardianship system, including the limits on accountability, as well as a survey of Clerks of Court to capture their guardianship practices and concerns
6. A school training module in Catawba County, developed to address transitions to adulthood for individuals with intellectual and developmental disabilities who are turning 18 (including youth aging out of the foster care system)
7. A volunteer supported decision-making program and training process in Catawba County
8. An education and training program on alternatives to guardianship for attorneys, guardians ad litem (GAL), Clerks of Court, and court employees in Catawba County.

Recommendations

In addition to describing the accomplishments of *Rethinking Guardianship*, this report makes the following recommendations based upon the work of this initiative:

1. *Common Agenda and Workgroup Maintenance*. First and foremost, the common agenda remains significant and central to future work. This is the “sustainable infrastructure” that will effect long-term change and heighten performance in North Carolina’s guardianship system.
 - ◆ Safeguard the common agenda, including the core concepts and basic principles of autonomy, liberty, freedom, and dignity; the

presumption of competence; and the right to lifetime decision-making support.

- ◆ Maintain the statewide workgroup by fostering a home base and central leadership role by the NC Administrative Office of the Court, thus aligning Rethinking Guardianship with the practice of most WINGS states.
2. *Statutory Reform.* Sustainability into the future is critical to seeing this initiative through. The statutory reforms are designed to heighten performance in North Carolina’s guardianship system and to promote less restrictive alternatives to guardianship. The Rethinking Guardianship Workgroup must:
 - ◆ Engage all key guardianship stakeholders, including state agencies and the Clerks of Court as well as all disability groups across the lifespan, to inform and support reform efforts.
 - ◆ Leverage momentum and specific project goals to secure additional funding for Rethinking Guardianship into the future.
 3. *Practice Modifications.* Opportunities to promote less restrictive alternatives currently exist within the purview of the Clerks of Court.
 - ◆ Increase the use of the limited guardianship option.
 - ◆ Increase the use of Multidisciplinary Evaluations (MDEs).
 - ◆ Apply the appropriate standards of evidence for restoration.
 4. *Improved Data System.* Existing data systems hinder individual well-being, guardian accountability, and effective program planning. Ultimately, improved data systems are critical to heightening performance in North Carolina’s guardianship system.
 - ◆ Create a modern data system that is built on an accessible and easy-to-use platform for all relevant users, which includes processes for tracking guardianship cases, including petitions filed, types of guardianship, petitions filed for restoration, restorations granted, and how and when guardianship ends due to the death of the person under guardianship.
 - ◆ Ensure accurate descriptive data of the guardianship population so that families and self-advocates can provide quantitative information when asking for policy changes and service provision.
 5. *Education and Awareness.* These are critical to the well-being of individuals and families, and therefore, to the success of the guardianship system.
 - ◆ Promote awareness and use of the *Rethinking Guardianship* website.
 - ◆ Distribute educational materials widely throughout the state.

- ◆ Use educational materials to promote less restrictive alternatives and mitigate common negative experiences of guardianship, such as surprise or shock about what was not known before, during, and after guardianship, and foster positive experiences, such as empowerment and pride at the prospect (and realization) of restoration.

Introduction

This report summarizes the third and final year of the Collective Impact initiative, *“Rethinking Guardianship: Building a Case for Less Restrictive Alternatives.”* A grant for this initiative was awarded to the North Carolina Division of Aging and Adult Services (DAAS) in partnership with the Jordan Institute for Families, School of Social Work, at The University of North Carolina at Chapel Hill by the North Carolina Council on Developmental Disabilities.

The Division of Aging and Adult Services has responsibility for overseeing social services and some benefits programs for older adults and for persons with disabilities and their families, as provided by the state’s 100 county departments of social services (DSSs). One of these programs is guardianship services, for which county DSSs act as disinterested public agent guardians. Through its involvement with public guardianship, DAAS recognized that although guardianship is the most restrictive option of legal substitute decision-making, its use continued to increase, specifically for younger adults with disabilities.

Past efforts to examine guardianship in the state have been time-limited and narrowly focused on a specific guardianship issue. DAAS’s goal in pursuing a grant from the NC Council on Developmental Disabilities was to create a sustainable infrastructure to effect long-term changes in NC’s guardianship system, promote less restrictive alternatives to guardianship, and respect the rights of individuals in guardianship and those facing guardianship. The foundation of the initiative was establishment of a statewide, long-term workgroup representing a range of guardianship stakeholders (see Appendix B), based on the Collective Impact model for social change used by WINGS, the Working Interdisciplinary Networks of Guardianship Stakeholders.

From the outset, and even now as the initiative has been sustained beyond the three-year grant period, the effort is committed to working with individuals affected by guardianship and the many systems—including the court system—that are involved, to support individual well-being and improve accountability.

A Complex Problem—A Call to Action

As has been described in earlier reports, guardianship has received increased attention and scrutiny in North Carolina, the United States, and throughout the world, as many individuals fall under full

guardianship without a thorough assessment of their abilities to make life decisions. They often do so because they and their families; medical, social and behavioral health providers; and other formal and informal systems, do not fully understand their rights or that less restrictive alternatives are available. Full guardianship involves the loss of individual control over one's person and finances. (See Appendix C for definitions of types of guardianship.)

Others under guardianship, whose capacity for decision-making has improved (i.e., physically, behaviorally, or socially), are not aware of the steps that could be taken to restore their rights. Exact counts of the number of people under guardianship are impossible to get, but a report by DAAS in 2013 estimated that there would be over 23,000 people under guardianship in 2017, of whom about one-third (approximately 8,000 people) would be served by public guardians. Fewer than 2% of the nearly 16,000 individuals in the North Carolina court system for guardianship from 2012 to 2015 had their rights restored. Given changes in their circumstances, many more might seek restoration of their rights and avail themselves of the opportunity to use less restrictive alternatives rather than full guardianship.

Like many other states, North Carolina's guardianship "system" has offered limited oversight and accountability, limited information on alternatives and rights to legal counsel, and an absence of accessible education and training for guardians. However, not all the challenges are legal in nature. Many involve issues of awareness, education, and practice. Where the issues are legal, the focus is on improving the relevant statute, NC 35A. Where the issues involve awareness, education, and improving practice standards and accountability, the focus is on making citizens aware of their rights, easing access to less restrictive alternatives, and restoring those rights when appropriate. Fostering community engagement by creating an aware, knowledgeable, and accountable citizenry and system has been central to the initiative's success.

Addressing the Challenge:

A Summary of Years One and Two

Looking back, Year One of this project is best understood as "The Year of Hunting and Gathering" because of the need to "hunt" for relevant data and information about the current system and "gather" a diverse and invested group of stakeholders to identify and work on priorities.

The first step in this effort, completed in 2015, was the establishment of a statewide, long-term workgroup representing a range of guardianship stakeholders. The workgroup was modeled on WINGS, a national initiative supported by the American Bar Association, which employs the Collective Impact model for social change. Year One also yielded several important insights.

- Families and individuals need more information about guardianship and its alternatives.
- County Clerks of Court, who make guardianship decisions, rely on varying and sometimes inconsistent sources of information.
- Monitoring of private guardianship of the person is optional, not mandated.

Year Two (2016) could be dubbed “The Year of Focused Action Toward Desired Outcomes.” Having established a committed workgroup and a basic understanding of the strengths and weakness of the current guardianship system, the initiative was ready to take off, and stakeholders were prepared to focus on actionable steps toward the goals of the grant.

In its second year, the workgroup continued to assess and evaluate North Carolina’s guardianship system to determine when formal or informal adaptations were needed. This included examining the use of guardianship alternatives, such as advance directives and supported decision-making, to avoid the appointment of an individual or public entity as guardian.

In Year Two, the workgroup accomplished the first required element of Collective Impact, namely identifying a common agenda, which included the following core concepts and basic principles:

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

In addition, the common agenda included a vision of “The System-as-it-Should-Be,” namely, one that would

- be less restrictive and based on best practices
- rest on a process in which all stakeholders are identified and engaged
- provide options and pathways toward guardianship, as well as alternatives, that are communicated to and understood by stakeholders
- be held accountable
- offer easily available and accessible information about guardianship and its alternatives.

Also in Year Two, the workgroup established three working subcommittees and launched the Catawba County pilot. Each group was able to focus on one aspect of the initiative while contributing, through mutually reinforcing activities, to the larger picture.

The *Legislation, Policy, and Practice Subcommittee* reviewed NC statutes, identified barriers and gaps, selected which states/counties (including model states) to compare, and developed short- and long-term policy and practice recommendations. By the end of the year, the subcommittee had researched and deliberated over such changes to Statute 35A as addressing the conflict of interest within the guardian ad litem role, ending the presumption of permanence in guardianship, and modernizing the language within the statute, and it was ready to share recommendations with key leaders in the coming year.

The *Education, Awareness, and Training Subcommittee* reviewed training materials from several other states to identify learning objectives for a guardianship training curriculum and to identify content and format/modality that could be incorporated into new training materials. The subcommittee also worked with the Jordan Institute to develop a comprehensive project website (<http://ssw.unc.edu/rethinking/>), which provides information about the *Rethinking Guardianship* Initiative.

The *Data and Story Collection Subcommittee* gathered more than sixteen stories from individuals, family members, and professionals affected by guardianship. Although each story is distinct, themes were identified among them: outrage or despair when a system or individual within the system takes control of an adult's life (and in some cases, abuses this power), as well as empowerment and pride at the prospect and realization of restoration.

This subcommittee also looked more closely at the limited administrative data that the courts collect to discover what is knowable about people who have guardianship filings, identify gaps in reporting and record keeping, and recommend data/record-keeping changes that could increase accountability with guardianship.

The Catawba Pilot, *Rethinking Guardianship: Options for Independence*, was developed during that year and was led by the Catawba County Adult Collaborative. The core team is comprised of the Catawba County Department of Social Services, Partners Behavioral Health Management, the Greater Hickory Cooperative Christian Ministry, and Sipe's Orchard Home. Based on the input of stakeholders, this group decided to focus on three areas, transitioning

to adulthood, supported/surrogate decision-making, and community education and awareness. Here are the actions taken.

1. Transitioning to Adulthood
 - ◆ focused on individuals with intellectual and developmental disabilities (I/DD) who are turning age 18 (including youth aging out of foster care)
 - ◆ developed a training module for schools to use in educating school staff/parents/families and children/teens on options for independence
 - ◆ involved the three public school systems in Catawba County to develop the training.
2. Supported Decision-making
 - ◆ increased knowledge and availability of alternatives to guardianship and supported decision-making in the community
 - ◆ created a volunteer and training process that would help create a “support team” for potential persons needing assistance in decision-making (in lieu of guardianship or as an added support)
 - ◆ partnered with a provider with the expertise to help achieve this goal.
3. Community Education and Awareness
 - ◆ developed education/training for attorneys, Clerks of Court, and court employees on alternatives to guardianship (including limited guardianships)
 - ◆ developed material to share with petitioners about alternatives.

Catawba County’s recommendations to other counties:

- You don’t need more money or resources to make an impact.
- Meet with your Clerk of Court to discuss the process.
- Identify what Collective Impact issues you have in your communities.
- Read *“Rethinking Guardianship: Building a Case for Less Restrictive Alternatives,”* published by the Jordan Institute in 2015 and 2016.
- Create a process for youth aging out of foster care.
- Assess your current process for annual reviews and restorations.
- Evaluate where you can use supported decision-making.

Year 3 Outcomes

Year Three is characterized as “The Year of Balanced and Sustained Effort,” as it became clear through the year that a balanced view of guardianship was essential to gaining buy-in and traction across the state.

Initiative leaders recognized increasingly that it was important to acknowledge the protection guardianship may offer individuals through the court system under extremely difficult circumstances, while maintaining a firm commitment to an approach that offers less restrictive measures that promote the greatest autonomy possible. Also, because of the reality of the grant’s end, the year was infused with an awareness that to continue the work, additional support would be necessary.

Year Three saw continued effort and progress among all three of the Rethinking Guardianship subcommittees.

The Statewide Workgroup Meetings in Raleigh, 2017: A Summary of the Year’s Work

January	<ul style="list-style-type: none">• summarized the accomplishments of 2016• established goals and action steps for 2017• gained understanding of supported decision-making and legislation in Texas and Delaware• considered legislation regarding supported decision-making in North Carolina• continued subcommittee work towards goals and action steps for 2017
March	<ul style="list-style-type: none">• revisited goals and action steps for 2017• tracked progress of subcommittees• increased knowledge of guardianship from international, national, and state perspectives• participated in Wake County guardianship training presentation• set next steps within subcommittees
May Held at the Administrative Offices of the Courts (AOC)	<ul style="list-style-type: none">• increased understanding of the AOC• tracked progress of subcommittees• gained awareness of the SSA Representative Payee program• considered ways to sustain the <i>Rethinking Guardianship</i> after 2017• agreed to next steps within subcommittees

The Statewide Workgroup Meetings in Raleigh, 2017: A Summary of the Year's Work

- September**
Held at AOC
- received updates on the initiative
 - gained insight on the Clerks' view of guardianship and less restrictive alternatives in NC
 - learned about the role of the UNC School of Government and findings from the its Multidisciplinary Evaluation (MDE) project
 - considered the accomplishments of Texas WINGS and implications for NC's initiative
 - agreed to next steps within subcommittees
-

- October**
Held at AOC
- received updates on the initiative
 - celebrated a story of restoration
 - reviewed and responded to draft legislation and educational materials
 - learned about progress being made in Catawba County
 - discovered the findings of the Catawba County File Review
 - agreed to next steps with the work group as a whole and within subcommittees
-

Legislation, Policy, and Practice Subcommittee

In Year Three, this subcommittee focused its work on identifying policy recommendations, including developing possible statutory language for reform to Statute 35A, to be put forward in the 2019 legislative session. Additionally, the group drafted goals for supported decision-making and a guardianship bill of rights, continued to engage the Administrative Office of the Courts with the *Rethinking Guardianship* initiative, and realized the creation of a new AOC restoration form.

These are the group's policy recommendations, including possible changes to Statute 35A, which will be discussed at length during 2018 with key guardianship stakeholders, including state agencies and Clerks of Courts.

- Provide for appointed counsel in addition to guardians ad litem for respondents to a petition and to any incapacitated person in proceedings under this statute.
- Clarify that an individual's capacity can be limited in one or more functional domains and restrict the scope of guardianships to only those functional domains where there is an unmet need.
- End the presumption of permanence in adult guardianship, providing Clerks of Court with discretion and guidance on periodically revisiting the appropriateness of the guardianship.

- Simplify the requirements of spouses acting as guardians, at the discretion of the Clerk.
- Clarify that professional guardians, as agents of the State of North Carolina, have an obligation under current statute to support people under guardianship in seeking the least restrictive setting appropriate to their needs.
- Improve the quality, consistency, and availability of Multidisciplinary Evaluations.

Education, Awareness, and Training Subcommittee

In Year Three, this subcommittee continued to work on refining the *Rethinking Guardianship* website, adding a set of Frequently Asked

Questions (FAQs), illustrative stories of individuals and families and guardianship, and a comprehensive set of resources. The website is hosted and maintained through the School of Social Work at UNC-Chapel Hill.

The subcommittee worked with the AOC and Guardian Advocacy, Inc., to prepare a 26-minute educational video, entitled “Understanding Guardianship.” The video outlines the role and responsibilities of private guardians. This training video is available online and is promoted by the AOC to the Clerks of Court across 100 North Carolina counties.



<http://ssw.unc.edu/rethinking/home>



<http://www.nccourts.org/Training/Guardianship.asp>

The subcommittee also finalized the content for an informational brochure to inform stakeholder audiences of the available options and resources related to guardianship and its alternatives. This brochure was developed in partnership with the NC Division of Social Services. The material is appropriate for multiple audiences, including but not limited to youth turning 18 and their parents/guardians, educators, and service providers, as well as adults of all ages and those who may be interested in understanding guardianship and its alternatives.

Among the alternatives to guardianship that are covered in the brochure is North Carolina’s Foster Care 18–21 Program. Brochures will be made available through Clerk of Court offices as well as online and in electronic form, to be distributed throughout the *Rethinking Guardianship* statewide network.

During Year Three, the Catawba County pilot worked closely with this subcommittee to share resources and lessons learned from county efforts. The pilot is currently developing trainings on guardianship and less restrictive alternatives within the local school system and has provided packets of information to key community partners throughout the county. They remain committed to working with the state group to ensure alignment of the message and approach to reform efforts.

Language Matters

People First Language in Guardianship Proceedings

<p>Outdated</p> <ul style="list-style-type: none"> Disabled adult Ward Incompetence 	➔	<p>Updated</p> <ul style="list-style-type: none"> Adult with disabilities Person under guardianship Capacity (lack of or limited)
---	---	---

Data and Stories Subcommittee

To gain greater insight about guardianship in North Carolina through the lens of one county’s files, this subcommittee began Year Three by reviewing case records at the Clerk’s office in Catawba County. For a brief description of the methods underlying the numbers quoted in this section, please see Appendix D. Methods and Sources for the Data Reported.

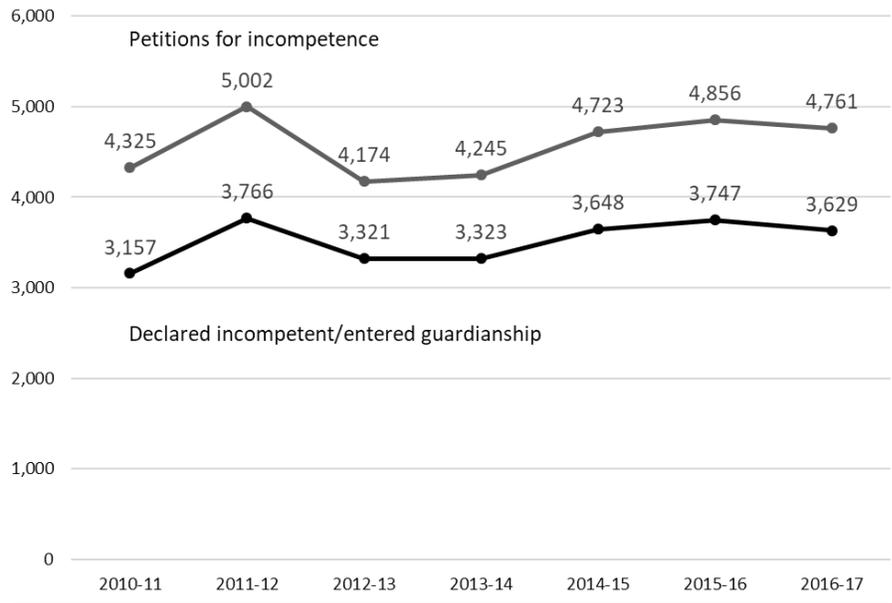
Adults Entering Guardianship

For the past 7 years, an average of 4,584 petitions per year have been filed to have adults declared “incompetent” by the courts. Of these, an average of 3,629 (79%) reach the hearing stage and are declared incompetent. Chart 1

shows the figures for individual years. These figures represent a little fewer than 5 out of every 10,000 adults in the state each year.

While we know the incidence of new guardianships, we do not know how many people are living under guardianship at any given point in time. We know the number for which the DSS serves as “disinterested third party” guardian: 6,217 directly under DSS supervision and

Chart 1. Petitions and Declarations of Incompetence: NC State Fiscal Years 2011–2017

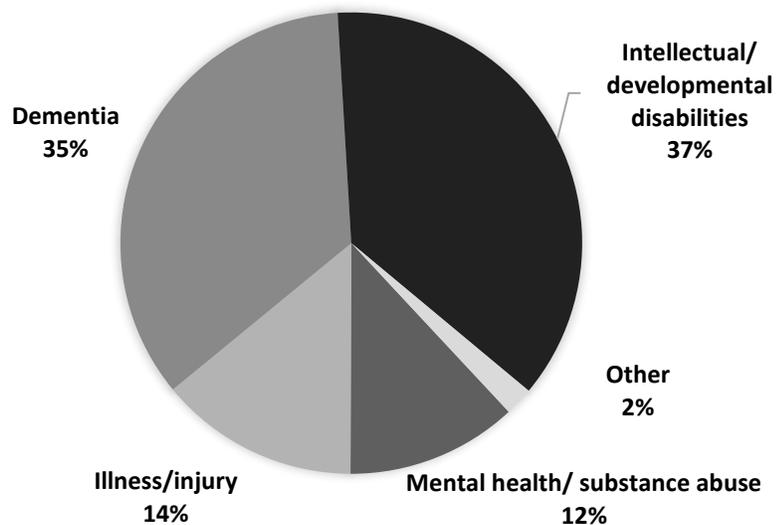


another 842 through contracts between DSS and guardianship corporations in SFY 2016–17. We also have reasonably good estimates that this accounts for about one-third of the total number. However, for people who enter private (family) guardianship of the person, no one keeps systematic records of how they are doing or how many are still alive. No one keeps statewide, computerized records, even for those whose guardians are required to make annual reports, except for those whose guardianship is through DSS, as described above.

Changing Guardianship Demographics

Historically, guardianship was a way to care for aging adults who were perceived as unable to continue managing their own affairs. Current demographic data, as abstracted from the Catawba County data review in Year Three, shows that people with intellectual or developmental disabilities (I/DD; 37%) make up the largest group for whom guardianship is filed, followed by people with dementia (35%), those with injuries or illnesses (14%), and people with mental health or substance use concerns (12%). This shift toward younger adults primarily with I/DD was noted in NC DSS data by the Public Guardianship Ad-Hoc Workgroup sponsored by the Division of Aging and Adult Services in 2013–2014.

Chart 2. Alleged Reason for Needing Guardianship (Catawba County, 2015–16)



Also noteworthy from these data was that the age of the individual and the reason for entering guardianship were highly correlated, such that 91% of people under age 22 had I/DD and 83% of people age 70 and older had dementia or a related disease. Overall nearly one-third of the people entering guardianship were under age 22, and half were under age 50. The gender breakdown was unremarkable, with 52% female and 48% male, although this varied predictably by age group (more younger men, more older women).

Families: Heavily Involved but Often Unprepared

Analysis of casefile data in Catawba County showed 80% of petitions were filed by family members, parents accounting for 39% and other family members (adult children, siblings, spouses, and other relatives) accounting for 41%. As a result, about 76% of guardians appointed in the records were family members of the person under guardianship. However, in the first year's work with Clerks of Superior Court, more than two-thirds of clerks responding to the survey (68%) reported that "most of the time" a family member seeking to be the guardian is largely unaware of what the role entails. In addition, 72% checked that they would like to have more resources to share with family guardians. In focus groups, Clerks commented frequently (14 times in 3 groups) that families really did not know what they were getting into—especially as general guardian or guardian of the estate. Because of these findings, the Education Subcommittee has made education of family members about alternatives to guardianship and about the role and responsibilities of guardianship a high priority.

Exiting Guardianship: Restoration of Rights

Analysis of individual-level statewide data revealed that only about 2.1% of those under guardianship have their rights restored over time. Record review in Catawba County in Year Three showed that the small group of adults who come into guardianship through injury or illness (e.g., head injuries from automobile accidents or strokes) are the most likely group to have their rights restored when they petition for restoration because they are able to document their recovery. Those with mental illness/substance abuse problems are the largest group petitioning for restoration and are second to those with illness/injury in having their petitions granted. There is anecdotal evidence that some Clerks are slow to restore the rights of people with these conditions, fearing relapse and return to incompetence. Other Clerks have said that the law requires that the person not be under guardianship if they are not impaired at that moment—without regard to what the future may bring.

The median time from petition for restoration to granting of restoration is a little less than two years. This may include continuances by the Clerk to establish more progress toward or stability of recovery (found in statewide and Catawba data) or more than one petition. However, very few petitions for restoration are filed. DSS guardianship caseworkers are required to document work toward preparing people under guardianship for restoration of their rights, but family members may or may not recognize this as an important goal. This may be especially true for people under guardianship because of intellectual and/or developmental disorders.

Limited Use of Limited Guardianship

Limited guardianship is a tool at the Clerk's disposal for allowing individuals to maintain decision-making authority in some areas of their lives, while delegating other areas to a guardian. For example, a guardian might make financial decisions, while an individual retains all other decision-making realms of life. This option, however, is not often used.

The statewide data does not include a code for limited guardianship, so it appears in those data only when the individual county enters it with an "other" code. This was true for less than 1% of all individual adults in the dataset. However, in the Catawba record review, the team found 11% of incompetency rulings were "to a limited degree," which is the best available estimate.

It is possible that people needing guardianship have such intense needs that limited guardianships are impractical. However, the practice wisdom and belief of the workgroup suggest that more limited guardianships are possible. They are, however, more difficult for Clerks to parse out and appropriately adjudicate. Therefore, Clerks may need additional evidence about strengths as well as limitations of the person responding to the guardianship petition, other than the "capacity questionnaire" that is often filled out by the person filing the petition. Some Clerks might also benefit from information and support from other professionals about the capabilities of those with disabilities.

Low Use of Multidisciplinary Evaluations (MDEs)

One source of evidence available to clerks are MDEs, but these vary widely in cost and quality across the state. The UNC School of Government convened meetings with Clerks and Local Management Entities/Managed Care Organizations (LME/MCOs) on this topic. Through those meetings participants affirmed several suspicions.

- There are multiple, inadequate sources of funding to pay for MDEs.
- There is confusion over how to access funding.
- Current law has not kept up with changes in mental health service delivery systems, which creates procedural errors and confusion in obtaining, overseeing, and delivering MDEs.

In a survey in Year One, Clerks of Court indicated very low usage of MDEs: only 12% of the clerks used an MDE in at least half of their hearings. The primary reasons they gave for low inclusion of MDEs were not needing additional information, the amount of time to get an MDE, and funding/cost barriers to obtaining an MDE. A smaller number also reported poor quality of the MDEs available to them.

This workgroup has not delved into the policy, practice, and funding supports that would be needed to improve access to high quality and timely MDEs. However, the School of Government report outlined numerous suggestions for improvement. These included requesting additional funds for MDEs from the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services; getting guidance from that Division about appropriate billing procedures; revising form SP-200 and seeking reimbursement through insurance; creating a legislative work group to assemble statutory change recommendations; gathering data on MDEs ordered; and encouraging Clerks to request them when needed, regardless of funding concerns.

Given the interest among the workgroup and the expertise housed at the School of Government, this is an area that deserves further attention to begin follow-up action on recommendations. The School of Government also took a vital initial step toward improving the use of MDEs by brokering connections between Clerks of Court and LME/MCO representatives such that they now have direct lines of communication with one another.

The UNC School of Government report contained many more suggestions than listed here. For the full report please go to: <https://www.sog.unc.edu/sites/www.sog.unc.edu/files/reports/20170719%20Multisciplinary%20Evaluations%202017-10-19.pdf>

Conflicting Responsibilities for Guardians ad Litem

The most widely available and relied upon evidence in incompetency/guardianship hearings is from the Guardian ad Litem (GAL). Fully 94% of Catawba County case files reviewed contained a report from the GAL. In a survey of Clerks, 90% rated testimony of the GAL as “very important,” and 31% said that the GAL’s testimony was the single most important source of information—more than any other type of testimony—in a hearing. Not quite two-thirds (62%) also said that the GAL had tried to identify a family member to serve as guardian “most of the time.” Thus, an important function of the

“If I didn’t trust a GAL I wouldn’t appoint them. I put a lot of faith in what they tell me. . . . The GALs see how they react, how they respond to questions in their own setting. They can also see the home surroundings. They tell me if everyone in the family is seeing the same thing or different things—not only for the ruling of incompetence but for the decisions about the guardian—whether or not the parents/family members are able and willing to take care of the ward for the rest of their lives.”

—Clerk in a focus group

GAL is to provide assessment/investigation for the court into the “best interest” of the person being considered for guardianship.

Although people responding to a petition to have them declared incompetent have the right to hire a lawyer to advocate for their wishes, they do not currently have the right to have an attorney appointed if they cannot afford one. They do not necessarily know that they might need or can hire a lawyer, and many believe that the GAL is serving in that role for them. As the statute and practice currently stand, GALs have a dual role within guardianship. They serve both as the court investigator, advising the court on the best interest of the respondent, as well as expressing the wishes of the respondent. This puts them into the impossible position of divided loyalty to the court and the person whose competence is questioned.

Unnecessarily High Standard of Evidence for Restoration

In most system change efforts, the goal is to raise standards and expectations. However, in this case, encouraging Clerks to embrace a lower standard of evidence would support individuals seeking restoration.

According to North Carolina’s GS 35A, the standard of proof for declaring someone incompetent is “clear, cogent, and convincing” while the standard of proof for restorations of rights is the lower legal standard of a “preponderance of evidence.” This means that from the standpoint of evidence, it requires *less* evidence to have rights restored and *more* evidence for a declaration of incompetency. However, practice suggests that Clerks may be feeling pressure to use higher evidence standards in restoration cases than is necessary.

In Catawba County, for example, MDEs were used as evidence in 75% of restoration cases but in only 38% of incompetency proceedings. In the focus groups with Clerks, and anecdotally through the course of this project, Clerks have indicated such concerns about restoration as opening a revolving door in and out of guardianship, particularly for people with mental health or substance use concerns; public safety; protecting individuals under guardianship from themselves; and even their own potential liability (real or perceived).

Given this finding, increasing the number of people able to restore their rights could be achieved with two main approaches. First, address Clerks’ concerns about safety for the people under guardianship through increased use of supported decision-making tools. Second, through the continuing education and professional support provided at the School of Government, help educate Clerks

about the different evidence standards and the limits and precedents related to individual liability in guardianship cases.

Stories Drive Change: Creating a New Narrative

In addition to the analysis of Catawba case files detailed above, over 20 stories were gathered from individuals experiencing guardianship in Years 2 and 3 (see the Year Two report for more stories). Central to the methodology of Collective Impact and success of this initiative is the creation of a *new narrative*—one grounded in the stories, voices, and values of those whom current guardianship practices directly affect. Data alone cannot produce change. Rather, it is enhanced by such narratives, which become the knowledge that drives solution finding and change. (See Fisher, 1994, and Rao, 2011.)

These stories are critical to the process of thinking about guardianship *as it is now*. They are indispensable to the process of Rethinking Guardianship and designing the system *as it should be*—one that optimizes support for individual autonomy, choice, and self-reliance. The success of this initiative is deeply indebted to the individuals who lent us their voices, and it honors their experience and lessons. They provide the moral grounding for the initiative.

The values and voices reflected in this emergent narrative, when combined with the other structured collective measures, drive a process of discovery and complex problem solving, aided by reflection, imagination, and experimentation. This process of discovery and innovation has been central to identifying less restrictive alternatives to guardianship that are customized to the needs and wants of diverse individuals, verified through measurable outcome data, and institutionalized as a new way of doing business in this changing field. Among all the stories collected over the past two years, two stand out as emblematic of the lessons learned about guardianship and restoration.

Fisher, W. R. (1994). Narrative rationality and the logic of scientific discourse. *Argumentation*, 8(1), 21-32.

Rao, V. G. (2011). *Tempo: Timing, Tactics and Strategy in Narrative-driven Decision-making*. Ribbonfarm.



Pictured here: Rob Jennings, Davis, Humbert & Jennings, PA; Carol Kelly; Syd Alexander, Alexander, Miller & Schupp LLP; and Sean

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 1 is excerpted from the *Year Two Report* with his name corrected. Part 2 reveals what unfolded in the past year.

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."

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 a 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 going through the Tree Industry Association.

Regarding decision-making, Sean is looking to put a team together that includes a realtor and a certified accountant. He recognizes the value of connections, saying “the right legal 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 he 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*.



“I went from being everyone’s problem to becoming a valued part of society.”

Jason’s Story

Jason Hines, now 33, grew up the youngest of six in a religious and supportive family in Winston-Salem, NC. When Jason was just 11, his dad died, and it was a difficult adjustment. Nonetheless, he loved music, wrestled and played football in high school, and looked forward to an adulthood accompanied by marriage, a nice house, and a career.

In college, Jason began experiencing mental health issues. He would have an episode in which he heard voices and saw visions, but then would be fine. He used drugs as a form of self-medicating. Initially diagnosed with bipolar disorder, Jason believed he was experiencing a spiritual battle (both his parents were ministers). His sister, a clinical psychologist, helped the family recognize that Jason needed more than spiritual help. Eventually, Jason was diagnosed with schizoaffective disorder.

However, Jason’s behavior got worse and he refused to take medication. His family established clear boundaries and tried to help. After being in and out of the hospital many times, Jason was finally hospitalized for 13 weeks, during which he finally agreed to medication.

The strain this caused for Jason’s mother was great. She didn’t sleep, lost weight, and finally expressed the need for help. She filed a petition for guardianship in Forsyth County, and a hearing date was set. Jason came to the hearing from the hospital. Despite majoring in pre-law while in college, he did not understand what was going on. “I knew that I didn’t want my rights taken away. I thought it was a plan for my mom to be against me. It turned out to be the best thing that happened to me.” The Clerk ruled in favor of guardianship.

Initially, Jason was considered high risk and was placed in a less-than-ideal boarding house where he wasn’t safe to even walk down the street to the store. He complained to his guardians and, as he reports, they told him, “We don’t want you to have a guardian for the rest of your life. We think you are smart. If you want another place, YOU find it.” And he did!

He had two co-guardians from Empowering Lives, “one with a tough love approach and the other a good friend. I wouldn’t be this well without them.” They challenged him to improve his own life. They supported him in managing his mental illness and recommended

switching to a periodic injection to replace daily medications and to interrupt the ups and downs associated with a daily dose.

Based on significant improvement, one year after he was placed under guardianship, Jason’s guardians suggested that he seek restoration of his rights. He was not expected to speak at his hearing, but the Clerk asked him if he was ready. Jason, accompanied by his mother and two guardians, acknowledged that he now needs medication to manage his mental illness. Jason recognizes that mental health problems are stigmatized, especially in African American culture, which expects that personal inner strength will always lead to a positive solution. But he also recognizes that he “can’t just pray it away.”

Today, Jason works as a Visitation Specialist at Empowering Lives. His ability to relate, coupled with his sensitivity, generates good success. “I’ve been through a lot of the struggles that many people with mental disabilities go through. I’ve heard voices, seen visions, and had the mania. I’m not just getting it from a book. I’ve been through it, and when I get together with others, we are united in the struggle.” He still gets some support from the mental health system, mainly in the form of appointment reminder calls, as well as for the decision-making process.

“I do it completely on my own now. Once in a while, I ask my mother for her opinion, but I’m an adult. I make my own decisions. The challenges I faced have brought me to a place where I value the opportunity to help others and appreciate the path that led me to a place of mental wellness.”

Accomplishments, Recommendations, and Conclusions

Rethinking Guardianship: Building a Case for Less Restrictive Alternatives began as a three-year (2015–17) initiative of the North Carolina Division of Aging and Adult Service. It was designed to create **a sustainable infrastructure that effects long-term changes and heightens performance in North Carolina’s guardianship system and promotes less restrictive alternatives to guardianship.** Through its three subcommittees and the Catawba County pilot project, and using Collective Impact as a framework, *Rethinking Guardianship* has achieved a number of important accomplishments toward its intended goals.

Accomplishments

1. A website with Frequently Asked Questions (FAQs), illustrative stories of individuals and families and guardianship, and a comprehensive set of resources on guardianship and its alternatives
2. An educational video, titled “Understanding Guardianship,” available online through the Administrative Office of the Courts and distributed to all Clerks of Court across North Carolina
3. An informational brochure to inform stakeholder audiences of the available options and resources related to guardianship and its alternatives, to be distributed electronically throughout North Carolina
4. A set of shared values and experiences, which emerged from the more than twenty stories collected from individuals, family members, and professionals impacted by guardianship, and which, when paired with other data, become knowledge that drives solution finding and change
5. Analysis of the available administrative data that courts collect to reveal what is knowable about the guardianship system, including the limits on accountability, as well as a survey of Clerks of Court to capture their guardianship practices and concerns
6. A school training module in Catawba County, developed to address transitions to adulthood for individuals with intellectual and developmental disabilities who are turning 18 (including youth aging out of the foster care system)
7. A volunteer supported decision-making program and training process in Catawba County
8. An education and training program on alternatives to guardianship for attorneys, guardians ad litem, Clerks of Court, and court employees in Catawba County.

These past three years have allowed *Rethinking Guardianship* to establish a strong foundation for future work. Sustainability into the future is critical to seeing this initiative through the 2019 long session of the NC General Assembly and beyond, to complete all of the desired activities for ongoing implementation and education. Fortunately, some additional funding through the North Carolina Division of Social Services and the Division of Aging and Adult Services will carry the effort through September 2018, and other opportunities are on the immediate horizon.

Recommendations for future work come directly out of, and build upon, the work of the past three years.

Recommendations

1. *Common Agenda and Workgroup Maintenance.* First and foremost, the common agenda remains significant and central to future work. This is the “sustainable infrastructure” that will effect long-term change and heighten performance in North Carolina’s guardianship system.
 - ◆ Safeguard the common agenda, including the core concepts and basic principles of autonomy, liberty, freedom and dignity, the presumption of competence, and the right to lifetime decision-making support.
 - ◆ Maintain the statewide workgroup by fostering a home base and central leadership role by the NC Administrative Office of the Court, thus aligning Rethinking Guardianship with the practice of most WINGS states.
2. *Statutory Reform.* Sustainability into the future is critical to seeing this initiative through the 2019 long session of the NC General Assembly and beyond. The statutory reforms are designed to heighten performance in North Carolina’s guardianship system and to promote less restrictive alternatives to guardianship. Specifically, the Rethinking Guardianship Workgroup must:
 - ◆ Engage all key guardianship stakeholders, including state agencies and the Clerks of Court as well as all disability groups across the lifespan, to inform and support reform efforts
 - ◆ Leverage momentum and specific project goals to secure additional funding for Rethinking Guardianship into the future.
3. *Practice Modifications.* Opportunities to promote less restrictive alternatives currently exist within the purview of the Clerks of Court, specifically,
 - ◆ Increase use of limited guardianship option.
 - ◆ Increase use of Multidisciplinary Evaluations (MDEs).
 - ◆ Apply the appropriate standards of evidence for restoration.
4. *Improved Data System.* Existing data systems hinder individual well-being, guardians’ accountability, and effective program planning. Ultimately, improved data systems are critical to heightening performance in North Carolina’s guardianship system.
 - ◆ Create a modern data system that is built on an accessible and easy-to-use platform for all relevant users. It should include processes for tracking guardianship cases, including petitions filed, types of guardianship, petitions filed for restoration, restorations granted, and how and when guardianship ends due to the death of the person under guardianship.

- ◆ Ensure accurate descriptive data of the guardianship population so that families and self-advocates can provide quantitative information when asking for policy changes and service provision.
5. *Education and Awareness*. These are critical to the well-being of individuals and families and, therefore, to the success of the guardianship system.
- ◆ Promote awareness and use of the *Rethinking Guardianship* website.
 - ◆ Distribute educational materials widely throughout the state.
 - ◆ Use educational materials to promote less restrictive alternatives and mitigate common negative experiences of guardianship such as surprise or shock about what was not known before, during, and after guardianship, and to foster positive experiences, such as empowerment and pride at the prospect (and realization) of restoration.

Conclusion

Over the course of these three years, much progress has been made to more fully understand guardianship and less restrictive alternatives. Significant steps have also been made to create awareness and offer education to the individuals and families affected by guardianship in North Carolina, as well as to key stakeholders in the system. It is with continuing commitment and momentum that *Rethinking Guardianship: Building a Case for Less Restrictive Alternatives* moves forward to a new chapter in the life of the initiative.

Appendixes

Appendix A

A Means to an End: Using Collective Impact

The use of a Collective Impact framework, which combines grassroots learning and experience with state and national perspectives, resources, and learning, was integral to the *Rethinking Guardianship* initiative during the three-year grant period.

It takes buy-in, learning, and aligned action at all levels to create holistic, sustainable solutions for the complex problems reflected in guardianship policy and practice. Collective Impact's theory of change includes these elements:

1. crafting a common agenda
2. maintaining continuous communication
3. fostering mutually reinforcing activities
4. tracking learning and progress through shared measurement
5. supporting all elements of the backbone organization and infrastructure.

This is how each element of the Collective Impact framework was used throughout the initiative.

1. Crafting a Common Agenda

A common agenda emerges from within and through group process. First, all stakeholders must share their experiences, hear each other's experiences, and find the common thread to tie them all together. This is an evolutionary process. In the three years of *Rethinking Guardianship*, the entire first year was spent seeking this common agenda: *To create long-term changes in North Carolina's guardianship system and to promote less restrictive alternatives to guardianship.* Once established, it remained front and center. As a matter of process, there is tremendous value in stating it at the beginning and end of each meeting, and in attaching it in writing to meeting agendas, minutes, reports, as a way of keeping it before the participants.

2. Maintaining Continuous Communication

The success of Collective Impact requires a tremendous amount of communication. Over the course of Year 3, the workgroup met five times, as did each subcommittee (in addition to various telephone subcommittee meetings in between the statewide meetings). The agenda for each meeting not only stated the project's overall common agenda, but also identified expected outcomes for each meeting, and the meeting notes for each followed up with outcomes achieved. Subsequent meetings reviewed the progress made at the previous meeting and collected information from subcommittees on progress made between statewide meetings. By checking in on the common agenda, and sharing progress made between meetings, it was possible for the entire workgroup to grasp the big picture and the ripple effects of the groups' and each individual's efforts.

3. Mutually Reinforcing Activities

With the help of a common agenda and continuous communication, all participants in a Collective Impact effort are engaged in mutually reinforcing activities, sometimes even unbeknownst to one another. However, by touching base with the statewide workgroup at each meeting, subcommittees build upon one another's work. For example, the brochure developed by the Catawba pilot project was used as the basis for the education subcommittee's statewide brochure.

In addition to mutually reinforcing activities taking place within the initiative, as it progressed into Year 3, word spread throughout the state and across the nation. As organizations and individuals became aware of the issues it was addressing, its leaders were invited to speak to various professional groups including the North Carolina Association of County Directors of Social Services (NCACDSS), The North Carolina Training, Instruction, Development and Education (NC TIDE) Committee, a nonprofit training organization for the behavioral healthcare industry; NC Area Agency on Aging Directors; three of the state's Local Management Entities/Managed Care Organizations (LME/MCOs); the NC Department of Public Instruction Conference on Exceptional Children; and the North Carolina Guardianship Association.

In July 2017, *Rethinking Guardianship* facilitator Linda Kendall-Fields made a presentation at the National Association of Councils on Developmental Disabilities (NACDD) conference in Salt Lake City, Utah, and in October, Barbara Leach and Tamara Norris, both of the Jordan Institute for Families, made a presentation about the initiative to the Parent to Parent Leadership Institute in New Haven, Connecticut.

4. Tracking Learning and Progress Through Shared Measurement

When the initiative began in 2015, it quickly became apparent that although the workgroup had an incredible depth and breadth of knowledge regarding the policy, practice, and laws surrounding adult guardianship, no one had very usable data. Information about the guardianship process and experience in North Carolina, broadly speaking, comes from two sources: the courts and the NC Division of Aging and Adult Services. However, these data are inaccessible (i.e., paper records maintained in 100 different counties). When centralized, they were incomplete for the group's purposes (i.e., no age, gender, or disability recorded) or otherwise insufficient for ascertaining the quality, consistency, and necessity of guardianship, or to identify interventions that promote less restrictive alternatives to guardianship. As a result, advocates, private service providers (nonprofit and commercial), and government agencies do not have accurate, complete data on the size of the guardianship population in North Carolina, much less any greater detail about need and eligibility for specific kinds of supports.

Thus, before *Rethinking Guardianship* could identify shared measures, it was important to establish a baseline and benchmarks for such things as the numbers of guardianships and percentages of restorations sought and granted. Through this work, and the unsuccessful attempts at identifying useful existing data, the workgroup began building a data agenda and

a strategy for results-based accountability. Possible shared measures that could be achieved and would be measurable outcomes of our efforts, with the aid of a more comprehensive data system, included:

- reduced rate of young adults with I/DD coming into guardianship
- reduced rate of older adults with dementias coming into guardianship, with the increased use of advanced directives
- higher rates of petitions for restorations, especially among people who entered guardianship before age 27
- higher rates of successful restorations, especially among people who entered guardianship before age 27
- higher rates of limited guardianships.

5. Supporting the Backbone Organization and Infrastructure

Backbone infrastructure is critical to the success of Collective Impact, and the Jordan Institute has continued to provide core support to *Rethinking Guardianship*. As of the close of Year 3, the Jordan Institute is prepared to continue in this role, provided future funding becomes available and the project is actively seeking sponsors and other potential sources for this funding. Simultaneously, the Administrative Office of the Courts may be a possible future backbone organization, and the project is considering how to build a bridge to that possibility. In general, it is important to recognize the long-term nature of Collective Impact as a framework, which typically can take 7 to 10 years to effect substantial and lasting social change. Given that estimate, *Rethinking Guardianship* is still fairly young.

Despite its relative youth, *Rethinking Guardianship* has provided great opportunities for insight about Collective Impact as a framework for change. Here are some lessons learned.

- **Collective Impact Requires Patience.** The first year of “hunting and gathering” eventually yielded a clear common agenda. However, it was accompanied and challenged by a sense of urgency. The energy and enthusiasm that something needed to be done had to exist in the midst of the necessarily slower process of understanding the landscape of the statewide guardianship system. In the case of *Rethinking Guardianship*, this patience paid off.
- **Stay close to the source.** Over and over again, the *Rethinking Guardianship* workgroup was reminded by those individuals and families with lived experiences of guardianship of why this work was so important and meaningful. Those affected by the issue create energy for the movement, and it is critical to continue to have such individuals involved and sharing their experiences with the group.
- **Let go of the need to centralize control.** With so many stakeholders, it is easy to desire some way of centralizing control of a Collective Impact project. However, by allowing multiple drivers to work within their spheres of influence, there are multiple, parallel champions moving toward a common agenda, thus ensuring a greater impact.
- **Carry the common agenda wherever you go.** As described above, maintaining the common agenda at the fore of the work ensures both group alignment and a ripple effect of the impact of the work.

- **Long and detailed strategic action plans drain energy.** With a common agenda and continuous communication, the ability to be responsive and more effective is enhanced. Action plans can therefore be shorter and can stay responsive to change and emerging ideas and opportunities.
- **Provide leadership but keep humility.** Leadership via the backbone organization is, by definition, from the back. This allows for new ideas and solutions to emerge, as well as for individuals to take initiative on new, mutually reinforcing activities.
- **Welcome and engage diverse and dissenting voices.** Large social issues, such as guardianship, are by definition complex and messy. Despite a common agenda, stakeholders can hold diverse and opposing views. Engaging with multiple voices can reveal blind spots that, if ignored, can sabotage the entire effort. In the interest of moving things forward quickly, it is important to not lose sight of all the possible perspectives. This lesson was learned the hard way by the workgroup. When a small subset of the legislative committee hastily submitted a rough draft of a bill of rights to the General Assembly without having enough time to get input from key stakeholders, including the Conference of Clerks, the effort nearly derailed. Although the effort was put forth with the best of intentions, it required a careful strategy of engagement. The legislative agenda, now reflecting a wider audience of stakeholders, was not destroyed.
- **Maintain a commitment to being a learning community.** Use this to evaluate, grow, and change course. Over the years, experts in the field increased our knowledge base of best practices by educating and informing the workgroup on such relevant trends in guardianship reform as identifying alternatives like advance directives, supported decision-making, and self-determination. They also provided information on system accountability and less restrictive models of guardianship adopted by other states (specifically the programs of Missouri, Minnesota, Texas, and Washington, DC).

Appendix B

The Statewide Workgroup

Adelmann, Richard, NAMI
Adolphus, Sobeida, Forsyth County Department of Social Services
Alleman, Cynthia, Elder and Special Needs Law Firm
Baldwin, LeShana, North Carolina Division of Aging & Adult Services
Baluyot, Erin, North Carolina Department of Health and Human Services, Social Services, Foster Care Coordinator
Barlow, Pam, North Carolina Clerk of Superior Court (Ashe County)
Beauchamp, Kelly, North Carolina Council on Developmental Disabilities
Bilos, Helaine, Neuro Community Care
Bing, Erica, Alliance Behavioral Healthcare (MCO)
Brady, Diane, Legal Aid of North Carolina
Brinkley, Nicole, Assistant Clerk of Court, Wake County
Burney, Wanda, Forsyth County Department of Social Services
Burrus, Craig, Wake County Department of Human Services
Cabe, Samantha, Orange-Chatham County Departments of Social Services
Caison, Walt, North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services
Cameron, Kathleen, National Alliance for the Mentally Ill North Carolina
Clark, Sam, North Carolina Health Care Facilities Association
Climo, Ali, University of North Carolina, Jordan Institute
Cole, Lori, North Carolina Court System
Colwell, Beverly, North Carolina Department of Public Instruction
Corbett, Lisa, North Carolina Department of Health and Human Services
Cronin, Julie, North Carolina Department of Health and Human Services, Assistant General Counsel
Davis, B., North Carolina Center for Independent Living
Dawkins Berry, Kim, Area Agency on Aging for Region G
Donohue, Bill, Parent Advocate
Dorton, Robyn, Self-advocate
Dunn, Corye, Disability Rights North Carolina
Eubanks, Annette, Mid-East Commission Area Agency on Aging
Farmer-Butterfield, Jean, ARC of North Carolina, North Carolina General Assembly
Flowers, Kent, Craven County Department of Social Services
Franklin, Rodney, Catawba County Department of Social Services
Frederick, Daina, Rowan County Department of Social Services
Fredricksen, Dorian, Corporation of Guardianship, Inc.
Fuller Cooper, Charmaine, North Carolina AARP
Funderburk, Amy, North Carolina Administrative Office of Court
Garton, Gloria, North Carolina Center for Independent Living
Graham, Carey, Elon University, Elder Law (Intern)
Greenarch, Keith, North Carolina Statewide Independent Living Council, The Adaptables-Winston Salem
Haber, Michele, Geriatrics Consulting Services, Inc.
Hefner, Tami, Catawba County Department of Social Services (Catawba Pilot)
Henson, Chandra, Catawba County DSS
Herr, Matthew
Hines, Jason, Community Member
Hippler, Debbie, North Carolina Statewide Independent Living Council
Hurley, Pat, NC General Assembly, House Committee on Aging (Chair)
Jackson, Kathy, Social Services Attorneys Association
Jackson-Diop, Damie, NC Families United
Jett, Laura, Mid-East Commission Area Agency on Aging
Johns, Frank, Booth, Harrington, & Johns, Elderlaw Firm
Karim, Nicholle, National Alliance on Mental Illness
Keith, Jessica, North Carolina Department of Health and Human Services
Kelly, Carol
Kendall Fields, Linda, University of North Carolina, Jordan Institute
Kinch, Athena, A Helping Hand
Kipnes, Joanna, Duke University
Kirk, Gale, National Guardianship Association

Lanier, Kathryn, NC DHHS, Division of Aging and Adult Services

Lassiter, Jamie, NC Conference of Clerks of Superior Court

Lawson, Terri, Assistant Clerk of Court, Catawba County

Leach, Barbara, University of North Carolina, Jordan Institute

Lee, Tameka, ARC of North Carolina

Levy, Helayne, Elder Law - NC Bar Association

Lewis, Mya, NC DHHS, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services

Luong, Tienna, Mecklenburg County Department of Social Services

MacMichael, Betsy, First In Families North Carolina

MacMichael, Janie, Self-advocate

Maid, Seth, National Alliance for the Mentally Ill North Carolina

Manly, Regina, Trillium Health Resources (MCO)

Manus, Roger, Campbell University, Senior Law Clinic

Marsh, Sarah, University of North Carolina, Jordan Institute

Massey-Smith, Joyce, North Carolina Division of Aging and Adult Services

McDowell, Letha, Hook Law Center

Merrill, Suzanne, Division of Aging and Adult Services, DHHS

Mewhinney, Kate, Wake Forest University, Elderlaw Clinic

Meyer, Graig, Representative, General Assembly

Miller, Natalie, North Carolina Bar Association

Miller, William T., North Carolina Statewide Independent Living Council Staff

Nelson, Bonnie, ARC of North Carolina

Nelson, Gary, University of North Carolina, Jordan Institute

Norris, Tamara, University of North Carolina, Jordan Institute

Nowacki, Shevodka, Catawba County

O'Donnell, Mark, NC DHHS, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services

Owen, Michael, University of North Carolina, Jordan Institute

Pegram, J. Mark, North Carolina Clerk of Superior Court (Rockingham County)

Pender, Richard, Forsyth County Department of Social Services

Pettyford, Belinda, North Carolina Department of Health and Human Services

Pettyford, Rosalyn, North Carolina Guardianship Association

Pitchford, Evelyn, North Carolina Division of Aging and Adult Services

Premakumar, Raj, North Carolina Department of Justice

Ransome, Sharnese, North Carolina Association of County Departments of Social Services Directors

Reed, Glenda, Wake County Department of Human Services

Reeves, Larry, Southwestern Commission Area Agency on Aging

Register, Jack, National Alliance for the Mentally Ill North Carolina

Riddle, Holly, North Carolina Department of Health and Human Services

Rogers, Denise, Office of the State Ombudsman

Ross, Cynthia, Pitt County Department of Social Services

Rozycki, Amanda, Duke Children's Hospital and Health Center

Salmon, Mary Anne, University of North Carolina, Jordan Institute

Schmidt, Winsor, University of North Carolina at Charlotte

Secor, Scott, First In Families North Carolina

Sigmon, Kim, North Carolina Clerk of Superior Court, Catawba County (Catawba Pilot)

Simpson, Shayna, North Carolina Department of Health and Human Services

Skradski, Stacey, Empowering Lives Guardianship Services LLC and NC Guardianship Association

Smith, Meredith, University of North Carolina School of Government

Smith, Michael, Partners Behavioral Health Management (MCO), Catawba Pilot

Smithmyer, Judy, Autism Society of North Carolina

Strom, Steve, NC DHHS, Division of Medical Assistance, Money Follows the Person Program

Terhune, Peggy, Monarch North Carolina

Trickel, Cynthia, North Carolina Department of Public Safety

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

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

Vaughan, Hannah, Elon University, Elder Law

Walfall-Flagg, Cheryl, Parent Advocate

Walker, Sunni, University of North Carolina, Jordan Institute

Walls, Jason,

Walton, Kate, NC DHHS, Division of Aging and Adult Services

Ward, Heather Carty, Elder Law (Private Practice),
Charlotte NC
Warren, Nancy, NC DHHS, Division of Aging and
Adult Services (retired)
Watkins, Alice, Alzheimers North Carolina, Inc.
Webster, Debbie, NC DHHS, Division of Mental
Health, Developmental Disabilities, and
Substance Abuse Services, Community Mental
Health Section
Welsh, Polly, NC Health Care Facilities Association
Whitaker, Carrie, Duke University
Wilhelm, Jeanette, Monarch North Carolina
Woodward, Philip, NC Council on Developmental
Disabilities
Woolard, Deborah, Parent Advocate
Zuver, Deborah, Carolina Institute for
Developmental Disabilities at University of
North Carolina

Appendix C

Glossary of Guardians

Guardian of the Person is a guardian who is appointed solely to perform 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 to manage the property, estate, and business affairs of an individual, essentially, all financial aspects of the individual's life. This includes

- initiating, defending, or settling lawsuits
- lending or borrowing money
- making a will for the individual
- managing or possessing the property or income of the person under guardianship
- paying or collecting 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 a “disinterested public agent,” assigned when there is no family member or friend available or appropriate to serve as guardian. In North Carolina, Directors and Assistant Directors of county Departments 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 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 D

Methods and Sources for the Data Reported

During each of the three project years, the Data group of the Data and Stories Subcommittee had one major analysis project. Data from each of these has been synthesized in the Data and Stories Subcommittee section of this report. Below is a brief description of each project

Ongoing

The Administrative Offices of the Court (AOC) reports on the numbers of guardianship petitions filed, adults declared incompetent, types of guardians appointed, and restorations of rights which can be downloaded from <http://www.nccourts.org/Citizens/SRPlanning/Statistics/QuickFacts.asp> and clicking on the year of interest. This dataset includes all special pleadings cases. Those related to guardianship can be identified by issue code, and both statewide and county data can be read.

These data are for administrative purposes only and as such do not contain any of the social data (such as demographics or underlying condition) that advocates, planners, or researchers in the field would wish to know. They are as complete and accurate as the work of courthouse employees in each individual county and the priority that these different locations give to the data entry task. There are some marked inconsistencies among counties in the way some information is filed and some noticeable variations from the training instructions they are provided by the AOC, but it is the best and only data available for *all* adult guardianships.

These data were first analyzed in Year 1 and extended as new reports have come out. Population figures to serve as the denominator for incidence calculations were downloaded from www.census.gov, American Factfinder, and are drawn from the 5-year American Community Survey estimates.

Year One

The focus group–like sessions (too large to be actual focus groups) were held on Wednesday, August 19, 2015, at the summer conference for Clerks of Superior Court. At the sessions, one team member led the discussion while two took detailed notes (as close to verbatim as possible), and one took more general notes.

The online survey was delivered using Qualtrics software and was broken into sections that asked about the Clerks' experience with petitions and preparation, the incompetency hearing, making a ruling on competency, activities after the hearing, and some demographic information. All survey responses were anonymous, and the surveys were sent to the 100 Clerks of Superior Court. Seventy-five Clerks completed the majority of the survey questions, resulting in a very high (75%) response rate.

Copies of both the survey questions and the focus group protocol are available in the appendix to the first year's report.

Year Two

Through a request by the NC Division of Aging and Adult Services, the AOC made available individual-level records, providing each entry for people who had had at least one guardianship-related activity between July 1, 2012, and December 31, 2015 (SFYs 2013, 2014, 2015, and first half of 2016). If a person included in these criteria had records from before July 1, 2012, these were also included in the file. Although records were provided for both Special Proceedings (SP), which includes ruling of incompetence and restoration, and Estate (E), which includes appointment of guardians and reports from guardians, analysis focused on the SP cases. While these data were an improvement on the published data in allowing us to see multiple actions for each person over time, it had the same limitations discussed above.

The AOC includes this disclaimer with all data they release: “No analysis of or conclusions drawn from these data may be attributed to the Administrative Office of the Courts.” Findings here are the work of Mary Anne Salmon, PhD, and Sarah Marsh, MSW, of the 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.”

Year Three

As discussed above, the only source of data about the adults who come into guardianship is in the paper Special Proceedings files kept in the courthouses of the counties in which the petition was filed or to which guardianship was later transferred. The Clerk of Superior Court in Catawba County gave us access to these files (which are legally public record). Although these data are for one county and should not be over-generalized to the state as a whole, they remain the best available about the characteristics and experiences of people who come into guardianship.

A team of researchers from the Jordan Institute for Families reviewed 176 files with some action related to guardianship. This included 128 files (125 petitions, 3 transfers) from calendar year 2015 and first three quarters of 2016. All information not involving restoration is based on these data. The team also reviewed all 48 available files with restoration activity going back to 1985. Because of the rarity of restoration to rights, it was necessary to draw from a wide period to capture this modest number of cases (3 of the 48 restoration files were from the 2015–2016 study period).

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
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

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
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
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

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
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.