

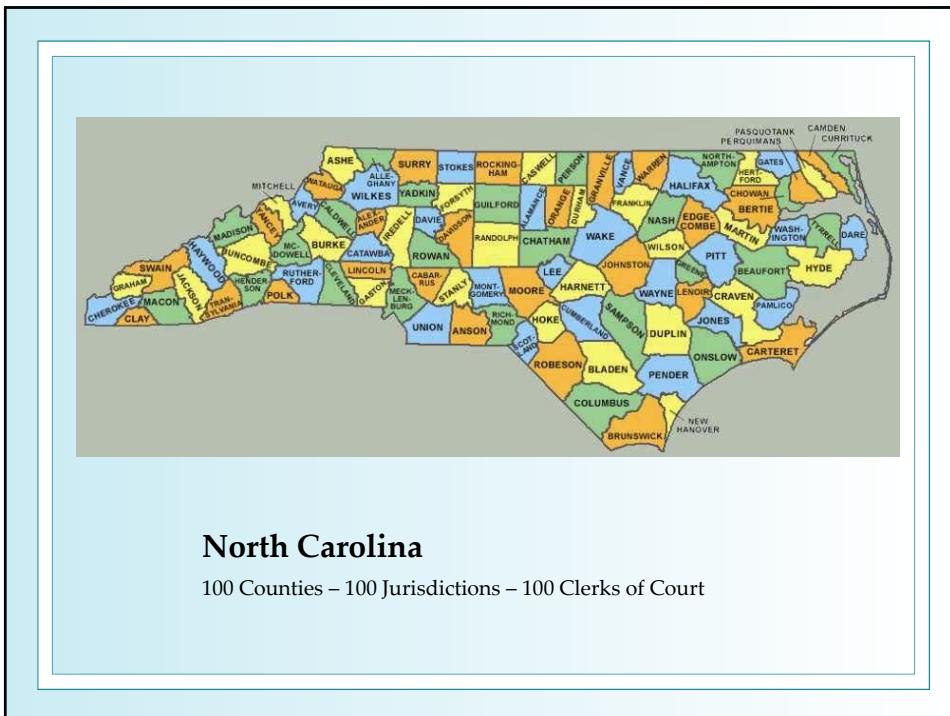


Building a Case for Less Restrictive Alternatives

July 13, 2017

Background on Guardianship

- Guardianship removes an adult's rights to manage his or her life decisions and places those decision-making responsibilities with a court appointed guardian.
- Out of more than 5,000 adults in North Carolina who are served by a **public guardian**, nearly 3,000 (56%) are adults ages 18-59 years old, the majority of whom (85%) have an intellectual/developmental disability and/or mental illness
- Approximately one-third of individuals under guardianship have a public guardian; approximately two-thirds have **private guardians**, many of whom are family members. There has been little to no training and oversight of these guardians and little to no data collected and understood.



Funding:

- NC Council on Developmental Disabilities through the NC Division of Aging and Adult Services to the UNC Chapel Hill Jordan Institute for Families, School of Social Work
- Three-year grant beginning January 2015 - completed Year 1 & Year 2; now in the midst of Year 3

Collective Impact framework:

- Statewide workgroup – 120 members
- National WINGS (Working Interdisciplinary Network of Guardianship Stakeholders)
- Catawba Pilot Site

Rethinking Guardianship is...

- 1) Creating long-term changes in the state's guardianship system
- 2) Promoting less restrictive alternatives to guardianship
- 3) Using the process of Collective Impact to create change in the guardianship system of a pilot community in North Carolina.



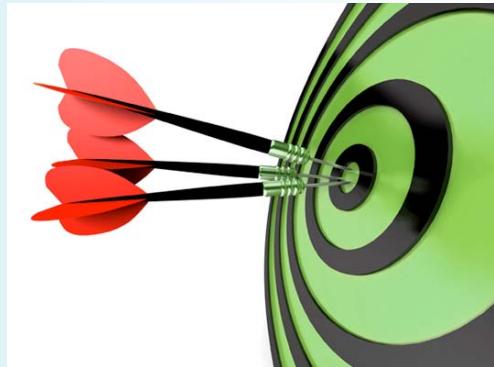
Year 1

The Year of Hunting and Gathering...



Year 2

The Year of
Focused Action
towards Desired
Outcomes...



Year 2 Results: Common Agenda

- **Core concepts and basic principles:**
 - Autonomy, liberty, freedom, dignity
 - Presumption of competence
 - Right to life-time decision-making support

Common Agenda/Shared Aspiration

The System-as-it-Should-be 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.

Year 2 Results: Engaged and Diverse Work Group

Three subcommittees:

- 1) Legislation, Policy & Practice
- 1) Education, Awareness and Training
- 1) New Information: Stories & Data

The screenshot shows the homepage of the Rethinking Guardianship website. The header features the organization's logo with the text "RETHINKING GUARDIANSHIP". Below the logo is a navigation bar with links: HOME (highlighted in green), OUR MISSION, WHO WE ARE, RESOURCES, PILOT PROJECTS, STORIES, and CONTACT US. The main content area has a "Welcome" heading and a photograph of two women, one older and one younger, smiling and holding coffee cups. Below the image is the website's URL: <http://ssw.unc.edu/rethinking/home>.

Catawba Pilot: *Rethinking Guardianship - Options for Independence*

A map of the Catawba region in North Carolina, highlighting Hickory, Statesville, and Mooresville. Major roads shown include Interstate 40 and U.S. Route 321.

- 1. Transitioning to Adulthood
- 2. Supported/Surrogate Decision Making
- 3. Community Education and Awareness

About the Data

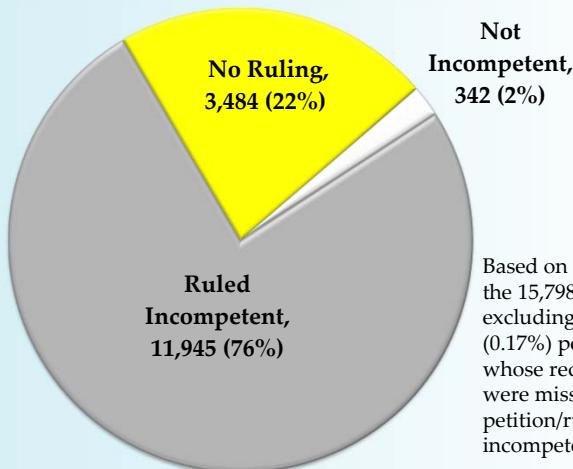
- Guardianship cases from 7/1/12 –12/31/15
- Limitations
 - Entered by each county for court purposes
 - No age, gender, reason for guardianship
- 37,789 records representing 15,798 unique people

Guardianship Rates



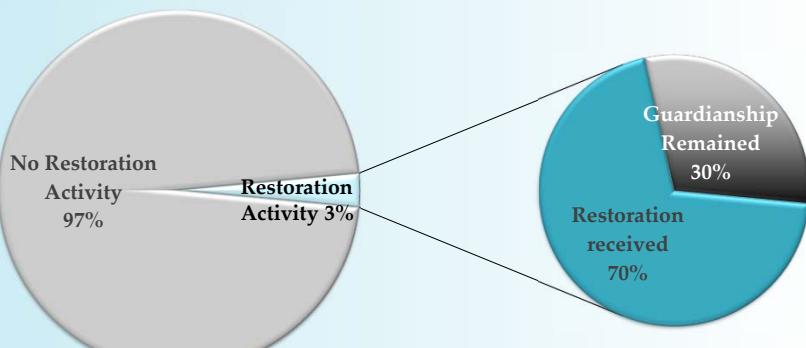
- 15,798 people had guardianship action
- 21 for every 10,000 adults in the state
 - Gates County (low) 7 per 10,000 adults
 - Graham County (high) 63 per 10,000 adults
 - Wake County had the largest raw number—2,229 people which is 32 per 10,000

How Many People Placed Under Guardianship?

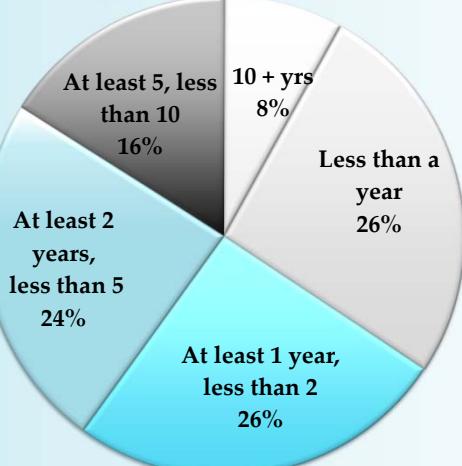


Based on 15,771 of the 15,798 cases--excluding 27 (0.17%) people whose records were missing any petition/ruling on incompetence

How Many People Sought & Received Restoration?



Length of Time from First Court Action for Incompetence to Restoration



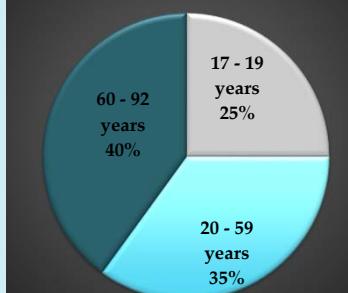
Average was 3 years and 7 months, but median was 1 year and 10 months.

N=315*

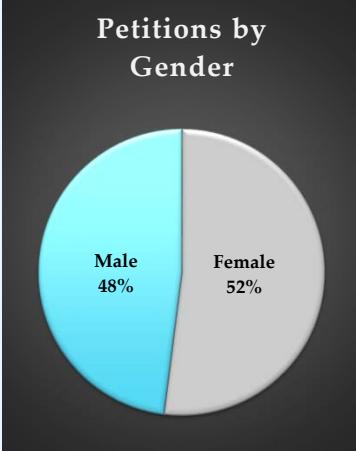
*11 of the 326 excluded because of issues in their records

Preliminary Catawba Data

Petitions by Age

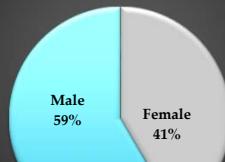


Petitions by Gender

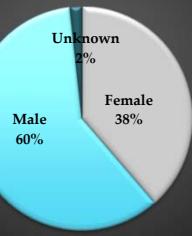


Preliminary Catawba Data

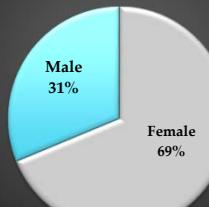
17 - 19 year olds (n= 41)



20 - 59 year olds (n=57)



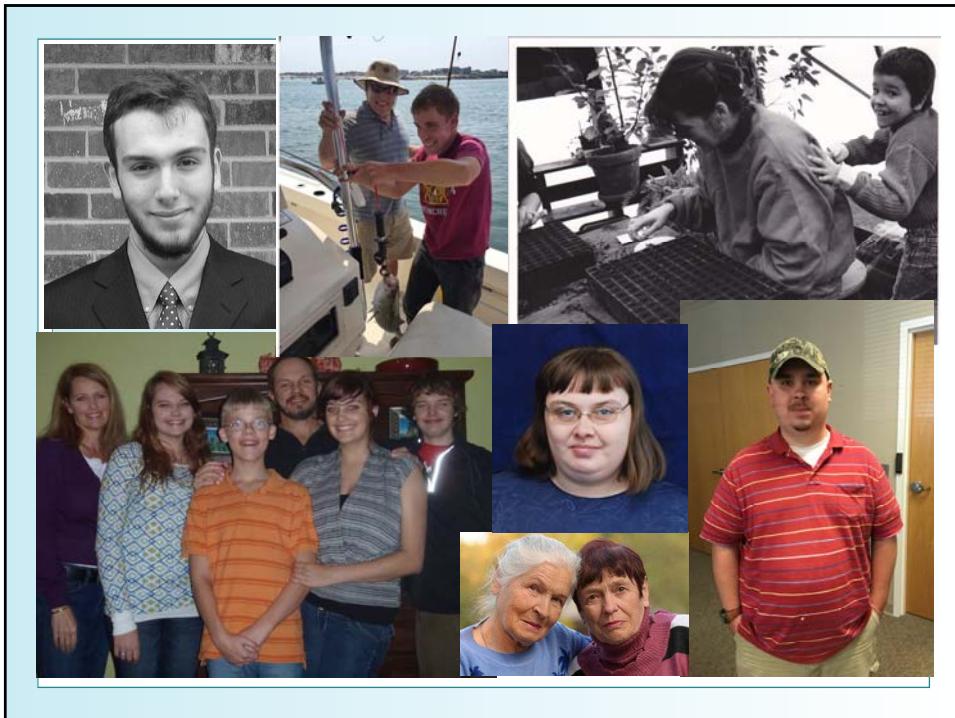
60 - 92 year olds (n=64)



Stories Drive Change!

"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)



Story Themes

- **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.



Year 3: The Year of Balance & Sustained Effort
Autonomy - Support - Protection



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