



Supported Decision-Making & Other Guardianship Alternatives

Focus on Family and Disability Seminar

February 11, 2020

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Center for Aging Research & Educational Services (CARES)

Have you ever had the feeling that everything in your life has been leading up to this moment?



Today's Learning Objectives...

Upon completion of this the workshop, participants should be able to:

- Explain North Carolina's Rethinking Guardianship Initiative
- Describe at least 3 types of adult guardianship alternatives
- Discuss values and principles of self-determination, self-advocacy, and how these relate to a range of decision-making options
- Identify 4 essential elements of supported decision-making agreements, in lieu of guardianship
- Locate 3 state and national resources to assist individuals and families in assessing the best form(s) of decision-making for each situation.

What does the word “guardian” mean to you?



Background on Guardianship in NC

- **Guardianship removes an adult's rights to manage his or her life decisions and places those decision-making responsibilities with a court appointed guardian.**
- It is estimated that there are more than 23,000 adults subject to guardianship in NC. Out of 5,000 adults in the state who were served by a public guardian in 2013,, nearly 3,000 (56%) were adults ages 18-59 years old, the majority of whom (85%) had 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.**
- Even now, due to the way that records are kept, **it is not possible to know how many adults in North Carolina are currently under guardianship.**

Types of Guardians

➤ **Guardian of the Person**

- has authority to make decisions in most areas of a adult's personal life, exclusive of assets. This includes giving consent or approval for the adult subject to guardianship to receive any needed medical services (with some limitations such as sterilization, amputations and end of life).

➤ **Guardian of the Estate**

- has authority to manage the adult's assets such as bank accounts, brokerage accounts, vehicles, real estate, personal property, cash and income such as pensions, dividends, wages, interest and rental income.

➤ **General Guardian**

- has the powers and duties of both a guardian of the person and a guardian of the estate.

➤ **Interim Guardian**

- A limited duration version of any of the above, appointed by the Court due to an emergency. Its termination date (when the authority ends) will be shown on the face of the document.

The Process of Obtaining Guardianship



Petition

- A Petition is filed with the Clerk of Court alleging incompetence.
- Respondent (alleged incompetent) is served by the Sheriff and appointed an independent attorney (Guardian ad Litem) to represent them.
- Respondent can hire independent attorney as well.
- Petition must include the respondent's correct information. Copy of the petition is sent to the respondent as well to the respondent's next of kin and other persons known to have an interest in the proceeding.
- If there is an emergency, an "interim" hearing can be requested.

Hearing

- All parties are entitled to present evidence and question witnesses.
- Typically the Courts conduct the hearings in an informal manner to allow the best understanding to be presented so that a decision can be made that is in the best interest of the alleged Incompetent (Respondent).
- Court will enter a decision that the party is or is not Incompetent. If found to be Incompetent the Court will appoint a Guardian.

Guardianship Capacity Questionnaire

- A. Language & Communication
- B. Nutrition
- C. Personal Hygiene
- D. Health Care
- E. Personal Safety
- F. Residential
- G. Employment
- H. Independent Living
- I. Civil
- J. Financial

| GUARDIANSHIP CAPACITY QUESTIONNAIRE | | |
|---|---|---|
| <p><i>There is no need to complete this questionnaire if the respondent is in a coma, persistent vegetative state, or is not responsive.</i></p> <p><i>The questionnaire is designed to help all parties in an incompetency proceeding gather information that will assist the Clerk of Court in determining what if any rights, powers and privileges the respondent can retain under guardianship or limited guardianship. The form may also assist the parties in determining whether alternatives to guardianship such as a representative payee for government benefits, a power of attorney, or a special needs trust might solve a problem thereby avoiding the need for incompetency hearing.</i></p> <p><i>This form can be used by the petitioner, the respondent, or any other person who has information that is useful to the court such as family or friends of the respondent or staff of a facility who knows the respondent well. It should be used by the Guardian Ad Litem to both gather the respondent's answers if the respondent cannot fill it out for him/herself and for the GAL's own opinion.</i></p> | | |
| Name Of Respondent | | Date Of Birth |
| Address | | Telephone No. |
| Nature Of Impairment | | County Of Residence |
| Is there a representative payee for governmental benefits? <input type="checkbox"/> Yes <input type="checkbox"/> No If Yes, Name of Payee | Are there any Powers of Attorney in place? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> General/Durable <input type="checkbox"/> Health Care If Yes, Who has the POA? If Recorded, What County(ies)? | Are there any trusts in place? <input type="checkbox"/> Yes <input type="checkbox"/> No If Yes, Name of Trustee and location of trust |
| Name And Address Of Person Completing This Form | | Telephone No. |
| | | Has Known Respondent (years/months) |
| | | Relationship to the Respondent |
| | | |
| A. LANGUAGE AND COMMUNICATION | B. NUTRITION | |
| 1. Does the person understand and participate in social conversation in his/her primary language (including such topics as sports, family, activities)? <input type="checkbox"/> Yes <input type="checkbox"/> No | 1. Does the person make reasonable decisions regarding eating (e.g. when, where, and what to eat)? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> With assistance | |
| 2. Does the person communicate independently with acquaintances in the community? <input type="checkbox"/> Yes <input type="checkbox"/> No | 2. Is the person able to eat and drink independently? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> With assistance | |
| 3. Can the person understand and respond to verbal communications? <input type="checkbox"/> Yes <input type="checkbox"/> No | 3. Is the person able to prepare food that requires cooking and mixing? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> With assistance | |
| 4. Can the person read and write? <input type="checkbox"/> Yes <input type="checkbox"/> No | 4. Is the person able to prepare food that does not require cooking and mixing? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> With assistance | |
| 5. Can the person understand various signs (e.g. keep out, stop, men, women, poison)? <input type="checkbox"/> Yes <input type="checkbox"/> No | 5. Does the person know which foods, if any, he or she is unable to tolerate? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> With assistance | |
| | 6. If the person has a health condition such as diabetes, is he or she able to follow a prescribed diet? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> With assistance | |
| ADC-SP-208, New 6/04 © 2004 Administrative Office of the Courts | | (Over) |

Who can be appointed as guardians?

N.C.G.S. § 35A-1214

- The clerk shall consider appointing a guardian according to the following order of priority:
 - An individual recommended in a written instrument (such as a Will, Power of Attorney, etc);
 - an individual;
 - a corporation or a disinterested public agent.
 - No public agent shall be appointed guardian until diligent efforts have been made to find an appropriate individual or corporation to serve as guardian
 - In every instance the clerk shall base the appointment of a guardian or guardians on the best interest of the ward.

What does the current statute say about the practice of guardianship?

N.C.G.S. § 35A-1201(a)(5)

1. Guardianship should seek to preserve for the incompetent person the opportunity to exercise those rights that are within his comprehension and judgment, allowing for the possibility of error to the same degree as is allowed to persons who are not incompetent.
2. To the maximum extent of his capabilities, an incompetent person should be permitted to participate as fully as possible in all decisions that will affect him.



North Carolina

100 Counties – 100 Jurisdictions – 100 Clerks of Court

Background

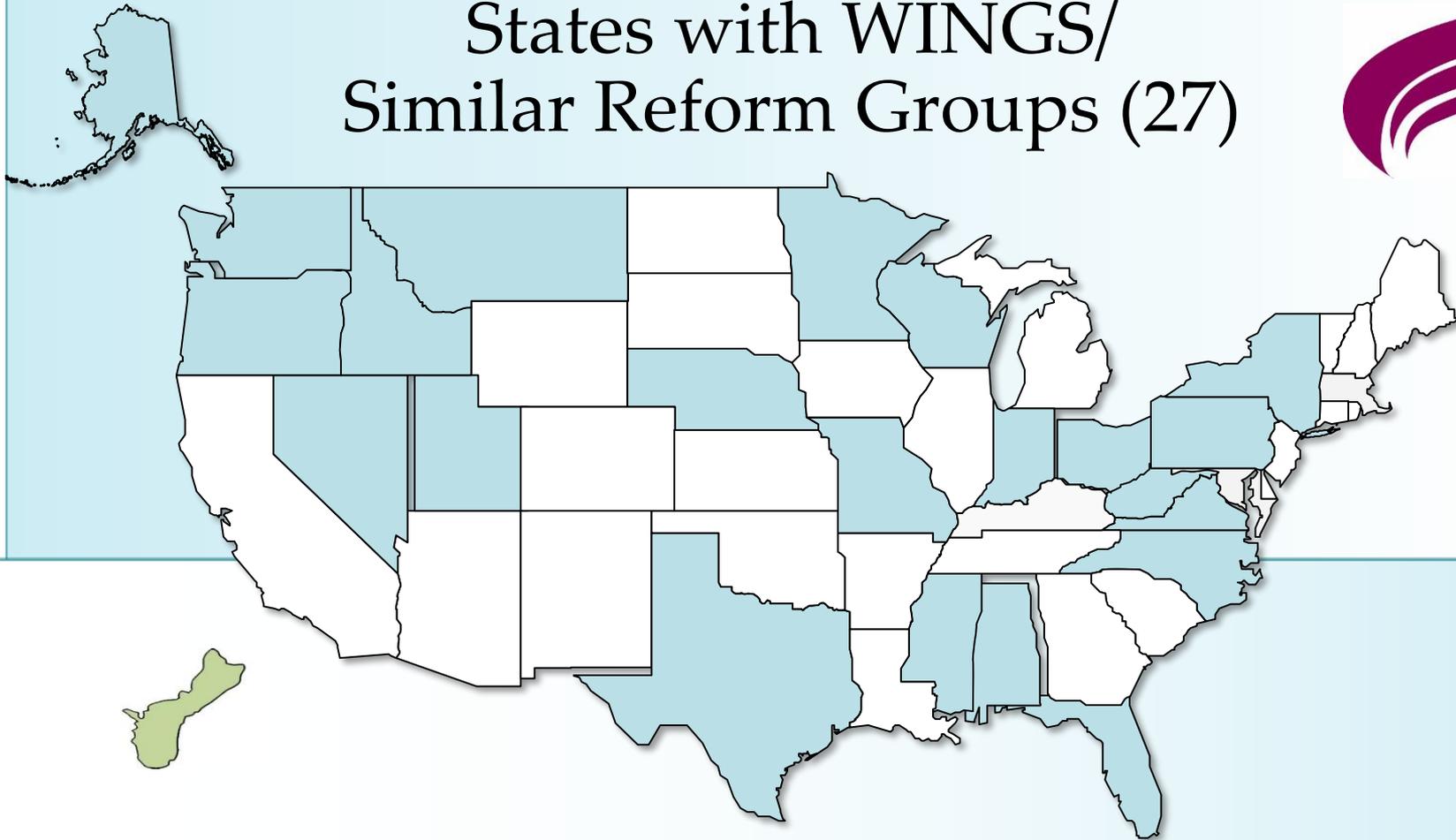


- *Rethinking Guardianship: Building a Case for Less Restrictive Alternatives* – January 2015 - December 2017
- *Rethinking Guardianship: A Person-Centered Approach*
July 2018 – December 2019
- *Rethinking Guardianship Bridge Initiative*
January 2020 – June 2020

Collective Impact framework:

- Statewide workgroup – 120 members, including Clerks
- National WINGS (Working Interdisciplinary Network of Guardianship Stakeholders)
- Catawba County Pilot

States with WINGS/ Similar Reform Groups (27)



AL, AK, DC, FL, Guam, ID, IN, KY, MA, MD, MN, MS, MO, MT, NE,
NV, NY, NC, OH, OR, PA, TX, UT, VA, WA, WV, WI (2019)

It's About Ensuring Rights and Protecting Elders...



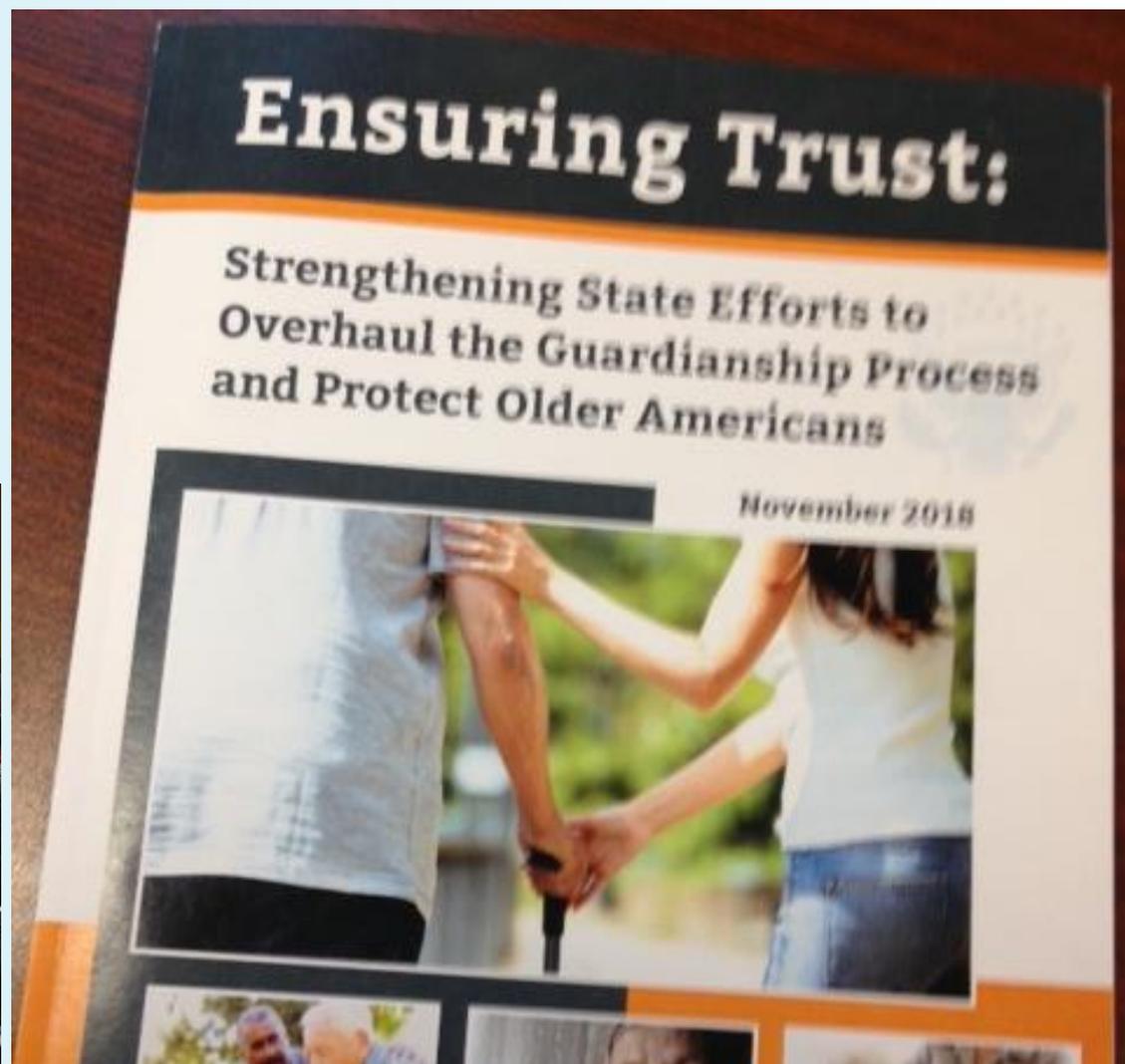
“I’m Petitioning . . . For the Return of My Life,”
New York Times, John Leland, 12-07-18



New Yorker; Media Accounts of Abuse/Exploitation



November 2018 Senate Committee on Aging



It's Also About Adults with Disabilities of All Ages...



Jenny Hatch –“I don’t need a guardian. I just need a little help”

National Council on Disability 2018 & 2019 Reports



Beyond Guardianship:

Toward Alternatives That
Promote Greater
Self-Determination



National Council on Disability
March 22, 2018



Turning Rights Into Reality:

How Guardianship and Alternatives Impact the Autonomy of
People with Intellectual and Developmental Disabilities



National Council on Disability
June 10, 2019

School-to-Guardianship Pipeline



“For a variety of reasons, youth with I/DD are disempowered by schools actively encouraging guardianship to the exclusion of less restrictive alternatives and not providing families and students with sufficient information about the availability of a full continuum of decision-making supports.” *NCD 2019 report*

Rethinking Guardianship is ...

- 1) Creating long-term changes in the state's guardianship system
- 2) Promoting less restrictive alternatives to guardianship



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.



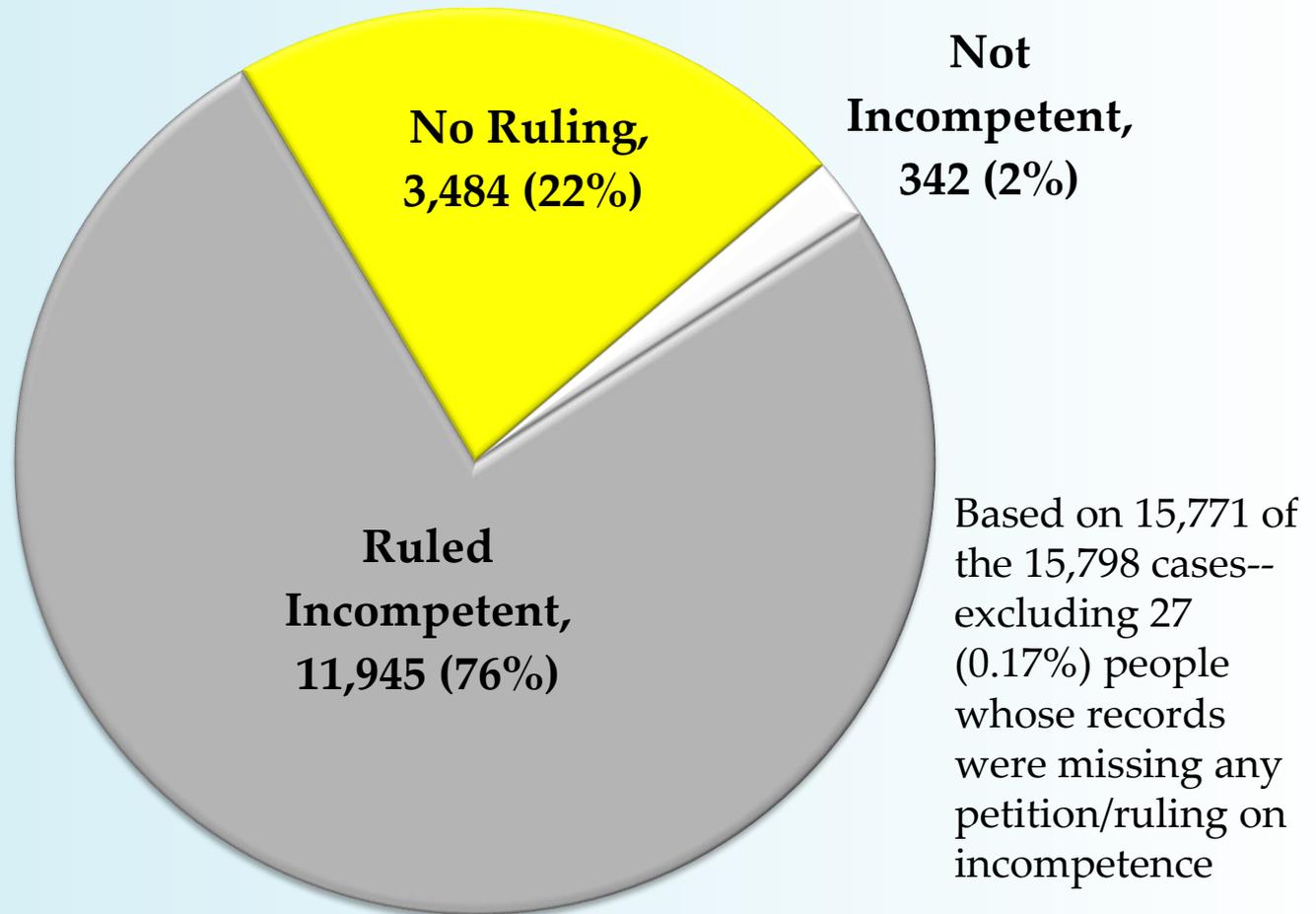
The Importance of a Balanced Approach
Autonomy - Support - Protection

Engaged and Diverse Work Group

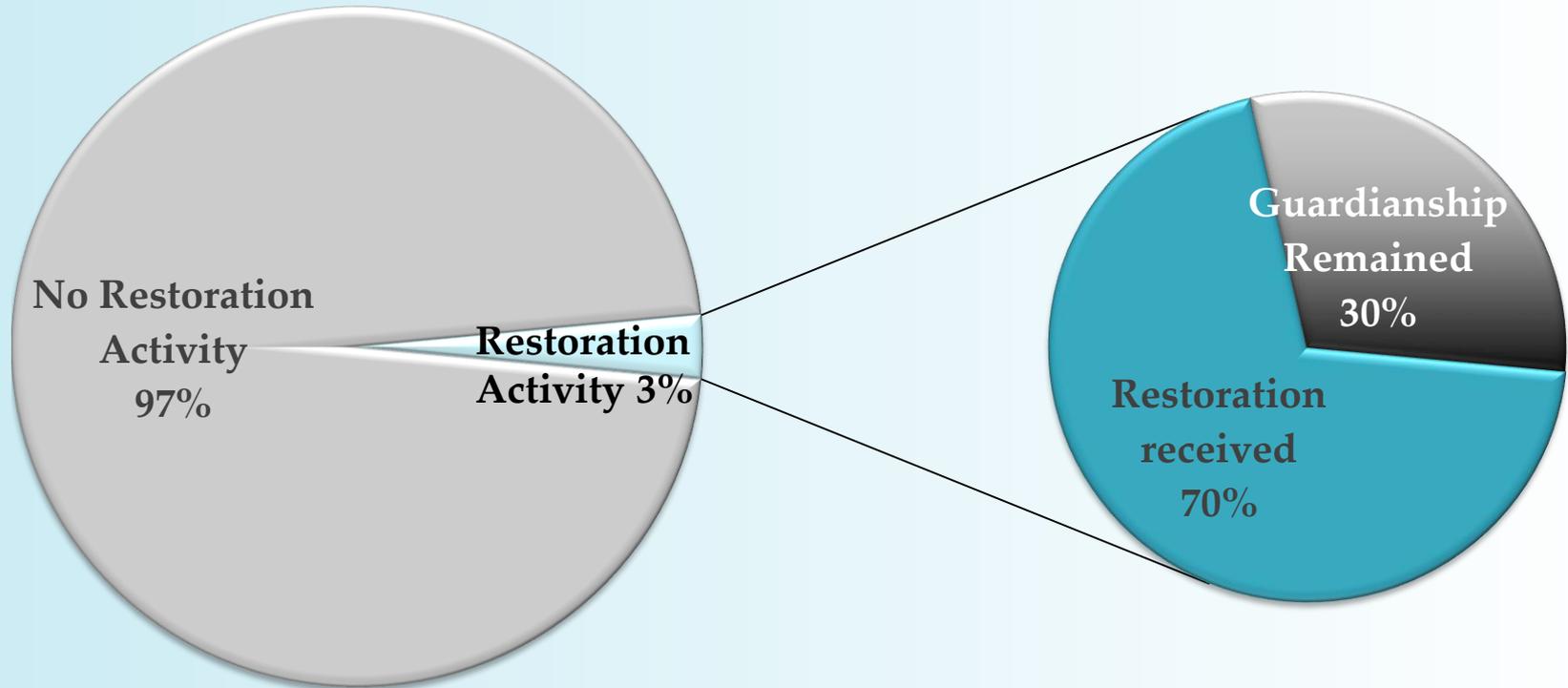
- New Information: Stories & Data
- Education, Awareness and Training
- Legislation, Policy & Practice

How Many People Declared Incompetent in NC?

July 1, 2012 – December 31, 2015

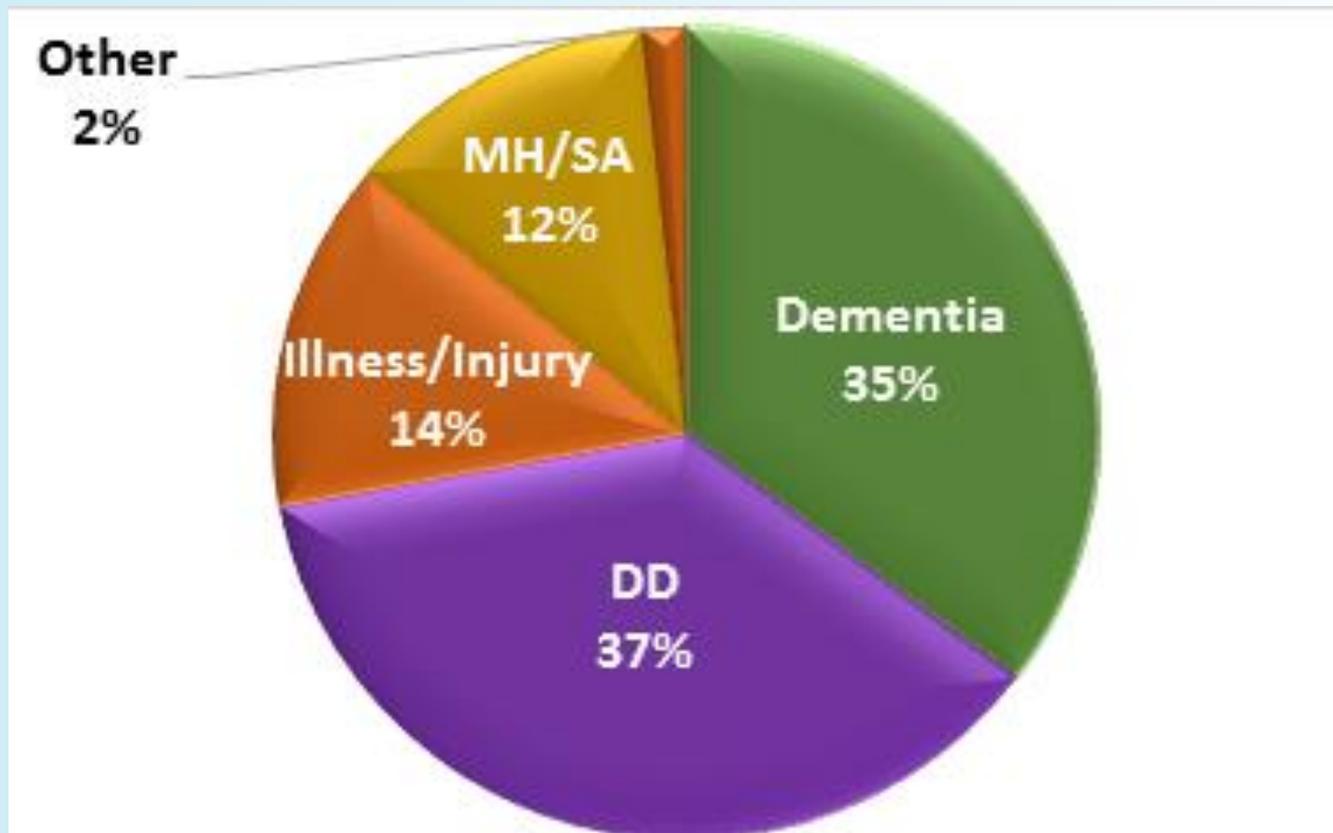


How Many People Sought & Received Restoration?



Catawba Data Analysis

January 1, 2015 – September 30, 2016



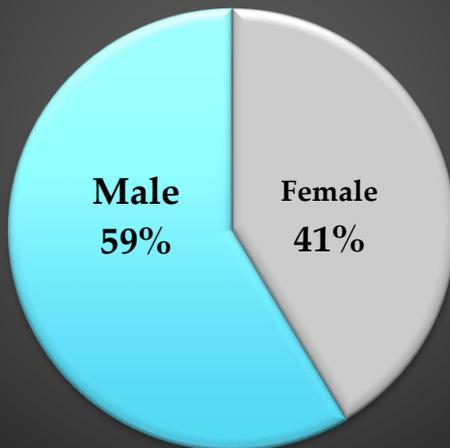
Who Petitioned (by Condition)?

January 2015 – September 2016

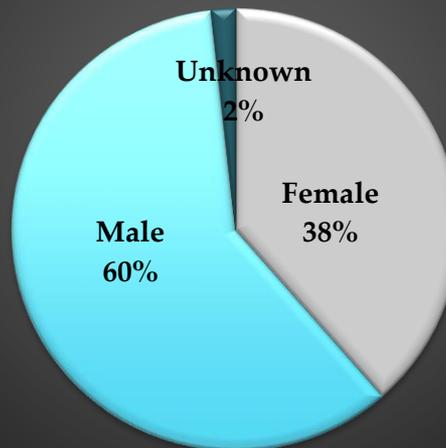
| Condition | Family | DSS | Other |
|------------------------|---------------|------------|--------------|
| DD | 95% | 4% | 0% |
| MH/SA | 86% | 7% | 7% |
| Illness/ Injury | 75% | 19% | 12% |
| Dementia | 67% | 35% | 5% |

Catawba Data by Age & Gender

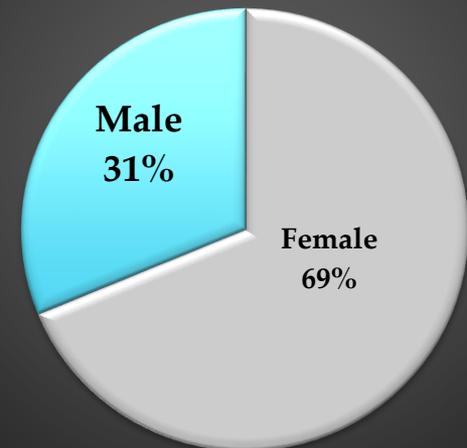
17 - 19 year
olds (n= 41)



20 - 59 year
olds (n=57)



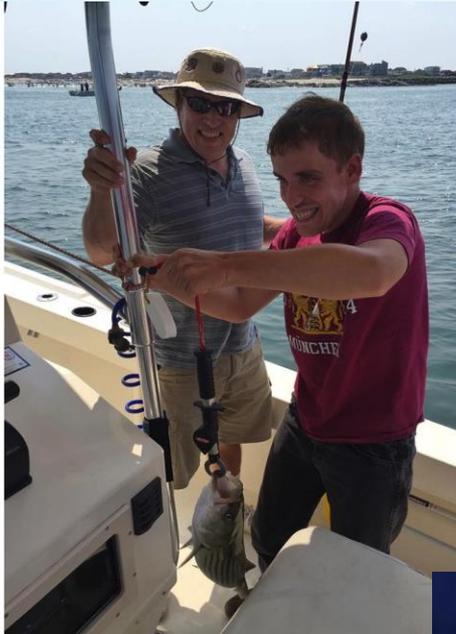
60 - 92 year
olds (n=64)



Stories

“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 perceived that the court appointed guardian took control of an adult's life and abused this power
- **Empowerment and pride** at the prospect (and realization) of restoration.

Sean's Story



Jason's Story

"I do it completely on my own now. Once in awhile, I ask my mother for her opinion, but I'm an adult. I make my own decisions...I value the opportunity to help others and appreciate the path that led me to... mental wellness."



Education, Awareness & Training

- A website with Frequently Asked Questions (FAQs) www.rethinkingguardianship.org
- An educational video, titled “Understanding Guardianship,”
- An informational brochure for all stakeholders



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[OUR MISSION](#)

[WHO WE ARE](#)

[RESOURCES](#)

[PILOT PROJECTS](#)

[STORIES](#)

[CONTACT US](#)

Welcome



UNDERSTANDING GUARDIANSHIP





An Introduction to Options



TYPES of Guardianship

General Guardianship

Appointed as both Guardian of the Person and Guardian of the Estate

Guardianship of the Person

Appointed solely for the purpose of performing duties relating to care, custody and control

Guardianship of the Estate

Appointed solely for the purpose of managing property, estate, and business affairs

Limited Guardianship

Tailored to fit the individual in the areas that assistance with decision-making is needed

Interim Guardianship

Appointed when there is an imminent or foreseeable risk of harm to the individual or their estate.

Adult guardianship exists to protect our most vulnerable citizens — such as people who have intellectual and developmental disabilities, mental health conditions, traumatic brain injury, and other vulnerable adults of any age

Which is YOUR situation?

- A professional has encouraged you to seek guardianship of a family member or friend
- You have a child with a developmental disability who is age 16 or 17
- You are in foster care, age 16 or 17 and someone has told you that you may need adult guardianship when you turn 18
- You have been told that someone is seeking guardianship over you
- You have a family member or friend with mental illness who is having difficulty making decisions
- You have a family member or friend with dementia
- You have a family member or friend who is aging and you or they are concerned about their future
- You have a family member or friend who has suffered a traumatic physical event that has rendered them physically and mentally incapable of making decisions, such as a traumatic brain injury

FIND OUT MORE

The **Rethinking Guardianship Initiative** provides information and resources about guardianship and alternatives in NC <http://ssw.edu/rethinking/home>

What is guardianship?

Guardianship is a legal relationship in which one individual is given the authority by the court to make decisions on behalf of another individual who is unable to make and/or communicate decisions on their own.

Not all vulnerable adults need guardianship.

Guardianship can take away people's right to make the most basic decisions for themselves—such as where they will live and what they will do in the course of a day. Before pursuing guardianship, consider less restrictive alternatives.

ALTERNATIVES to Guardianship

Family, Friends & Community Support Services

A system of support for an individual in various areas of their life.

Supported Decision Making

A written plan identifies individuals to assist in key areas of life, such as financial, health/medical, and daily living.

Foster Care 18-21

Continued supportive and financial services for young adults aging out of foster care at age 18.

Joint Bank Account

An account which allows another person to help pay bills and manage money. Check with your financial institution.

Living Trust

A legal arrangement for an individual who is having difficulty managing property or assets themselves.

Special Needs Trust

A legal arrangement that allows an individual who has a disability to preserve assets while maintaining eligibility for government benefits.

Representative Payee for Social Security Benefits

Provides financial management of Social Security benefits.

Fiduciary for Veteran's Benefits

Provides financial management of VA pension benefits.

Power of Attorney (Durable/General)

A legal document giving someone the right to conduct financial business on behalf of someone else without a court order.

Health Care Power of Attorney

A legal document giving someone the right to make health care decisions on behalf of someone else.

Advance Instruction for Mental Health Treatment

A legal document in which an individual indicates what treatment and care for mental health conditions they want in the event that they are unable to communicate their wishes.

Living Will or Advance Directive

A legal document that sets out an individual's desires for medical care and treatment when they can no longer communicate and are near the end of life.

**All adults have rights,
including the right to
self-determination.**

Adults have the right to make decisions — good *and* bad.

Recommendations Going Forward

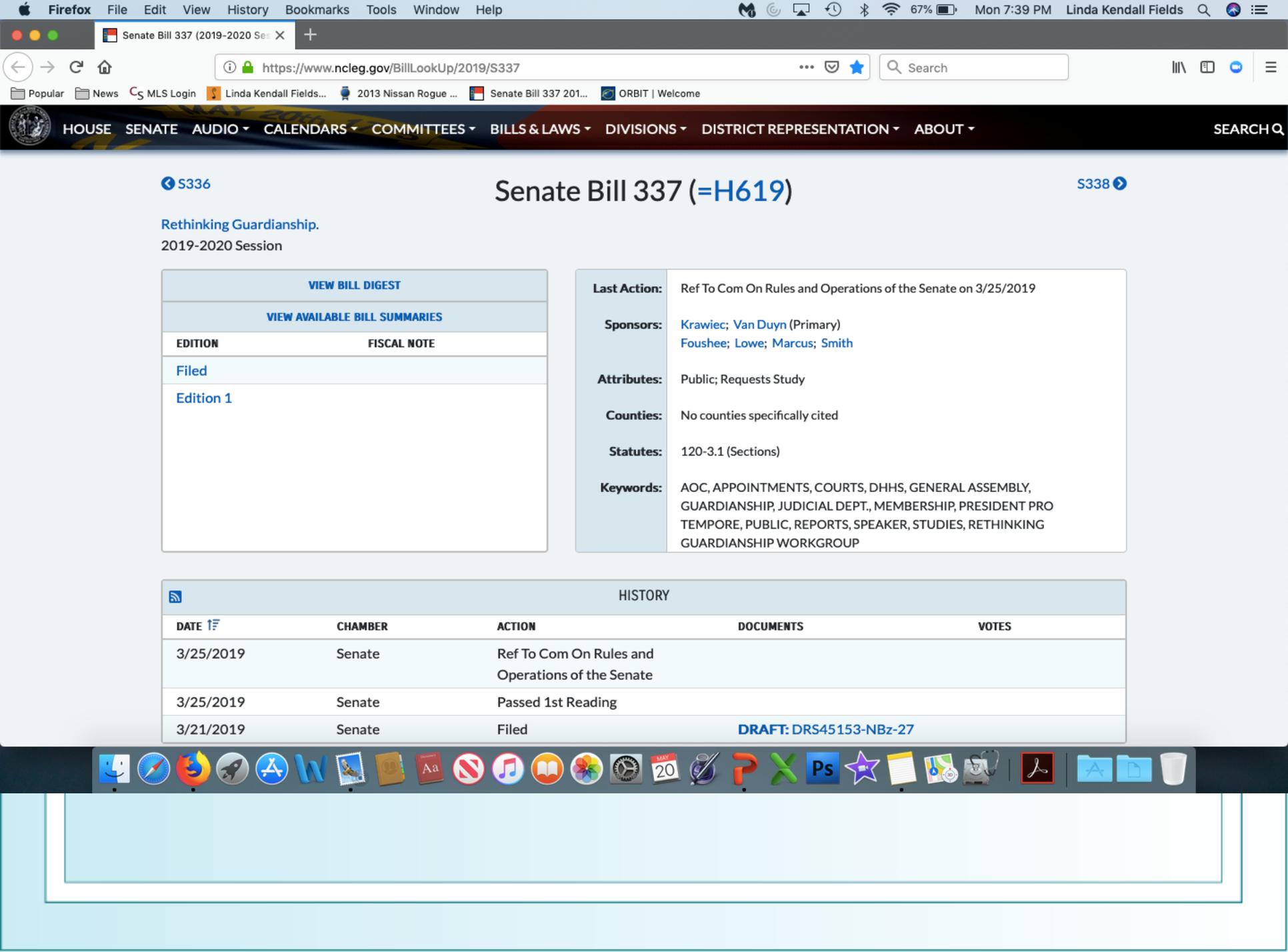
(From January 2018 report)

- Common Agenda and Workgroup Maintenance
- Statutory Reform
- Improved Data System
- Practice Implications
- Ongoing Education and Awareness



North Carolina GS 35A Reform Items

- requirement for **consideration of alternatives** to guardianship
- provide for **appointed counsel** in addition to GAL
- process for **regular review** (rather than presumption of permanence) with possibility of increased use of limited guardianship and restoration
- **change language** (e.g., ward/incompetence, etc.)
- **rights** for those under guardianship
- **simplify requirements of spouses** acting as guardians, at discretion of the clerks
- improve quality, consistency and availability of **MDEs**
- Increase **court monitoring and oversight**



S336

Senate Bill 337 (=H619)

S338

Rethinking Guardianship.
2019-2020 Session

[VIEW BILL DIGEST](#)

[VIEW AVAILABLE BILL SUMMARIES](#)

| EDITION | FISCAL NOTE |
|-----------|-------------|
| Filed | |
| Edition 1 | |

Last Action: Ref To Com On Rules and Operations of the Senate on 3/25/2019

Sponsors: Krawiec; Van Duyn (Primary)
Foushee; Lowe; Marcus; Smith

Attributes: Public; Requests Study

Counties: No counties specifically cited

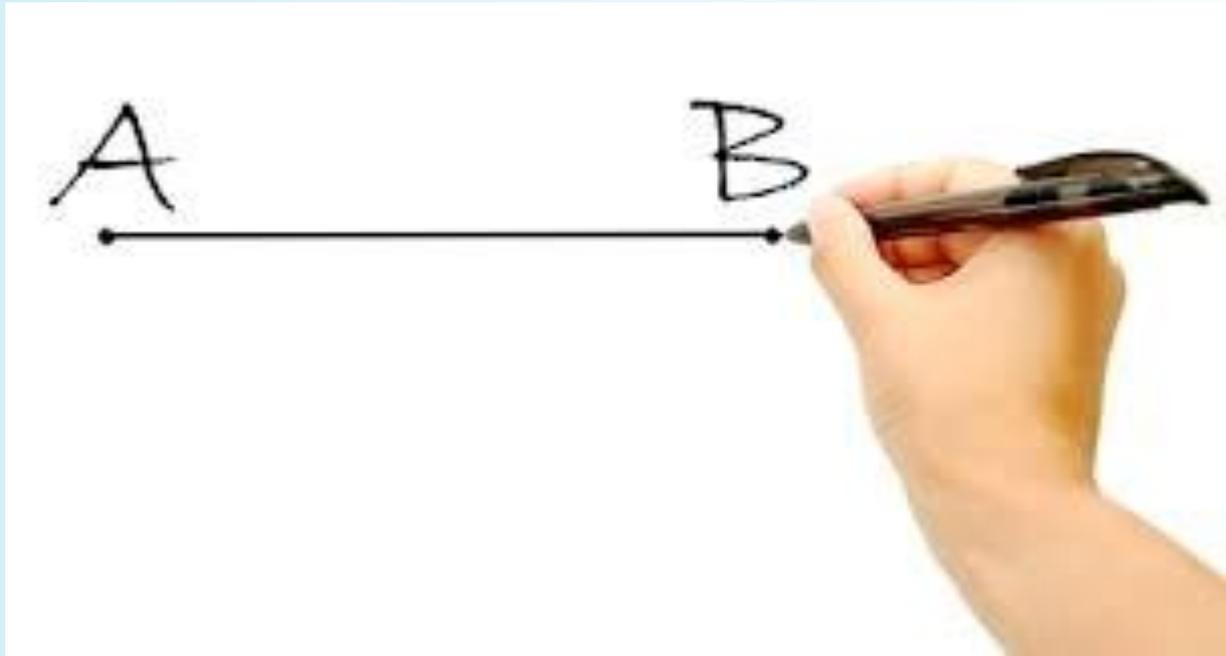
Statutes: 120-3.1 (Sections)

Keywords: AOC, APPOINTMENTS, COURTS, DHHS, GENERAL ASSEMBLY, GUARDIANSHIP, JUDICIAL DEPT., MEMBERSHIP, PRESIDENT PRO TEMPORE, PUBLIC, REPORTS, SPEAKER, STUDIES, RETHINKING GUARDIANSHIP WORKGROUP

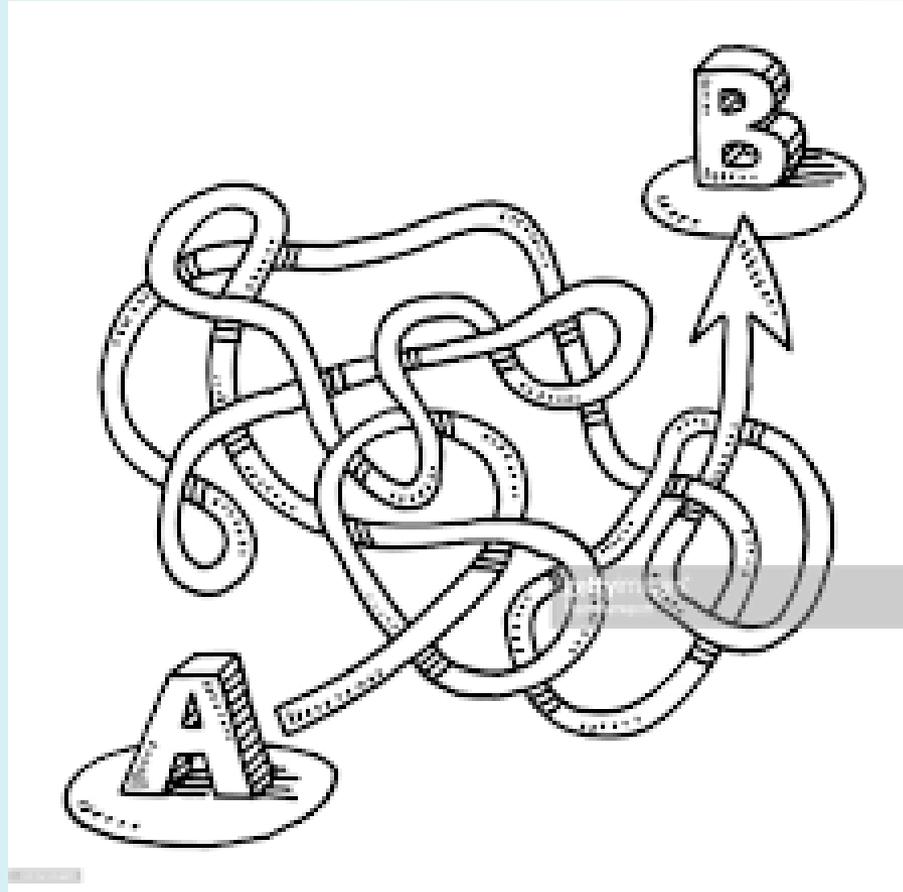
| HISTORY | | | | |
|-----------|---------|--|--|-------|
| DATE | CHAMBER | ACTION | DOCUMENTS | VOTES |
| 3/25/2019 | Senate | Ref To Com On Rules and Operations of the Senate | | |
| 3/25/2019 | Senate | Passed 1st Reading | | |
| 3/21/2019 | Senate | Filed | DRAFT: DRS45153-NBz-27 | |



How the change story is told: Plan the Work – Work the Plan



The real story of how change happens: Act- React- Adapt



To do list

- ✓ Finish GS 35A with present members of Rethinking Guardianship stakeholder group – pilots?
- ✓ Engage in a Rethinking Guardianship Bridge Grant for 6 months and develop “informed decision-making tool for transition coordinators”
- ✓ Prepare for “Making Alternatives to Guardianship a Reality in NC”
- ✓ Keep educating and building awareness!!

Making Alternatives to Guardianship a Reality in North Carolina

- Recommended by *Rethinking Guardianship* - NCCDD Funded for July 2020 – June 2023

“If you want fewer guardianships, stay out of the courtroom”

- Focused on Youth Transitioning to Adulthood and Adults Transitioning to the Community from Long Term Residential Facilities

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**All adults have rights,
including the right to
self-determination.**

Adults have the right to make decisions — good *and* bad.

The diagram consists of a central grey circle containing the text 'Right to lifetime decision-making support'. Surrounding this central circle are four smaller light blue circles, each containing a different type of decision-making support: 'Full autonomy' at the top, 'Informed decision-making' on the right, 'Supported decision-making' at the bottom, and 'Substituted decision-making (guardianship)' on the left. The entire diagram is enclosed in a light blue border.

**Right to lifetime
decision-making
support**

Full autonomy

**Informed
decision-making**

**Supported
decision-making**

**Substituted
decision-making
(guardianship)**

Guardianship - a legal relationship in which an individual is given the authority by the court to make decisions on behalf of another individual

While clearly the most restrictive of all decision-making approaches, it is still possible to include and honor any individual's choices about his or her life while under guardianship.

Substituted vs. Best Interest Decision-Making

Stoplight Tool to Assist in Exploring Alternatives

IDENTIFYING ALTERNATIVES TO GUARDIANSHIP

This tool was designed to assist with identifying a person's ability to make decisions and manage key areas of life. It is intended to assist with exploring alternatives and less restrictive options to plenary or full guardianship.

Name of Individual: _____

Name of person completing this form: _____

Relationship to individual (*circle one*): Self Family Friend Guardian Other: _____

How long have you known the individual? _____

Step 1: Decide for each question if the answer is yes or no. If yes, put a checkmark in the GREEN column – this means the person is good to go. If NO, put a mark in the yellow column.

Step 2: When you have completed all the questions, explore alternatives to guardianship to meet the supported decision making need for all questions marked in the yellow column.

Step 3: ONLY if NO alternative can be identified, then limited guardianship might be considered for those specific areas of need.



Can person decide or direct this activity independently most of the time?



Can person decide or direct this activity with assistance most of the time?



Does the person requires substituted decision making support?

DAILY LIFE & EMPLOYMENT

| | | | |
|--|--|--|--|
| Can the person make and communicate choices in regard to employment? | | | |
| Can the person look for and find a job (<i>go to employment agency, respond to ads, use contacts</i>)? | | | |
| Is the person able to manage their money (i.e. meet financial commitments, such as regular bills)? | | | |
| Is the person able to manage the monetary benefits he or she is supposed to receive? | | | |
| Is the person able to identify and resist financial exploitation? | | | |

HEALTHY LIVING

| | | | |
|---|--|--|--|
| Does the person make decisions about where, when, & what to eat? | | | |
| Can the person follow a prescribed diet and/or take medicines as directed? | | | |
| Does the person understand the need to maintain personal hygiene and dental care? | | | |
| Can the person make and communicate decisions regarding medical treatment, including understanding the consequences of not accepting treatment? | | | |
| Does the person understand health consequences associated with high risk behaviors (<i>substance abuse, overeating, high-risk sexual activities, etc.</i>)? | | | |
| Can the person alert others and seek medical help for serious health problems? | | | |
| Is the person able to decide and direct what kinds of support they need or want and select who provides those supports? | | | |

| | | |
|---|--|--|
|  Can person decide or direct this activity independently most of the time? |  Can person decide or direct this activity with assistance most of the time? |  Does the person requires substituted decision making support? |
|---|--|--|

Moguardianship.com

UMKC Institute for Human Development, UCEDD

Informed Decision-Making results in a decision that is based on knowledge of a subject or situation.

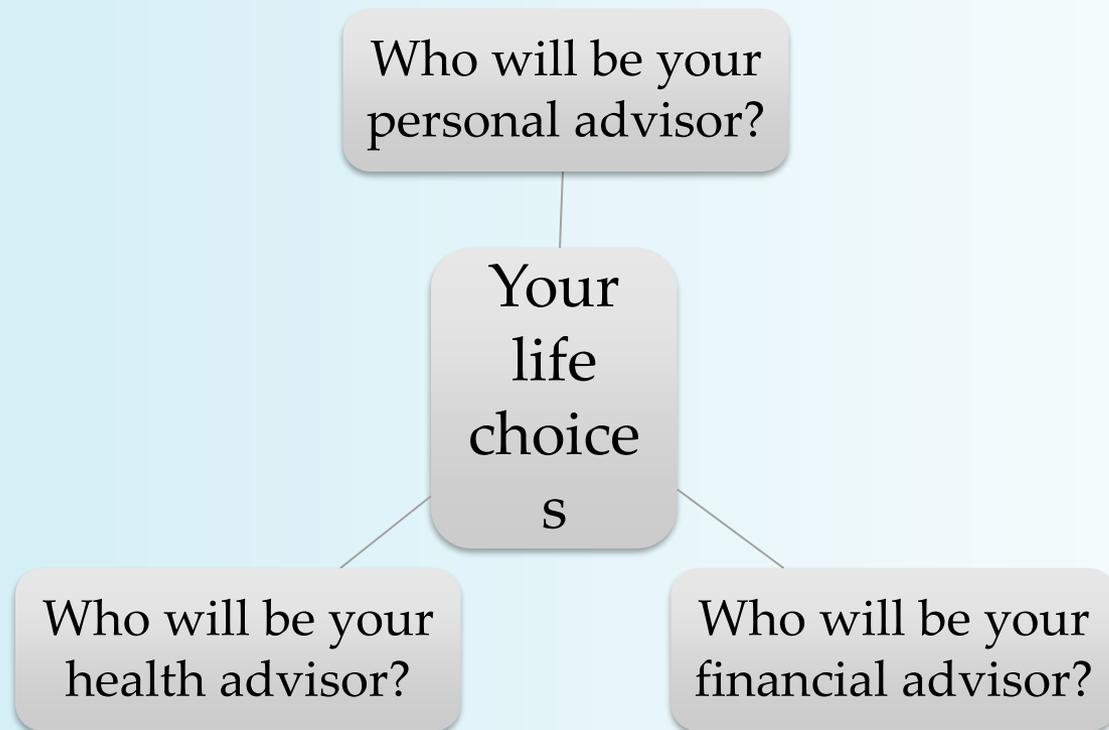
- If you were deciding where to live...
- If you wanted to learn something....
- If you want to get married....
- Visit different places, talk to other people who had experience; research online
- Seek out someone who had done it; practice it; research it; go to school
- Date; learn from past relationships

A Story...Janie and Suvya



“Living on one’s own for two years together, they have figured out who can help most effectively with what. They have also figured out (most of the time) when something is an emergency, and if it is, who to contact: a neighbor? Family who is further away? 911? Only through practice in real life experiences can individuals learn these nuances.” *Story told by Janie’s mother Betsy MacMichael, Executive Director, First in Families of NC.

Supported Decision-Making consists of building a support team - empowers the individual to make decisions with support



Supported Decision-Making...



Resources

North Carolina Rethinking Guardianship Website

rethinkingguardianshipnc.org/

National Council on Disability (NCD) - Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities -

<https://ncd.gov/publications/2018/beyond-guardianship-toward-alternatives>

National Council on Disability – Turning Rights Into Reality

<https://ncd.gov/publications/2019/turning-rights-into-reality>

National Resource Center for Supported Decision-Making

<http://supporteddecisionmaking.org/>

MO Guardianship: Understanding Your Options and Alternatives

<http://moguardianship.com/#materials>

The Jenny Hatch Justice Project

<http://jennyhatchjusticeproject.org/home>



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