

Making Alternatives to Guardianship a Reality in NC

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A Personal Introduction to This Work…







Today's Objectives…

- Build awareness of adult guardianship in NC and the NC Rethinking Guardianship initiative
- Share resources about guardianship and less restrictive alternatives
- Provide an update on significant activities in 2022
- Invite participation in evolving family and societal systems change around decision-making

Decision-Making Core Concepts & Basic Principles

A range of decision-making options exists for adults with disabilities of all ages - from full autonomy (and no one is fully autonomous) to supported decision-making strategies, and as a last resort, guardianship (substituted decision-making)



Autonomy

- Everyone likes autonomy, including older adults and people with disabilities
- For that reason, guardianship is, at its best, a necessary evil and an option that should be considered as a last resort
- No one is fully autonomous. Who helps you with important decisions?

Think about your own life…

What rights are most important to you?

Name three major decisions you have made in your life (Examples: Where you live, what you do, the relationships you have).

1. _____
2. _____
3. _____

How would you feel if you didn't have the right to make these choices and **someone made them for you and/or took them away**?

Self-Determination Makes a Difference

People with greater self determination are:

- More independent
- More likely to work
- More well-adjusted and healthier
- Safer and better able to recognize and resist abuse

- Khemka, Hickson, & Reynolds, 2005; O'Connor & Vallerand, 1994; Wehmeyer & Schwartz, 1998

But guardianship MAY be needed

- To support people:
  - Who do not have the interest or ability to make important decisions
  - Who need immediate protection from exploitation or abuse

- In emergencies when
  - The person is unable to give consent
  - The person did not previously create a plan for making decisions in an emergency
  - The person does not have someone else in their life who is able to provide consent through a Power of Attorney, Advanced Directive, or other means

Just be Careful!!

What is guardianship?

Guardianship is a legal relationship. The Court gives a person the authority to make decisions in place of another person.

- The VAST majority of guardianships give the guardian the power to make ALL decisions - Teaster, Wood, Lawrence, & Schmidt, 2007

- Guardianship is not case management, a guarantee of good health or safety, effective for preventing all bad decisions or risky behavior and a guarantee of never being victimized

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. In 2019, there were just over 6000 public guardianships provided by county departments of social services and contracted corporations. **Of those, 64% were for people aged 18-59 with intellectual and other developmental disabilities and/or mental health conditions.**

- 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.**



North Carolina

100 Counties – 100 Jurisdictions – 100 Clerks of Court

Types of Guardians

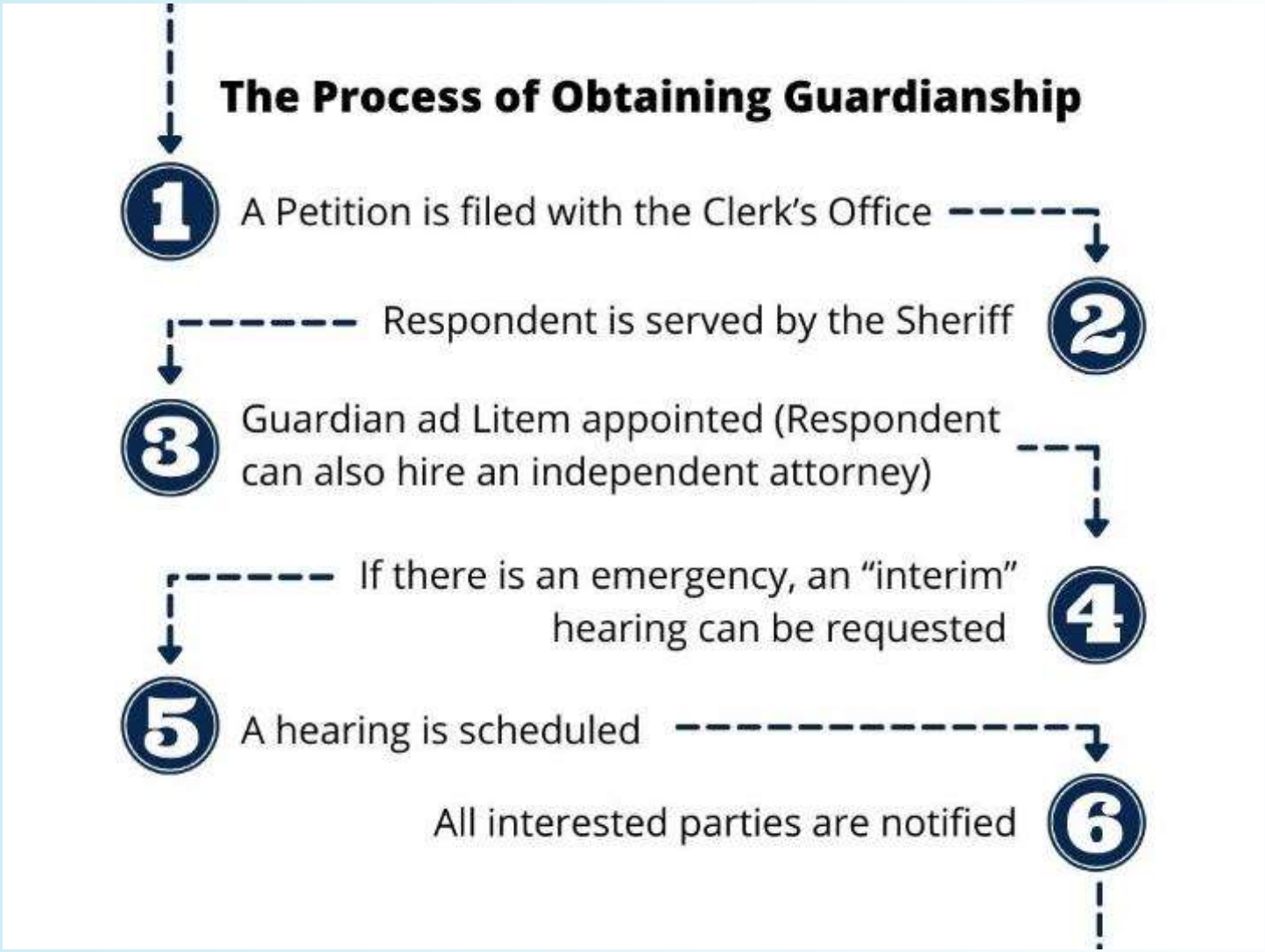
- **Guardian of the Person**
  - has authority to make decisions in most areas of a adult's personal life, exclusive of assets. This includes giving consent or approval for the adult subject to guardianship to receive any needed medical services (with some limitations such as sterilization, amputations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

- **Limited Guardianship**
  - Tailored to fit the individual in the areas in which assistance with decision-making is needed


The Process of Obtaining Guardianship
1
A Petition is filed with the Clerk's Office
2
Respondent is served by the Sheriff
3
Guardian ad Litem appointed (Respondent can also hire an independent attorney)
4
If there is an emergency, an "interim" hearing can be requested
5
A hearing is scheduled
6
All interested parties are notified

At the Hearing

- All parties are entitled to present evidence and question witnesses.
- The Clerk of Court will enter a decision regarding the respondent's need for guardianship.
- If found to be in need of a guardian by clear, cogent and convincing evidence, the Clerk will determine the type and extent of guardianship needed and will appoint a Guardian.



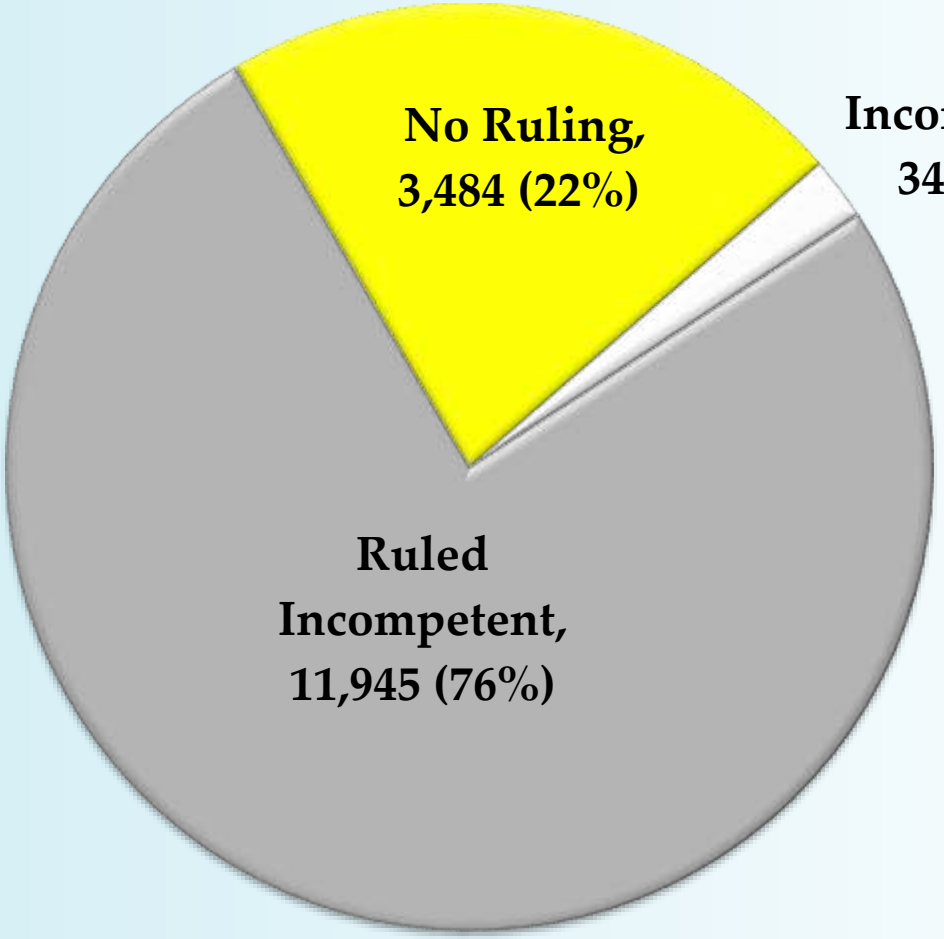
Who can be appointed as guardians?

N.C.G.S. § 35A-1214

"The Clerk shall consider appointing a guardian according to the following order of priority:

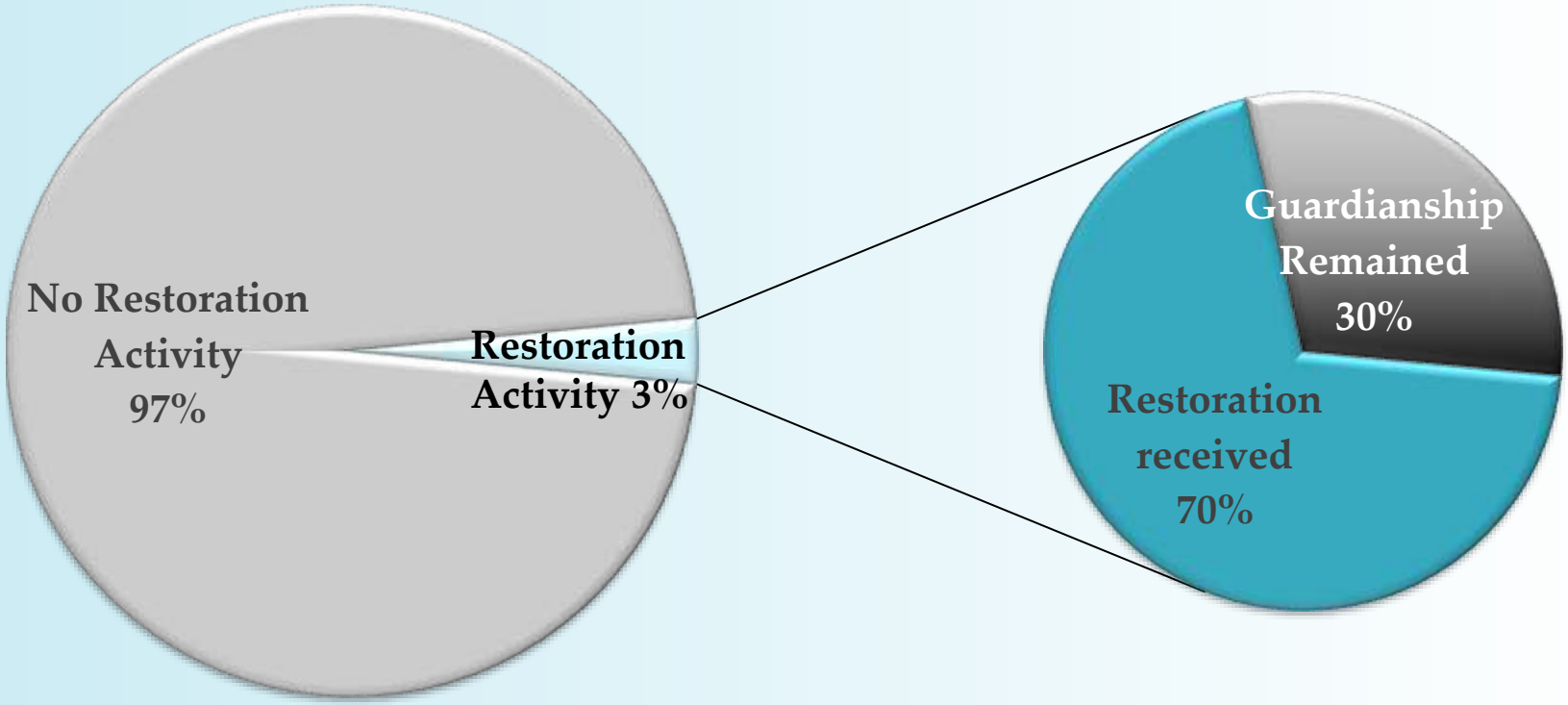
- An individual recommended in a written instrument (such as a Will, Power of Attorney, etc.);
- an individual;
- a corporation or a disinterested public agent.
- No public agent shall be appointed guardian until diligent efforts have been made to find an appropriate individual or corporation to serve as guardian
- In every instance the Clerk shall base the appointment of a guardian or guardians on the best interest of the [ward] *adult subject to guardianship*."

How Many People Declared Incompetent in NC? July 1, 2012 – December 31, 2015



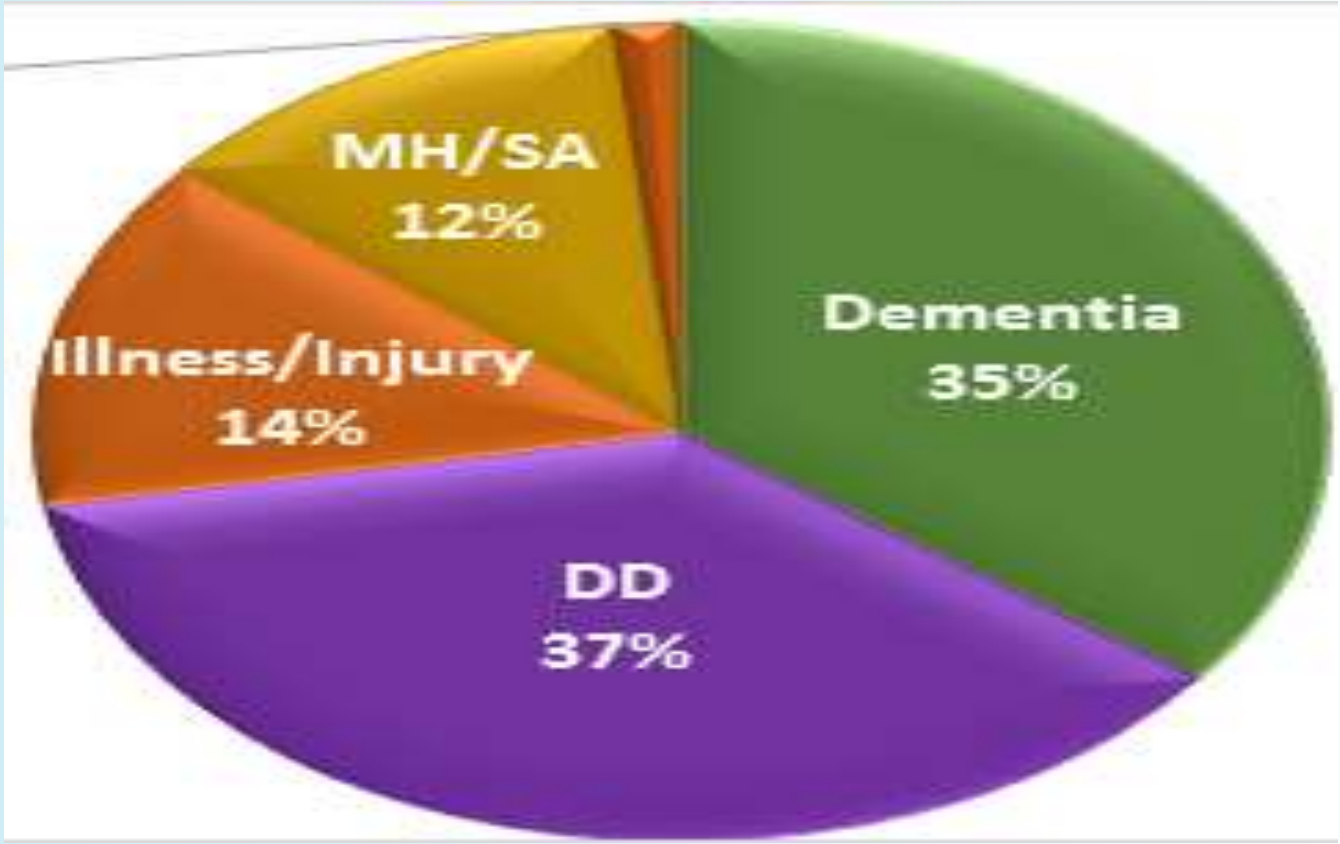
Based on 15,771 of the 15,798 cases--excluding 27 (0.17%) people whose records were missing any petition/ruling on incompetence

How Many People Sought & Received Restoration?



Catawba Data Analysis

January 1, 2015 – September 30, 2016



Rethinking Guardianship is …

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

RETHINKING GUARDIANSHIP


First In Families of North Carolina
nc4a
advocacy | action | answers on aging
NC DEPARTMENT OF HEALTH AND HUMAN SERVICES
Division of Mental Health, Developmental Disabilities and Substance Abuse Services
RETHINKING GUARDIANSHIP
AARP North Carolina
FSN of North Carolina
NC ABLE
National ABLE Alliance Member
Disability Rights North Carolina
NCSILC
Public Schools of North Carolina
State Board of Education
Department of Public Instruction
The Arc North Carolina
NCCDD
North Carolina Council on Developmental Disabilities
Cares
Facilitating systems change
WITH AND FOR ADULTS OF ALL AGES
DISABILITY PARTNERS
Your Pathway to Independent Living
UNC
SCHOOL OF GOVERNMENT
NAMI
National Alliance on Mental Illness
North Carolina
NORTH CAROLINA ADMINISTRATIVE OFFICE of the COURTS
North Carolina Families United
MFP
MONEY FOLLOWS THE PERSON
DEMONSTRATION PROJECT
NCGA
North Carolina Guardianship Association
NORTH CAROLINA STATE BAR
NC CONFERENCE OF CLERKS of Superior Court
NC DEPARTMENT OF HEALTH AND HUMAN SERVICES

Our History- Our Present – Our Future

- ***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

- ***Making Alternatives to Guardianship a Reality in NC***
  July 2020 – June 2023

Collective Impact framework:

- Backbone, Common Agenda, Shared Measurement, Continuous Communication, Mutually Reinforcing Activities
- Statewide workgroup with diverse affiliations and Steering Team
- National WINGS (Working Interdisciplinary Network of Guardianship Stakeholders)

It's About Ensuring Rights and Protecting Elders…











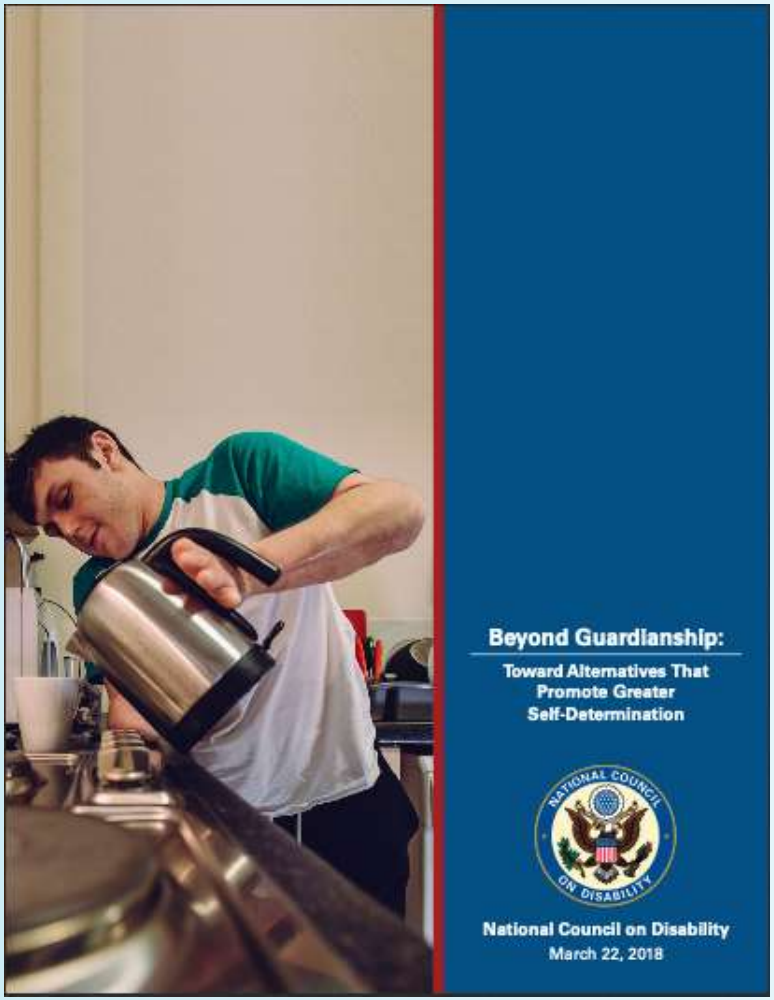
https://www.youtube.com/watch?v=ZcgkRkokEQ4

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





2018 Report
2019 Report


LIVE
BRITNEY SPEARS ADDRESSES CONSERVATORSHIP


Britney Spears
Fighting for Her Future


npr
WUNC
Britney Spears Says She Will Not Perform Under Her Father's Conservatorship
FREE
BRITNEY


Via Webex by Cisco
Minneapolis
8:44 AM CT
LinkedIn/Getty Images
FIGHTING FATHER'S CONSERVATORSHIP
BRITNEY SPEARS GOES TO COURT SEEKING HER FREEDOM
CNN
Sarah Wentz | Attorney, Fox Rothschild
SMERCONISH


FREE
BRITNEY
#FREE
BRITNEY
MOTHER.
ARTIST.
PRISONER.




BRITNEY SPEARS'S
CONSERVATORSHIP
NIGHTMARE


Britney Spears' conservatorship case prompts bipartisan 'Free Britney' bill

Sean's Story



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

- **Always use least restrictive options** and be based on **best practices**
- Offer easily **available and accessible information** about options and alternatives to guardianship that is communicated to and understood by stakeholders
- Rest on a process in which **all stakeholders are identified and engaged**
- Have built-in **accountability** for all stages of guardianship and less restrictive alternatives.

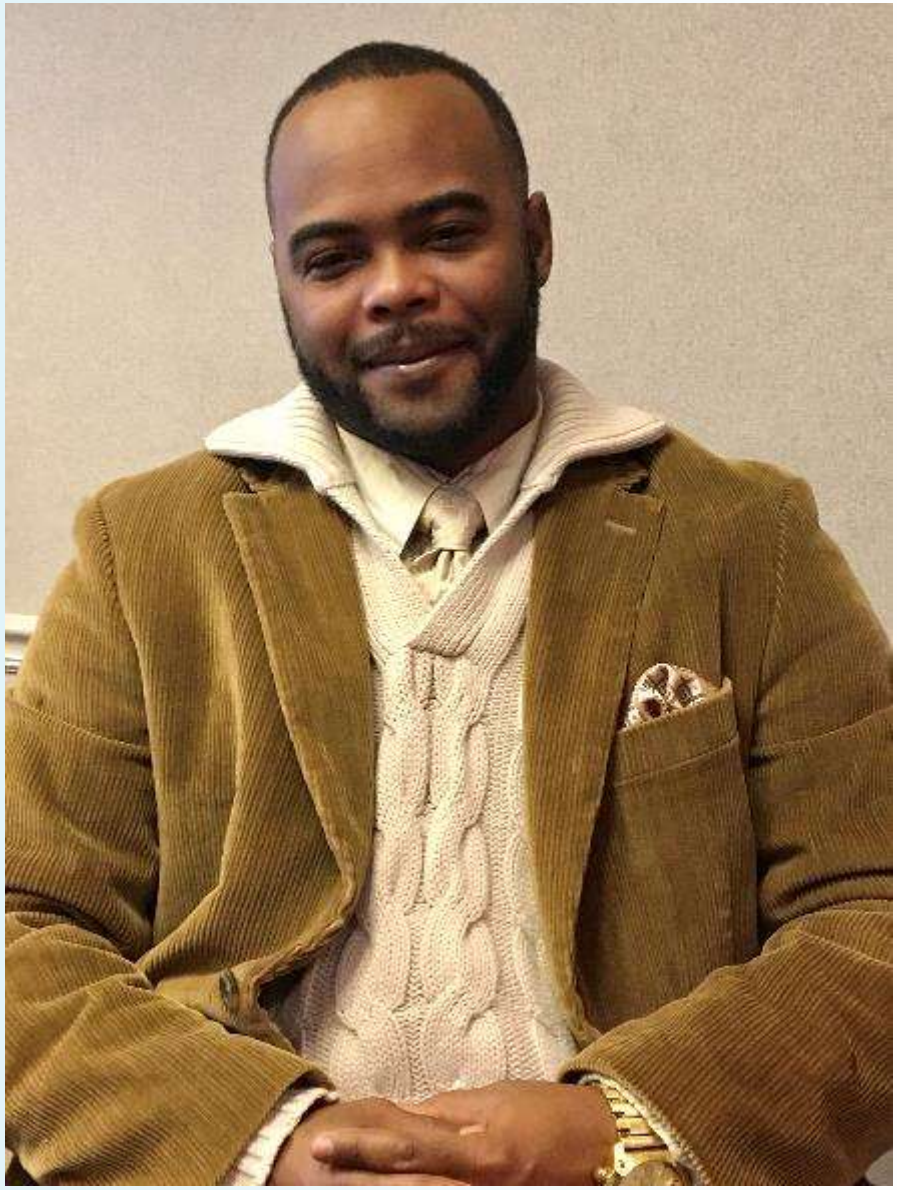


The Importance of a Balanced Approach

Autonomy - Support - Protection

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."



Making Alternatives to Guardianship a Reality in North Carolina

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

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

"If you want fewer guardianships, stay out of the courtroom"

NCCDD
North Carolina Council on Developmental Disabilities

2021- 22 Areas of Focus

1. Reforms to GS 35A in preparation for the 2023 long session

2. Addressing the school to guardianship "pipeline"

3. Participating in the Olmstead planning process and implementation

4. Creating accessible, on demand educational modules on Supported Decision-Making strategies

NC General Statute 35A Reform

- ✓ **change language** (e.g. adult subject to guardianship)
- ✓ requirement for **consideration of alternatives** to guardianship
- ✓ process for **regular review** (rather than presumption of permanence) with possibility of increased use of limited guardianship and restoration
- ✓ **rights** for those under guardianship
- ✓ provide for **appointed counsel** in addition to GAL

The Mighty 35A Statute Writing Team



Steps Towards Reform in **2023**

- Meetings with the NC Bar representatives to refine concepts/language
- Complete final strike-through draft of the proposed reform legislation
- Work with interested clerks on separate pilot initiative to provide Right to Counsel.
- Meet with the Conference of Clerks and AOC; as well as other stakeholders (DAAS, DSS Directors, etc)
- Find advocacy organization [lobbists] to champion the bill
- Identify legislative sponsors

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*

A North Carolina Example

NC Local Education Agency (school district) Message to NC Department of Public Instruction, Exceptional Children's Division to review transfer of rights brochure…

As it arrived:

"The guardianship/conservatorship process should begin… If families and students feel uncomfortable with the transfer of the decision-making abilities of the student, the prospective guardian needs to petition for guardianship at the local probate court."

Suggested Change… Interrupting the "Pipeline to Guardianship"

"If families and students feel uncomfortable with the transfer of decision-making authority to the student, there are many strategies and opportunities to support the student's transition into adulthood."

"Parents and students can learn about free or low cost options by visiting https://rethinkingguardianshipnc.org/ and the National Resource Center for Supported Decision-Making at http://supporteddecisionmaking.org

As a last resort, parents may petition for limited or full guardianship at the local probate court."

Educating groups including Exceptional Children's Teachers

From a parent (email received in 2021):

"I was able to watch a recording of the Rethinking Guardianship talk you recently gave.

***Thank you so much for making this available. I have an 18-year-old daughter with IDD. We fit in the pipeline you mentioned. An EC high school counselor recommended guardianship** and after much deliberation and research we proceeded with the process.*

*We live in Watauga county and have been given limited guardianship. This just happened back in June. **Looking back, we might have been able to meet her needs with alternatives**. I look forward to one day dissolving the guardianship but at present it does meet her needs. Thank you again for this information and all the work you do on our behalf!"*

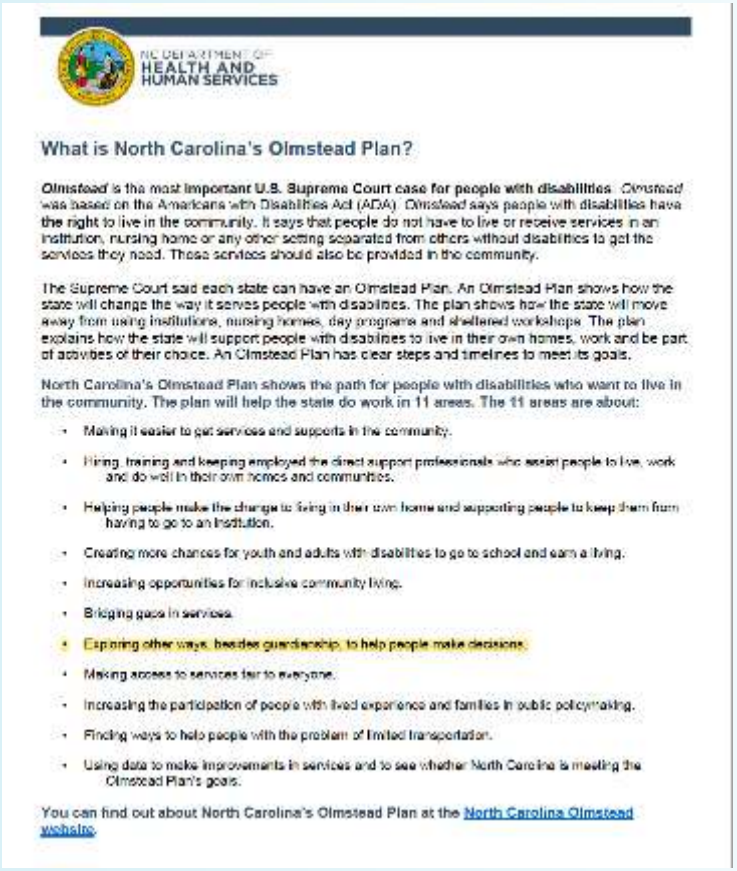
Olmstead and Choice

What is *Olmstead*?

The US Supreme Court held that public entities (state and local government) have an affirmative obligation under the **Americans with Disabilities Act (ADA)** to ensure that individuals with disabilities live in the least restrictive, most integrated settings as possible, provided the setting is appropriate for the individual.







NC DEPARTMENT OF HEALTH AND HUMAN SERVICES

What is North Carolina's Olmstead Plan?

Olmstead **is the most important U.S. Supreme Court case for people with disabilities.** *Olmstead* was based on the Americans with Disabilities Act (ADA). *Olmstead* says people with disabilities have the right to live in the community. It says that people do not have to live or receive services in an institution, nursing home or any other setting separated from others without disabilities to get the services they need. Those services should also be provided in the community.

The Supreme Court said each state can have an Olmstead Plan. An Olmstead Plan shows how the state will change the way it serves people with disabilities. The plan shows how the state will move away from using institutions, nursing homes, day programs and sheltered workshops. The plan explains how the state will support people with disabilities to live in their own homes, work and be part of activities of their choice. An Olmstead Plan has clear steps and timelines to meet its goals.

North Carolina's Olmstead Plan shows the path for people with disabilities who want to live in the community. The plan will help the state do work in 11 areas. The 11 areas are about:

- Making it easier to get services and supports in the community.
- Hiring, training and keeping employed the direct support professionals who assist people to live, work and do well in their own homes and communities.
- Helping people make the change to living in their own home and supporting people to keep them from having to go to an institution.
- Creating more chances for youth and adults with disabilities to go to school and earn a living.
- Increasing opportunities for inclusive community living.
- Bridging gaps in services.
- Exploring other ways, besides guardianship, to help people make decisions.
- Making access to services fair to everyone.
- Increasing the participation of people with lived experience and families in public policymaking.
- Finding ways to help people with the problem of limited transportation.
- Using data to make improvements in services and to see whether North Carolina is meeting the Olmstead Plan's goals.

You can find out about North Carolina's Olmstead Plan at the North Carolina Olmstead website.

NC's Olmstead Plan – Published January 2022

Priority #7: Exploring other ways, besides guardianship, to help people make decisions.

Olmstead in Action: Informed Decision-Making Tool

Peer/In-Reach Form A

North Carolina Transitions to Community Living Initiative
Informed Decision-Making Tool

This form is designed as a tool for the In-Reach Peer-Specialist to guide conversations and document an informed decision-making process with TCLI eligible individuals who have chosen to remain in an adult care home (ACH) or transition to an ACH or state psychiatric hospital (SPH) instead of the community.

Recognizing decision-making as an ongoing process, the approach outlined in this form is designed to take place over time with the individual and their guardian (when applicable). The ultimate goal is to raise the value of self-empowerment and each individual's right to choose where they want to live while pursuing pathways to recovery and community integration.

Whether or not their choice remains the same, it is critical that individuals have been fully informed of the available alternatives to living in a licensed facility and that any barriers have been identified and addressed.

Before using this form, it's important for In-Reach Specialists/Staff to acknowledge and explore the individual's current preferences and choices. This may be done in consultation with the individual's guardian and/or natural supports. For example, if an individual has chosen to remain in an ACH or SPH you may consider saying:

> *You are the expert in yourself. May I ask you more about where you are currently staying (or where you would like to live)?*
>
> *I remember a time plans were being made for me to move from (name setting) to (name setting)….* As an In-Reach Specialist, you can share your experience as a peer considering a transition to an integrated setting.
>
> *My role is to just make sure that when a person says they want to live (name setting), that choice is an informed choice.*
>
> *May I ask you what you like about where you are staying now?*

If the individual says they don't want to be asked, you may reply:

> *There is no pressure for you to change your mind or make a decision today. I value your right to choose. That is one of the main reasons for visiting with you. There's no wrong or right answer here but, what have you been told about informed choice?*
>
> *So your choice is to (restate their decision)? I've had the opportunity to meet a lot of individuals who have made a similar decision. (Offer an example of a person you worked with who benefited from having more information.)*

If the individual's guardian does not want the person to participate, you may reply:

> *I understand your role as this individual's guardian and that you have the responsibility to make decisions with and for this individual. So you are probably already familiar with your obligation under NC General Statute 35A-1201(5), which states:*
>
> > *"Guardianship should seek to preserve for the incompetent person the opportunity to exercise those rights that are within his comprehension and*

Individual Form B

North Carolina Transitions to Community Living Initiative
Informed Decision-Making Tool

Name & Contact Information:

The purpose of this form is to support you in making an informed decision about where you want to live with the help of conversations, experiences and reflections.

You can complete this form with the support of the In-Reach Specialist, your guardian, and any other person you wish to include. It will remain with you after each conversation or be mailed to you shortly after the visit.

I. Exercising Your Right to Choose

1. What does it mean to you that you have a right to choose where you live?
2. Do you want to choose where you live? Why or why not?
3. How have you made important choices in the past?
   (examples: ask family and friends, read about choices, try something on a trial basis)
4. How far along are you with making a choice about where you live?
   ☐ Not thought about it ☐ Thinking about it ☐ Close to choosing
   ☐ Made a choice What is the choice?
   Date:
5. If you have made a decision, how did you go about making that decision?
6. How can you gain more confidence about this choice?

Support for Your Decision:

Who else is involved?
What option do they prefer?
Is the person pressuring you?
How can they support you?
In what ways can the In-Reach Specialist help you?
What role do you prefer in making the choice?
Share the decision with …
Decide myself after hearing views of…
Someone else decides…

From NC – TCLI Informed Decision-Making Form
for Community Transitions from Licensed Facilities
(RG Bridge Grant 2019-20)

If the individual's guardian does not want the person to participate, you may reply:

- *I understand your role as this individual's guardian and that you have the responsibility to make decisions with and for this individual.* ***So you are probably already familiar with your obligation under NC General Statute 35A-1201(5), which states:***

  "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."

Also, given your role as the guardian, you play a critical role in implementing Title II of the Americans with Disabilities Act (ADA) and the U.S. Supreme Court's Olmstead Decision, an integration mandate which:

- *Prohibits discrimination by public entities in services, programs, and activities on the basis of disability;*
- *Requires that services, programs, and activities be administered in the most integrated setting appropriate; and,*
- *Enables people with disabilities to interact with people without disabilities to the fullest extent possible*

You may follow up these replies by asking the guardian:

- *What integrated living options have you explored with (name the individual)?*
- *What would it take for (name of the individual) to live in the community?*

Supported Decision-Making

"a recognized alternative to guardianship through which people with disabilities use friends, family members, and professionals to help them understand the situations and choices they face, so they may make their own decisions without the 'need' for a guardian."

- Blanck & Martinis, 2015

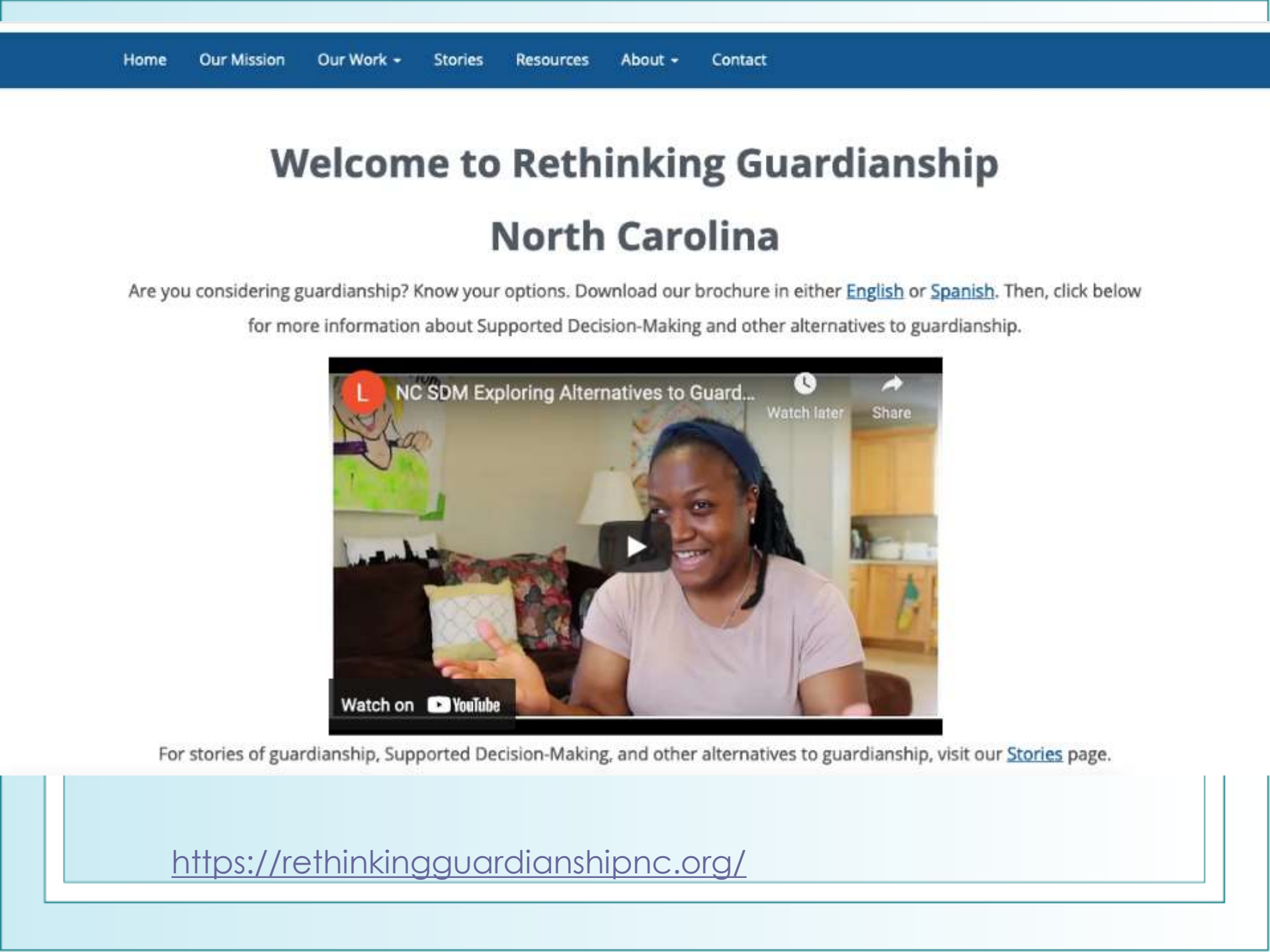






"Living on their own for two years together, Suvya & Janie have figured out who can help most effectively with what. It is incumbent on people supporting these women to push them to make their own decisions when it is clearly in their power. This does not mean they will always get it right, but without stretching the muscles, there is no growth. This has clearly led to less asking, more acting, and greater self-determination."

**Shared by Janie's mother Betsy MacMichael, Executive Director, First in Families of NC*



https://rethinkingguardianshipnc.org/

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 in which 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

Find out more

Place your organization's contact information here.

The **Rethinking Guardianship Initiative** provides information and resources about guardianship and alternatives in NC http://rethinkingguardianshipnc.org/

NCCDD North Carolina Council on Developmental Disabilities

NC Department of Health and Human Services

UNC School of Social Work Jordan Institute for Families

This document was developed as a partnership between the North Carolina Council on Developmental Disabilities, the North Carolina Division of Aging and Adult Services, and the Jordan Institute for Families in the School of Social Work at the University of North Carolina at Chapel Hill.

RETHINKING GUARDIANSHIP

An Introduction to Options



Adult guardianship exists to protect our most vulnerable citizens — but **not all** need guardianship

Which is YOUR situation?

- ❑ A professional has encouraged you to seek guardianship of a family member or friend
- ❑ You have a child who has 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 who has a mental health condition and is having difficulty making decisions
- ❑ You have a family member or friend who has 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 a traumatic brain injury and needs help making decisions

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.



Twelve User-Friendly Instructional Sheets on Using Less Restrictive Options

RETHINKING GUARDIANSHIP

Decision-Making Options to Support Choice and Self-Determination








Resources Available at RG Website

- ✓ Self-advocacy tools
- ✓ Stories and videos
- ✓ Frequently Asked Questions
- ✓ Educational materials on SDM and other options
- ✓ Research and data
- ✓ Court procedures information
- ✓ Articles

Jeremy's Story



Rethinking Guardianship: Bill Donohue & Deborah Woolard

https://www.youtube.com/watch?v=itHOGVgouT0

More information?

Visit the Rethinking Guardianship website
https://rethinkingguardianshipnc.org/

Join the Rethinking Guardianship Workgroup!
Email me at lkfields@email.unc.edu

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
https://moguardianship.com/#materials

The Jenny Hatch Justice Project
http://jennyhatchjusticeproject.org/home



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