Who's In Charge of My Life?  
- Understanding Guardianship -

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Who we are...

Rethinking Guardianship is...

1) Creating long-term changes in the state’s guardianship system

2) Promoting less restrictive alternatives to guardianship
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.
Data and Stories Drive Change

Around 5,000 individuals enter the system each year. Of the nearly 16,000 individuals who had some involvement with the North Carolina court system for guardianship issues in the three state fiscal years 2012–15, just over 2 percent had their rights restored.
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.
Guardianship is About Making Decisions

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

- Jenny Hatch

Who doesn’t need a little help?
When?

Under NC Law guardianship may be ordered in limited circumstances where a guardian will afford the individual **fuller** capacity for exercising his or her rights.

- Individual is allowed the possibility of error to the same degree as is allowed to competent persons, and is permitted to participate as fully as possible in all decisions.
- Guardianship is as limited and as individualized as possible, and seeks to preserve the opportunity for the person to retain all those rights that are within his or her comprehension and judgment.
North Carolina Guardianship Law

• Current Law:

  • Provides a route to restoration or modification

  • requires consideration of the functional capacity of potential wards, and consideration of the appropriateness of limited guardianship. (since 2003)
What is NOT in the law:

• A preference for absolute safety over reasonable risk

• A preference for institutional placements over independent, community-integrated living

• Authority for guardians to require rigorous behavioral standards or substitute judgment without consulting the person under guardianship
However, the law is not always applied as written

• Limited Guardianships are under-utilized. Their use varies among Clerks and Guardians *ad Litem*.
• Multidisciplinary Evaluations can be difficult to get.
• Removal of a public guardian is difficult. There may be no alternative individual; there is no recourse for benign or even more significant neglect.
• Most older guardianships are full and have never been reconsidered.
• No requirement for training on the needs and treatment options for persons under guardianship.
North Carolina Guardianship Law

• Current Law Does NOT:
  – Provide adequate oversight of Guardians of the Person.
  – Require any training or cultural competence of Guardians.
  – Does Not Require the Clerk or the Guardian to EVER re-evaluate the individual’s capacity.
  – Does not provide reliable source of payment for Multidisciplinary Evaluations.
Recommendations

• Bottom line: Avoid overbroad and undue guardianships. We need both less dependence on guardianship for decision-making support and less restrictive guardianships.

• We need to make sure the law is applied fairly and ensure we are keeping up with the needs of the population.
Recommendations cont’d

• Right to appointed counsel
• Eliminate the presumption of permanency
• Oversight of all Guardians of the Person
• Guardian ad Litem and Guardian Training that specifically addresses the needs of adults with dementia, IDD, TBI, and/or mental health needs
Recommendations cont’d

• Public/contract guardians need training in cultural competency, accessible communication, behavioral health

• Public/contract guardians need improved policy: guidelines for responsiveness, minimal contact, person-centered plan, revisiting capacity periodically.
ALTERNATIVES TO GUARDIANSHIP
Alternatives to Guardianship

Assistance with finances:
• Social Security Representative Payee
• Special Bank Account
• Special Needs Trust and/or ABLE Account

Assistance with care/independent living:
• Home Health Care
• Supportive Housing
• Health Care Power of Attorney
• Advance Instruction for Mental Health Treatment
• Living Will

Assistance with life decisions:
• Power of Attorney
• Supported Decision Making Agreement
Supported Decision-Making and Self-Determination

“Supported Decision-Making has the potential to increase the self-determination of older adults and people with disabilities, encouraging and empowering them to reap the benefits from increased life control, independence, employment, and community integration”
(Blanck & Martininis, 2015)
**Supported Decision Making Agreement**

- Agreement between a person with a disability and a network of supporters.

- The Agreement:
  - Is based on the interests and needs of the person with a disability.
  - Gives written guidance to network participants.
  - Is designed to help the individual make a decision, not to make it for them.
  - Can cover financial, health, and/or daily living needs.
  - Voluntary and revocable.
Representative Payee

• Social Security Agency (SSA) selects a person or organization to receive and manage benefits on behalf of a beneficiary who is legally incompetent or whom SSA determines is not capable of managing benefits.

• Main responsibilities of the rep payee are to (i) use the benefits to pay for current and foreseeable needs of the beneficiary; (ii) save any benefits not needed to meet current needs; (iii) keep records of expenses; and (iv) provide SSA with an accounting.

• Must be approved by SSA to be rep payee.
Special Bank Account

• A variety of arrangements can be made.

• Personal banker can discuss options.
Special Needs Trust

- A trust designed to hold funds for the benefit of a person with a disability.
- Typically useful when a person with a disability receives a large, lump sum of money that will impact his or her eligibility for Medicaid or other lifeline benefits.
- ABLE Accounts
  [https://www.nctreasurer.com/able/Pages/default.aspx](https://www.nctreasurer.com/able/Pages/default.aspx)
Home Health Care

- Home health agencies can assist with activities of daily living such as bathing, dressing, cooking, and cleaning and can support someone in the community if the person can make decisions about their care.
Supportive Housing

• Permanent housing with services. The type of services depends on the needs of the residents. The housing is usually “affordable” (intended to serve persons on an SSI income).

• Supportive Services: services such as case management, medical or psychological counseling and supervision, child care, transportation and job training provided for the purpose of facilitating the independence of residents. (definitions from NC Housing Coalition glossary of terms)
Health Care Power of Attorney

- Allows the person designated as POA to make health care decisions in the event of incapacity.
- The appointment of a guardian terminates a health care power of attorney for the ward.
- You may nominate someone in POA document to be your guardian in the event you are later adjudicated incompetent.
Advance Instruction for MH Treatment

• Also known as a “Psychiatric Advanced Directive”
• Allows a person to give instructions and preferences regarding mental health treatment, and to appoint an agent to make these decisions if they become incompetent.
Living Will/Advance Directive

• Declaration that person desires to die a natural death under certain circumstances. A living will gives medical professionals permission to withhold or withdraw life support systems under certain conditions.
Power of Attorney

• Person grants authority to the attorney-in-fact to handle some or all affairs. The POA may grant authority regarding one transaction or the authority to handle most of the person’s personal and financial matters.

• The POA:
  – Can be effective immediately, or
  – Can be springing (i.e., at a point in the future, if a person becomes unable to handle their affairs, either temporarily or permanently) and
  – Survives appointment of guardian, but guardian can revoke.
Questions
Supported Decision-Making Resources

National Resource Center for Supported Decision Making
http://supporteddecisionmaking.org/

Rethinking Guardianship
http://ssw.unc.edu/rethinking/home

First in Families of North Carolina
http://www.fifnc.org/
LET'S TRY IT
Thank you!

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Thank you!