

Partnering with Guardians:

Using Person-Centered
Principles to Support Autonomy
and Decision-Making with
People Who Have Guardians

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North Carolina Person-Centered
Planning Initiative

November 7, 2024



Housekeeping



We will **mute audio for ALL** to reduce interference. You can unmute as needed.



For technical issues with audio, video, Zoom, please direct questions in chat to Ingrid Padgett.



Access your chat box for exercises and to post questions! We want to hear from you.

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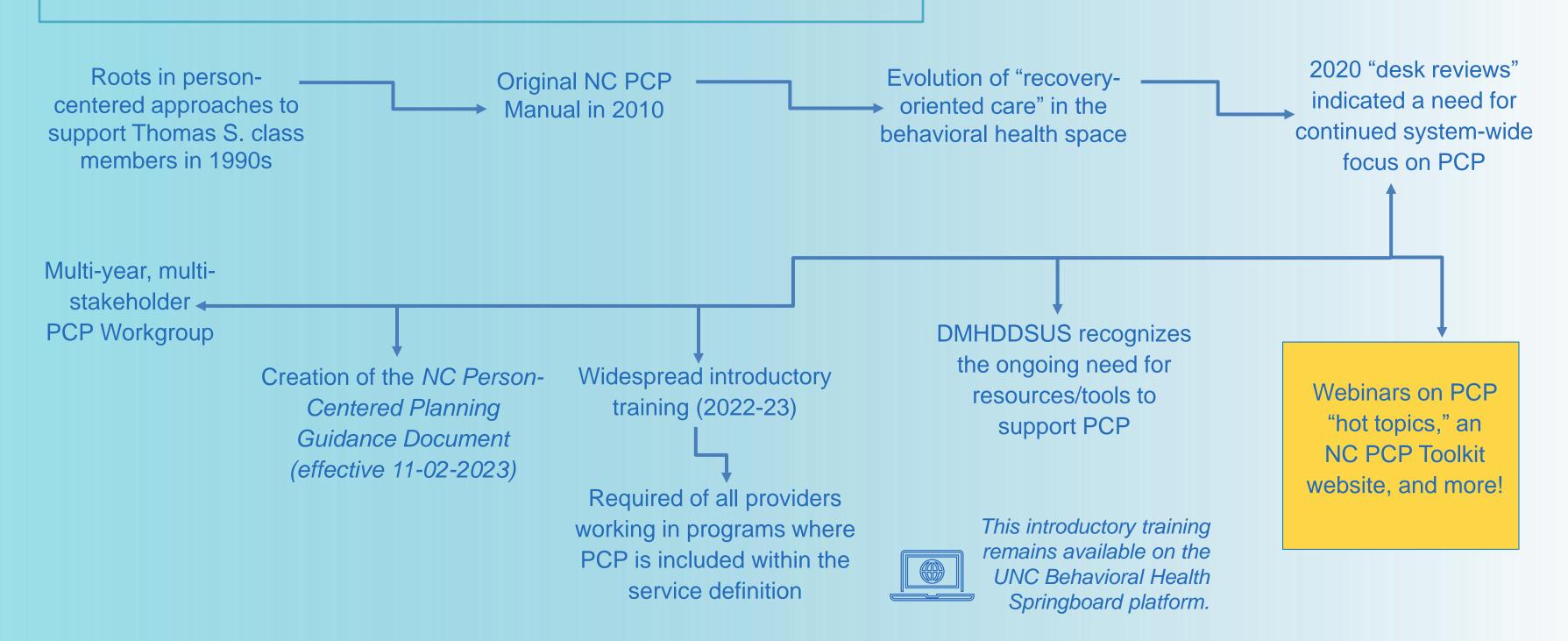
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ONE month after today's event.

History of PCP in NC Timeline





Leigh Ann Kingsbury, MPA, Gerontologist (she/her), is the principal consultant of InLeadS Consulting. For more than 30 years she has used best practices in personcentered approaches to support people who live with disabilities, including psychiatric diagnoses, intellectual/developmental disabilities, and people living with dementias. She has published widely on the topic of person-centered practices and has consulted across the US, Canada and the UK on using person-centered practices to facilitate healthcare decisions and advance care planning. She is the author of People Planning Ahead: A Guide to Communicating Healthcare and End of Life Wishes.



Fun Fact: Leigh Ann loves to spend time outdoors with plants and flowers and she has a 30-year passion for rescuing Persian cats.

What are the challenges you experience when working with guardians? (click all that apply)

- a. Lack of involvement
- b. The guardian is a safety-net and they advocate for the person; they involve the person in decision making.
- c. Too much involvement that limits the person's autonomy
- d. Guardian is unsure of their responsibilities
- e. I am unsure of the guardian's responsibilities



...the idea that people with disabilities have rights and can make decisions for themselves is still relatively new.

The Historical Context of Guardianship

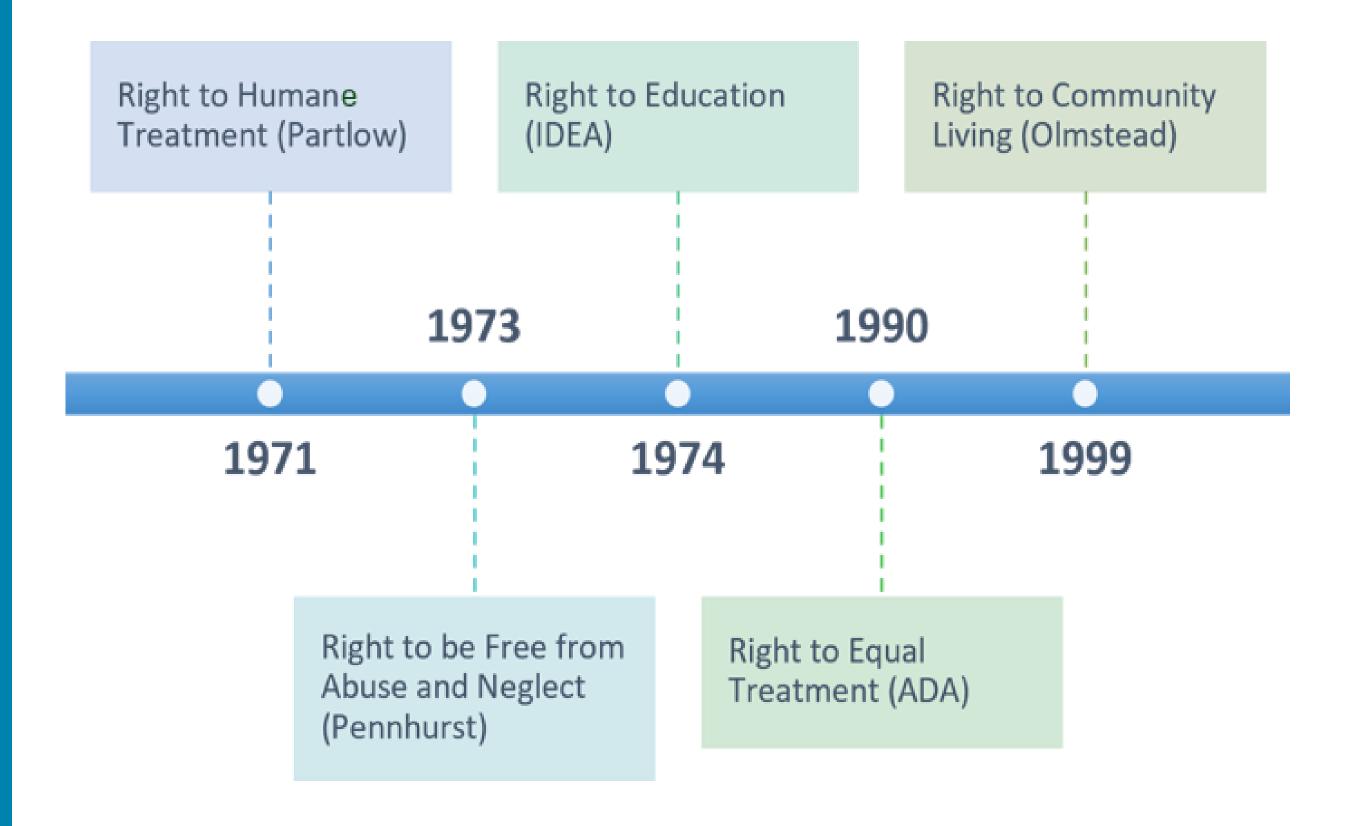
Dates back to Ancient Rome

Roots in English Common Law





Timeline of Rights in the U.S.



POII #2

True/False:
All guardianship is local, so laws vary from state to state

Capacity and Competency

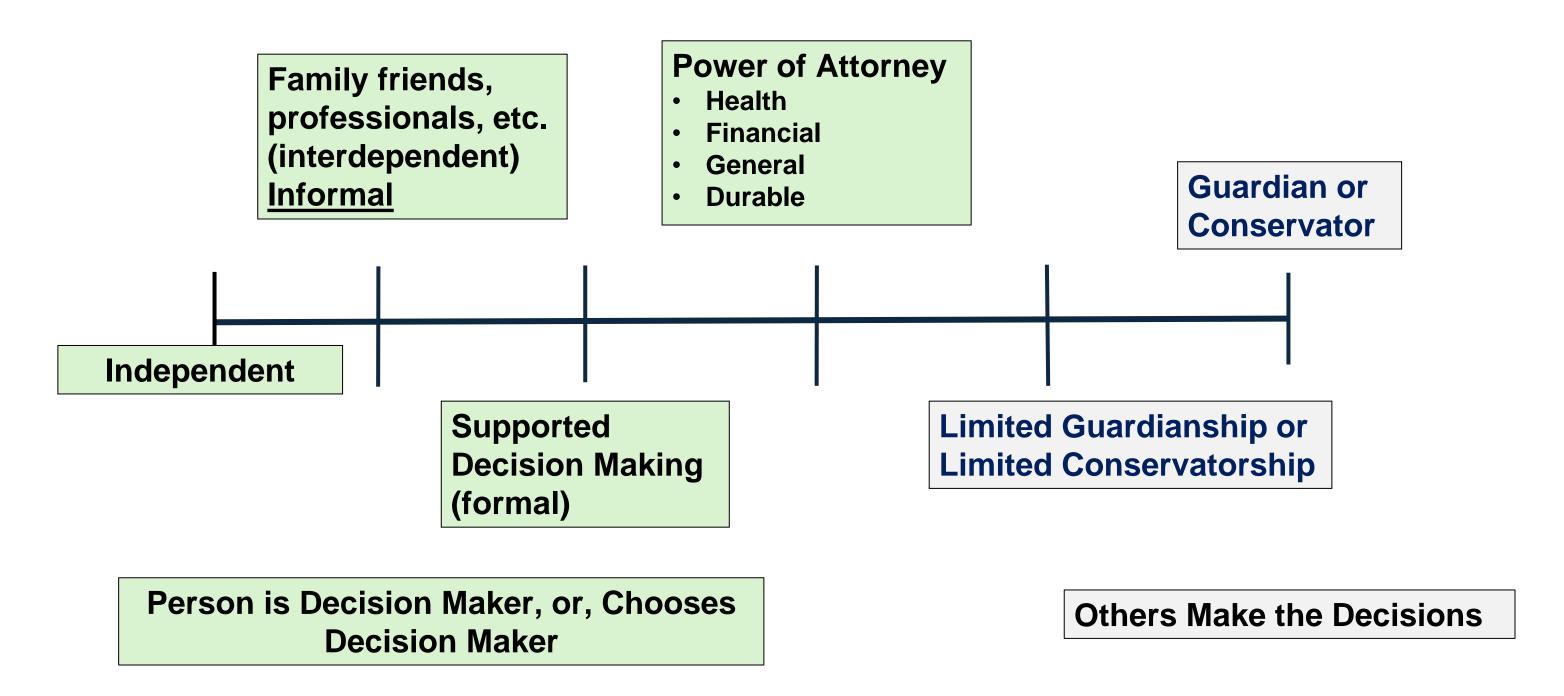
Capacity

- The ability of one to make a decision...
 - About a specific issue...and,
 - At a moment in time
- One can have capacity for some decisions and not others
- Everyone has capacity until determined otherwise

Competency

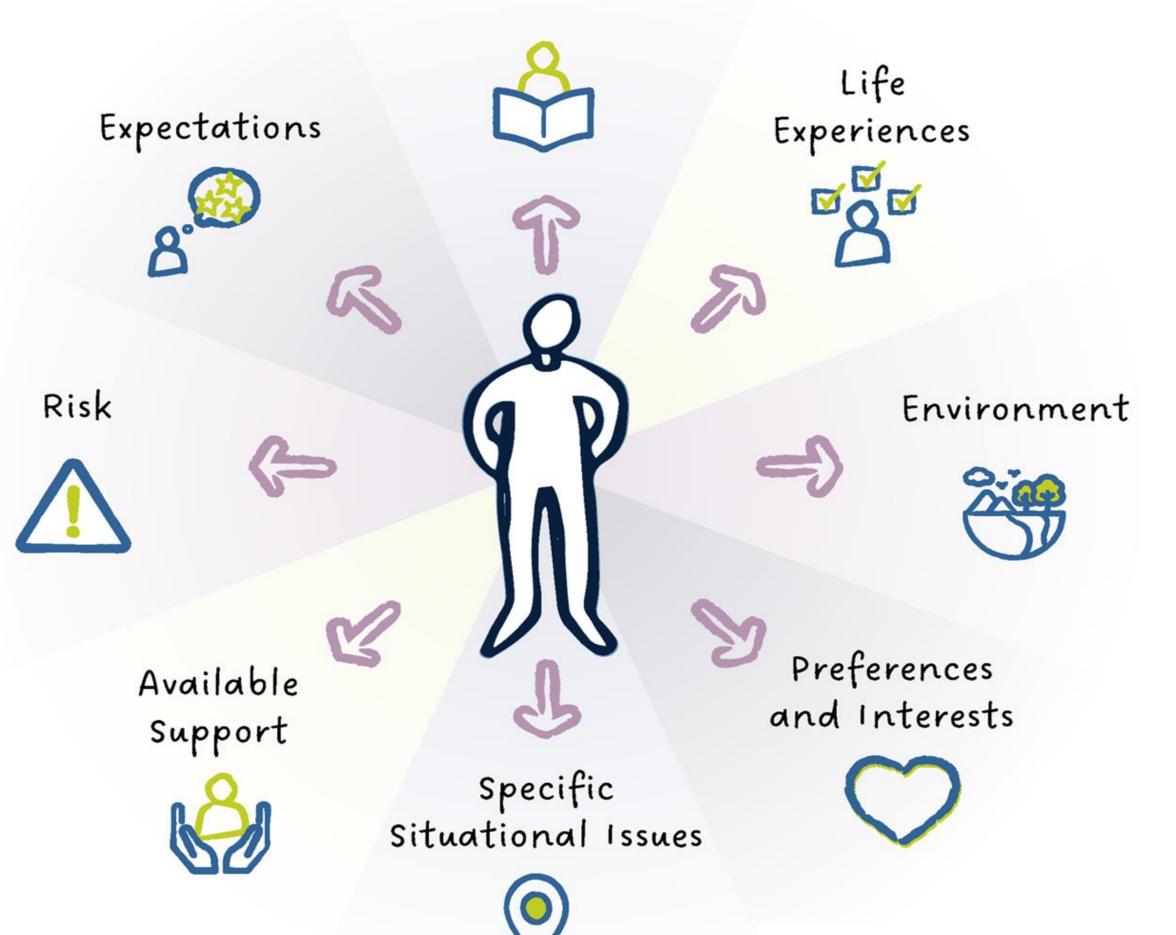
- A legal decision regarding one's ability to make decisions or take care of certain parts of their life
- Requires a court decision and engages the court in the person's life
- Guardians act on behalf of the court

Decision Making as a Continuum of Options and Conversations



Learned Skills

Decision
Making
Considerations
and Influences



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Poll 43

Multiple choice: National guardianship standards say that guardians should:

- Honor the person's preferences as reasonable
- Always use a "best interest" standard for decision making
- Limit the risks a person can take
- Use least restrictive alternative in decision making
- Remind the person of their right to request restoration of rights from the court

National Guardianship Standards of Practice (2022) (some, not all)

Guardians shall comply with the requirements of the court that made the appointment

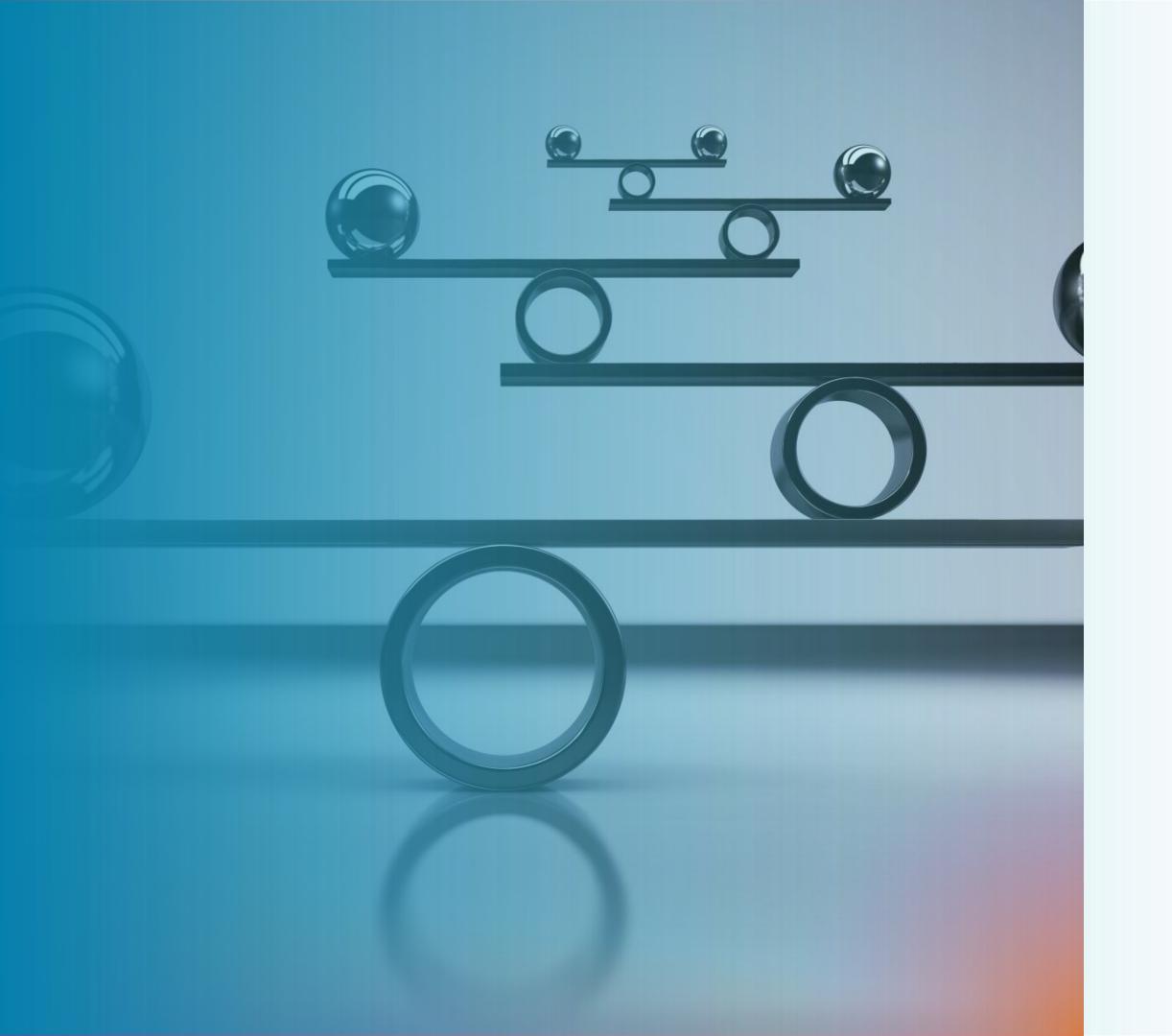
Guardians should be held to the same standards, regardless of familial relationship between the guardian and the person.

Guardians shall advise the person of the right to seek restoration of their rights from the court.

Guardians shall treat the person with dignity.

Guardians shall maximize the person's self-reliance and independence

Guardians shall seek ongoing education about person centered planning, supported decision making, conflict resolution (and much more).



Substituted Judgment

- Decision making based on the decision the person would have previously made when they had capacity, or would make based on their known preferences, interests and goals
- Promotes the underlying value of self determination and recognizes the dignity of risk

Best Interest Principle

 Used in the absence of any currently existing information about what is important to the person, or to prevent "substantial harm" to the person

North Carolina Least Restrictive Alternatives Brochure

Person Centered Tools for Partnering

Understand the "why" behind guardianship

Sort what matters to the person and what matters to the guardian

Assess what works and doesn't from all perspectives – developing action to reach agreement

3

Action plan for alignment

What does guardianship achieve?





Jason's Story

Listen deeply for the "why"



When Situations Challenge Us

- What is important to the person?
- What is important to people who know and love the person?
- Are these two sets of information aligned?
- How does each person feel about – and understand – what the other thinks?

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What Does Alignment Look Like?

- Where there is disagreement...
- What would everyone getting on the same page look like?
- What would need to happen (or not happen)?
- Who would do what (or not do)?
- What is the person's vision? The guardian's vision?

Ask about the **current state** (regarding the situation causing tension):

- From the person's perspective, what is working?
- From the perspective of others, what is working?
- From the person's perspective, what is not working?
- From others' perspective, what is not working?
- Look for common ground where do we agree on what works or doesn't work?
- Use the elements of agreement and disagreement to work on action toward consensus

Assess what is working and not working, right now

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	What is Working, Going Well, Needs to Stay the Same?	What is not working, is causing difficulty, needs to change?
Person's Perspective	 Having my own bedroom Deciding my own bedtime and wake-up schedule Wearing a uniform to work Dad coming by my workplace to see me do my job well 	 My roommate using my toiletries My mom calling to wake me up for work Roommate bringing too many people to the apartment Missing the bus to work sometimes and having to pay for Uber
Parents' Perspective	 Having a job he really likes with a boss who supports him Reminding him to get up on time so he isn't late for work Having a roommate to share expenses but having his own space 	 He goes to bed too late and is too tired in the morning Getting up too late and missing the bus to work Too many people coming and going from the apartment

Working & Not Working

- Negotiation tool
- A way to hear everyone's voice
- Gain clarity around worries and concerns
- Sets up action planning

Attribution: The Learning Community for Person Centered Practices

Revisit "why," and plan next steps

Knowing what you know now, what is important to the person?

What is important to those who know and love the person?

What options are available?

What would trying one of those options look like?

Moving Forward Past Experiences List past life experiences and events that List current or future life experiences or have supported your vision for a good life goals that will continue to support your good life vision List past life experiences that List things to avoid that could pushed your trajectory toward keep you from your good life vision or lead to what you don't want things you don't want

Vision for What I Want

List what you want your "Good Life" to look like:

What I Don't Want

List the things you don't want or what is NOT a "Good Life"

Tips for Advocating



Explore the decision the persons makes regularly and how they make them – understand the person's capabilities, their experience, and others' expectations of them



Lean into – dig into respectfully – why others believe the person needs guardianship. What do they hope it achieves?



Explore if the person is comfortable with, or interested in, making more decisions; or, are they okay with how things work now?



Discover and explore if there are already other tools for decision support in place, such as a power of attorney, representative agreements, FERPA or HIPAA – or can there be?

Resources

North Carolina Least Restrictive Alternatives Brochure

North Carolina Notice of Rights

National Guardianship Association Standards of Practice (2022)

National Resource Center on Supported Decision Making

Center for Public Representation Supported Decision Making

Center for Youth Voice Youth Choice

The Stop Light Tool

Working and Not Working Template

Charting the Life Course Tools

Planning with Individual and Families' Tools

The PRACTICAL Tool for Lawyers

The National Resource Center on Psychiatric Advance Directives

State-by-State Healthcare Directives

Prepare For Your Care

Prepare for Their Care

Caring Info

<u>AARP</u>



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The evaluation will close after three weeks. If you do **NOT** complete it within that time frame, you will lose the opportunity for a Certificate of Completion.

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Chart the Journey: Ways to Use the New North Carolina Person-Centered Planning Resource Toolkit Website

> Wed., November 20, 2024 1:30 PM - 2:30 PM, ET

Join the official online launch of our PCP resource collection—designed to streamline access to high-quality personcentered planning tools and resources.

REGISTER NOW





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