

Letter of Intent Excerpted from:

The Future of Aging Families

The Case for Family Support in North Carolina's Managed Care Climate

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Supporting Families to Plan for the Future

Future Planning Checklist
Steps to consider when planning for the future of your loved one with an Intellectual/Developmental Disability or TBI:

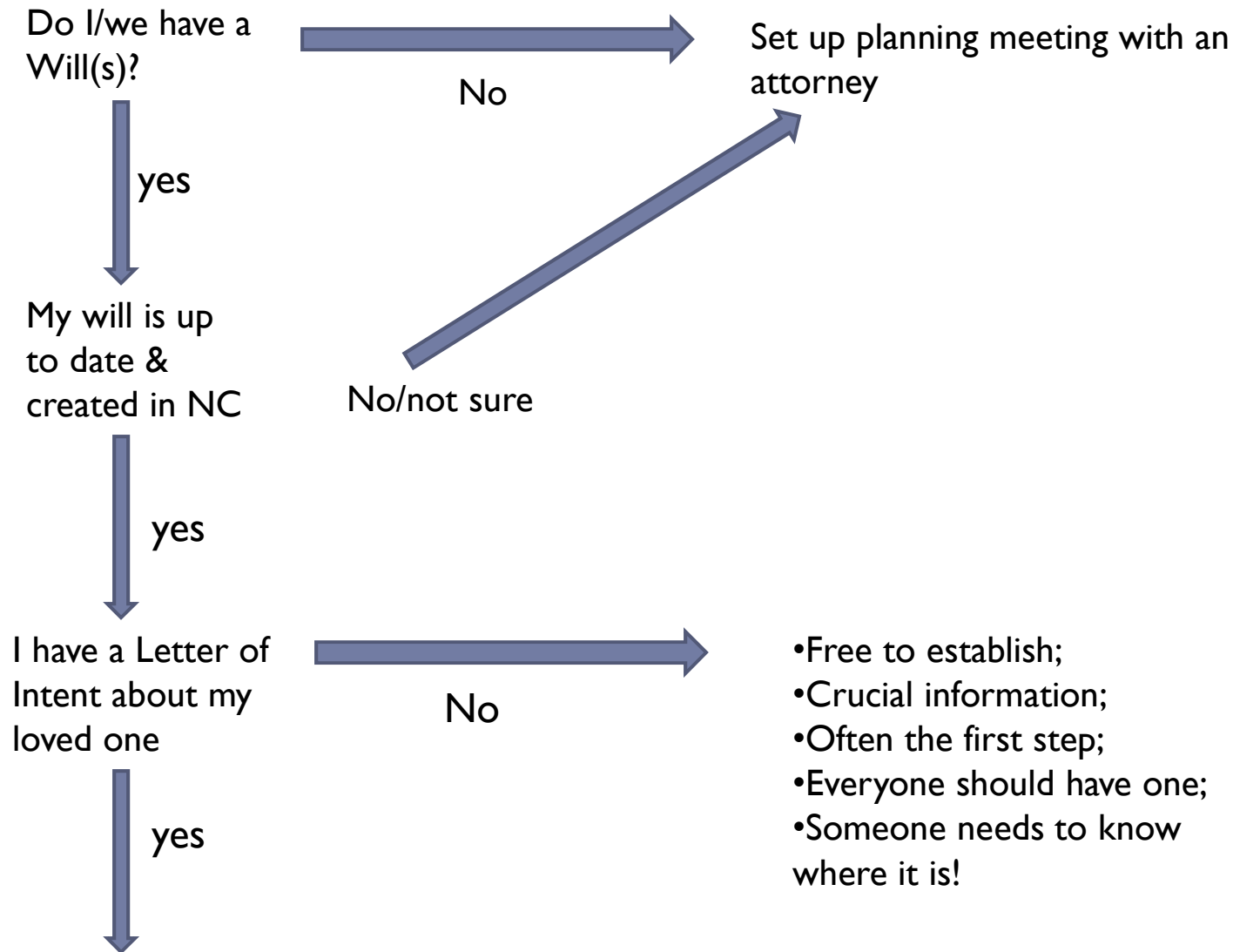
Future Planning Task:

- Do you have a Will, or a recently updated Will?
- Have you prepared a Letter of Intent pertaining to your family member?
- Do you have an Executor named?
- Do you have a Special Needs Trust or participate in a Pooled Trust?
- If so, do you have a personal and/or agency Trustee?
- Do you need or want a Trust Protector?
- Do you have life insurance or other means to fund a Trust?
- Have you considered alternatives to Guardianship? For example:
 - Do you have Representative Payee for your family member?
 - Has your family member given you Power of Attorney?
 - Has your family member given you Health care Power of Attorney?
- Do you have a personal support network?
- If you plan to pursue Guardianship, do you know what steps to take?
- Do you have an Attorney that specializes in Elder care or is knowledgeable about Disability issues?

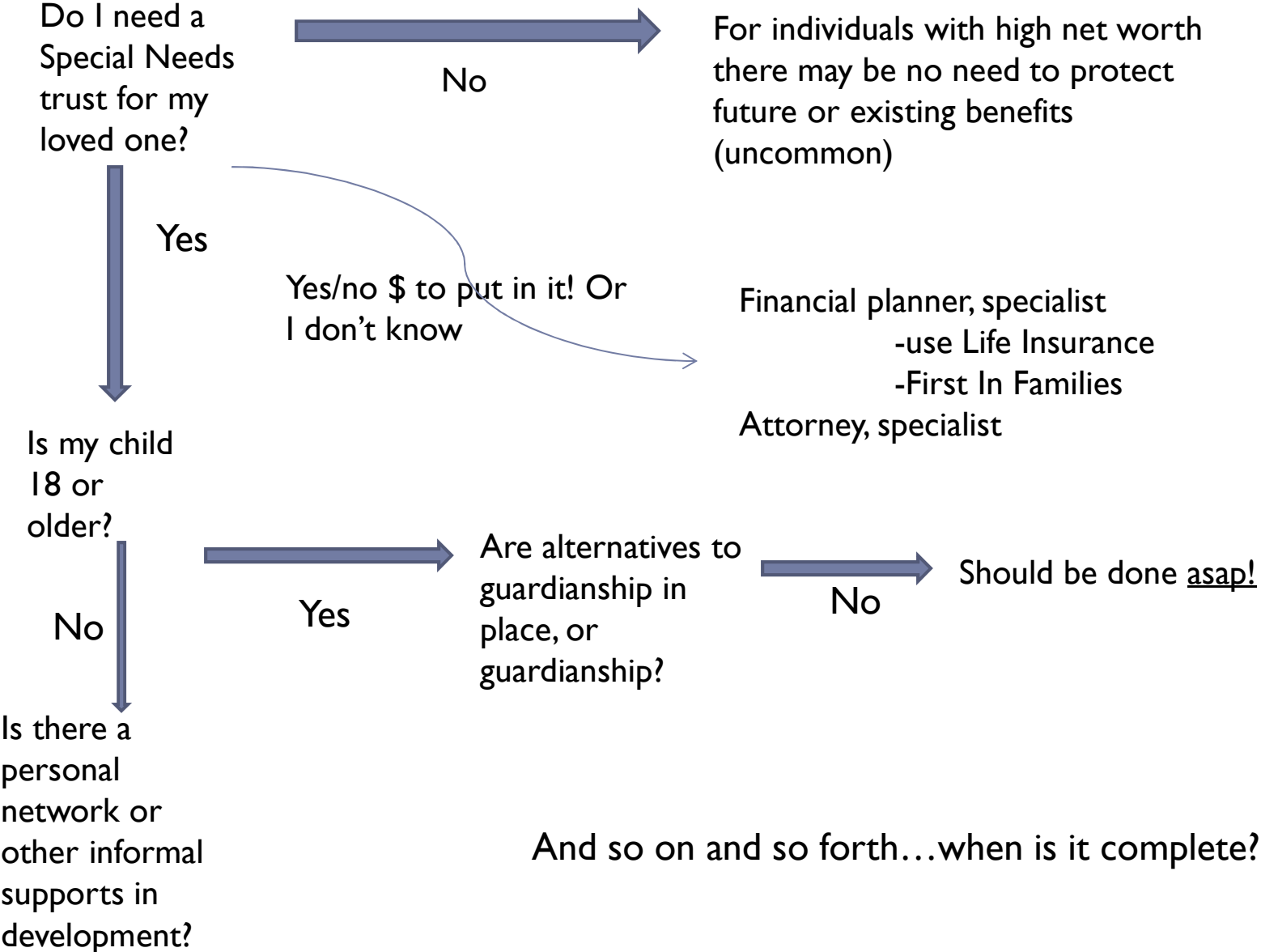
If you can check off any of these boxes, congratulations! You have begun your planning and are ahead of the majority of people! If not, and you would like to begin there are many resources available to help you. (See Back)



Components of Future Planning



Components of Future Planning (Continued)



Letter of Intent Exercise - 5 minutes



- ▶ *Imagine this:*
- ▶Paris
- ▶son or daughter..
- ▶ ...all is in place?
- ▶what to say to the total stranger...

Instructions: In small groups talk about and list the things you would want that person to know. This is the beginning of your letter of intent.

Important Components of a Letter of Intent

- ▶ **Factual information:**
 - ▶ key medical clinics, key contacts for any publicly funded services
- ▶ **Personal “only Mom/Dad knows” information:**
 - ▶ current likes/dislikes; struggles of any nature; names of friends; when/where favorite activities occur
- ▶ **Location of SS card, health insurance card, trust documents, etc**
- ▶ **Your personal vision, dream statement**
- ▶ *FIF suggests you update it annually*

Where does the *individual* fit into future planning by families?



- ▶ Self-determination can be consistent with family choice
 - ▶ Include individual in all phases of future planning; worksheets
 - ▶ Supported decision-making
- ▶ Employment First gaining momentum in NC
- ▶ Explore and utilize alternatives to guardianship whenever possible

Examples of Viable Alternatives to Guardianship


- ▶ Special needs trusts
- ▶ Representative payee
- ▶ HCPOA and POA
- ▶ Advanced directives on health care
- ▶ Natural supports in the community
 - ▶ Personal Network with Supported Decision-making (Lifetime Connections) for example
- ▶ Microboards (popular in Tennessee)

When all Legal and Financial matters are in place, is future planning done?

Personal Network

- ▶ Most people get the Will(s), trust, and alternatives/guardianship in place first;
- ▶ A personal network ensures that what is in place will continue to evolve as circumstances change
- ▶ Provides “social security” and well-being

And/or Siblings




**Supporting
Adult Siblings**

*Developing Leaders in
the Club Sandwich
Generation*

*A First In Families of
North Carolina initiative
funded by the NC Council on
Developmental Disabilities*

Of all there is to cherish in families, our relationships with our siblings are distinctly special. Our goal is to understand the concerns, needs, and ideas of adult siblings of individuals with intellectual/developmental disabilities as well as how to best support these relationships. Through this initiative First In Families of North Carolina will find and mobilize adult siblings to build the first ever adult Sibling Leadership Network in North Carolina. To learn more please visit tinyurl.com/ncsibling or contact Bryce Coleman at Bryce@fifnc.org.

 First In Families
of North Carolina
www.fifnc.org

Policy Recommendations

- ▶ Identify Barriers to Future Planning for Caregivers of Individuals with I/DD
- ▶ Require Future Planning as a Component of Every Person Centered Plan
- ▶ Provide access to information and resources on Future Planning as a Medicaid Billable Service through the LME/MCO network
- ▶ Identify older family caregivers to provide resources before the point of crisis.
- ▶ Continue and increase cross-training and collaboration between Aging and Disability sectors.

Conclusions/Summary

- ▶ The huge majority of adults with I/DD live in unlicensed homes
- ▶ Family support is vital because of the reality of aging baby boomers and related impact on the economy + state of the debt (perfect storm)
- ▶ Future planning, as a component of family support, is also essential
- ▶ Many helpful resources exist but must include the aging resources generally not accessed
- ▶ Comprehensive support saves money...critical to MCO model



Thank you and Questions!

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