GUARDIANSHIP AND SURROGATE DECISION-MAKING

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AGENDA

- Guardianship and Alternatives to Guardianship
- Surrogate Decision-making
- Self-Determination and Informed Consent: *Preserving Choice and Control*
- Supported Decision Making: *Life Plans are key to communication*
ABOUT PLAN/NJ

- Statewide non-profit organization
- Established in 1982
- Member of the National PLAN Alliance

THE PLAN/NJ MISSION is to help families answer the question, “Who will care for my loved one when I am gone?”
HOW CAN PLAN/NJ HELP
People with Disabilities and Families?

- Trustee; Representative Payee; Guardian
- Life Planning
- Home Visit Monitoring, Advocacy
  - Proactive eyes on the person
  - Service coordination
  - Advocacy for quality services
  - Expertise in public benefits and disability and mental health service systems
WHAT IS LEGAL GUARDIANSHIP?

- At age 18, parents no longer have legal rights to make decisions or gain information
  - medical, housing, legal, financial
- A person or agency is appointed by the Court to act on behalf of the individual
  - Limited Guardianship
  - Guardian of Person; Property or both
WHAT ARE ALTERNATIVES TO GUARDIANSHIP?

- Powers of Attorney and Health Care Proxy
  - Capacity to understand POA is required; revocable; no Court involvement
- Representative Payee for Social Security Benefits
- Trustee for a Special Needs Trust
WHAT ARE THE DUTIES AND RESPONSIBILITIES OF A GUARDIAN?

- Personal visits; Annual report to the courts
- The balancing act: promoting autonomy and independence while protecting from harm
- Promote self-determination
- Assist with revocation if appropriate
GUARDIAN RESPONSIBILITIES: HELPING YOUR LOVED ONE HAVE A GOOD LIFE

- Self-determination means choice and control
  - Supported decision-making
  - Informed consent: options, opportunities
- Help to achieve and respect person’s
  - Goals, needed supports
  - Wishes and preferences
GUARDIAN RESPONSIBILITIES: SURROGATE DECISION MAKING

- Make a substituted judgment decision rather than a best interest decision
  - **Substituted Judgment**: What the person would do
  - **Best Interest**: What a reasonable person would do if preferences unknown
  
  - *Not decisions in the interest of others*
HOW TO INCLUDE THE PERSON IN DECISION-MAKING

- Disclose information: facts, benefits and risks, supports
- Assess person’s understanding
  - Ask and rephrase questions in different ways so as to avoid “yes or no” responses
  - Multiple conversations, ample time to discuss
PLANNING AHEAD: FAVORITE THINGS

- What are the person’s favorite ways to spend his/her time?
- Who does the person like to spend time with?
- What places does the person like to go?
- What are the person’s hobbies?
PLANNING: THINGS THE PERSON DOES NOT LIKE

- What are the things that the person does not like or annoy him/her?
- Are there people the person doesn’t want to be around?
- What makes him/her bored or grumpy?
- What is the person afraid of?
- Are there procedures that are necessary but that the person doesn’t like (e.g. dialysis)?