



**PLAN|NJ**

# **Person-Centered Life Planning: Securing the Future for People with Disabilities**

**Planned Lifetime Assistance Network of New Jersey  
(PLAN|NJ)**

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# AGENDA

- ▶ Life Planning: Securing a Good Life
  - Legal
  - Financial
  - Home and Community
- ▶ Guardianship and alternatives to guardianship
- ▶ Special Needs Trusts
- ▶ ABLE Accounts

# ABOUT PLAN|NJ



- ▶ Statewide non-profit organization
- ▶ Established in 1988
- ▶ 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 THEIR FAMILIES?

- Trustee for Special Needs Trusts
- Guardian; Support for family/sibling Guardian
- Representative Payee
- Life Planning
- Case management, advocacy, home visit monitoring
  - Proactive eyes on the person
  - Service coordination
  - Advocacy for quality services
  - Expertise in public benefits and disability and mental health service systems

# SUPPORTING FAMILY AND SIBLING GUARDIANS



# FUTURE LIFE PLANNING

- Develop a LifePLAN: **Who is your loved one?**
  - Detailed description of the needs of the person with a disability or mental illness
  - Person and family wishes, preferences and goals
- **Locate resources** to support the plan
  - Living: home, school, work, friends
  - Financial status and support roles: income, benefits, ABLE Account; Special Needs Trust; Rep Payee
  - Legal: Guardian or POA; Health Care Proxy
- **Identify appropriate people** to implement the plan

# MAKE A PLAN: KEY PEOPLE

## ► Legal Roles

- Successor Guardian; Power of Attorney; Health Care Proxy

## ► Financial Roles

- Trustee; Representative Payee; ABLE account manager; True Link Card manager; budget coach

## ► Home and Community Supports



- Advocate for medical coordination; ISP meetings; emergency response; work; recreation and enjoyment; friends

# CHARTING the LifeCourse



## Mapping Family Roles

This tool is to help families think through the roles they play in their loved one's life, and to help them plan for who else could help fulfill those roles now and in the future.

Reciprocal Roles		People's Roles in _____'s life	Looking Ahead	What's important to know, make sure continues, or make happen?
 <b>Caring ABOUT</b>	<b>Affection and Self-Esteem</b>	Who loves and cares about him/her?	Who else makes him/her feel loved?	
	<b>Repository of Knowledge</b>	Who else knows things that others don't know well? (celebrations, traditions, habits, history)	With whom does he/she have special memories or experiences?	
	<b>Lifetime Commitment</b>	Who has a lifetime bond with him/her?	Who else would step up when/if needed?	
 <b>Caring FOR</b>	<b>Provider of day-to-day care</b>	Who makes sure activities of daily living and healthcare needs are met?	Who else could provide oversight for these needs?	
	<b>Material and Financial Needs</b>	Who makes sure his/her day-to-day basic and quality of life needs are met?	Who else could help make sure this happens?	
	<b>Facilitator of Inclusion and Membership</b>	Who helps connect him/her to inclusive opportunities and maintain relationships?	Who would be good at helping him/her connect with and maintain inclusive activities?	
	<b>Advocate for Support</b>	Who helps him/her advocate in planning meetings?	Who else could help advocate for/with him/her?	





## Charting the LifeCourse Integrated Supports Star: Mapping



Access the Charting the LifeCourse framework and tools at [lifecoursetools.com](http://lifecoursetools.com)

Charting the LifeCourse Portfolio is a template of the UMKC IHD, UCEDD. More materials at [lifecoursetools.com](http://lifecoursetools.com)

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What supports does Conner already have in his life to help him achieve his good life?

What is the source of these supports?

What might this look like in 10 years? How might this change in different stages of Conner's life?

For fillable forms, visit [Lifecoursetools.com](http://Lifecoursetools.com).

# Sample Planning Trajectory for Future Residential Vision



## LIFE TRAJECTORY | PLANNING

KR - Future Residential Vision - Current Life Stage: Transition

### Past Life Experiences

List past life experiences and events that have supported your vision for a good life

KR enjoys outdoor activities  
KR spends time with his parents outdoors (hiking)  
KR loves nature, especially animals  
KR spends hours throwing rocks in water  
KR loved his summer camp experience in NY

List past life experiences that pushed your trajectory toward things you don't want

KR's family lives in an urban setting without access to open natural spaces

### Moving Forward

List current or future life experiences or goals that will continue to support your good life vision

Will continue to seek out situations that meet some of the important aspects of a good future living situation

Will consider purchasing the ideal property and having a home built to accommodate a group residence

Will explore staffing options and agencies that might partner in running a group home that meets the good life expectations

Will explore LifeSharing Communities as a possible alternative to a traditional Group Home setting.

List things to avoid that could keep you from your good life vision or lead to what you don't want

Many group home residences are in more urban or suburban areas

Few existing group homes have the setting and experiences with nature and animals that are desired

Settling for the status quo

### Vision for What I Want

List what you want your "GOOD LIFE" to look like

Safe home that is well staffed  
Camp-like environment where friendships and relationships can flourish  
Open space  
Large yard with nature to explore  
Stream  
Small farm animals to care for - sense of purpose and responsibility  
In natural environment - woods and trails nearby

### What I Don't Want

List the things you don't want or what is NOT a "good life"

Home in an urban environment  
No access to nature

Note: Sometimes it is easier to begin with "what I don't want" to narrow the vision of what you do want.



Developed by the Charting the LifeCourse Nexus - LifeCourseTools.com  
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This planning tool can be used for specific areas of life – like employment, recreation, residential – or as an overall vision of a person's good life.

# WHAT IS LEGAL GUARDIANSHIP?

- ▶ Parents no longer have legal rights to make decisions or gain information at child's 18<sup>th</sup> birthday
  - Medical, housing, legal, financial, educational
- ▶ 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 THE DUTIES AND RESPONSIBILITIES OF A GUARDIAN?

- Duties
  - Personal visits
  - Annual report to the courts
  - Promote self-determination
  - Assist with revocation if appropriate
- The balancing act: promoting autonomy and independence while protecting from harm

# WHAT ARE ALTERNATIVES TO GUARDIANSHIP?

- Powers of Attorney and Health Care Proxy
  - Both documents require capacity to understand
  - No Court involvement
  - Both documents are revocable
- Representative Payee for Social Security Benefits
- Trustee for a Special Needs Trust



# Supported Decision Making

- What is Supported Decision Making?
  - Assisting a person to make informed choices
  - Help to understand, consider and communicate decisions
- Why Supported Decision Making?
  - Promotes self-determination and dignity
  - Does not remove rights
  - Avoids Court actions

# Ways to Support Decision Making

- Disclose information: facts, benefits and risks, supports
  - Use plain language / audio or visual forms
  - Ample time to discuss choices
  - Role play to understand choices
  - Make pro's and con's list
- Assess person's understanding
  - Ask and rephrase questions in different ways so as to avoid “yes or no” responses
  - Multiple conversations

# The Need to Recognize SDM Under Law

- Secure individuals' control over decisions: person makes choices
- Accept formal SDM agreement for supporter's participation
- Reduce doctors, bankers, and lawyers fear of malpractice
- Limit Court involvement and removal of rights: less restrictive options
- Enable ease of changing supporters and agreements



# WHAT IS A SPECIAL NEEDS TRUST (SNT)?

- ▶ Funds used to supplement public benefits for improved quality of life
- ▶ The beneficiary does not have direct access to the trust, thereby is protected from exploitation
- ▶ Prevents beneficiary from owning assets that could eliminate means tested government benefits such as SSI, Medicaid, Food Stamps, HUD Housing, other
- ▶ The trust can provide things to enhance his or her life, such as personal care assistance, transportation, education, recreation, clothing, electronics, furniture

# TWO TYPES OF SPECIAL NEEDS TRUSTS

## ➤ Third Party

- Funds from parents, grandparents, friends, insurance
- Remainder to designated beneficiary

## ➤ First Party (Self-Settled)

- Funds from the beneficiary, a settlement, direct inheritance, earnings, savings, child support
- Remainder: Payback provision to Medicaid

# WHAT IS A POOLED TRUST?

- Held by a non-profit organization
- Multiple individual sub-accounts pooled together for investment and fee reduction purposes
- **PLAN|NJ Community Trust:** Families may join at no cost
- Parents, family members and friends of a person with a disability may contribute to benefit the individual
- A pooled trust functions like a Special Needs Trust
  - Funds to supplement public benefits, not replace them
  - Improve quality of life
  - Can be 3<sup>rd</sup> party or 1<sup>st</sup> party sub-accounts

# TYPES OF SPECIAL NEEDS TRUST VEHICLES

## PRIVATE TRUST

Attorney prepares document; up-front cost; remainder goes to designated beneficiaries

### ► Third Party

- Someone else's money funds the trust (parent, grandparent, etc.)
- Prepared in advance
- **NO MEDICAID PAYBACK**

### ► Self Settled or First Party

- Beneficiary's money funds trust (settlement, direct inheritance, etc)
- **MEDICAID PAYBACK**

## POOLED

Sign joinder agreement; no up-front cost; 50% remainder goes to non-profit

### ► Third Party

- Someone else's money funds the trust (parent, grandparent, etc.)
- Prepared in advance
- **NO MEDICAID PAYBACK**

### ► Self Settled or First Party

- Beneficiary's money funds trust (settlement, direct inheritance, etc)
- **MEDICAID PAYBACK**

# EXAMPLES OF TRUST DISTRIBUTIONS

- Treatments or equipment not covered by Medicaid or Medicare
- Tuition, books
- Clothing
- Utilities such as cable and telephone
- Real estate
- Transportation, vehicles, repairs
- Insurances
- Pre-paid funeral arrangements



# ABLE ACCOUNTS: ACHIEVING A BETTER LIFE EXPERIENCE ACT OF 2014

- ▶ Protecting eligibility for Medicaid, Supplemental Security Income, other Federal benefits
- ▶ More choice and control over spending
- ▶ A new avenue to save and promote independence





# ABLE ACCOUNT: THE BASICS

- ▶ If the account grows to more than \$100,000, Supplemental Security Income (SSI) payments will be discontinued, but Medicaid remains intact
- ▶ There is an annual contribution limit, currently set at \$17,000
- ▶ It must be established for a disabled individual whose disability onset was prior to the age of 26
- ▶ A person can only have one ABLE account

# ABLE ACCOUNT BASICS

*continued*

- ▶ While the account balance remains below \$100,000, gains in the account are not taxed
- ▶ Distributions will not be taxed if made for qualifying disability-related expenses (QDE)
- ▶ Upon death, state Medicaid agencies must be repaid out of the account balance for any benefits provided to the beneficiary while the account was in existence



# HOW CAN PLAN|NJ HELP?

- ▶ Successor (back-up) for key legal roles
  - ▶ Sibling guidance and family support
  - ▶ Eyes and ears for Guardian and Trustee, including out-of-state Guardians and Trustees
- ▶ Life Planning consultations
- ▶ Routine home-visit monitoring and advocacy
- ▶ As needed statewide support services



## FOR MORE INFORMATION, CONTACT:

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