



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

This presentation is for informational and discussion purposes only. Nothing herein should be construed as legal advice.

ABOUT PLAN|NJ



- Statewide non-profit organization
- Established 1988 under **NJ Community Trust Act 3B:11-19**
- Serving all people who are differently abled
- 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

FUTURE LIFE PLANNING

- **Who is your loved one?**
 - Detailed description of the person with a disability or mental illness
 - Person and family wishes, preferences, needs and goals
- **Locate resources** to support the plan
 - Living: home, health, school, work, friends
 - Financial status and support: 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; budget coach
- Home and Community Supports
 - Advocate for medical coordination; ISP meetings; emergency response; work; recreation and enjoyment; friends

CHARTING the LifeCourse



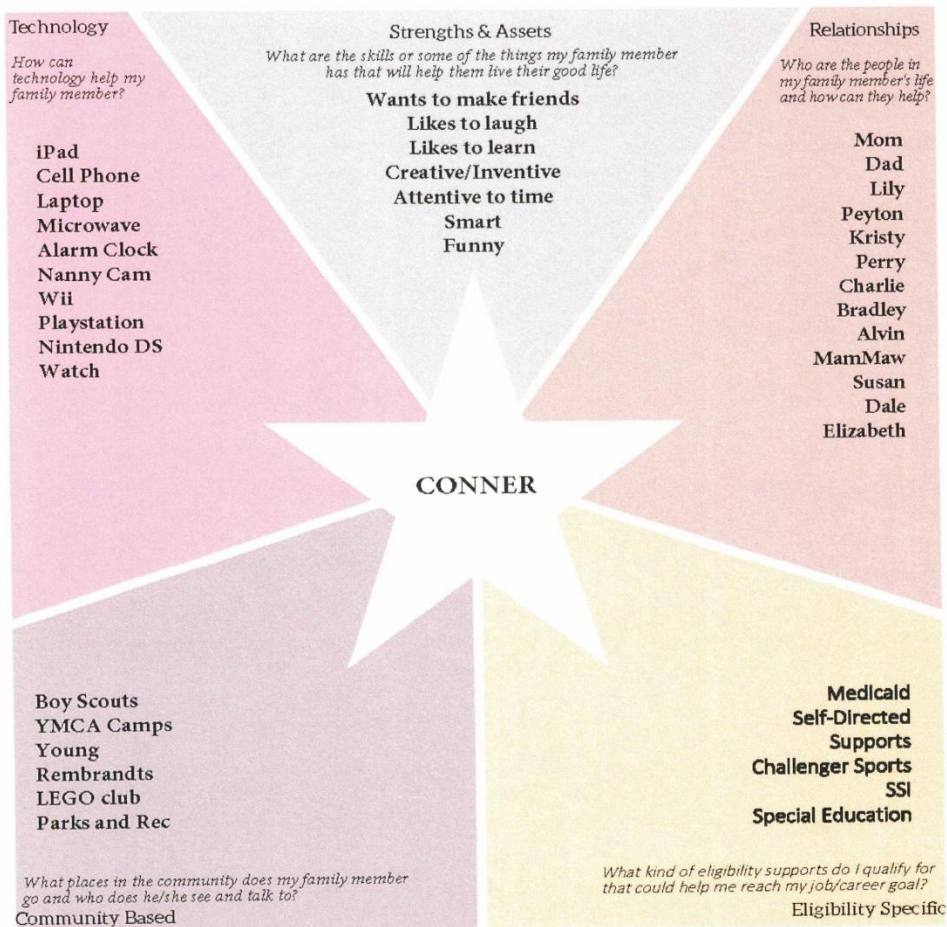
Mapping Family Roles

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?
 Caring ABOUT	Affection and Self-Esteem	Who loves and cares about him/her?	Who else makes him/her feel loved?
	Repository of Knowledge	Who else knows things that others don't know well? (celebrations, traditions, habits, history)	With whom does he/she have special memories or experiences?
	Lifetime Commitment	Who has a lifetime bond with him/her?	Who else would step up when/if needed?
 Caring FOR	Provider of day-to-day care	Who makes sure activities of daily living and healthcare needs are met?	Who else could provide oversight for these needs?
	Material and Financial Needs	Who makes sure his/her day-to-day basic and quality of life needs are met?	Who else could help make sure this happens?
	Facilitator of Inclusion and Membership	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?
	Advocate for Support	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

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

Sample Planning Trajectory for Future Residential Vision



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.



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 18th 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

WHAT IS A SPECIAL NEEDS TRUST (SNT)?

- Funds used to supplement public benefits for improved quality of life
- Protects eligibility for means tested benefits
 - SSI, Medicaid, Food Stamps, HUD Housing
 - Assets are owned by the trust rather than the person
- Provide things to enhance life
 - transportation, education, recreation, clothing, electronics, furniture, personal care assistance
- Prevents exploitation
 - The beneficiary does not have direct access to the trust account

TWO TYPES OF SPECIAL NEEDS TRUSTS

THIRD PARTY



- Someone else's money funds trust (parent, grandparent, friends, beneficiary of life insurance, etc.)
- **Remainder to designated beneficiary**
(no remainder payback to Medicaid)

FIRST PARTY/SELF-SETTLED



- Beneficiary's money funds trust (settlement, direct inheritance, earnings, child support, savings, etc.)
- **Remainder payback 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
- Functions like a Special Needs Trust
 - Funds to supplement public benefits, not replace them
 - Improve quality of life
 - Can be 3rd party or 1st party sub-accounts



EXAMPLES OF TRUST DISTRIBUTIONS

- Treatments or equipment not covered by Medicaid or Medicare
- Tuition, books, school supplies
- Clothing
- Furniture, electronics
- Utilities such as cable and telephone
- Transportation, vehicles, repairs
- Auto insurance and gas
- Pre-paid funeral arrangements
- Vacations, entertainment



ABLE ACCOUNTS: ACHIEVING A BETTER LIFE EXPERIENCE ACT OF 2014

- Protects 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 exceeds \$100,000, Supplemental Security Income (SSI) payments will be discontinued, but Medicaid remains intact
- Annual contribution limit is \$20,000 in 2026*
- Eligibility: disability onset was prior to age 46
 - The eligibility age changed to 46 as of 1/2026.
- Only one ABLE account is allowed per person
- Deposits can be made by individual, family, SNTs, 529 College Savings Account rollovers

* *Annual contribution limits may change annually*



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)
- Medicaid Payback
 - 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

Together We
PLAN: A
PLAN|NJ
Podcast Series

featuring disability rights
leaders from New Jersey

Learn more and listen:
<https://plannj.org/together-we-plan/>

- **E1: Advocacy in Action: Empowering Families and Individuals with Disabilities** w/ Paul Aronsohn and Hazeline Pilgrim
- **E2: Navigating Special Needs Trusts and ABLÉ Accounts: A Guide for Families** w/ Shirley Whitenack, Esq.
- **E3: Beyond Guardianship: Exploring Supported Decision-Making** w/ Nina Weiss, Esq.
- **E4: Unlocking Supportive Housing: Navigating Resources and Solutions for Individuals with Disabilities** w/ Diane Riley
- **E5: The Challenge to Change: Learning from Lived Experiences with Disabilities** w/ LeDerick Horne and Hazeline Pilgrim
- **E6: One Mother's Journey: Securing Residential Services for a Daughter with Autism** w/ Maria Fischer, Esq.
- **E7: Toward Better Mental Health Supports and Services** w/ Joyce Benz and Michael
- **E8: Available Public Benefits and Services for Comprehensive Supports** w/ Crystal West Edwards, Esq.
- **E9: Your Legacy of Love: Estate and Financial Planning for Families with Disabilities** w/ Tom Begley, Jr., Esq. and Emily Schurr, Esq.



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