

Life planning for Families of Loved Ones with Disabilities

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Important Questions



- What supports will be needed to ensure the best quality of life necessary for the loved one?
- What supports will the caregivers need?
- In the event that a caregiver is no longer available, who will step in?
- Who will manage the on-going care?
- Who will make educational, vocational, housing and financial decisions?
- Will there be enough money to provide for a good quality of life for my child?

Life Planning

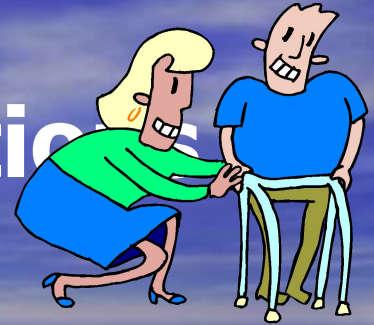
Life planning is well-thought out plan that recognizes and addresses the unique needs of individuals with disabilities. Developing this plan will allow individuals and caregivers to provide the best quality of life possible for the individual and assist caregivers to provide proper supports for maximum independence.



What does the Life Plan Consider?

- The individual's medical, behavioral, social, emotional, educational, vocational needs
- The caregiver's assessment of the patient's needs and their hopes for the future
- An assessment of the financial commitment necessary to provide the individual with the proper amount of care and support.

Other Important Considerations



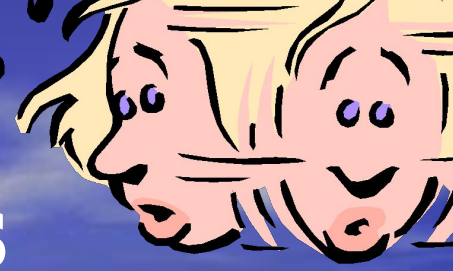
- An individual with disabilities may or may not be able to self-support.
- The need for care may be life long.
- Government benefits and supports might not be available long term.
- An assessment needs to be made as to what supports may be needed

Possible Actions



- Do nothing and hope for the best-NO
- Rely solely on government benefits-NO
- Develop a Life Plan-YES
- Put together a team of professionals to assist in the development of the plan-YES
- Review the need for guardianship and special needs estate planning.
- If you are a caregiver, get your own house in order.

The Life Plan Components



- A discussion with the loved regarding goals and objectives and identification of advocacy needs
- A letter of Intent
- A well-thought out estate plan
- A special needs trust
- Advance directives and/or
- Consideration of guardianship
- Supported Decision making
- Access to supports such as OPWDD and Medicaid



Advocacy

Be sure there is always an advocate for the individual

- An individual, often a parent, sibling or relative or organization who is familiar with the needs of the patient
- Make sure evaluations, IEP's, IESP's and medical information are always updated to allow advocates to make informed decisions when necessary.
- Make sure the advocates have copies of all life planning documents



The Letter of Intent

A non-legally binding document that communicates:

- The wishes and desires of the individual and caregiver
- The needs of the individual
- Important contact information
- The “Letter” can be in any form you desire-audio, video, written etc.
- Review the Letter on a regular basis

Special Needs Estate Planning

Includes:

- A Last Will and Testament naming an executor and Trustee if necessary
- Special Needs Trust
- Guardianship provision for minor children
- Understanding of the role of testator, executor, guardian and trustee
- Advance Directives
- A discussion of supported decision making
- Meeting with a qualified planner

Guardianship and Alternatives

Article 17 A of SCPA
Article 81 of the MHL
Advance Directives
Supported Decision Making



Guardianship Process

- A petition
- A potential hearing
- Periodic accounting and reports

Continued court involvement provides added protection to the child and the guardian

ADVANCE DIRECTIVES

- Power of Attorney with Gift Rider
- Health Care Proxy
- HIPAA release (health insurance portability and accountability act)
- Living Will
- Disposition of Remains



SPECIAL NEEDS TRUSTS

Self-Settled Special Needs Trusts

- Created with the individual's own assets
- Must contain a "payback" provision for Medicaid but not for SSI
- Must be established a by a parent, grandparent, guardian, court order or Individual
- Trust that is typically used when there is a settlement

Supplemental Needs Trusts-3RD

Party Trusts

- A trust set up by a testator under a Will or a settlor under an intervivos trust.
- Intervivos or testamentary
- Assets must “supplement” not “supplant” government benefits
- Contains certain limitations on the use of trust property as indicated above
- A non-countable asset for Medicaid eligibility purposes
- No payback requirement if set up and managed properly
- Designation of a trustee is a very important decision

Pooled Trusts

- Established with the individual's own assets
- Managed by a non-profit organization
- Assets are pooled for investment and management purposes only
- Modified payback provision
- Only trust that may be utilized after an individual turns 65

Government Benefits

Social Security
Social Security Disability
Medicare
vs.

Means-based programs
Supplemental Security Income
Medicaid

Resource Information

- www.arkontakylawgroup.com
- Academy of Special Needs Planners
 - Special Needs Alliance
- Council of Parent Attorneys and Advocates
 - Social Security Administration

Conclusion

- Every individual is unique and the plan should be tailored to the individual's unique needs
- Plan early and review plan on a regular basis.
- Look for team players who are familiar with with special needs planning
- Involve the individual as much as possible



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