



## Family Support

At the St. Louis Arc, parents, siblings, significant others – all family members are welcome. We are committed to helping you connect to resources and become effective advocates for your loved ones. Whether you are looking to interact with people going through the same challenges, or in search of an activity for the entire family, the St. Louis Arc provides a lifetime of support.

The St. Louis Arc Family Workshop Series provides in-depth information on supporting a family member with an intellectual or developmental disability. Most of our workshops are free, open to everyone, and take place at the St. Louis Arc Centene Family Center or Childgarden Early Childhood Center.

### **State and Federal Benefits**

Presented Thursday, February 15

Do you have questions about what benefits your family member is eligible for when they turn 18? Medicaid, Medicare, Social Security, SSI – find out who is eligible, what the differences are between the programs, and how to access the appropriate contacts in order to apply for services. Information about working while receiving benefits will also be covered.

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# Planning for Loved Ones with Special Needs

St. Louis Arc

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# Providing Funds for Loved Ones with Special Needs

- Public Funding
  - Understanding the basics of public benefits
  - Important types of public benefits
    - Supplemental Security Income (SSI)
    - Social Security
    - Medicare and Medicaid
- Private Funding
  - Supplementing Public Funds
  - Avoiding Pitfalls in Planning
  - Special Needs Trust

# The Importance of Public Funds

- Public funds are benefits set aside by the federal government and state government to be used to care for people with special needs.
- These funds are meant to be used and there is no reason to avoid taking full advantage of them.
- With a little planning, these funds can be available to just about anyone with special needs, regardless of their family's financial situation.

# Public Benefits Basics

- Benefits not based on financial need
  - Social Security
  - Medicare
  - Special Education
- Benefits based on financial need
  - Supplemental Security Income (SSI)
  - Medicaid
  - Food stamps, legal aid, and utility payment assistance
  - Housing subsidies (H.U.D. or Section 8)

# Supplemental Security Income

- SSI is a federal program, administered by the states, and is based on sufficient evidence of disability and financial need.
- SSI is intended to pay for the beneficiary's food and shelter and nothing more.
- Two tests determine eligibility for SSI.
  - Resource test determines eligibility
  - Income test determines how much is received

# Resources and SSI Eligibility

- Anything that can be converted to cash for support is a resource.
- If resources exceed \$2,000 (\$1,000 for Medicaid) on the first day of a calendar month, the beneficiary's public benefits will be lost until resources are reduced.
- Assets that the beneficiary does not have the legal right to demand are not counted for SSI purposes.
- If qualify for SSI, then will qualify for Medicaid.

# Exempt Resources from SSI

- **A home**
  - If individual has an ownership interest and it serves as his/her principal residence
- **Household goods**
  - All together worth no more than \$2,000 market value
- **A burial plot or burial space**



# Exempt Resources, cont.

- **One automobile**
  - Completely excluded regardless of value if necessary for employment, medical treatment, modified for operation by or transportation of a handicapped person; or is necessary to perform essential daily activities
  - Otherwise excluded to the extent current market value does not exceed \$4,500
- **Life insurance policies with cash surrender value**
  - If their total face values amount to less than \$1,500, and all term life insurance

# Income Affecting SSI Benefits

| Unearned Income   | Earned Income   | In-Kind Support   |
|---|---|---|
| <ul style="list-style-type: none"><li>- Gifts</li><li>- Payments from annuities &amp; pensions</li><li>- Alimony &amp; support</li><li>- Dividends, interest, rents, awards</li><li>- Payments of other benefit programs.</li></ul> | <ul style="list-style-type: none"><li>- Wages</li><li>- Royalties</li><li>- Net earnings from self-employment</li><li>- Any honoraria received for services rendered.</li></ul> | <ul style="list-style-type: none"><li>- Actual receipt of:<ul style="list-style-type: none"><li>Food</li><li>Clothing</li><li>Shelter</li></ul></li><li>- Something that can be used to get one of these.</li></ul> |

All of these sources of income will reduce benefits

# Social Security Benefit (SSDI)

- A disabled child may be eligible for Social Security if a parent is eligible and the child's disability began before age 22.
- Benefits do not become payable until the eligible parent dies, retires, or becomes disabled.
- Social Security is not affected by the child's assets, but the child's income may result in an ineligibility determination.

# Social Security Eligibility

- Upon the disability or retirement of the parent, an eligible disabled child will receive an amount equal to 1/2 of the parent's benefit
- Upon the death of the parent, an eligible disabled child will receive an amount equal to 3/4 what the parent's SSDI benefit
- Example
  - Helen has been disabled from birth, and is receiving \$720 in SSI monthly.
  - Helen's father, Earl, retires and receives \$1,000 a month. Helen begins to receive \$500 per month.
  - Receipt of the SSDI is unearned income which reduces Helen's SSI by \$480. Helen now receives \$240 SSI and \$500 SSDI.

# Basics of SSI Eligibility Exempt Resources.

- Life insurance policies with cash surrender value, if their total face values amount to less than \$1,500, and all term life insurance
- A burial plot, or other burial space, worth any amount
- ABLE Account
- ASSETS IN A PROPERLY DRAFTED SPECIAL NEEDS TRUST!!!!!!

# Medicare and Medicaid Basics

- Medicare is a federal health insurance program for people over 65 and people under 65 who have been receiving Social Security based on disability for two or more years.
- Persons can be eligible for both Medicare and Medicaid.
- Medicaid is payor of last resort and covers long term care costs.

# Any Questions?

- Importance of public funds?
- Need based benefits vs. general benefits?
- SSI eligibility and income?
- Social Security benefits and eligibility?
- The role of Medicare and Medicaid?
- General access to public funds?

# Private Funding

- Public funding alone will only provide for the bare minimum needs of an individual. This level of resources will leave a loved one near poverty.
- Private funds can be used effectively to supplement public funds.
- But private funds must not be seen as supplanting public funds, or else a loved one may lose access to public benefits.



# Common Pitfalls

- Transfers to Minor Act Accounts
- Unstructured Beneficiary Designations
- Directing funds to be held informally by another family member
- Gifts from non-parents (other friends or family members)
- No planning at all

# Missouri Transfers to Minor Act

- Once the child takes control of the account, the child may then use the money for purposes other than education – regardless of the custodian's wishes.
- If your family is applying for need-based financial aid, having an MUTMA may reduce the size of the benefits package or result in a finding of ineligibility.
- MUTMA accounts are considered available resources for purposes of SSI eligibility.

# Unstructured Beneficiary Designations

- Designating a retirement plan, insurance policy or annuity directly to an SSI or Medicaid recipient will cause a reduction or elimination of public benefits.
- Many IRAs or 401K s have as default that the employees children are beneficiaries.

# Directing Funds to Another Family Member

- Some people try to avoid having a special needs individual's inheritance included as a resource by giving that inheritance to another family member to administer on behalf of the individual.
- Informal plan with no binding contract
- Dangerous plan with several flaws
  - These assets would be reachable by the family member's creditors.
  - The family member may predecease the special needs individual without leaving an adequate administration plan.

# Gifts from Non-Parents

- Often overlooked source of funds
- Gifts directly to an individual are considered unearned income and may make someone with special needs ineligible for SSI and other public benefits.
- Gifts do not have to be turned away altogether, but they must be made in the right form.

# No Planning at All

- Dying intestate (without a will or trust) will usually leave all or a portion of the estate to the decedent's children.
- Any child on SSI or Medicaid will lose eligibility until the inheritance is either spent down, converted to a exempt resource, or placed in a Medicaid Payback Special Needs Trust.

# More Information

- Social Security Administration
  - [www.ssa.gov/disability](http://www.ssa.gov/disability)
    - Security Disability Insurance information
    - SSI eligibility information
    - Applying for federal benefits
- Missouri Division of Medical Services
  - [www.dss.mo.gov/dms](http://www.dss.mo.gov/dms)
    - Missouri Medicaid information

# Purpose of a Special Needs Trust

- Special Needs Trusts are a way to provide private funds to an individual with special needs while maximizing his or her access to public funds.
- A well structured Special Needs Trust can provide financial security for the life of an individual.



# Advantages of a Special Needs Trust

- Provides private funds to an individual with special needs in a way that will not reduce his or her access to public funds.
- Allows trustee(s) to manage distribution of assets
- May include a wide array of funding sources

# Advantages, Cont.

- Permits anyone to give gifts directly to the trust for the benefit of the individual
- Ensures privacy for the individual and the family
- Private funds are protected from predators and creditors

# Basics of a Special Needs Trust

- A trust is a contract to control property that will be administered by a trustee for the benefit of a beneficiary to meet an objective.
- The trust agreement contract can dictate how and when a trustee distributes funds to a beneficiary.
- The Social Security Administration describes a discretionary trust as “a trust in which the trustee has full discretion as to the time, purpose and amount of all distributions.”

## Basics, cont.

- If a trustee has complete discretion over the distributions, the trust is not counted for SSI eligibility.
- The funds in the trust may be used to supplement the beneficiary's needs without a reduction of SSI or Medicaid.
- A SNT should be drafted by an attorney to ensure that it achieves this legal objective.

# Questions?