

Theresa Varnet, Attorney-at-Law, on Government benefits, estate planning, and guardianship options for adult children with special needs

Government benefits:

Three types: Entitlements, welfare and sliding scale

Entitlements:

- FAPE: free and appropriate public education, to the day before 22nd birthday. Mandated by federal IDEA law (Chrisa's note: www.wrightslaw.com is an excellent resource for IEP and IDEA law)
- SSDI: supplemental security disability insurance. Child can earn this one of two ways:
 - Based on their work history, earned after a certain number of quarters worked (formula based on child's age when work started and current age) – AS LONG AS the child earns LESS than \$980 gross per month. Once the child shows they can earn more, child may be ineligible for SSDI permanently
 - If the parent of the child is disabled, retired, or deceased, based on the parent's work history
 - Must be able to prove the child is permanently disabled before the age of 22 (ICG grant could be proof of this) – this considers them a **DAC** – disabled adult child – unable to earn a sustainable living
 - The child can have a job, as long as the earnings per month are under \$980.
 - If the employer is a “benevolent employer” such as DORS or a family business or family friend giving the child a job as a favor, note this to the SSA
 - Note on insurance: many group health plans will cover adult children that are permanently disabled as long as you are covered. This is not law, check with your policy.
- Welfare benefits: child must be poor – less than \$2,000 in his or her name at any time (includes savings bonds, savings accounts). Over the age of 18, qualifies a DAC for SSI and Medicaid.
 - You can keep your child “poor” even if they live at home by charging him or her rent, for food, utilities, phone. Usually does not count as rental income for tax purposes because you do not make a profit on this.
 - If the SSA asks you if you charge rent – no matter how they phrase the question – say YES.
 - Can put that money in a separate account under your name, create a special needs trust (see below) and have that money pour over to the trust at your death
 - SSA looks at the child's ability to be employed. A high school diploma may prove some employability.

- There are seven categories of SSI payment – see the ssa.gov website for details.
- Sliding scale fee benefits: services based on your ability to pay for them
 - KidsCare in IL is an example
 - Title 19 waiver program in Wisconsin
 - Over 18 is based on child's ability to pay, not yours

Special Needs Trust:

- You can create as many special needs trusts for your disabled child as you like
- Trust is NOT a support trust. The trust, when created, must not have the phrase, “for the care, comfort, and support of child.” – that proves to the government they don't need government support, and can make them ineligible for government benefits
- Trust must be created as a third party special needs trust for the purpose to supplement government benefits and/or provide a higher quality of care than the government provides
- Trustee must be a third party – can be a friend, relative, or in IL, there are three non-profits that can act as trustee (see Theresa's website)
- The child cannot control the funds – must go to the trustee to have things paid
- Trustee decides what gets paid and what doesn't – if the child runs up a lot of bills, the trustee can refuse to pay them as not what was intended by you when you set up the trust
- A special needs trust does not require guardianship of the adult child
- Many lawyers that do regular trusts screw up creating special needs trusts – be sure the lawyer you use is a member of the Academy of Special Needs Planners or the Special Needs Alliance
- The trust stays empty until you die, then money from your estate pours over into the trust
- Can make the trust revocable so you can change the rules while you are still alive
- If someone else wants to create a special needs trust for your child – like a grandparent, they can, but must make it irrevocable
- Can have a “spray” trust to cover more than one special needs child

NOTE: Interesting life insurance policy for special needs parents called “second to die” – pays out only after both parents have died. Theresa has one and the beneficiary is an irrevocable special needs trust for her daughter, so that the payout goes into the trust. MetLife has a division of estate planning for special kids that has a policy like this. Cheaper the younger you are.

Guardianship:

- Powers of attorney are the most important:

- Healthcare power of attorney gives you rights to get the child healthcare, hospital admission, medical records
- Power of attorney for advocacy gives you the right to apply for benefits, attend meetings (IEP, etc) and act as the child's agent
- Many parents of DACs find this is enough
- All single adult children should sign a medical power of attorney for parents so you can act on their behalf if they are in an accident, etc – this is a standard form you can download from the internet
- Limited guardianship:
 - Can have guardianship over specific things, like finances
 - Can start with a limited guardianship and move to a full guardianship if needed later
 - This is determined by the court – must go before a judge and prove that the DAC requires this level of protection from themselves
- Plenary guardianship:
 - Total guardianship of the DAC
 - However, for extraordinary medical measures, such as donation of an organ, or clinical trials, must go before a judge to prove it is in the best interest of the child
 - Guardian is really the courts – you are the agent of the court
 - Once you have this type of guardianship, very hard and very expensive to back it down to a limited guardianship
 - If the child is you guardian, you can buy guardianship services for after you die, if you feel it is necessary

Other items:

- ALWAYS make the SSA put a “no” in writing. They are overturned on appeal 60% of the time
- Become familiar with work rules and earned vs. unearned income on the www.ssa.gov site
- Guardianship is under state law – if your child lives in a different state than you, must get guardianship in the state the child lives in
- DON'T pay your child's credit card bills if they have a habit of running them up – this just establishes good credit for them and makes it easier for them to get credit