

Have I done everything?

Things you need to stay on top when caring/planning for the future for your child with special needs

1. Guardianship

Unless your special needs child is competent to manage her/himself, to enter a contract, or to make decisions on health care, guardianship or alternatives to guardianship should be considered as a protection to your child when s/he turns 18. www.ffasn.org >Core Issues>Guardianship

If you are court appointed guardian for your child, remember to renew guardianship letter annually.

2. Finance:

SSI (Supplemental Security Income)– To qualify for SSI, individual's countable income must be below a set amount (\$735 in 2017) and resource must be below \$2,000

RSDI (Retirement, Survivor and Disability Insurance) – Unmarried individual disabled before age 22 is eligible for up to 50% of (either) qualifying parent's social security retirement benefit and up to 75% of that amount when the parent passes.

Your child will only get one check with whichever amount that is higher. However, if the amount of RSDI is higher than that of SSI, the spending restrictions on SSI are lifted.

If your child's total monthly income exceeds three times that of SSI, s/he loses eligibility for Medicaid Waiver. You can set up an income diversion trust, called Qualifying Income Trust (QIT) or Miller Trust. QIT has a Medicaid lien, at the death of the trust beneficiary, trustee must pay back to the state of Texas with unspent funds in the trust, up to the full amount of Medicaid benefits provided to the beneficiary.

How to assist your special needs child financially? For details, please follow the links

ABLE (Achieving a Better Life Experience Act of 2014) Account, www.ffasn.org >Core Issues>Master pooled Trust and The ABLE Act

Special Needs Trust, or Supplemental Care Trust allows families to set aside funds for the benefit of loved ones with disabilities while protecting their SSI and Medicaid benefits. www.ffasn.org >Core Issues>Special Needs Trust LW2016

A non-profit pooled trust such as The Arc of Texas Master Pooled Trust is a good alternative for families with limited fund or without a candidate for trustee. www.ffasn.org >Core Issues>Master pooled Trust and The ABLE Act

3. Medical Insurance:

Employer-sponsored insurance – If your child has Medicaid and is under your employer-sponsored insurance policy, you can apply for Texas Medicaid to pay for the premium at www.gethipptexas.com

To keep your disabled child under your policy beyond age 26, you must contact the HR before s/he turns 26 and provide evidence of disability.

Medicaid – In state of Texas, as long as your child gets SSI at any amount, even just a dollar, s/he is eligible for Medicaid.

Medicare – Two years after your child receives RSDI on your work record, s/he qualifies for Medicare.

Medicare Part B has a monthly premium, depending on the amount of benefit your child receives, s/he may get Qualified Medicare Beneficiary (QMB) benefits which pays for Medicare premiums, deductibles and copay.

What happens during the two years your child waits for the Medicare?

- As long as your child's accountable monthly income does not exceed the current SSI amount, s/he still has Medicaid.
- When the income exceeds the amount of SSI, s/he needs to reapply for Medicaid using form H1200-A, Medical Assistance Only (MAO) Recertification
- If your child is on any Medicaid or Medicaid Waiver program, you need to acquire a cover letter from your provider using form H1746-A. Please note that this form may not be copied as it includes a scan bar. Below is the link for instruction on the HHSC website.

<https://hhs.texas.gov/laws-regulations/forms/1000-1999/form-h1746-a-mepd-referral-cover-sheet>

Thereafter, Medicaid needs to be renewed annually. Remember, to avoid lapse of service, you need to renew within two weeks after you receive renewal notification.

You can renew online at www.yourtexasbenefits.com

Coordination of benefit:

Private insurance, then Medicaid.

Medicare, then Medicaid

Medicare, then private insurance, then Medicaid.

4. Will

When a person dies without having a valid Will in place, his/her property passes by “intestate succession” to heirs according to state law. His/her special needs child may receive assets valued at \$2,000 or more, and become ineligible for SSI and Medicaid.

Your Will contains your directives on how to distribute your estate. It allows you to allocate money into a Supplemental Care Trust for your child with special needs, which will prevent your child from exceeding asset limit and losing benefits. Your Will also allows you to name successor guardian and successor trustee for the special needs trust.

5. Beneficiary designation

Do not list your special needs child as beneficiary for your 401K account, IRA account, pension or life insurance. Direct all relatives and friends to exclude your special needs child from inheritance/gift. Instead, leave funds into the special needs trust set up for the individual with special needs.

6. Letter of Intent

Organize everything you know about your child in a Letter of Intent. This should include a complete medical history, current physician and medication, allergy list, dietary restriction, routines, holiday traditions and other details you deem important. Leave a copy to the successor guardian and the provider or whoever will take care of your child after you pass. A template is available at www.ffasn.org>Core Issues>Core Documents Library. Letter of Intent should be updated annually.

7. Personal Support Network

Invite your relatives, friends and your child’s care staff to form a personal support network. Meet regularly. The support network will be invaluable if anything happens to your child’s primary care giver.

8. Letter of Last Instruction

This letter is for whoever takes care of your affairs immediately after your passing. List who will break the news to your child with special needs, who will take care of your child from that point on. List your desire for funeral arrangement. List the name and contact information of your lawyer and the location of all your important documents. List all of your financial account information and service account information. List people and organization to be notified of your passing

An up-to-date copy should be kept with a close friend/family member to be opened at your passing.

9. Legislative update and Advocacy

Your special needs child depends on you to protect her/his government benefits. Be diligent on legislative changes and talk to your representatives on preserving the state/federal benefits for your child.