This Q & A article is from BDSRA’s “Ask An Expert” Facebook Chat in the BDSRA Closed Facebook group for parents and caregivers.

\*Please note: the information contained in this material is intended to provide

basic information to Batten families and caregivers. It is not intended to be, nor is it, legal or financial advice for individual children or an individual family. Parents and caregivers should consult with an attorney or accountant for specific guidance on legal and financial matters.

“Financial Planning & Special Needs”

Featured Experts:

Brayden Falk and Nathan Buckles

Special Needs Project for Education & Advocacy

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Q: What does the Special Needs Project for Education & Advocacy do?

A: They help educate families around special needs planning and cover areas like legal planning, government benefits, budgeting, and planning one’s finances to accommodate factors such as lifestyle.

Q: When should families begin the process of planning for their child/teen?

A: Families should start the planning as soon as possible. Although a lot of what we deal with is for the future when mom and dad aren't able to care or no longer here we never know what tomorrow holds. If assets are not left properly to their loved one on government benefits those benefits could be lost and Medicaid can actually claim payback from your child. A lot of families want to know how do we do this, the best option to consider is using a Special Needs Trust.

Q: Has anyone ever heard of a Special Needs Trust before?

A: By using a Special Needs Trust families (mom, dad, grandparents, aunts, uncles) can leave assets for their loved one without risking government benefits and there is not payback on money left to a Special Needs Trust by Medicaid.

Q: What about guardianship?

A: Guardianship is a decision that needs to be made as your child approaches 18. If you feel it is appropriate for your loved one then you can start the process 6 months before their 18th birthday. Depending on what state you are in the process will be a little different. Bust basically you apply through your local probate court and go through the process of getting a medical professionals opinion, meeting with a court investigator and meeting with court appointed attorney assigned to your child. There is a big misconception out there that you need an attorney to do the guardianship. Unless it is a contested case where mom is trying to keep dad out, as an example, you do not need an attorney. You must have a will created to name your successor guardians. If you have no will and something happens if your child is a minor or you have guardianship of your adult child, the state you live in gets to make the decision around who will be the guardian in your place. So far have not met a family that is excited about that.

Q: What if there I'd no one to be a guardian do you just pick a home?

A: In each county (larger ones) they are public fiduciaries and possible guardians that could be named. If not then they would become a ward of the state and probably placed in a home.

Q: Is there a place to do a simple will online or do you need a lawyer? I have one just should be updated since 2007?

A: You can use online services for a will, like Legal Zoom or even check with your local disability law center. They may have some work they will do for free. The only concern is to make sure wording is correct that no assets are left directly to your child by name. You would want to also create a special needs trust and in your will stipulate that their assets go to the special needs trust not to them directly. Otherwise government benefits could be lost. Assets left to a special needs trust are not a countable resource by Social Security or Medicaid. This way you can leave money for your loved one and maintain eligibility. The special needs trust is not a document you would want to do online. This is a document that has to be created correctly or the government agencies can interpret things incorrectly in the future count the money as a countable resource. One of the most common ways the Special Needs Trusts are funded is through life insurance. This can often be the most inexpensive way to ensure there will be a lump sum of money to go into the special needs trust. Also you need to know that all Life insurance, retirement accounts (IRAs, 401k, etc) and annuities pass by beneficiary designation. So if your child is named as a beneficiary on any of those products their money would go directly to them and not the special needs trust. One of the steps we take families through is to make sure all the beneficiary designations are updated once the documents have been created. One of the most important parts of the planning is what we call Lifestyle planning. This part of the planning is about your child. What is unique about them, how do they need to be cared for. What foods do they like, what do they not like. What medications are they on, who is their doctor etc. This is all captured in a document called a letter of intent. If you think about it how is someone supposed to know that daily routine of your loved one unless they have lived it. So by creating this document we are giving future care givers a letter of instruction around who your child is. The one we use is 19 pages long. It not only can help in the future but maybe you want to get away for a weekend. Give your respite worker the letter of intent. Now they know everything they need to know. The reason we are all here today is to help preserve our loved ones health, quality of life, happiness, how can we do that if no one knows all the little things in life that make life enjoyable?

Q: I thought I needed it before since in our state 14 year olds make their own medical decisions so the pharmacist said I can't get her meds or have access to her records.

A: No, that is not correct. At the age of 14 our loved ones do have their own voice and can speak for themselves but she is still a minor and you can make those decisions on her behalf as mom.

Q: How do we know if the special needs trust is accurate. Our regular lawyer did it, do we need a special attorney?

A: I would suggest for you is that we can review them for you for free just to make sure or if you have a local attorney who specializes in Special Needs. They are hard to find. One thing we have learned over the 35 years we have been planning with families is that just because someone is an attorney does not necessarily mean they know what they are doing in this realm.

Q: I'd like to know if parents have been successful in obtaining SSI benefits for their child? What roadblocks have you faced? Any with having family assets?

A: Right SSI is typically available at 18 based on the child’s income and assets under the age of 18 it is based on the parent’s income and assets to qualify.

Q: What I found irritating when trying to get assistance back then, was they did not take into account the medical expenses. Our insurance did not c9ver office visits and we had 5000 deductible which included meds. I remember paying over $400 a month in meds. What can I do?

A: Wow right unfortunately it is based on gross income and also assets that are in your name. Does your state have Medicaid for children under 18? These medical expenses are a great example of what parents need to plan for. If mom and dad are not in the picture any longer then the Special Needs Trust would be there to help fund your child’s supplemental needs. Medicaid for a child under the age of 18 should be based on the child’s income and assets not yours. As long as they don't have more than $2000 in their name they should be able to qualify for Medicaid under the age of 18. What we see in some states is the funding for Medicaid of a minor is grossly underfunded and you may end up on a wait list and never get the benefit until the child turns 18 anyway. There is also help available from the United Healthcare Children's Foundation. If eligible, they provide medical grants to help pay for medical services, equipment, PT, OT, Speech therapy, counseling, surgeries, prescriptive medications, wheelchairs, orthotics, eyeglasses and hearing aids. Their web site is: [www.uhccf.org](http://www.uhccf.org).