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Special Needs: Who do you trust?

Most of us have been independent for our adult lives. We went to school, got a job, bought a car, drove to work, handled our finances and purchased the items that improved the quality of our lives. If we wanted something we simply reached out for it. Being independent doesn't mean that I can't use some help once in a while or have no need of society, but it means that I have freedom to choose and do most anything I want. For a person with a disability most if not all the actions on my list are not possible.

They may desire to purchase a car or go to work but sometimes the severity of the disability prevents them from achieving the freedom to acquire those things. If I am dependent on someone to take me somewhere and they don't show up, then I don't go anywhere. Think about the necessity of needing someone to feed, cook, drive, shelter, and make the medical decisions for you.

Parents with special needs children are the first line of defense. This is their child and the effort necessary to provide these necessities is not a responsibility but a loving opportunity to help someone they love. Unfortunately, since no one lives forever, planning for an uncertain future for themselves and their spouse becomes difficult when a special needs child is involved.

As parents age their own health issues may interfere with delivering the time and attention that a person with a disability needs when it is needed. One parent may have a stroke or perhaps develops dementia. As the focus shifts from caring full time for a child to caring for oneself or a spouse, a risk develops that care may not be as available as in the past. Since many people with a disability outlive their parents today this lapse, which can last many years, could easily move to neglect whether it is intentional or not.

The second line of defense comes into play. If there are siblings the assumption is that they will maintain the continuation of care. A loving and close family is more appealing than having strangers get involved. That may seem an obvious solution but what if there are no siblings? More difficult yet is whether the children wish to take on that role.

Parents need to think carefully about the selection of a sibling to take over the parental caregiver role. When I went to court to seek conservatorship for my sister, who was born with Down's syndrome, to put me and not the state as the person responsible for her care the judge explained to me the reasons why he was reluctant to appoint a sibling.

I was young and as such I would have my own family to look after. The needs of my children would be different than my sister's. What about the difficulties added to my wife's duties?

My career may require that I relocate to another state. Do I uproot my sister from her home, job, friends or program? He pointed out that, being young, my future was very unpredictable and for someone with a disability uncertainty creates instability. This presented a risk that neglect and lack of supervision would put my sister in a vulnerable situation.

If a trust is created, then the trustee, who is probably trustworthy, still needs someone or a group of people to provide oversight and review of the trust administration.

Trusts also require financial management and accountability. Paying the bills, keeping thorough records for tax purposes and investigating services before paying for them place an enormous responsibility on the trustee. If something goes very wrong then who is accountable? What is the likelihood of recovery if that trustee, is not a professional fiduciary with resources and insurance to recover mismanaged money? The beneficiary does not have the ability to recreate funds to provide for themselves.

I was wisely counseled by my attorney to seek conservatorship of my sister and not the finances. It was the best advice I ever got. As I would receive copies of her bills and benefits I could see I the possibility of being overwhelmed.

Being conservator had enormous responsibilities too as I had to make her healthcare decisions and visit her regularly for almost 50 years. As she aged her health problems multiplied, and, between signing all the forms, reviewing her medications, talking and meeting with her healthcare providers at the end of her life, her needs became overwhelming for me. The judge's predictions would turn true. I had three children; and only moved a couple times but my career required so much of my time and energy I was often conflicted in my scheduling. I grew accustomed to the demands of caring for my sister, if not out of love then out of the recognition that if I cut her adrift she could end up back in a state run hospital. Fortunately for me, I did not seek conservatorship of my sister's finances.

These questions are important to consider whether or not to use a professional trustee. There are many professional trustees who can provide different levels of services and provide individualized programs while acting as a regulated, bonded protector. They have the resources and contacts to deliver these necessities to your child.

But if, in the end control, over the trust is important then the option to include a Trust Protector can be helpful. Your attorney can assist you in the selection of a Trust Protector and designate the powers that he has over the trust. He could veto investments decisions for example.

Planning for a Special Needs child will require a lot of thought and effort. Take the time to investigate the role and advantages of a private trustee. There are a lot of resources available to help you in your search.

Ultimately if I had to make a tough decision like this, I would ask myself "what do I want if this was a trust for me?" Would I really want my brother to take care of me and manage my money?



Robert McLalan is a Financial Advisor with the Wealth Management Division of Morgan Stanley in San Mateo, CA. The information contained in this article is not a solicitation to purchase or sell investments. Any information presented is general in nature and not intended to provide individually tailored investment advice. The views expressed herein are those of the author and may not necessarily reflect the views of Morgan Stanley Smith Barney LLC, Member SIPC, or its affiliates.

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