
Mental Health News – A Mother’s Challenge: Planning for the Transition of Decision-Making

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By Carolyn Wolf

On a recent airing of National Public Radio’s “This American Life” the narrator tells the story of Emily Feldman, a New Jersey woman in her 70’s who has been caring for her 39 year old autistic son, Scott, all his life. Emily is getting on in years and she knows she cannot continue to care for Scott much longer. So Emily buys her son a house and begins a long, but ultimately unsuccessful journey to find someone to help care for Scott when she no longer can. She questions officials at City Hall, puts fliers in the newspaper, and even knocks on neighbors doors, all with a single task in mind; help my son when I’m gone. Despite Emily’s lack of success the story does have a happy ending. Scott, despite his autism, is high functioning and more resilient than his mother gave him credit for. He learns to fend for himself where he can, and more to the point, ask neighbors and others for help when he can’t.

In the world of individuals with serious [mental illness](#) and Autism Spectrum disorders, and the mothers who care for them, usually adult children, there are a myriad of stories like Emily and Scott Feldman’s. Mothers of children with mental illness often play the simultaneous roles of mother, health care decision maker and financial manager. They are intimately involved in their often adult child’s medical and psychiatric care as well as managing their finances and paying their bills. This article will attempt to answer the vexing questions that arise when these mothers are either no longer capable of taking on this herculean task due to age or illness, or are no longer around because they have passed away. Questions arise, such as who will make psychiatric and medical decisions for them and how can I ensure that they are financially taken care of and protected from abuse.

Advance Directives

While it is impossible to find someone with a mother's dedication to her differently abled child, the law does allow for several avenues by which others can make medical decisions. A Health Care Proxy allows a mentally ill person to appoint another individual to make medical decisions in that person's place. Moreover, a Health Care Proxy can be created which can appoint the individual's mother as the initial decision maker (Health Care Agent), and then a successor Agent who will step in to make decisions when the mother is no longer capable of doing so. This all assumes that the child in need has the capacity to choose a health care agent and successor agent and one is available to act in that role.

In the event that the person lacks the capacity to appoint an agent, the newly enacted Family Health Care Decisions Act allows for family, and/or friends to make decisions even if a Health Care Proxy is not completed. The law creates a hierarchy of decision makers; the spouse, if not legally separated from the individual, or the domestic partner; a son or daughter eighteen years of age or older; a parent; a brother or sister eighteen years of age or older; or a close friend.

It is important to note, however, that whether applying a Health Care Proxy or the Family Health Care Decisions Act, no one may make decisions to involuntarily hospitalize an individual or to force someone to take medication over their objection.

When dealing with end of life issues, there are other options, such as a Living Will or Do Not Resuscitate Order, which will ensure that an individual's medical needs and desires will be properly cared for. These instruments create specific instructions for health care providers on what treatment the person wants and does not want in the event they are suffering from a disease that will surely take their life. (Again assuming the person has the mental capacity to execute such a document or directive.)

Financial Planning

Perhaps the easiest way to make sure a differently abled finances will be cared for when the parent no longer can take on these duties is the creation of a *Durable Power of Attorney*. A Durable Power of Attorney allows an individual to make financial decisions on behalf of the child. Unlike the Health Care Proxy, which only goes into affect when the person loses capacity to make decisions, a Durable Power of Attorney authorizes the agent, called an "attorney-in-fact", to make decisions while the person is capacitated and also when the person loses capacity. A Durable Power of Attorney can be as broad or limited as the individual would like, authorizing the "*attorney-in-fact*" to make all or only specific financial decisions.

Another option, which becomes very important in protecting access to government benefits, is the creation of a Supplemental Needs Trust. Any assets placed in this kind of Trust will not affect an individual's eligibility for Medicaid, Social Security Disability, or Social Security Income provided that the funds are used to supplement not supplant benefits already received. This type of Trust can be created for anyone who has a severe and long-term disability. Generally, people with severe mental illness who receive Social Security Disability will qualify for the creation of a Supplemental Needs Trust. Once the Trust is created a Trustee will approve all money expended from the Trust and has a fiduciary duty to make sure that the money is spent for the benefit of the person for whom the Trust was created.

The downside to a Supplemental needs Trust, however, is that the Trustee administering the Trust, often a bank, will take administration fees. Not only does this diminish the value of the Trust, but unless the Trust is very large it will be difficult to find a Trustee to administer it. In this event, one should look to

Pooled Trusts, typically run by a charity, where many people pool their money together. The drawback of a Pooled Trust is that once the person dies, any money still in the Trust must either stay in the Trust, or if it is removed from the Trust it must be used to payback Medicaid for money it has expended on the person's medical expenses.

Guardianship

Another possibility is to petition the Court to have a [Guardian appointed](#) for the child in need of assistance. A Guardian can be granted extremely wide ranging authority, such as making medical decisions, financial decisions, where the person should live, if they can travel, and what their social environment can be. Likewise, [Guardianships](#) can be tailored to be less restrictive and therefore a Guardian will only have limited authority over a person's life. The flexible nature of the Guardianship proceeding is one of its distinct advantages. Moreover, a Guardianship proceeding allows the mother to choose exactly whom they think will make the best decisions for her child. Another advantage that a Guardianship has over the other options already discussed in this article is that a Guardian can make decisions for the person even if and when the person disagrees with the decision.

Like Health Care Proxies and the Family Health Care Decisions Act, under New York Law, a Guardian cannot make psychiatric decisions for a patient over their objection. Only a psychiatric hospital can involuntarily hospitalize someone and only a Court can order treatment over a person objection.

Psychiatric Case Management/Geriatric Care Manager

A [Psychiatric Case Manager](#) or [Geriatric Care Manager](#) is someone specially trained, generally a social worker or a nurse, who can assist on a daily basis with the logistics of overseeing the care, interventions or management of an individual with serious mental illness or Autism Spectrum disorder. They often can most efficiently and effectively monitor and make active the proposed psychiatric and/or medical care plan as well as keep a close eye out for financial management in the best interest of the individual or potential financial abuse, and intervene timely and appropriately.

Conclusion

Mother's who have cared for their differently abled child all their lives must plan in advance of their declining years to ensure that their child will have someone to make the decisions they no longer can. It is important to talk with your child to see what it is they want, and what it is they can handle on their own. Some children may be perfectly capable of handling their medical and psychiatric care and only need some help for financial matters, others cannot. It is also helpful to contact a legal specialist in this area, for example a [mental health attorney](#), who is familiar with mental health issues and has the specific experience to advise and guide a mother through an often extremely difficult and confusing array of options.