

# THE MENTAL HEALTH LAWYER



## A Mother's Challenge: Planning for the Transition of Decision-making

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**O**n 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



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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

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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.

**System Reform from page 16**

*(18% rated this "very/somewhat likely" to use).*

A recent Rand Report found about one-fifth of all service members returning from Iraq and Afghanistan screen positive for mental health problems, and that multiple barriers prevent about half from seeking the information and care they require. These barriers include "perceived stigma, physical access barriers, and limited resources."

The T2 Virtual PTSD Experience is a self-guided exploration which immerses the visitor in a simulated combat-related traumatic event to demonstrate how PTSD may be acquired, its triggers, the role of avoidance, and the "use of time outs" through a series of interactive activities

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to speak openly about sexual traumas, out of fear of being disloyal to the family or being perceived by their community as disloyal.

PTSD symptoms of avoidance and hyper-vigilance may cause women to terminate treatment prematurely. A client who is normally very compliant may avoid sessions once she is processing her trauma(s) (Davis et. al. 2008). Hispanic women may experience this in a more conflicting manner. On the one hand, they want to avoid painful feelings, yet they want to uphold the cultural value of "saving face." Case in point, as a child, Tanya, now 33, was sold for sex by her mother, enabling her mother to purchase drugs. As our work intensified, Tanya began to skip sessions. When this avoidance was addressed, Tanya said "I did not want to disappoint you." She valued me as her therapist and thought I would be both-

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rate, brain wave patterns, and internal biochemistry. When a stressor is time limited, our bodies return to their usual state. Ongoing stress can produce what Herbert Benson MD calls a "pathological stress response" where these physical changes persist. A mother constantly experiencing pathological stress can have more frequent illness due to a depressed immune system, depression, anxiety, physical problems such as headaches and stomachaches, and even decreased fertility. Being overly stressed can make her more likely to overreact.

Based on my work with many Moms, there are strategies that help, even if they don't solve the underlying situation. Combating isolation is critical. A support group can be important to counter her sense of alienation. Other Moms who

**Psychiatric Case Management or 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

controlled by the visitor. It is anonymous, available anytime and free of charge.

Preliminary research has shown it is a significant adjunct to web-based resources and face-to-face care. Future applications could include suicide prevention, how to avoid substance abuse and sexually transmitted diseases, pregnancy, etc. among teens and pre-teens.

**Remote Job Skills Training**

While distance learning has been around for many years, we are just beginning to explore its full potential for vocational training at group and private homes with special needs populations (e.g. Autism Spectrum Disorders/Asperger's Syndrome, mild Mental Retardation, and the physically challenged).

ered by her not wanting to explore her trauma. Clients may also dread the realistic fear that hyper-arousal symptoms will resurface or get worse as the treatment progresses. A mother's symptoms of hyper-vigilance, which had dissipated, resurfaced when she became increasingly concerned about her daughter. The mother's fear that someone would break into her home caused her to sleep with a knife under her pillow. This was her way of gaining back control.

Other barriers to accessing treatment for a Latina survivor of trauma include a lack of therapists who speak her native language, ineligibility for services, active self-mutilating behaviors/being actively suicidal and past or current substance abuse (Davis et. al. 2008). Dealing with one's trauma(s) can trigger a relapse, as can any crisis. An example is Alma's grief over the death of her 21 year-old nephew, who hung himself. During stressful times, Alma's unresolved grief com-

know of resources, strategies and tips for managing school, home and family issues are invaluable and give hope. If this kind of support group doesn't exist, a professional, organization or even religious group might help form one. Friends can be helpful if Mom can reach out and let them know how to be helpful, whether by providing emotional or logistical support or simply time out from worrying. Mental health providers working with the child should communicate empathy and understanding; parents can feel less defensive and more open to change. The feeling of distance or even blame only intensifies the stress and the reactions to stress that are detrimental to all involved.

Therapy can be important in bringing together parents, or parents and children, in a constructive way. Marital therapy can help address the differences in roles and perceptions between the Mom and Dad. It

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.

The Center for Career Freedom began handing out webcams to those students who lived too far away to come to our Microsoft Office training classes every day and to student in group homes who had difficulty accessing the proper transportation. The webcams enabled folks to participate in live interactive classes from the comfort of their own home, regardless of the weather. Facial expressions are clear, through the audio can have a slight delay and there are a few "bugs" that need to be worked out. Files are easily transmitted including templates, completed work, quizzes, teacher feedback, etc.

Cameras run from \$20 - \$80. Skype.com provides free 1:1 video services. Other applications we are exploring include: staff training, family video

pelled her to consume more alcohol to escape painful emotions. Another example is a mother who resumed drugs when she realized her daughter's hypersexuality mirrored her own behavior that resulted from her traumas. An additional obstacle is that the therapeutic relationship is built on trust, and a Latina's traumatic history can make establishing such a rapport difficult. Hispanic women who have experienced sexual traumas and whose perpetrators were men will have an extremely hard time opening up to male therapists, if at all.

When treating Latinas with traumatic histories, clinicians must take into account the aforementioned barriers. The following are practice considerations when working with Hispanic women: 1) When a Latina's sessions revolve around her children, the therapist must acknowledge the importance of her family, while assessing whether her focus is resulting from avoidance. 2) An Hispanic client who lacks childcare may need the thera-

can help him understand the illness if he doesn't and take a more active role so the mother is less burdened (and resentful). The parents can become a team. Family therapy can validate the feelings of siblings, and address family issues exacerbated by having a child with such strong needs. Therapy for the mother can help her with self-blame and provide a more balanced understanding of the situation.

Moms often put their own needs last on their "to-do" lists; they are often "running on empty." Outside activities that refuel her, such as exercise, yoga or music can be a break, give some pleasure, and a sense of having a part of life independent of being a caretaker. Mindfulness meditation can lower the baseline level of stress and diminish the ongoing level of the stress response.

Having worked with the hundreds of mothers I've seen in my 25 years of prac-

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.

visits, building your on-line community, "Town Hall" meetings, health screening, and dispute resolution.

We may agree challenging times requires innovative thinking (creative problem solving, new tools, experimentation, pilot studies, etc.) but I believe the most effective and efficient solution(s) will be found by providers who have the skills to listen and learn from their clients and the courage (and funding) to turn "solutions" into action.

*Publisher's note: This is Don's final column for Mental Health News. He is busy launching the Center for Career Freedom's Microsoft Office Skills Employment Program for persons with mental and physical disabilities. We wish him all success.*

pist to help her obtain childcare. Or, the therapist may postpone dealing with emotionally laden issues while waiting for such services. 3) In order to remove the burden of traveling with limited finances, the therapist might consider home visits. 4) The therapist must uphold the Latino value of "respeto" (not bringing shame to one's family/community) that a Hispanic woman may feel when processing her trauma. Of equal value is acknowledging that silencing painful traumas will not help her feel better. 5) A woman receiving Trauma-Focused Treatment must be informed that she will likely feel worse before she feels better. A Latina experiencing avoidance may feel the double bind of not wanting to deal with the pain of the trauma and not wanting to disappoint her therapist. The therapist will need to acknowledge this and possibly allow the processing of the trauma to slow down. As therapists, we must commend Latinas who, despite all these barriers, are able to effectively process their traumas.

tice, unfortunately what I've described here is commonplace. I've seen them worn down and in tears when they feel someone "gets it." I've seen Moms who feel helpless and hopeless about having life improve. Some respite services are now available, but unfortunately, many mothers hesitate to be open about their needs. They fear looking inadequate or out of control. One Mom used the image of a duck to express how she felt: from the surface it looks like it's gliding along, but it's paddling furiously underwater. It's important to remember that Moms in particular need the encouragement of families, friends and professionals to meet their own needs, to have stamina and the calm to persevere.

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