Adult Children with Developmental Disabilities

By Joanne L. Erickson

While the laws governing guardianships are now “uniform” thanks to the Massachusetts Uniform Probate Code, I find that the stories behind guardianships are anything but uniform. The forms streamline the facts and fit the cases into the new model. However, the personal stories and family histories continue to make the cases unique and challenging, as ever, especially when told by people who are living these stories every day. The dedication of families who care for their adult disabled children and siblings is a humbling experience for anyone fortunate enough to observe their efforts.

There are a growing number of adult disabled children who are now outliving their parents. Families are driven to find a plan that ensures that their loved ones will be safe and well cared for when they are no longer able to care for them. In addition to living longer, adult disabled children are now experiencing age-related impairments at a much earlier age when compared with the general population. As a result, families need to address medical issues that compound existing impairments that their loved ones have lived with.

Case Study
It may be helpful to show how these developments can weave their way into a person’s life by looking at Brian’s story. Brian is a delightful 48 year old adult male with Down syndrome. He has lived with his parents his entire life – it is the only home that he has ever known. He has two older siblings who try to help their parents with Brian but they have their own family responsibilities; the family dynamic is very good.

Brian interacts well with others, although sometimes he is shy, but overall, he is very trusting of people. His impairment has been diagnosed as within the moderate range, but he is able to take care of most of his daily needs with supervision. He is always in a supervised setting – either with his parents, his siblings, or program workers.

His health is generally good but when he has an issue, he is not always able to communicate his needs. He takes medication for hypothyroidism which is monitored regularly. His eating habits have always been an issue as he prefers foods that exacerbate his weight which his parents try to watch. They understand that obesity can quickly occur and that it can bring with it diabetes and other related issues. His parents always work to keep Brian physically active and bring him with them on most occasions. He has lost many of his teeth due to grinding and his parents are looking into possible transplants as he is having increased difficulty chewing food.

His parents have worked with the local agency for many years. Both Brian and his parents enjoy activities where families, such as theirs, can interact and enjoy themselves. Brian is enrolled in a work program a few days per week. However, lately there have been days when he has been less interested in going. Also, recently Brian has forgotten some regular routines that are an important part of his day such as walking the dog, taking out the trash and getting the mail. He does not complain about things but has often appeared quieter than in the past.

Brian’s mother has been experiencing difficulty sleeping, anxiety attacks and appears to be showing signs of care-taker burnout as she is now care-taking for two.

Attorney Joanne Erickson

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Over the years, state case workers mentioned to Brian’s parents that they should look into being appointed as Brian’s guardians. However, as they have been handling Brian’s medical care for many years without incident, they did not think it was necessary. Recently, however, as they have been having their own health issues, they are now thinking that it might be a good idea to contact an attorney for assistance. They want an attorney who will understand their worries and help them get things in place should they not be able to care for Brian. They also heard of a situation through one of the families they know through the agency, where one of the parents died unexpectedly and the family had to go to court on an emergency basis. Brian’s parents do not want that to happen to them.

Growing Population

Generally, life expectancy of adults with mild to moderate range developmental disabilities is similar to that of the general population. However, this has not always been the case. In the 1930’s, a developmentally disabled person’s life expectancy was 19 years whereas today it is 70 years—an increase of 250%. The disabled population’s increased life expectation, like that of the general population, is due in large part to advances in medicine. Further, there has been an increase in availability of programs, services and supports for disabled individuals and their families. These quality of life improvements produce benefits that may never appear as a line item on the state budgets but are truly invaluable assets to those who participate in and benefit from these programs.

Care-taking for this population continues to primarily be done in the private family setting with an estimated 76% of persons with developmental disabilities live at home. In 25% of these households, the family caregiver was age 60 or older, and the average age of the disabled person was 38. Extended life expectancy is translating into extended care-giving periods for individuals and their families.

As seen in Brian’s story, he will always need some form of supervision. The most important relationship in his life has been with his parents. As a result of their efforts, Brian can do many things for himself. He also is able to participate in activities outside the home which allows him to interact with his peers— an important part of his life. With these supports and activities, brings with it a sense of purpose, independence and accomplishment that are key elements of Brian’s continued well-being.

However, as we have seen, Brian’s parents are aging and beginning to have their own health issues. If his quality of life is to continue after his parents are not able to care for him, a permanent legal representative (a guardian) will be needed to step in to help with his daily activities, medical decisions as well as other matters.

As Brian’s parents have been in control of things throughout his life, it would seem logical for them to be his guardians. However, given their age and current situation, it would be best to appoint a guardian who will fit into the long-term plan for Brian’s care. A possible option would be to have one or both of his parents to serve as his co-guardian(s) along with another individual who could serve in the event that Brian’s parent(s) are no longer able to do so. His siblings have their own families and responsibilities. Whether Brian’s siblings are willing and able to take on these additional responsibilities would need to be determined. It is best if these decisions can be made in a non-crisis mode and not on an emergency basis which can be expensive and burdensome at a difficult time. Brian’s family is aware of the impact that the loss of a parent will have on Brian and they all want to mitigate that impact. A compassionate guardian/advocate for Brian can make these difficult times much smoother for him.

Medical Issues

There are an estimated 641,000 adults with developmental disabilities. It is expected that this figure will double by 2030 to more than 1,200,000 when the baby boomers are in their sixties. Age-related medical issues are increasing in this population and are appearing earlier in individuals with disabilities.

Disabled individuals are now experiencing major changes in their health, functional abilities and psychosocial status at a much earlier age. Cognitive and physical impairments of a disabled person’s life have always impacted their health. Chronic health conditions (including diabetes, cardiovascular disease, respiratory disease and infection),
pain, loss of energy and endurance are impacting disabled individuals and their families at a much younger age. Timely and appropriate diagnosis and treatment of these conditions is needed so that individuals can remain active and independent for as long as possible. In the Down syndrome population, there is a growing issue with the increase of early-onset Alzheimer's disease. The occurrence of dementia, of the Alzheimer's type, is much higher in this group (15%-40%) and it may occur as much as 15 to 20 years earlier than compared with the general population.

The subtle changes in Brian's activities and interests could be a sign that he may be experiencing cognitive changes. Reaching out to his primary care physician for assistance is the first step and hopefully will lead to further testing. As Brian is not a good reporter of his health, one of the most effective steps would be to arrange for an early baseline test by a neuropsychologist who is familiar with this population.

This is done to determine if Brian is experiencing dementia-related symptoms. Early diagnosis and treatment will help his parents, as well as any future caretakers, to understand better what he is experiencing cognitively and physically as he ages.

Guardian's Pivotal Role
The role of a guardian is pivotal. This person has authority to speak on Brian's behalf, has access to his records and has the ability to advocate for testing now and in the future, if needed. A guardian can also arrange for suitable housing for Brian. The goal is to keep Brian in a family setting but his parents understand that things can change as they have recently experienced.

Having someone with legal authority to make decisions for Brian that are in his best interest when his parents are gone seems to be more and more important to them. Although a difficult decision, they have decided that they will book an appointment with an attorney who does this type of work so they can get some piece of mind about their Brian.

ABOUT THE AUTHOR
Joanne J. Erickson is an elder and disability attorney with offices in Abington, Quincy and Hingham. She assists families, disabled individuals (privately and court appointed) and is a member of the Massachusetts Guardianship Association Board of Directors and ARC of the South Shore. You may reach Joanne by calling (781) 871 – 7223 or visit her web site at www.jericksonlaw.com.

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