

parenting plus

My Child is Turning 18 Years-Old... Do I Need to Become Guardian?

By Nancy Mercer, L.C.S.W.

Executive Director of The Arc of Northern Virginia



For the parent of a child with disabilities, the fear of “what is going to happen when the yellow school bus doesn’t stop here anymore” is a very real one. In Virginia, most families find that the supports they have access to during their child’s early life are offered primarily through the public education system. But, beginning at age 16 (as mandated by the Individuals with Disabilities Education Act (IDEA)) families are asked to begin planning for their child’s “transition” to adulthood. During Transition services, families begin to realize that the long-term supports their young adult children will need in the community are terribly underfunded if they exist at all, and it is not unusual for parents to feel as if they must become the guardian for their adult child — to provide the ongoing support and guidance where the school system leaves off.

Unfortunately, guardianship — although a way for a parent/sibling to take on the responsibilities of deciding where their loved one will live and how meals, personal care, transportation and recreation will be provided and health care decisions made — can come into direct conflict with allowing their loved one with a disability to enjoy their civil liberties and develop their autonomy as an individual.

Guardianship revokes the rights guaranteed to an individual by the Constitution and the Bill of Rights — and should never be entered into lightly if any other reasonable alternative exists. It is important to understand the basics of guardianship:

- 1.** It is a court-ordered relationship in which one individual becomes the substitute decision maker for another;
- 2.** Its creation, conduct, and termination, are legislated by the state;
- 3.** It is rooted in the legal power of the state to protect persons with disabilities;
- 4.** While it provides protection, it also, by definition, takes away many rights.

The individual is afforded the following rights under guardianship:

- The right to express one’s wishes and to have others listen;
- The right to make decisions for oneself in so far as they are able.

Ultimately, an individual does not have the legal authority to carry out their wishes or decisions without the final consent of the guardian. And furthermore, guardianship should not be confused with securing the ultimate safety of your loved one with a disability; individuals and families should continually work on building community living, health and safety skills regardless of guardianship status.

Guardianship is an option of “last resort” that should be entered into only if it is determined that the individual does not have the appropriate supports in place to manage his/her own affairs and protect his/her health, safety, and welfare. It is important to take the time to investigate alternatives to guardianship, and find a good lawyer and financial planner who can help you make informed decisions that will protect your loved one and their siblings today and tomorrow.

Ideally, during the transition from school to adulthood the individual, family, and representatives from the school and the adult system will begin the process of defining and tailoring a roadmap which affords the young adult with the opportunity to grow and thrive as

an autonomous individual (without full guardianship) while at the same time, creating an avenue for addressing those skill areas where he/she may need some support— typically in the area of finances and making complex medical decisions.

By taking the time to understand the strengths and needs of the adult child with a disability the family can make some educated decisions about how best to support their loved one in his/her new role as young adult/community member. Some different options are listed below.

If the family does not feel that their loved one could serve as his/her own decision maker even with the types of supports described above, or they do not have the formal/informal support network necessary to help him/her serve in such a capacity, then guardianship may be the only option.

At that point, a formal assessment should be completed and documented. There are a variety of methods available to assess an individual's capacity to make decisions.

These include:

- o Cognitive Functioning Tests
- o General Evaluations for Capacity; and
- o Specific Evaluations of Capacity.

(Professionals must administer these tests.)

Even when guardianship is the option you choose,

remember that

- o Our loved ones are people first — not a disability;
- o They need to be treated with dignity;
- o They need to be treated with respect;
- o Listen to them whether they use words or not; and
- o Promote their full participation in decision making whether others like their decisions or not.

The Arc of Northern Virginia, an organization “Committed to Building Communities for Citizens with Disabilities”, is a wonderful resource for developing a life plan and pulling the pieces together to identify how best to support your loved one with a disability and your family. For more information please call The Arc of Northern Virginia at 703-532-3214 or visit The Arc Web site at www.thearcofnova.org.

Find out about Guardianship and Alternatives by visiting www.vgavirginia.org ■

Ms. Mercer is a licensed clinical social worker with 23 years of experience working with children, adults and families living with lifelong disabilities, in both the private non-profit and public school system. In addition to her role with The Arc of Northern Virginia, Ms. Mercer is also a board member of The Arc of Virginia and the Virginia Guardianship Association. Most importantly, Ms. Mercer is the proud mother of two young men ages 18 and 8, who both actively work to “build community opportunities for all citizens”.

Activity	Alternative(s)	Court Ordered Relationships
Money Management	Self with Support Person <ul style="list-style-type: none"> • <i>Representative Payee</i> • <i>Special Needs Trust</i> 	Conservator
General Medical	Self with Support Person <ul style="list-style-type: none"> • <i>Develop a Life Plan and include role of Advanced Medical Directives</i> • <i>Living Wills</i> 	Medical Guardianship
Daily Living Decisions	Self with Support Person <ul style="list-style-type: none"> • <i>Develop a Life Plan</i> • <i>Case Management</i> • <i>Service Coordinator</i> • <i>Circle of Friends</i> 	Limited/Temporary/ Stand-by Guardianship
Complex Medical	Self with Support Person <ul style="list-style-type: none"> • <i>Advanced Medical Directives</i> • <i>Living Wills</i> 	Medical Guardianship
Legal	Self with Support Person <ul style="list-style-type: none"> • <i>Power of Attorney</i> 	Limited/Temporary Guardianship