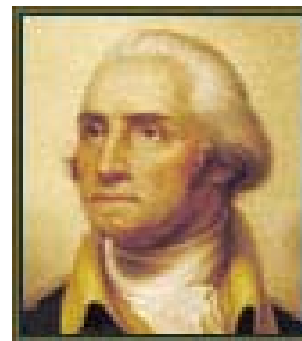


The George Washington University HEATH Resource Center



My child is turning 18 years old...do I need to become his/her guardian?

By: Nancy Mercer, L.C.S.W.
Executive Director The Arc of Northern Virginia

As a 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. For many individuals with disabilities and their families, learning to live with a disability starts shortly after birth and then supports are provided in a comprehensive fashion from pre-school programming until 22 years of age. The time of “transition” is defined as starting by age 16 according to the Individuals with Disabilities Education Act (I.D.E.A.). During Transition services individuals and families begin to learn that the long term supports their young adult children need in the community are terribly under-funded if they exist at all. It is not unusual for parents to feel as if they must become the guardian for their adult child—to provide the on-going 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 listens.

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.

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

Activity	Alternative(s)	Court Ordered Relationships
Money Management	Self with Support person Representative Payee Special Needs Trust	Conservator
General Medical	Self with Support person Develop a Life Plan and include role of Advanced Medical Directives Living Wills	Medical Guardianship
Daily Living Decisions	Self with Support person Develop a Life Plan Case Management/ Service Coordinator Circle of Friends	Limited/Temporary/ Stand-by Guardianship
Complex Medical	Self with Support person Advanced Medical Directives Living Wills	Medical Guardianship
Legal	Self with Support person Power of Attorney	Limited/Temporary Guardianship

If the family does not feel that with support or believes that they do not have the formal/informal support network necessary to help their loved one serve as their own decision maker, then the next steps need to be taken to pursue the role of guardian. 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:

- Cognitive Functioning Tests
- General Evaluations for Capacity; and
- Specific Evaluations of capacity.
(Professionals must administer these tests.)

Given the person's limited decision making capacity in combination with a lack of appropriate support, guardianship may be the only option. Even when guardianship is the option you choose, remember:

Our loved ones are **People first**—not a disability:

Treat them with **Dignity**;

Treat them with **Respect**;

Listen to them whether they use words or not; and

Promote their full Participation in decision making whether others like their decisions or not...

Guardianship is an option of “last resort” if we determine that our loved ones do 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, 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. The Arc of Northern Virginia 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 website at www.thearcofnova.org.

About the Author:

Nancy Mercer is the Executive Director for The Arc of Northern Virginia, an organization “Committed to Building Communities for Citizens with Disabilities.” In this capacity Ms. Mercer oversees advocacy, resource development, support services, long term planning, a guardianship program and one of two pooled trusts in the commonwealth of Virginia. A small team of staff members provides services to primarily the Northern Virginia area, but has also become a valuable resource to individuals seeking advice and support nationwide. The Arc of Northern Virginia was chosen as the Community Trustee—Non-Profit award by Leadership Fairfax, Inc. in November 2004.

Ms. Mercer is a licensed clinical social worker with twenty-three 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”.

Find out about Guardianship and Alternatives by visiting the following websites:

The Arc of Northern Virginia <http://www.thearcofnova.org>

The Virginia Guardianship Association (VGA) www.vgavirginia.org

The VGA has a wonderful handbook that addresses the practicalities of guardianship and alternatives. E-Mail the above web address and ask to purchase, for \$15.00 the:

Molumphy, J.T. & Shivers, H.H., Virginia Handbook for Guardians and Conservators: A Practical Guide for Court Appointed Guardians and Conservators of Adults, 3rd Edition (2005).

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