

## Supported Decision-Making as a Foundation for Alternatives to Guardianship

Chelsea E. Russell, VCU Center on Transition Innovations  
Dana V. Yarbrough, VCU Partnership for People with Disabilities  
May 2016

### INTRODUCTION

Experts agree that self-determination is critical for individuals with disabilities to lead more fulfilled lives (Wehmeyer & Schwartz, 1997). Controlling one's own life is important throughout the aging process as people strive toward independence and positive personal, educational, and career outcomes. As youth move towards adulthood, it is important for them to be as involved as possible in decisions that affect them, especially when they reach age of majority. Supported decision-making is a process of engaging with youth to make decisions that embodies the person-centered principles of self-determination. When utilizing supported decision-making, a trusted family member or friend provides different levels of support with decisions rather than a guardian having full control (Kohn & Blumenthal, 2014). Supported decision-making presumes that all individuals have both the capacity and the right to make decisions and to be actively involved in all decision-making processes about their lives (United Nations, 2006).

### WHAT THE RESEARCH TELLS US

All people have the right to be respected and listened to (Tracy, 2015). In some situations, guardianship may be necessary if a person does not have capacity to make decisions in a certain area, or if he or she may never have capacity (Traynham & Yarbrough, 2013). However, just because a person has a disability does not mean that he or she doesn't have the ability to make decisions (Traynham & Yarbrough, 2013).

Guardianship takes away a person's rights, carries great stigma, and is expensive (Traynham & Yarbrough, 2013). Thus, it is worthwhile to consider how supported decision-making reinforces alternatives to guardianship that are less restrictive and can provide room for more agency and autonomy (Kohn & Blumenthal, 2014). While parents usually have the best interests of their children at heart, their desires may not always be in line with those of the individual. Additionally,



as youth with disabilities age into later stages of adulthood, parents pass away. This makes it absolutely necessary for individuals with disabilities to have appropriate supports in place and ample practice leading their own lives to the highest degree possible.

## **IMPLICATIONS FOR FAMILIES AND PRACTITIONERS**

The best place to start is with the individual at the center of any decision-making process. Respecting that the person has as much control and autonomy as possible fosters self-determination, leading to better outcomes in all areas of adult life. It is important for those involved in supporting decision-making to be totally trustworthy and to have the best interests of the individual in mind at all times. Some specific, less restrictive alternatives to guardianship can include:

### **Advance Medical Directive**

The individual selects someone to make healthcare decisions for him when he is not able to make them on his own.

### **Caregivers**

Trusted friends and family who are heavily involved in a person's life, caregivers help to make decisions when needed but are not appointed by a court.

### **Power-of-Attorney**

This allows one person to make decisions for another in different situations. A limited power of attorney gives authority to perform a specific action, while general power of attorney gives the person authority to perform any action for the other.

### **Representative Payee**

An individual is appointed by an agency such as Social Security Administration to take care of someone else's money.

(VDA, 2007)

When supporting a young person with a disability as he or she makes decisions, families and educators should learn all about the individual's likes, dislikes, support needs, and communication abilities (Tracy, 2015). It is helpful to take a genuine interest in the individual as a complex and multifaceted person, and to pay attention to what he or she truly wants, needs, and desires.

## CONCLUSIONS

Currently, empirical data on supported decision-making is limited, indicating a need for continued examination of this process as a best practice (Kohn & Blumenthal, 2014). However, given the restrictive nature and ethical concerns associated with guardianship, supported decision-making is internationally recognized as a favorable alternative. Supported decision-making can take different specific forms, but the unifying principle is that all people have the right to control their own lives and the role of families and friends is to support the individual's choices.

Supported decision-making presumes that everyone has the capacity to make decisions, regardless of cognitive, communicative, or physical ability. Important decisions can be made by the individual alone or as a supportive unit, with the young person who is affected at the wheel.

## REFERENCES

- Kohn, N.A., & Blumenthal, J.A. (2014). A critical assessment of supported decision-making for persons aging with intellectual disabilities. *Disability and Health Journal*, 7(1). Retrieved from [www.sciencedirect.com/science/article/pii/S1936657413000599](http://www.sciencedirect.com/science/article/pii/S1936657413000599)
- Tracy, J. (2015). Supporting Nick to make decisions: An exploration of ways to promote choice and control. *Research and Practice in Intellectual and Developmental Disabilities*, 2(1). Retrieved from [www.tandfonline.com.proxy.library.vcu.edu/doi/abs/10.1080/23297018.2015.1028091](http://www.tandfonline.com.proxy.library.vcu.edu/doi/abs/10.1080/23297018.2015.1028091)
- Traynham, D.W., & Yarbrough, D.V. (2013). *Supported decision-making: Is Guardianship the only option?* Retrieved from <https://centerforfamilyinvolvement.vcu.edu/files/2013/11/Parent-Summit-2013-Yarbrough-PPT.pdf>
- United Nations (2006). Convention on the rights of persons with disabilities. Retrieved from <http://www.un.org/disabilities/convention/conventionfull.shtml>
- Virginia Division for the Aging (2007). Alternatives to guardianship. Retrieved from <http://www.vda.virginia.gov/altguardianship.asp>
- Wehmeyer, M., & Schwartz, M. (1997). Self-determination and positive adult outcomes: A follow-up study of youth with mental retardation or learning disabilities. *Exceptional Children* 63(2). Retrieved from [https://kuscholarworks.ku.edu/bitstream/handle/1808/6230/SD3\\_SD%20and%20Positive%20Adult%20outcomes.pdf?sequence=1](https://kuscholarworks.ku.edu/bitstream/handle/1808/6230/SD3_SD%20and%20Positive%20Adult%20outcomes.pdf?sequence=1)