

**REPORT OF THE SECRETARY OF
HEALTH AND HUMAN RESOURCES**

**Supportive Decision-Making
Study (HJR 190, 2014)**

**TO THE GOVERNOR AND
THE GENERAL ASSEMBLY OF VIRGINIA**



HOUSE DOCUMENT NO. 6

**COMMONWEALTH OF VIRGINIA
RICHMOND
2015**

**Supportive Decision Making Study
House Joint Resolution 190**



To the Governor and the General Assembly

**Prepared by the
Secretary of Health and Human Resources**

November 2014

Executive Summary

The attached report contains information about the background and context for the alternative to guardianship known as Supported Decision Making. Below is an executive summary that provides specific responses to the three elements of HJR 90 as written.

- i) *examine the use of supported decision-making for individuals with intellectual and developmental disabilities in the Commonwealth;*

At the present time, the Commonwealth has no official position on Supported Decision Making. Its use as an alternative to guardianship and other forms of substitute decision making is not codified in code, policy, or documents detailing appropriate standards of care. It is not formally or widely used within the Commonwealth at this time. While it is true that the concept of using natural supports, such as family and friends, to aid in the decision making process is discussed as a strategy for implementing guardianship arrangements, this occurs more by happenstance than by any conscious orchestration.

- ii) *compare the Commonwealth's policies and practices related to supported decision-making and informed choice to the policies and practices used in other jurisdictions; and*

The Commonwealth currently has no defined policies or practices related to Supported Decision Making. Other jurisdictions have no structured mechanism in place to implement the Supported Decision Making model; states are in the process of exploring the utility of the model for their communities. One state is presently conducting research on the application of Supported Decision Making within the disability community. Other countries are exploring the model as well.

- iii) *after consultation with The Arc of Virginia, Voices of Virginia, the Autism Society, the Down Syndrome Association, the Jenny Hatch Justice Project, and other stakeholders, recommend strategies to improve the use of supported decision-making in the Commonwealth and ensure that individuals with intellectual and developmental disabilities are consistently informed about and receive the opportunity to participate in their important life decisions.*

Recommendations based upon consultation with the above referenced agencies may be found at the end of the full report.

Background

The State of Virginia has developed extensive plans to close all but one training center in the Commonwealth. While these efforts have been guided by the tenets of the settlement agreement with the Department of Justice, they also reflect a broader understanding within the disability community that persons with intellectual disabilities are entitled to live lives that are as independent and self-directed as possible. As a result, the entire array of services offered to those with cognitive deficits is under review, from employment practices, to housing options, to crisis response systems. In ensuring that changes to the system meet the needs, preferences, and values of the individuals served, those practices and legal codes related to decision making capacity are likely to move to a prominent position in the process.

The issue of decision making capacity and what should be done to support those who need assistance in exercising this capacity has taken a position of prominence in the state in recent years. The case of Ms. Jenny Hatch has challenged disability providers, the guardianship system, and, perhaps, the legal community to reconsider the notion that individuals with more than a very mild intellectual disability cannot make effective decisions on their own behalf. In the case of Ms. Hatch, a petition to codify a guardianship relationship between Ms. Hatch and her parents was denied by the Virginia Circuit Court in Newport News, with Judge Pugh opting instead for a limited, time-restricted guardianship relationship between Jenny and her long-time friends, Kelly Morris and James Talbert. During the course of that trial, the practice of Supported Decision Making was presented as the rational, ethical, and most healthy psychological approach for assisting individuals with disabilities, such as Ms. Hatch, to be as autonomous as possible.

In understanding the relationship between Supported Decision Making and legal decision making capacity, it is important to understand that plenary decision making capacity does not exist. Capacity is specific to the type of decision that needs to be made. Generally, decision-making capacity falls within certain areas of a person's life including medical care, housing, finances, support services, and personal decisions (i.e., whether to get married, vote, or live with a friend). A person may have capacity to make one type of decision, yet lack the capacity to make decisions within another life arena. Therefore, any evaluation of an individual's decision making capacity must be determined in the context of the issue at hand. Supported Decision Making assumes that the individual has some ability to participate in and communicate about decisions that will influence their own lives. It assumes capacity while buttressing this skill with input from trusted friends, relatives, or support providers. Supported Decision Making replicates what we all do naturally: talk to our support system when confronting an important life decision and, when needed, ask professionals to present information to us in "layman's terms".

The theory behind Supported Decision Making is consistent with the state's vision for a system of care that is person-centered, community-based, and rooted in respect for the rights of the individual. To be consistent with this vision, the Supported Decision Making model should be used in any case where the issue of decision making capacity has been legitimately raised. This process will allow the individual to continue to use and improve their ability to make good decisions, while ensuring that they understand the relevant elements that need to be considered.

Virginia's Position on Supported Decision Making

The Commonwealth appears to have no formal position on the use of Supported Decision Making. Virginia continues to adopt the approaches as defined in the Commonwealth's Rules and Regulations to Assure the Rights of Individuals Receiving Services from Providers Licensed, Funded, and Operated by the Department of Mental Health, Mental Retardation, and Substance Abuse Services (i.e., the *Blue Book*). But at least one court in Virginia has positively evaluated the utility of the model as an alternative to guardianship as evidenced by the Jenny Hatch case. Given the legal outcome in the case of Jenny Hatch, it appears that Virginia may be in a unique position to assume a leadership role in this area of human rights, translating the model of Supported Decision Making into a defined standard of care.

Other states are also exploring supported decision making. For example, Pennsylvania's Disability Rights Network has published a booklet entitled *Consent, Capacity, and Substitute Decision Making*. While helpful, this resource primarily offers definitions and explanations about types of decision making and types of substitute decision making. The concept of Supported Decision Making as a specific practice is not mentioned in the document. The State of Massachusetts has initiated a small pilot study to offer supported decision making to a group of 10 individuals currently under guardianship. North Carolina and Maryland are also exploring the value of Supported Decision Making within their communities.

Other countries such as Australia, Canada, Sweden and England are also examining Supported Decision Making as an alternative to guardianship or other court-sanctioned substitute decision making arrangements. Indeed, reviews of these efforts have been published in Australia and Canada.

Initial Recommendations

1. In an effort to begin to formalize Supported Decision Making as a legitimate alternative to Guardianship, add Supportive Decision Making to the less restrictive alternatives in guardianship and conservatorship statute as well as to DBHDS code concerning Authorized Representatives.
2. Individuals who are appointed to positions as guardians or authorized representatives should be required to receive training in Supported Decision Making and Person Centered Planning. They should espouse their commitment to incorporating such practices into their roles. Failure to participate in designated training would be grounds for removal of the individual from their decision making role.
3. Because a capacity evaluation should always be the first step in any discussion of programs or processes that seek to impact a person's right to make a decision freely and at will, it is recommended that the Commonwealth develop a standardized procedure for completing capacity evaluations. Additionally, it is recommended that a minimum standard relative to the written report summarizing the findings of the capacity evaluation be developed.
4. Capacity is a poorly understood concept among providers and some mental health professionals. It is recommended that a general training on capacity and Supported Decision Making be developed and offered. It is recommended that part of this training include a discussion of all types of decision making assistance commonly in use and what type of clinical presentation is appropriate for each.

These recommendations in whole or in part were endorsed by representatives of The Arc of Virginia, the Down Syndrome Association of Northern Virginia, Voices of Virginia, the Autism Society of America- Central Virginia Chapter and the Autism Society of America- Northern Virginia Chapter. Quality Trust (Jenny Hatch Justice Project) and Down Syndrome Association of Greater Richmond are also in agreement with the recommendations.

Conclusion:

The Commonwealth may be in a distinct position to build momentum for the development of a formal position on supported decision making due to the national news coverage of the Jenny Hatch case and the on-going involvement of the Quality Trust for Individuals with Disabilities. Supported Decision Making is consistent with current expectations from the Centers for Medicare and Medicaid Services in their final rule around Home and Community Based Waiver Services as it relates to person centered practices. Developing some standardized expectations around assessing and reporting on capacity as well as training both provider staff and potential legal guardians and authorized representatives regarding supported decision making will only serve to enhance

and improve the way Virginia supports and respects the rights of individuals with developmental disabilities.

