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# Consumer-Directed Care and States' Nurse Practice Policies

Susan C. Reinhard
Winifred V. Quinn

Susan C. Reinhard & Marlene A. Walsh

Robert Mollica

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# *In Brief…*

## *Consumer- Directed Care and States' Nurse Practice Policies*

**Prepared by:**
**Susan C. Reinhard and Winifred V. Quinn**
**Rutgers Center for State Health Policy**

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One critical policy issue confronting states that are trying to promote consumer-direction is the extent to which unlicensed workers can assist consumers in their long-term care and support activities. State policy varies considerably, particularly in the area of nurse practice acts.

A review of the states' nurse practice acts and regulations found that few states have made substantial progress in developing nurse practice policies that specifically address consumer-direction, although most states have more flexibility for nurse delegation than nurses and consumers realize.[1] This issue brief summarizes a follow-up study conducted with the executive staff of state boards of nursing (BON). The goal of the study was to explore the executive staff members' understanding of consumer-direction trends and the extent to which their own policies support the desires of consumers to direct their own care tasks, that some may consider "nursing care".[2] Subsequent issue briefs will focus on specific states.

Introduction

The practice of consumer-directed care is increasing across the country. Driven initially by people in the disability community in their call for more autonomy and control in decision-making for long-term care (LTC), consumer-direction is now at the forefront of states' LTC policies. Most states are implementing new policies to respond to their constituents and to carry out the U.S. Supreme Court's Olmstead decision. This ruling encourages states to review and update their LTC policies and programs in order to allow people with disabilities of all ages to remain in or return to a community setting.[3] Through the "Real Systems Change Grants for Community Living", the Centers for Medicare & Medicaid Services (CMS) is providing significant grant funding to states to implement home and community-based services to help states succeed in altering their LTC options.

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[1] Reinhard, S.C. (2001). Consumer Directed Care and Nurse Practice Acts. New Brunswick, New Jersey: Rutgers Center for State Health Policy. That report is available at www.cshp.rutgers.edu.

[2] Dr. Susan Reinhard led a research team that included Dr. Rosalie Kane, Dr. Heather Young, Winfred Quinn, and Gina Kelly Aalgard. The interview protocol included questions related to nurse delegation, exemptions, assisted living, and consumer- direction. The team conducted interviews with 44 state boards of nursing executives. Three other states responded in writing; three others (IL, MI, & MO) did not participate. The findings related to assisted living and medication administration are available at www.cshp.rutgers.edu.

[3] Fox-Grage, W., Folkemer, D., & Lewis, J. (2002). The States' Response to the Olmstead Decisions: How are States Complying? Report available online at http://www.ncsl.org/programs/health/forum/olmsreport.htm

To implement consumer-direction principles, state governments must balance two policy goals. One goal is to promote independence, dignity, and choice for consumers and their families who seek long-term care alternatives. The other goal of government is to protect its citizens from harm. Persons with disabilities of all ages are seeking more autonomy and less "protection". Under consumer-direction policies, persons with disabilities have more autonomy in directing the care they receive from unlicensed assistive personnel (UAPs), such as "personal care assistants". However, state regulations that govern the practice of registered professional nurses often affect the extent to which this consumer autonomy is permitted by the state boards of nursing, which are charged with the responsibility to protect the public's safety.[4]

Findings

Of the 47 state boards of nursing included in this study, 11 reported that their nurse practice acts address consumer-directed care,[5] seven reported that they have policies that address consumer-direction[6] and 19 reported that other departments in their state have policies that address consumer-directed care.[7] Eleven states did not know if other departments in their state had policies that addressed nurse delegation and consumer-directed care. Most states that address consumer-direction in their nurse practice policies focus on adults with physical disabilities and they include family members of the consumer in their policies. Most BONs seem to be more comfortable with supporting self-direction in relation to adults with physical disabilities. Only four BONs' policies include people of all ages with any disability such as children and older adults with physical and/or mental disabilities.[8]

In addition to addressing consumer guidance, 17 states provide exemptions in their nurse practice acts (NPA) or regulations in order for UAPs to practice in consumer-directed care settings.[9] Nevada, New Jersey and Rhode Island plan to exempt consumers who are directing their own care. Boards of nursing traditionally allow exemptions in circumstances such as family members and other caregivers that provide gratuitous care and domestic workers that provide care as part of their daily duties. Some of the 17 states that exempt consumer-direction view the practice within this exemption area. Others, such as Oregon, see the consumer as a responsible participant in their own care. Oregon is exemplary of the type of support that nurses provide because the registered nurses (RNs) are involved in an educational role. The RNs in Oregon teach consumers about their care needs. In turn these educated consumers train their caregivers. In addition to Oregon, thirteen other states claim that their nurses support consumers who are directing UAPs in their care.[10]

Real Systems Change Grantee States and Consumer Directed Care Nursing Policies

The seven BONs that address consumer-directed care in their policies are located in states that have CMS-related grant activities. The relationship between the boards of nursing and

[4] Reinhard, 2001.
[5] AL, CO, KS, ME, NE, NJ, OR, SC, SD, TX, & WA.
[6] DE, KS, NE, NJ, OR, TX, & WA.
[7] AL, AZ, CO, CT, DE, KS, ME, MN, MT, NE, NH, NJ, OR, RI, SC, SD, TN, VT & WA.
[8] DE, NJ, OR, & TX
[9] AL, AZ CO, DE, ID, KY, LA, NE, NY, OK, OR, RI, SC, SD, TN, UT, & VT.
[10] AL, AZ, DE, FL, ID, KY, LA, NC, NE, NV, OR, RI, SD, & TX

the departments that are actively pursuing change in their LTC systems vary from state to state. This is reflected in BONs working with their counterparts in other departments in regard to updating LTC policies. This type of cooperative relationship is exemplified in Colorado where a BON member sat on another agency's advisory board whose purpose was to help design legislative language for a consumer-directed care program.

Most states' inter-agency relationships are not as advanced as those found in Colorado. Often, the regulations regarding consumer-directed care in a state's Department of Health and Social Services (or equivalent) are not supported by that state's BON. In turn, the BON's position is frustrating to a fellow state official who works with consumers who are wrestling to control their own care.

Implications

Although some states report nursing support for people who manage their own care, most boards of nursing do not address the issue in their nurse practice acts or governing rules. This is an important issue for the nursing profession because according to these data, nursing practice in general has not kept up with the modernization of community-based care for people with chronic conditions.

To sustain the movement toward home and community-based care for people of all ages, it is essential to form partnerships for innovative programs.[11] Several of the CMS Real Systems Change grantees exemplify how pioneering programs support partnerships between state departments and their Boards of Nursing. These partnerships are essential to sustaining the innovative activities of the Real Systems change grantees. Home and community-based care could benefit from the support of nurses. Nurses who support the independence and dignity of consumers need to involve themselves more with state policies that impede this goal.

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[11] The Corner Stone Consulting Group. (2002). End games: The challenge of sustainability. A report prepared for the Annie E. Casey Foundation. Available at http://www.aecf.org/publications/data/endgames.pdf as of October, 2003.