



U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy



AUTONOMY OR ABANDONMENT: CHANGING PERSPECTIVES ON DELEGATION

July 1997

Office of the Assistant Secretary for Planning and Evaluation

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The National Institute on Consumer-Directed Long-Term Services was established in 1995 to foster increased opportunities for consumer choice and direction in systems and services for adults with disabilities. Funded by the Administration on Aging (AoA) and the Assistant Secretary for Planning and Evaluation (ASPE), the Institute is also supported by The Robert Wood Johnson Foundation. It is housed at The National Council on the Aging (NCOA) and is a partnership between NCOA and the World Institute on Disability.

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I. INTRODUCTION

A. An Overview of the Issues: Factors Affecting Delegation

The "Autonomy or Abandonment: Changing Perspectives on Delegation" symposium was convened on October 24 and 25, 1996, in Alexandria, Virginia. The aim was to explore issues in and approaches to the delegation of "health maintenance" activities and to facilitate the delivery of home and community-based long-term services to adults of all ages with disabilities. To this end, the symposium brought together nurses, homecare providers, state-level policymakers, and consumers of long-term services. Participants discussed approaches taken by different states, looked at the implications of changes in services delivery systems for the future, and explored questions of cost, legal issues, barriers to service, and quality, as interpreted from the perspectives of the participating groups.

This document describes the highlights of the symposium and the findings of a state survey on delegation undertaken for the symposium. It also gives an overview of the legal and regulatory issues involved in delegation and provides a backdrop of the factors influencing our approach to delegation in the country today. It is the hope of the staff of the National Institute on Consumer-Directed Long-Term Services and the Planning Committee for the symposium -- representatives of stakeholder groups -- that the reader finds this document a valuable resource for their own exploration of the increasingly important issues surrounding delegation and our common concern with enhancing the safety, independence, and autonomy of persons with long-term service needs.

What Is Delegation?

Delegation is the transfer of authority from a licensed, professional health care provider to an individual not licensed to perform the delegated tasks, within a specified situation. Although delegation is not restricted to home and community-based service settings and, indeed, often takes place in hospital and other acute care settings, the symposium focused only on home and community-based services, including group homes and foster homes. Nurses are the primary professional group involved in this form of delegation, because the types of services that are delegated in home and community-based settings tend to be those services that nurses are licensed to perform, such as medication administration, skin care, bowel programs, and, arguably, even ventilator care. Consequently, the nursing profession has taken a leadership role in defining delegation and promulgating policies, procedures, and regulations.

There is considerable disagreement about which services are suitable for delegation and whether these services can in fact be performed safely by unlicensed personnel. It is therefore difficult to come up with a neutral term for the class of services

that are the subject of discussion. For the purposes of this document, we refer to these services as "health maintenance activities."

Currently, regulations relating to the performance of health maintenance activities by unlicensed personnel vary from state to state. The key legislation determining a state's policy is its Nurse Practice Act, which defines nursing's scope of practice. Regulations are promulgated by state boards of nursing, which are also responsible for enforcement of the Act -- boards can revoke a nurse's license, for example, in addition to making initial licensure decisions, renewing licenses, and taking other disciplinary actions when appropriate. The delegation of nursing activities to unlicensed personnel such as home care aides or personal assistants is allowable under some states' Acts, so long as the delegation has followed the state's guidelines and procedures. Often, nurses remain responsible and liable for the safe performance of the delegated task. Many states also exempt family members from Acts, making it illegal for anyone to perform health maintenance activities except for those who fall into the state's definition of "family" or to whom tasks have been legally delegated.

Two Prevailing Approaches to the Performance of Health Maintenance Tasks

There are, then, two prevailing approaches to allowing persons other than nurses to perform health maintenance tasks -- a legally defined approach to delegation and/or an approach that includes exemptions for either a category of individual or program. Within each of these approaches, considerable variation exists, depending on how state governments have chosen to articulate the delegation standards that apply within their state. In a legal approach to delegation, the procedures for how authority is transferred from the nurse to the unlicensed service provider are carefully specified -- who, where, when, and how are written into the statutes and other rules authorizing delegation. These procedures can be either narrow in scope or broad and lacking in specificity. The second is an "exemption" approach in which certain individuals, primarily family members, or specific programs are exempt from the regulations governing delegation. These two approaches are not necessarily mutually exclusive within a state, but are important to consider when policy is developed around delegation because of their implications.

The primary difference between specific delegation and "exemption" approaches is in where the authority and responsibility associated with each lie. In an "exemption" approach, it is the implicit right of the person needing service to manage the provision of this service as he or she prefer as long as the provider of service falls within the "exempt" category. Nurses are not held responsible for the provision of the service, but may continue to play an important role in educating the provider and the consumer of the service as well as, in some instances, monitoring the service over time. In the legally specified delegation approach, the responsibility of authorizing delegation, ensuring the quality of care, and monitoring its provision remains with the nurse.

The legal and regulatory issues surrounding delegation are discussed in the following section of this report. Examples of states that rely on the two approaches are also provided in Section II.B.

Demographic Factors Influencing Changes in Delegation

Currently, 12.7 million Americans have long-term care needs, 10.2 million of whom live in the community. All in all, there are 40.1 million Americans with activity limitations.¹ Many of these people require some ongoing medical services in their home. With an increasing population of older persons, particularly those over the age of 85, these figures are likely to grow in the future.

Although such demographic shifts are only one of the factors that have necessitated the recent emphasis on more cost-effective approaches to providing medical services, they are among the most important. Some of the demographic factors influencing changes in the way services are provided include:

- Increasing numbers of older Americans -- a group most likely to require some health services on a long-term basis as well as an intermittent basis;
- The increased likelihood that people with disabilities will have a "normal" life expectancy; and
- Increases in violence resulting in larger numbers of persons with disabilities.²

Today there are more than 34 million older adults. By 2010, we expect that there will be 40 million older Americans.³ Currently, the likelihood of needing long-term care is highest among older persons, particularly those over the age of 85 -- a rapidly growing group. And most of these services are community-based -- 80 percent of all long-term care services provided to this group are provided in their homes, not institutions. Although there has been a decline in the projected rate of disability among older persons,⁴ their sheer numbers in the future will mandate new and different approaches to the provision of long-term services in cost-effective ways.

While the incidence of disability among older persons may be lessening, it is increasing among younger Americans. This is due to two trends -- the increasing longevity of those born with disabilities and the increasing numbers of young persons surviving disabling conditions that result from illness, accidents, and crime. Today more than 40 percent of those needing long-term care services are working age (18-64 years of age); this percentage is likely to increase in the future.

¹ Adler, M. ASPE Research Notes: Focus on Disability/Long-Term Care. Washington, DC: ASPE. February 1995. [<http://aspe.hhs.gov/daltcp/reports/rn11.htm>]

² Portions of this discussion are based upon a key note address to Linda Redford, RN, Ph.D., Univ. of Kansas Medical Center, Kansas City, KS.

³ U.S. Bureau of the Census. Current Population Reports, Special Studies, 65+ in the United States. Washington, DC: U.S. Government Printing Office. 1996.

⁴ Manton, K., Corder, L., Stallard, E., NIH, March 17, 1997.

More of this growing population of people with long-term service needs can be supported in the home, both because of advances in technologies that permit enhanced independence opportunities and the development of a home and community-based service system that reduces reliance upon institutionally based services. The pressure remains, however, to deliver these services as inexpensively as possible. At the same time, a shift away from the "medical model" of delivering these long-term services has been inspired not only by the limited finances and labor pool available, but by the political forces of the consumers of long-term services.

Political Factors Influencing Delegation

The Independent Living Movement, begun by persons with disabilities in the 1970s, was effective in altering many of the national policies and service options for persons with disabilities and, ultimately, in passing the Americans with Disabilities Act (1990). The underlying philosophical change effected by the Independent Living Movement was to change the status of a disabled person from being a **patient** to being a **consumer**.⁵ The movement rejected the medical model approach to care which, independent living advocates argue, overemphasizes the importance of medical, rather than social or economic issues in the lives of those with disabilities or chronic conditions and, indeed, forces people with disabilities to assume inappropriately the "sick role," a role in which "patients" are reliant on medical expertise for resolving all aspects of their lives.⁶ Instead, the movement demanded autonomy and independence as well as control over services -- who provides services, where the services are provided, and how they are provided. In particular, health maintenance services, delivered on a daily, weekly, or other continuous basis, are viewed as ADLs for people with disabilities and are therefore amenable to consumer supervision and even consumer training of personal assistants to perform these tasks. Thus the movement resulted in increasing demands for changes in delegation approaches and modifications to policies affecting delegation.

At the same time, anxiety about the safety of home and community-based services has increased as their availability has increased. Much of this anxiety is related to the quality and accountability of personnel delivering services, particularly health maintenance services, in the community. Continued access to nursing expertise is seen as an important part of ensuring quality in home and community-based services. Consumers and program administrators alike are concerned about potential abuses.

More recently, shifts in the financing and organization of health care systems and long-term care providers have become a force in the practice and policies associated with delegation -- as well as the attitudes of those directly involved in delegation

⁵ Simon-Rusinowitz, L., & Hofland, B. "Adopting a Disability Approach to Home Care Services for Older Adults," *The Gerontologist*, 33 (2):159-67, 1993.

⁶ For a fuller description of "the medical model," see DeJong, Gerben. "Defining and implementing the independent living concept" (Chapter 1 in Crewe, Nancy M., Irving K. Zola, and Associates. *Independent living for physically disabled people*). San Francisco, CA: Jossey-Bass, pp.15-18. 1983.

activities. The two most important shifts have been the rise in managed care and the development of alternative service models for older adults.

Managed care, viewed by some policymakers as an important part of the solution to the problem of increasing health costs, has begun to make changes in consumers' access to health care and the ways in which care is provided. In particular, managed care organizations have begun to redesign staffing patterns for the most highly skilled, credentialed professionals in order to cut costs. For example, managed care organizations are increasingly using Physician Assistants and Nurse Practitioners to provide primary care services which previously were provided by physicians. More commonly, tasks previously assigned to RNs are being shifted to LPNs and nurse aides, particularly in acute care settings. Thus, delegation is seen as an important mechanism for cost savings -- unsurprisingly, the nursing profession is deeply concerned about the implications for service quality.

Delegation of nursing tasks to less skilled workers is also a strategy employed by Congregate Living and Assisted Living Facilities, which provide important community-based independent living opportunities for millions of older and disabled Americans. These and other similar models of residential programs were developed as alternatives to the medical models of care found in nursing homes and as a supportive environment for those who otherwise might be dependent upon family or friends for ongoing assistance and care. But now, with the average age of residents in the 80s, service needs have increased considerably. Medication management and nursing care are now integral components of the support received by residents of these facilities -- and the separation of medical from non-medical models is often not a simple matter. Meanwhile, the philosophical underpinnings of the models and available resources preclude the use of highly skilled health care professionals as core staff on-site to deliver these services. Delegation is a strategy that arguably allows these facilities to meet the needs of residents while maintaining a less "institutional" environment.

Perspectives on Delegation

Physicians can delegate tasks to others (such as nurses), as can other health care professionals. However, it is most often nursing tasks that are deemed suitable for delegation in home and community-based service settings. Consequently, the nursing profession has been the most active in the codification and articulation of delegation. Their leadership role in delegation has set the standard and provided the balance between autonomy of the patient and quality of the health care needed to ensure positive health outcomes.

Nurse delegation has been practiced since the 1940s, but has only recently been codified in statutes. The State Boards of Nursing have the responsibility for monitoring and dealing with violations of the Nurse Practice Acts -- the regulatory authority over delegation activities -- by both licensed and unlicensed persons. When there is a violation of the Act resulting in harm, the employer, the nurse, and the person providing the service can be legally liable if they are found to be negligent in carrying out their

duties (see Section I.B for a full discussion of legal and regulatory issues). Regulations and protocols are helpful in clarifying what these duties are; however, although many states that have modified their regulations to clarify the rights and responsibilities of nurses, many states have guidelines that are vague or incomplete.

The National Council of State Boards of Nursing's model nurse practice act states that "...the registered nurse decides what to delegate and to whom, is responsible for communication of the delegation ... and the evaluation of the delegation." Because nurses are ultimately responsible for services and outcomes and are concerned about the quality of care, they must carefully and thoroughly consider the many factors affecting delegation. Nurses consider the competency of individuals in performing tasks, their ability to apply knowledge beyond the task, and their motivation. Consumers or their surrogates must be able to make decisions, have knowledge and understanding of their service needs, have the ability and desire to direct services, and have the ability to monitor and evaluate services.

Nurses typically review the specific task to be delegated, determine when and if it should be delegated, and assess how easily accessible help and consultation are for the consumer. Nurses also must consider the context in which services are being delivered -- whether a disruptive family environment, for example, is likely to mean that delegated services will not be delivered with appropriate care. Some states specify which tasks can and cannot be delegated; others are silent on specific tasks and merely empower the nurse by allowing them to delegate nursing tasks." A few states regulate delegation differently in different service settings.⁷

The basic issue for nurses in delegation is quality of care -- an issue which is present in settings such as hospitals and nursing homes as well as in the consumer's own home. If a situation requires the education and judgment of a nurse on an ongoing basis, then nurses have the responsibility to withhold the delegation authority in order to ensure the quality of the needed service and the health outcomes associated with the service, even if they are permitted to delegate by the prevailing Nurse Practice Act. However, nursing judgment is not always the determining factor in who provides what services, as is the case with individuals or programs that are explicitly exempt from Practice Act provisions. As changes occur in the health care system, the nurse's role in delegation may also change -- thus increasing the concerns already in place about quality care and positive health outcomes.

Some consumers, on the other hand, view the process of delegation as an impediment to independence and autonomy. If a service is required on a daily basis, for example, and this service falls under the definition of a "nursing task," there can be a conflict between the needs and wishes of consumers and the legal responsibility of a nurse. To consumers, such services are basic activities of daily living rather than tasks that require a highly skilled professional. The idea of "asking permission" to manage

⁷ Rosalie A. Kane, Colleen O'Connor & Mary Olsen Baker, Delegation of Nursing Activities: Implications for Patterns of Long-Term Care (AARP, Public Policy Institute, Report #9515, November 1995)

daily activities can be repugnant to consumers and offensive to their sense of independence and autonomy.

Many consumers feel they are perfectly competent to oversee unlicensed personnel performing health maintenance tasks on their behalf. They cannot understand why nurse involvement is necessary for tasks which people who do not have disabilities perform for themselves all the time, such as administering oral medications or insulin injections. Consumers may also object to the authority nurses exert over individuals performing delegated tasks -- they may feel they know as much, if not more, about their condition as the unlicensed person to whom tasks are delegated; in their view, the person performing the task should be answerable to them, not to a nurse. After all, consumers argue, it's their health that will suffer if the unlicensed individual performs a task poorly. Reimbursement for services through governmental or other third-party sources can limit the authority of consumers, however, and therefore reduce the authority and autonomy of a consumer.

For some consumers, the exemption approach has been welcomed as a solution to the desire for both consumer control and access to needed services. The exemption approach allows consumers to receive services from family members or personal assistants (although the standing of personal assistants is less clear and is discussed in the following section). Under this approach, nurses have an important role to play in educating and acting as consultants -- thereby empowering consumers to exercise maximum control over their lives.

For those consumers for whom exemption does not apply because of their state's legislation, the delegation process can be difficult and psychologically damaging to their sense of autonomy. In states that restrict exemptions to family members, consumers who need to or prefer to receive needed services from friends or paid attendants can also find themselves unable to use the exemption approach. The balance between independence and quality of care is not always easy to achieve and poses a challenge for both consumers and nurses.

Summary and Organization of the Document

For the professionals, policymakers, and advocates who participated in the planning of the symposium, it was clear from the beginning of the planning process that we all shared the same goal, even though our perspectives on delegation may differ: To ensure that persons with long-term service needs have access to the highest quality care available in a fashion that enhances their quality of life, independence, and autonomy. The symposium was designed to explore divergent as well as consistent perspectives among the key stakeholders in delegation. Several issues emerged which frustrated all of the participants and exacerbated the divergence in opinions and approaches to delegation, including:

- The effect of fragmented funding streams, with their different requirements and standards, on the availability and nature of services;

- The pressure to seek lower cost care options for a growing population needing access to services;
- The difficulty of monitoring and evaluating health outcomes over time when services are located in individual homes;
- The legal ramifications for all parties involved in delegation, including professionals, service providers, and payers;
- Negotiation of "acceptable risks" in a system which can penalize one party in the negotiation and not another;
- Concerns about the accountability of unlicensed personnel performing health maintenance tasks;
- The need for more education of consumers, nursing professionals, and policy makers about delegation issues.

This volume is organized to provide information not only on the symposium itself, but on the overall topic of delegation. An overview of legal and regulatory issues involved in delegation is included, as are the findings of a study undertaken of states' approaches to delegation. The highlights of the symposium are provided, along with an overview of topics raised, recommendations resulting from the symposium, and presentations from four states with different legislative approaches to the issue (with an accompanying comparative chart). And, finally, we include the formal statements and positions of national associations on delegation and a list of informational resources. An appendix of the edited remarks of symposium participants provides insight into the flavor of the symposium, and gives a taste of some of the wider issues associated with the topic.

B. Review of Legal and Regulatory Issues

The most material legal issues relating to the delegation of "nursing" tasks in the context of personal assistance service programs may be described in two broad categories -- regulatory issues and personal liability issues:

Regulatory Issues:

- **What is the legal definition of nursing and, conversely, its exemptions?** This is the threshold issue concerning the applicability or reach of nurse practice acts.
- **What regulatory standards apply to delegation under state nurse practice acts?** These include operational issues, such as the question of how delegation must be implemented under the act or regulations.

Personal Injury Liability Issues:

- **What is the risk of liability of the nurse/delegator for injury to a client?** The answer determines in large part how viable nurse delegation is as a practice option.

Regulatory Issues

Regulatory issues are essentially policy issues -- that is, the law in the form of regulation flows from policy decisions that legislatures and executive agencies adopt. Thus, state nurse practice acts and regulations reflect policy decisions aimed at the safety and protection of the public. They were not originally conceived with consumer-direction and delegation in mind, although most state nurse practice acts at least make reference to delegation. Violation of regulatory standards primarily affects the licensure of professional nurses, although regulatory standards also help define standards of care that apply in personal injury and malpractice litigation (discussed further under Personal Injury Liability).

Two regulatory questions are central to nurse delegation.

1. What is the legal definition of nursing and, conversely, its exemptions?

The first legal puzzle in connection with nurse delegation is the reach of nurse practice acts in the first place. The answer is often uncertain because registered or professional "nursing" services are typically defined quite broadly -- and vaguely -- by state nurse practice acts.⁸ Consider, for example, the following two definitions of the practice of nursing. The first is from the Michigan nurse practice act and is quite brief:

Michigan

The "practice of nursing" -- the systematic application of substantial specialized knowledge and skill, derived from the biological, physical, and behavioral sciences, to the care, treatment, counsel, and health teaching of individuals who are experiencing changes in the normal health processes or who require assistance in the maintenance of health and the prevention or management of illness, injury, or disability.⁹

The second is from the California nurse practice act and includes greater detail by way of examples:

California

The "practice of registered nursing" -- those functions, including basic health care, which help people cope with difficulties in daily living which are associated with their actual or potential health or illness problems or the treatment thereof which require a substantial amount of scientific knowledge or technical skill, and includes all of the following:

⁸ Most states have several types of nurse licensure. All states license registered nurses (RNs) and licensed practical or licensed vocational nurses (LPN/VNs). Most states have mechanisms to grant authority to advanced practice registered nurses (APRNs), such as nurse practitioners. A few states are involved in the regulation of nurse aides, ranging from maintaining registries to, in two states, licensure of nurse aides. For the purposes of this summary, only the definitions, requirements, and issues under registered nurse licensing acts are considered, since the category is fairly comparable across the states, and similar issues cut across the other licensing categories.

⁹ Mich. Comp. Laws §333.17201 (1994).

- a) Direct and indirect patient care services that insure the safety, comfort, personal hygiene, and protection of patients; and the performance of disease prevention and restorative measures.
- b) Direct and indirect patient care services, including, but not limited to, the administration of medications and therapeutic agents, necessary to implement a treatment, disease prevention, or rehabilitative regimen ordered by and within the scope of licensure of a physician, dentist, podiatrist, or clinical psychologist...
- c) The performance of skin tests, immunization techniques, and the withdrawal of human blood from veins and arteries.
- d) Observation of signs and symptoms of illness, reactions to treatment, general behavior, or general physical condition, and (1) determination of whether such signs, symptoms, reactions, behavior, or general appearance exhibit abnormal characteristics; and (2) implementation, based on observed abnormalities, of appropriate reporting, or referral, or standardized procedures, or changes in treatment regimen in accordance with standardized procedures, or the initiation of emergency procedures.¹⁰

While the examples in the California statute attempt to provide greater clarity, they also suggest a breadth of definition that may include any form of support service that offers "safety, comfort, personal hygiene, and protection." The vagueness of scope inherent in these and other definitions of nursing is, in large part, unavoidable, for nursing is a knowledge-based "process discipline" and cannot be reduced solely to a list of tasks. The licensed nurse's specialized education, professional judgment, and discretion are essential elements of quality nursing care.¹¹

Delegation

Most state acts also include within the definition of nursing the "delegation" of nursing tasks by registered nurses or the "teaching and supervision of others." This component of nursing opens the door to the use of personal assistance service workers in performing a variety of "nursing" tasks. Delegated services performed by a personal assistant (PA) are generally treated as exempt from the nurse practice act, although a more accurate characterization may be that the PA's function is derivative of the nurse and therefore is indirectly subject to the nurse practice act. The model definition of nurse delegation used by the National Council of State Boards of Nursing reinforces the latter characterization:

[D]elegation is defined as the transferring of a span of authority, responsibility, and accountability for the performance of an activity from the registered nurse to an assistant to the nurse. The registered nurse decides what to delegate and to whom, is responsible for communication of the delegation and obtaining feedback, and is responsible for the evaluation of the delegation. The registered nurse retains final accountability for the decision to delegate, for the adequacy of nursing care provided to the client, and for client outcomes.¹²

¹⁰ Cal. Health & Safety Code §2725 (West 1992).

¹¹ National Council of State Boards of Nursing, Delegation: Concepts and Decision-Making Process 2 (1995).

¹² Vicky Burbach, "Delegation in Nursing," 15(3) *Issues* (1994) (newsletter of the National Council of State Boards of Nursing).

Other Exemptions

Other specific exemptions to a state's nurse practice act may also apply to nursing services performed by an unlicensed person. A 1994 survey of nurse practice act exemptions identified three other common exemptions that can easily apply to personal assistance service situations:¹³

- Care by friends and family -- This exemption is the most common one expressly recognized in most nurse practice acts. Some states limit the exception to gratuitous care by family members; others include gratuitous or compensated care. Few states define "family" or "friends" in this context.
- Care by domestic servants -- Intended historically to recognize the distinction between trained nurses on the one hand and maids, housekeepers, companions, or other household aides who perform some caregiving duties on the other hand, this exemption appears increasingly archaic as the range of home "help" and home "health" services have evolved and expanded to include more sophisticated levels of care. Whatever the title of the worker, the worker cannot hold himself or herself out as a professional nurse.

Definitions of domestic servant seldom rise above a list of job labels such as those used in the preceding paragraph. Nor do definitions of "domestic servant" under employment law or tax law dictate the meaning of the term for purposes of nurse practice acts, since such definitions are specific to their particular statutory framework.

Conceivably, a great deal of nursing-type caregiving could be swept under this exemption, although as skill levels of personal assistants rise, it is less likely that they would self-identify as domestic servants.

- Care under the direction of a physician (i.e., physician delegation) or other personnel.¹⁴ While not widely used, physician delegation is fairly common in the California In-Home Supportive Services program, the largest personal assistance program in the nation in terms of numbers served.¹⁵ Whether physician, nurse, or other professional, the principle in common to all is that the delegator can transfer responsibility for the performance of only those functions within the scope of practice of that professional, and the delegator assumes responsibility for the delegation process.

¹³ See Charles P. Sabatino and Simi Litvak, "Liability Issues Affecting Consumer-Directed Personal Assistance Services -- Report and Recommendations," *The Elder Law Journal* 247, 325 (Fall 1996) (also released as a report by the World Institute on Disability, Oakland, CA, 1995).

¹⁴ *Id.*

¹⁵ *Id.* At 333-334.

Program Exemptions

Another important exemption directly relevant to those favoring the expansion of consumer-directed personal assistance services is a *program exemption*, usually created by legislation, for purposes of avoiding the application of nurse practice act strictures to an identifiable state-sponsored consumer-directed program. This approach has only recently been used in a few states that have sought to expand or experiment with consumer-directed options. For example, the New York nurse practice act was amended in 1992 to carve out an exemption for the state's new "patient-managed home care program" (now called the "consumer-directed personal assistance program").¹⁶ Another example, the Kansas nurse practice act, specifically exempts attendants who work in the state's "in-home services program."¹⁷ To the extent that there are standards applicable to unlicensed persons who provide personal assistance services under these programs, those standards originate from state agency regulations governing the particular program. This fact underscores the need to be aware of the interaction or overlap among regulatory sources that control service delivery. The interaction can be a source of flexibility (in that it may give consumers more service options) or a source of confusion (in that consumers and even providers may be unclear about which standards, if any, apply).

2. What Regulatory Standards Apply to Delegation?

The elements and conditions of delegation can be looked at in several ways: first, from a regulatory perspective which focuses on legally prescribed minimum standards and limitations; second, from a clinical practice perspective which rests upon practice norms, professional skills, and judgment that go well beyond the minimum standards; third, from a program administration perspective which focuses on the efficient and appropriate utilization of resources; and finally, from a consumer perspective which focuses on delivering the supports the client wants and needs at the time needed and in the manner wanted.

This overview of legal issues looks only at the first perspective in summarizing the parameters of nurse delegation. And for purposes of this discussion, the differences among state nurse practice acts are broken down according to the following questions:

- Program limitations -- Is nurse delegation limited to only certain programs providing home and community-based services?
- Personnel limitations -- Who may be the delegate to whom authority to perform designated nursing tasks has been transferred?
- Setting limitations -- Are there limitations on the physical settings in which delegation is permitted (e.g., home and community-based care, institutional

¹⁶ N.Y. Public Health Law §6908 (McKinney 1995).

¹⁷ Kan. Stat. Ann. §65-1124(m) (1992).

care)? This is often, but not always, the same as the "program limitation" element identified above.

- Task limitations -- Does the law identify: (a) specific tasks that can be delegated, (b) tasks that are permitted without delegation (i.e., assignment), and/or (c) tasks that cannot be delegated at all?
- Required procedures for delegation -- Are specific procedures or process standards included in the law or regulation?
- Client limitations -- Must clients have the capacity to self-direct their care or are surrogates for consumers of impaired mental capacity permitted to oversee services?
- Consumer role -- What substantive or procedural rights of consumers are granted or specifically recognized? These rights could touch upon consent, or control over decisions, access to service, or rights to notice and information.

The chart at the end of this summary compares the above legal parameters in the four states that were highlighted in the October 1996 symposium -- New York, Oregon, Texas, and Washington. These states have made a reasoned effort to address nurse delegation in home and community-based setting, and, as such, do not really represent the norm. Most states simply have not addressed the issue at all.

Personal Injury Liability Issues

The primary question is: To what extent is a nurse-delegator liable for any injuries to clients caused by the acts of a nurse-delegate? The legal context for answering this question involves a combination of common law principles and nurse regulation. Under common law principles, these cases normally take the form of negligence actions. Negligence requires four elements generally: (1) the party allegedly at fault must have had a *duty* -- an ascertainable standard of care; (2) the party must have *breached* that duty; (3) there must be an *injury* to another; and (4) the violation of duty must be the *proximate cause* of that injury. If any one of these elements are missing, there is no liability. There may still be a lawsuit, because almost anyone can assert negligence in a personal injury suit, but it will not be successful unless all four elements are proven by a preponderance of evidence.

Nurse practice acts are relevant to the question of negligence because the standards established under the act contribute to defining the standard of care, or duty, for negligence purposes. Thus, to the extent that a nurse practice act prescribes criteria and procedures for delegation, these will be relevant to determining the first two elements of a personal injury negligence claim. In an actual lawsuit, the parties would have to use expert witnesses to testify as to the duty or standard of care applicable to the incident at issue. In states where delegation is not addressed in the act, it is somewhat more difficult to define delegation standards. However, in any case, one must

still keep in mind that a violation of duty under a nurse practice act is not enough in itself to create liability. If no one is hurt, there is no liability. Or if someone is hurt, but it was a result of something other than the nurse's violation of duty, there is no liability.

When one examines the nurse practice acts that actually prescribe delegation standards, some muddiness in the standards becomes apparent. Most emphasize that the nurse remains ultimately responsible for the care provided, but the scope of this responsibility is not entirely clear. It is essential that this be clear, because being responsible for the *task of delegation* is not the same as being responsible for the *actual performance of the delegated task*. For example, New Jersey nurse practice regulations make the nurse responsible for "exercising that degree of judgment and knowledge reasonably expected to assure that a proper delegation has been made."¹⁸ The Oregon nurse practice regulations suggest a somewhat higher duty of care by making the nurse "*strictly* accountable for that delegation."¹⁹ Both these standards focus on the task of delegation. In contrast, Texas nurse practice act regulations state: "The RN shall be accountable and responsible for the delegated nursing task."²⁰ On its face, the Texas language imposes a greater duty of care by making the nurse responsible not only for the task of delegation but for the ongoing performance of the delegate.

The Texas standard echos the responsibility borne by an employer for the acts of employees. This kind of liability is referred to as *vicarious liability*, derived primarily from the legal doctrine of *respondeat superior*, literally meaning "let the master answer." Under this doctrine, if an injury is caused by the negligence or wrongdoing of an employee acting within the scope of his or her employment, then the employer is held liable for that injury.

Under common law principles, a nurse-delegator would not normally be vicariously liable, because the delegate normally is not his or her employee. However, the statute can change the common law standard, and the Texas language, at least on its face, appears to do this, because it imposes responsibility "for the delegated task" and not just for the act of delegating. If nurses are held responsible to this higher standard, usually applicable only to employers, then they would face a tremendous disincentive to use delegation, for they would be liable for any act of negligence by a delegate, period, even if the nurse's training, supervision, and exercise of discretion in the case were flawless.

The New Jersey and Oregon language suggests a lesser form of liability -- that of direct liability for the delegation process only. Thus, if the worker, to whom a task was delegated, negligently harms the client, the nurse would be liable only if it were established that the nurse's assessment, training, supervision, or other aspect of *the delegating process* were performed negligently. These are matters of "direct" liability, not vicarious liability.

¹⁸ N.J.A.C. §13:37-6.2(b) (1992).

¹⁹ Oregon Administrative Regulations §851-47-000(11).

²⁰ Texas Board of Nurse Examiners, *supra* note 177, at §218.3(8).

At present, the implications of this distinction are largely theoretical. Kane's 20-state survey of nurse delegation found that in states that have made efforts to encourage nurse delegation in personal assistance service settings, nurse liability problems have not materialized.²¹ Of course this may be due, in part, to the lack of information systems to track such problems, as well as the lack of extensive experience with delegation. Nevertheless, greater clarity in the law would benefit the development of nurse delegation.

One additional perspective on the above discussion merits acknowledgment. The analysis above is based upon a three-part interaction: the consumer, an unlicensed individual provider, and a registered professional nurse. However, other actors may also be involved, specifically a home care agency and an entity that pays for care -- i.e., a governmental agency or insurance company. Home care agencies may be involved in delegation directly or indirectly. The home care agency may employ the nurse, may employ the unlicensed provider, or may employ both. In these instances, a home care agency, as employer, is liable for any injury caused by the negligence of its employees committed in the course of employment. As a practical matter, the liability buck usually stops with the agency since the presence of commercial liability coverage generally makes the agency a "deep pocket" and likely target. Despite an historical dearth of cases finding liability in delegation arrangements, agencies understandably worry about their theoretical risk under delegation arrangements.

Payers of care, public or private, normally have no liability for injury caused by the negligence of providers for whose services they pay, at least where the payer avoids influencing clinical decisions. Unfortunately, one trend seen today in the context of managed care is the blurring of the line between provider and payer decisions. If the payer interferes with or attempts to control clinical decisions, then it risks taking on the mantle of liability. For example, if a managed care plan enrollee were in medical need of a particular covered service, but the managed care organization refuses to authorize it for budgetary reasons, with the result that the enrollee's health is damaged, the managed care organization could very well be found liable for the injury to the enrollee. The boundary between payer and provider responsibility is a gray area increasingly being tested by litigation.

Another basis of liability that is sometimes raised in connection with nurse delegation is that of *abandonment*. In legal terms, abandonment is the unilateral termination of care when there is a need for continuing care and it is terminated without reasonable notice. These criteria are not likely to apply to a delegation situation. Where delegation is recognized under state law, then an act of delegation done improperly -- that is, below the applicable standard of care for delegation in that state -- may result in a finding of negligence, but probably not abandonment. For example, if it were agreed that the standard of practice for delegation in one's state required the delegating nurse to check the performance of the delegate every two weeks, and the nurse never got around to checking up, with the result being injury to the client, we may think of that as

²¹ Kane, Rosalie A., Colleen M. O' Connor, Mary Olsen Baker, Delegation of nursing activities: implications for patterns of long-term care. Washington, DC: American Association of Retired Persons, 77 pp., Nov. 1995.

virtual abandonment on one level, but it is not abandonment in a legal sense. It is negligence.

One other liability concept that often enters these discussions is that of *assumption of risk*. In some but not all jurisdictions, assumption of risk is a defense to a negligence action if the defendant establishes that the plaintiff knowingly and voluntarily assumed the risk of conduct which might otherwise be negligent. For example, a line of malpractice cases holds that if a patient refuses to follow the advice of his or her doctor, the doctor cannot be held liable for the resulting harm. The same cases can also be explained in terms of a related concept, that of *contributory negligence*. In other words, a patient's conduct in assuming a particular risk might be deemed contributory negligence in that it violates a duty to exercise reasonable care.

With respect to nurse delegation, the consumer may or may not be able to assume certain responsibilities related to the delegation. It depends on whether the state's law permits the consumer to take on a particular responsibility. Generally, risk follows the responsibility. However, if responsibility for the process of delegation rests clearly on the shoulders of the nurse, the consumer cannot relieve the nurse of that responsibility by choosing to waive the applicable standard of care and to assume the risk. As said earlier, the law flows from public policy. And public policy in most states dictates that one cannot consent to or assume the risk of another's negligence. Thus, the concept of assumption of risk has limited application to the construction of nurse practice acts. It is more pertinent to the underlying public policy debates that shape nurse practice acts and models of consumer-directed care in the first place.

As a final note to this review, it is important to recognize that responsibilities and related liability concerns in any endeavor change over time as functions and relationships between people change and as the law changes. Because delegation practices are in a formative stage, so too are the corresponding liability issues. Both can be expected to evolve in loose interaction. The purpose in examining these issues is not to sound an alarm over new or persisting obstacles to nurse delegation, but to assure that consumer needs and risks are responsibly and systematically addressed.

II. HIGHLIGHTS OF A NATIONAL CONFERENCE

Speakers

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Concepts of Independence
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Americans Disabled for Attendant
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A. Overview of Symposium Themes

In this section, we present an overview of the major themes and concerns that emerged from the symposium. Readers who wish to pursue these topics and to get a flavor of the discussions are advised to read the Appendix, which contains an edited, but still lengthy, transcript of the symposium question and answer sessions.

Distorting Role of Funding Streams

Symposium participants often discussed how funding streams for different home and community-based service programs affect the ability of nurses to delegate where they see fit. For example, the ability of unlicensed personnel to perform health maintenance tasks often depends on the funding stream under which a consumer receives services; it might be restricted to a Medicaid waiver program. This restriction creates access and equity issues for consumers. Alternatively, delegation activities (such as the training and oversight functions performed by nurses) may not be funded as separate activities. In these cases, even where the legal apparatus in a state allows unlicensed personnel to perform health maintenance tasks, the supportive services that would ensure that it is done safely and appropriately are not available.

Potential for Cost Savings

Symposium participants were interested to hear of the potential savings resulting from allowing unlicensed personnel to perform some health maintenance tasks. The New York State program, for example, attributed nearly \$10.5 million dollars in savings to implementation of its exemption policy. Similarly, Washington State's policy appears to have been driven by a desire for cost savings. In Texas, on the other hand, adding a delegation function to its Medicaid program appears to increase costs because it involves funding a new entitlement service, the activities needed to support delegation.

Covert Health Maintenance Activity

Participants acknowledged the difficulty of controlling and monitoring what really happens in peoples' homes in terms of health maintenance activities. They discussed the likelihood that a substantial amount of health maintenance activity is currently being performed by unlicensed personnel who receive no training for these activities because they are proscribed from performing them. It is open to question how widespread such covert performance of health maintenance tasks is in those situations where state policy forbids it; however, it appeared that symposium participants felt that it was fairly common. This acknowledgment of "covert activities" implicitly raises the question of how we can ensure that such services are performed safely, as it appears that they cannot be prevented.

Indeed, the fact that consumers are using unlicensed personnel highlights problems with the current system. Reasons why unlicensed personnel perform these tasks seem to be a lack of access to nurses, due to funding issues, and restrictiveness in the exemption for family members (which exists in most states); only a family member could be trained to perform tasks that might be more conveniently or more effectively performed by someone who did not fall within a state's definition of "family." It appears that sometimes -- with the agreement of the family member to whom the tasks were delegated -- this more suitable individual does in fact perform the needed activities; nurses reported frustration at not being able to train the appropriate individual directly.

Fear of Pressure to Delegate Inappropriately

A recurrent theme throughout the symposium was the fear that allowing wider ability to delegate would open the door for inappropriate delegation, and indeed, would shift the burden of proof from "why delegate?" to "why not delegate?" The same financial pressures that encourage the exploration of liberalized delegation policies also create pressures on nurses to delegate inappropriately: these pressures include state efforts to contain the costs of home and community-based services and the growth in managed care. To counteract these influences, nurses felt it was important that they retain the ability to make judgments about the appropriateness of delegation in all situations. Financial pressures in acute care settings are already forcing nurses to use

unskilled personnel in situations where nursing expertise is needed. Similarly, managed care appears to view nursing expertise as dispensable in many situations.

Different Circumstances Demand Different Responses

It was stressed that each consumer's situation needs to be evaluated individually. As one participant said, "the right person, the right place, the right setting" are needed. In a traditional model of delegation, the unlicensed attendant's competence needs to be determined. In a more consumer-directed model, the consumer's desire and ability to oversee services needs to be judged. Under both models, the consumer's overall situation needs to be evaluated to determine whether and for what services delegation is appropriate; this act of evaluation or judgment is an essential part of nurses' role. However, it was argued that nurses must also accept that consumers' judgment about their ability to monitor and ensure that services are performed correctly should count heavily in the decision-making process.

There was considerable disagreement about the situations in which delegation is appropriate, and some consumers expressed distrust of nurses' ability to judge the competence of consumers fairly. Some participants argued that the level of acuity was not the determining factor in deciding whether or not delegation was appropriate; they felt that even during acute episodes, consumers have some stable and predictable needs where delegation would be appropriate. Their suggestion was to focus on activities of daily living that are stable and predictable in nature.

Development of Nurse Education

There was considerable discussion of the role of nurse education in preparing nurses for the issues raised by the ability to delegate. Some nurses argued that public health/community health nurses were better prepared for the type of nursing that goes on in home and community-based service settings. Much nursing training has a more clinical/hospital-based focus. In particular, it was argued that training individuals in self-care activities is an important part of being a nurse -- and training families and consumers on how to perform or oversee health maintenance tasks is but an extension of this.

The training needed for the specialized skills involved in delegation in a home and community-based service environment were also stressed. For example, nurses need to assess care plans, teach individuals from a variety of backgrounds and educational levels, in a variety of environments, and consider the overall context of care.

Exemption Option

Much interest was expressed in the option of creating exemptions from Nurse Practice Acts for unlicensed personnel working directly for consumers. This option has the advantage that it would not, in most states, involve an overall review of Nurse

Practice Acts. An exemption approach would allow for nursing evaluation and oversight of unlicensed personnel, in the same way that exemptions for family members utilize nursing expertise (although it was noted that this is often not funded or recognized sufficiently).

Reconceptualization of Consumers' Roles

A number of symposium participants were intrigued by the possibility that the responsibility and authority to manage services be transferred to the consumer or his or her surrogate. Under this transfer of authority model, the individual receiving the training on the proper procedures for health maintenance tasks would be the consumer or surrogate, who would be responsible for ensuring that the unlicensed individual performing these tasks does them correctly. (This is the case under New York's exemption approach currently.) Nurses would act as consultants to the consumer, to be called upon whenever there was a need for nursing expertise. One of the benefits of this model is that it has the potential to deliver higher-quality services because of the ability of the consumer to monitor tasks on an ongoing and informed basis; another is that attendant turnover is dealt with more conveniently because the consumer need not arrange a nurse training session. This model also acknowledges and makes use of the extensive knowledge that individuals with chronic, long-term conditions often have regarding their conditions. However, the legal mechanisms for this shift would need to be developed more fully. It was also recognized that this model would be appropriate for only those consumers or surrogates who are capable of managing an attendant effectively.

Acceptable Levels of Risk

Participants expressed concern about increased risk due to delegation. Some participants argued that some risk is acceptable, if it results in an improved quality of life for consumers. In any case, some argued that it is for the consumer to decide whether a given level of risk is acceptable. However, others argued that if services are funded by public monies, a right to choose risky behaviors does not exist. Other consumers attempted to persuade participants that the polarization of risk and safety was false, and that quality is better assured through continual monitoring of health maintenance activities by well-trained and well-informed consumers who manage attendants and access nursing expertise when needed. Another point of view emphasized the importance of proper training and selection of personal assistants in order to minimize risk.

Concern for Personal Assistants

A number of symposium participants voiced concern for the unlicensed personnel who perform the health maintenance activities in lieu of a nurse. Participants voiced fear that individuals might be pressured into performing activities they did not feel competent to perform. Similarly, personal assistants might become liable should they make a mistake. If personal assistants have no recourse to information about their

appropriate role and the legal ramifications of performing such tasks, they are then left in a fairly powerless situation. In addition, the lack of certification or formal training for unlicensed personnel means that they lack the ability to develop a career through building on their skills and improving their earning potential.

Mechanisms for Accountability of Personal Assistants

In order for consumers to be protected against fraudulent or incompetent personal assistants, some symposium participants felt that a mechanism was needed to increase the accountability of personal assistants and to give consumers information about personal assistants they might hire -- for example, information on whether a potential worker has fallen short of standards in the past. While home health agencies, foster homes, group homes, and assisted living facilities can be held accountable for the workers they hire, it is less clear how consumers can have redress against personal assistants hired privately, short of resorting to the court system. However, it was emphasized that such consumers need training and support in hiring their personal assistants, and in this way, they could learn to select and manage personal assistants to perform tasks competently.

Importance of Addressing the Liability Issue

Symposium presentations stressed the rigorousness of the test of liability: that is, to be found liable, a person must have actually caused harm through breaching his or her duty of care. In other words, if nurses perform their delegation and oversight functions appropriately, no liability should apply. However, nurses, home health agencies, and personal assistants were all concerned about the possibility that they might be found liable should negative outcomes result from unlicensed personnel performing health maintenance tasks. There was fairly universal agreement that if this is to occur, in whatever form, the "duty of care" that each party holds in the process will need to be clarified.

Clear protocols will need to be developed and agreed among the various interested parties. There needs to be clarity about the evaluation procedure, the amount and type of training, and, in individual situations, the tasks that a nurse decides can be appropriately performed by a personal assistant. For example, states might wish to adopt Oregon's legislative accommodation, which involved an amendment to its Nurse Practice Act clarifying a nurse's lack of liability for negative outcome as long as she has followed appropriate training and delegation procedures.

However, these efforts would tend to protect nurses only. Symposium participants had few ideas on how to protect unlicensed personnel responsible for performing tasks.

There was substantial disagreement, however, in whether delegation was best regulated through lists of tasks, through the settings in which it is delivered, or in other

ways. Those states where detailed lists were used found the lists useful during the introductory period of delegation, but less useful over time.

Need for More Data

One of the biggest issues for policymakers and state legislators is the lack of reliable data, especially on costs and health outcomes. Even if data were collected on programs that currently allow delegation, there is no baseline data against which any new evidence could be compared. Such baseline data would need to include information on the extent to which unlicensed personnel are already performing health maintenance tasks and any negative outcomes associated with this. While the Washington State study on delegation will provide some useful information, significant concerns were expressed about survey methodology.

Need for More Conversation at a National and Cross-constituency Level

Symposium participants consistently expressed the need for more conversation about delegation issues on a national level that involve representatives from a variety of interest groups. Most discussions regarding the issue take place either at the state level, at times when actual changes are being proposed, or at the national level, within a constituency (such as the ANA or NAHC). Resulting discussions within these segregated environments tend to reflect polarized positions. In contrast, the opportunity to find out the experience of other states was valued by Symposium participants. Similarly, the opportunity of meeting with individuals from other constituencies, in a neutral environment, was also thought to be of value.

B. Approaches to Delegation in Selected States

In this section, the presentations of the four states highlighted in the symposium are provided in the order in which they were presented. The write-ups are based on a transcript of the sessions; however, although each of the states except Washington was represented by individuals with a variety of perspectives, their comments have been edited for a smooth reading.

Oregon

Oregon panelists included Cindy Hannum, manager of community-based care policy and licensing in the Senior and Disabled Services Division of Oregon; Pam Matthews, a nurse and division director of the home care network at Evergreen Hospice in Albany, Oregon; Susan King, Oregon Nurses Association, who is an RN with St. Vincent's Medical Center Emergency Department; Joan Bouchard, executive director of the Oregon Board of Nursing; and Loren Simonds, a consumer and a policy technician for the Oregon client employee provider program, in Senior and Disabled Services.

Oregon likes to do things a little bit differently. Back in 1981 in Oregon, a law was passed that gave people a right to live outside of traditional institutional nursing facilities; it was in fact the first state in the United States to have a home and community-based waiver. The state therefore has a very advanced system of home care, foster care, residential care, and assisted living.

Senior and Disabled Services Division is the administering agency for all of the Medicaid long-term care programs and does licensing and regulation for nursing and community-based care facilities. About 40 percent of people who require long-term care receive services that are Medicaid funded, while 60 percent pay privately.

The Medicaid agency is guided by an overall philosophy of shared values. These shared values apply to policy and program development for all Oregonians, not just those who rely on the Medicaid program -- this is important because most people do in fact pay for long-term care out of their own pocket. These shared values are public policy.

The first value is that care must take place in the least restrictive environment. All of Oregon's community-based care programs are built on the premise that people remain in their homes rather than being served in a traditional nursing facility. Whatever one's impairment, an Oregonian has the right to live in the most independent setting.

"Aging in place" is very important, as are autonomy and consumer-directed care. The aim is to combat the medicalization of long-term care. Other important factors are quality, access to services, and consumer satisfaction. Cost-effectiveness is important, too -- people have to be able to buy care. Quality of life, quality of care, and protection and safety are emphasized, along with the guiding operational principles of choice, dignity, independence, and a home-like environment.

These values seem to have an impact: Oregon has been successful in reducing institutionalization. Not only do all elderly and disabled persons in Oregon have access to services, most of these services are delivered in the community. Only a third are in nursing facility care. In Oregon there are more people with comprehensive long-term care needs outside of nursing facilities, than in.

Consequently, the state's home care program is huge, particularly when the proportion of funds devoted to home care is compared to other states. It is also extremely popular. As of July of 1989, there were 2,335 people served through that program. In 1996 there were 8,496 -- an increase of 364 percent in seven years. The main reason given for this popularity is that people value their independence and want to be able to direct their own care, whether they are elderly, newly injured, or born with a disability.

Oregon also has the highest number of licensed foster homes per capita in the United States. The total number is nearly 2,400 licensed foster homes for the general

public. These normally serve five or fewer residents, who tend to have fairly severe disabilities.

Oregon also has residential care assisted living facilities that serve a large number of people. These assisted living facilities fall into a very distinct model. These are private apartments in a residential setting, with a very strong philosophy of consumer-directed care.

Nurses contribute their high level of professionalism to ensure that nursing activities help to achieve Oregon's shared values. They play an important role in supporting people who live in the community and in other community-based settings; they act as visiting nurses and do overall health care assessments and planning.

Delegation is a key part of the system. The Medicaid agency has worked collaboratively with the Board of Nursing, and the Board has been generous in allowing nurses discretion to delegate largely as they see fit. Oregon Board of Nursing has had delegation rule since 1988, which has allowed nurses to assign administration of medication and delegate skilled nursing tasks to people in a variety of settings where nurses are not regularly scheduled. That includes adult foster care homes and assisted living settings, but not nursing homes and hospitals.

Delegation actually came about at the request of nurses. At the time, following the introduction of DRGs in 1983-84, people exiting hospitals were much sicker than before and required more intensive services in the home or wherever they went after the hospital. Nurses, particularly home care nurses, had a short time to deliver services and help a person become independent in their own care. They came to the Board to ask for a mechanism that would enable them to turn over some of their duties to others and yet be protected against liability.

Since the legislation came into effect, that goal has been achieved. The Board of Nursing has taken very few disciplinary actions in the eight to nine years that the delegation rules have been in place. One of the reasons is that delegation rules of the Board of Nursing are quite specific in terms of what a nurse must do in order to delegate.

The liability issues, which are one of the biggest barriers from a nurse's perspective, have also been addressed head-on. The Board of Nursing has a liability clause in the Nursing Practice Act that makes it clear that once a nurse complies with those rules, the nurse would not be liable for disciplinary action of the Board, even if there had been a bad outcome, as long as she had followed the appropriate delegation process. So, if the delegating nurse does the training and the delegation procedures properly, and there's a properly trained delegate in that person's home who negligently harms the individual, that delegate -- unlicensed person -- could be liable for the injury. But the delegating nurse isn't necessarily liable, if she/he has done everything properly nor is the nurse liable for civil action if she/he is in compliance with the Board rules and law.

But delegation is also incorporated into the state's public policy on long-term services. It is conceived of as a very specific type of nursing, a very sophisticated level of nursing -- not just teaching tasks. Nurses must have the capacity to assess care plans, teach in a variety of environments, and consider the overall context of care -- the big picture. Because many nurses have not had the experience and background to do this, the Medicaid agency has set a goal to improve nurses' abilities in these areas.

One of the key tools for ensuring that nurses fulfill their role as community nurses, responsible for delegation, is through policy guidelines developed by the Medicaid agency for nurses on contract and registered with the agency. Senior and Disabled Services employs about 150 independent professional nurses by contract. The guidelines set the standard of practice.

These guidelines cover a range of issues brought up by the Board of Nursing. They provide specifics on how to do delegation. They address issues around restraints and psychoactive medication. But most importantly, they set out that holistic pattern of assessment and care planning that nurses are expected to do.

The state does not have a list of tasks that can be delegated, although there are two task-specific restrictions -- the two things that absolutely cannot be delegated are intravenous medications and injections. Other than these two tasks, delegation is left to the discretion of the nurse. This is primarily due to the variability of situations and differences in the ability of delegates to perform certain functions. In some situations even the most simple basic task would not be appropriate -- it is the nurse's job to assess the situation and decide the tasks that can be safely delegated.

Nurses felt strongly the need to retain that ultimate authority over the appropriateness of delegation in individual circumstances. They need to feel that the person they are delegating to knows what they're doing and is doing it appropriately. They need to be able to say whether a person is or is not a safe person to delegate to. They need to be able to rescind the delegation.

Because delegation grew out of the needs of nurses, and because the procedures, including the guidelines mentioned, were developed in cooperation with nurses, the Medicaid agency and the Board of Nursing have maintained good relationships with nurse representatives. The Nurses Association in Oregon is committed to people receiving care whatever way they chose -- with certain caveats, of course, safety being one of them -- and in the environment that they choose. Most nurses in Oregon support delegation and seem to feel that the process works well.

There is also strong consumer representation in Oregon, through a forum called the Oregon Conference on Disabilities. This is not organized by professionals who say "we know what is best," but by persons with disabilities. It has been successful in creating an environment where people feel like they're being heard, rather than focusing

on bashing professionals. The Conference has been able to develop mutual respect and evolve solutions.

One of the big issues that the state has faced is the payment issue. Under Medicare, delegation is not considered a skilled service. Nurses who are setting up delegation for a Medicare client through training and setting up a care plan can be paid so long as there is something that resembles a skilled service reimbursable by Medicare. But once the consumer's situation is stabilized, Medicare does not continue to reimburse. Under the delegation rules, however, nurses are required to visit at least every 60 days to monitor the situation. Nurses are forced to suggest that clients pay for the service themselves in order to have the nurse come back and redelegate periodically. But the reality is that many of patients, particularly those on Medicare, can't do that. Home health agencies run into problems by not being able to be paid for the care and end up "eating the cost."

The Medicaid agency, on the other hand, pays for the function of delegation both through Medicaid personal care dollars and the waiver program. The agency does not buy delegation; it buys consultation. The nurse acts as a consultant by assessing whether delegation is appropriate in a given situation. Other issues are raised by the predominance of managed care in Oregon. While managed care is probably better at recognizing the need to reimburse activities associated with delegation, it is also more likely to exert pressure to delegate inappropriately, because it's less expensive than paying for nursing. Nurses are forced to justify the need for repeated visits.

Texas

Texas panelists included Anita Bradberry, Executive Director of the Texas Association for Home Care, previously with the Texas Department of Health; Linda Carsner, Health Policy and Quality Assurance Manager for Community Care Programs at the Texas Department of Human Services, which serves about 75,000 elderly and disabled individuals; Stephanie Tabone, Texas Nurses Association; Kathy Thomas, Executive Director and Director of Nursing Practice for the Texas Board of Nursing Examiners; and Bob Kafka, organizer and advocate for ADAPT of Texas and co-director of the Institute of Disability Access.

A number of years ago, advocates for persons with disabilities worked with the Texas Department of Human Services to formulate a policy on delegation. This policy allowed physician delegation of health-related tasks in two community-based programs serving people with disabilities -- Client-Managed Attendant Care (a state funded program) and Community Living Assistance and Support Services (a Medicaid waiver program for persons with related conditions who are not mentally retarded). Physician delegation to an unlicensed attendant was needed in order to support clients living at home within the cost ceilings established for their care. Another program also allowed delegation -- the Home and Community Services program (a Medicaid ICF/MR waiver

program), which is administered by the Texas Department of Mental Health and Mental Retardation for persons with mental retardation.

Physician delegation worked well in these programs because each client had a primary physician who was knowledgeable about the client's needs and capabilities, and comfortable in delegating the needed tasks. The success of physician delegation in these programs prompted advocate and state interest in RN delegation. A special task force on RN delegation was formed by the Texas Board of Nurse Examiners in conjunction with the Texas Department of Health. The task force included representatives of various state agencies, advocacy groups, and providers. This cooperative effort resulted in new delegation rules for Texas RNs.

Although delegation rules have been in place in Texas since 1987, the rules primarily addressed acute care settings, such as hospitals, long-term care facilities, and acute home health. In 1992, however, further changes to the rules were made because of the increased demand for community-based services and because of concerns expressed by advocates.

The changed rules addressed independent living environments, such as workplaces, schools, homes -- wherever the individual client is, provided the client has a stable and predictable condition and participates in the management of their care. As long as they met these conditions, clients were considered to be in the same situation as those who would be performing these services themselves -- except for their disability. Clients were broadly defined to include individuals receiving services as well as family members or significant others.

Currently, delegation in Texas is based on an itemized list of things that are delegable, things that are not, and things that are delegable as long as certain conditions are met. The rules provide a lot of examples, mostly because nurses were initially very reluctant to delegate and wanted very clear, detailed guidance on what was appropriate. Tasks include some forms of medication administration, including topical and oral medications, suppositories, assistance with tube feedings, catheterization, assistance with bowel programs, and other similar tasks.

In 1993, the health and safety code in Texas was amended to require the Texas Department of Health and the Board of Nurse Examiners to develop a Memorandum of Understanding (MOU) that would define certain limited situations wherein certain tasks performed by unlicensed personnel are not considered to be the practice of nursing. Although the state had never actively prosecuted anyone for practicing in these kinds of scenarios, the MOU was developed with the health department to make the legal situation clear. Basically it clarified that personal care was not considered nursing, nor was short-term respite (when families hire people to take care of their loved ones or family members when they go away). The registered nurse assigned to the client is responsible for determining the appropriate level and frequency of supervision.

Most of the services covered by the MOU are really traditional personal care services, rather than specific medical nursing or health-related tasks. With regard to respite, the types of tasks are broader and the delegation is limited to that time frame. Both delegation situations allow medication administration, of course, and other things.

The home care association was very supportive of the move toward delegation. It recognized in the late 80s that there was a need for the use of home health aides to administer medication. It was clear that the very fine line between assisting with medication and giving that medication was being crossed everyday. The first solution to this problem was to create a monster called a home health medication aide -- there are probably only 30 left in the whole state, because they can perform such a limited set of tasks and there's no reimbursement specific to the services they provide. But they were created to fill the need that existed -- to administer meds in an unstable, unpredictable environment.

Now, with the changes, a nurse can delegate administration of meds in those stable and predictable situations to an unlicensed person. Because the aide or attendant is normally in the home doing other things, it's logical for them to be able to administer the meds while they are there. The need to pay a nurse to travel to the home and perform the task is eliminated -- and that has worked very well.

The MOU was revisited in 1995. While recommendations for some revisions were made to the advisory committee, the Texas Department of Health did not accept the recommendations -- so the revised MOU is not in effect at this time. These changes would have allowed even more services to be delegated in respite situations, such as gastrostomy tube feedings. Consumer advocates felt strongly that aides should be able to do injections, too. However, the Board of Nurse Examiners was strongly opposed, as were individual nurses. Because the cooperation and support of nurses was considered so essential to the success of the effort, the compromise stood.

In addition, the lists of tasks that define the delegation process is now often seen as a barrier. Although it was necessary in the beginning because it gave nurses reassurance, it is now causing some problems because it limits delegation.

Another peculiarity of RN delegation in Texas concerns how the various community-based programs administered by the Texas Department of Human Services (TDHS) have addressed the issue. TDHS's large personal attendant services program, which currently serves about 73,000 individuals, does not allow RN delegation. However, the Community-based Alternatives (CBA) program (a Medicaid waiver program), which services 16,000 clients (but is now closed to intake), does allow RN delegation.

The reason for this limited access to delegation is because there is no funding to include RN delegation in the personal attendant services program. However, the Medicaid waiver program, CBA, provides reimbursement for delegation functions.

TDHS conducted a study which used department-registered nurses to assess how many of the clients who were getting attendant care services from the personal attendant services program could benefit from RN delegation. It found that about 12 percent of the people who were getting personal care could also benefit from getting RN delegation. The majority of those clients needed medication administration. However, it would have cost about \$8 million to add the RN delegation piece to personal attendant services. Unfortunately, as in most states, budget neutrality issues intervened. Because the legislature has restricted expansion of the services -- and this was considered an expansion of personal attendant services -- funding has not been approved.

Advocates, of course, want to expand the availability of delegation to the 73,000 people using the personal attendant care program. However, it doesn't seem likely that this will happen anytime soon, given the budgetary constraints placed on state-administered programs.

Texas, unlike Oregon, does not explicitly address nurse liability issues. However, the Board has taken very few actions against nurses for improper delegation. It has tried to encourage delegation through issuing guidelines and teaching in workshops how delegation applies in different settings. It's important to remember that, in Texas, delegation rules apply in acute settings as well as community-based settings. If liability were restricted, the fear is that inappropriate delegation will occur in some acute care settings, particularly given the pressure from managed care systems to delegate. Acute care nurses fear being the one nurse responsible for supervising 50 unskilled people.

The consumer role has been pretty active. In some cases consumers and program administrators have worked well together and in others, not. Participants in the process realized that there was a huge gap in mutual understanding. One of the key things advocates learned was that nurses' fear of delegation responsibilities weighed more heavily on the acute institutional side than on the community setting.

Nurses have a natural reluctance to delegate if they are acute care nurses and not used to the community setting. Even home health nurses were opposed to delegation in the beginning. However, once they become acclimated to a community practice, and they begin to see how it could work, the reluctance goes away. The same nurses who initially opposed it most vehemently have become the biggest advocates for it and active in the Medicaid Community-based Alternatives program.

However, advocates argue that the nursing community and the home care industry still don't get what advocates mean when they say they want control. They feel the health professionals and providers still focus on doing for and not working with, using health and safety concerns as the reason to limit consumer control. The most contentious issue has been the activities that advocates consider activities of daily living, such as catheterization, pill administration, tube feeding, and other such things.

But despite the differences, there appears to be a sense that all the parties can work together to develop compromises. The thing that really worked in Texas was

having the different groups sitting down at the table. Even though there were disagreements, everyone was at the table and had some input.

New York

New York panelists included Karen Ballard, Director of Nursing Practice and Services Program of the New York State Nurses Association; Marilyn Wumburger, member of the New York State Board of Nursing and Executive Vice President of San Camilas Health and Rehabilitation Center, in Syracuse; Ann Hallock, Program Manager for the Cash and Counseling Demonstration and Evaluation Program in the Office of Medicaid Management, New York State Department of Health; Ed Lichter, Director of Concepts of Independence, a consumer-directed personal assistance program, filled in for Ira Holland, who unfortunately could not attend.

Delegation in New York State to unlicensed personnel does not truly exist. Technically, "delegation" in New York State is the designation of professional responsibilities to an individual licensed and qualified by education and competence to perform them. So, the word "licensed" in the definition of delegation eliminates unlicensed personnel.

In the '80s home care came to the forefront and all kinds of problems starting surfacing. In particular, the question was raised of whether good home care nurses could teach, give information, or instruct friends and so forth in providing services to consumers.

Nurses had been finding themselves in impossible situations. They were allowed to teach only people who fell within the definition of "family" in the state of New York. But nurses would be put in situations where they knew they were not teaching the family member -- they were really training the person standing next to the family member, who would ultimately be delivering care. But nurses could not train that person directly.

Meanwhile, the labor pool was dwindling. Who was going to provide the services that were needed?

A very active consumer group, Concepts of Independence, got the ear of a very powerful legislator in New York State, who, in looking at the problem, saw the importance of the issue and decided to do something about it. A bill was introduced into the legislature to expand the tasks of home health aides and personal care aides. As this bill was introduced, it caught the attention of the state education department and the state board for nursing, which were then forced to address the issue.

At the same time, a task force had been set up with the social service department and the Department of Health to determine a matrix for what kinds of tasks could be performed by personal care workers and home health aides. It produced a very thick packet of itemized lists of tasks.

These events brought everyone to the table. The consumers, representatives from legislators' offices, the state board for nursing, home care providers, representatives of the nursing industry, and representatives of the social service and state health departments all came to the table. All came with their own agenda, but with a common goal -- to work on this problem and to see how it could be rectified.

What they produced was an amendment to the exemption clause of the New York State Nurse Practice Act. The existing language created an exemption from the Act for family members. (That in itself caused problems because the term "family member" lacked definition.) The amendment said that a family-employed substitute would be the same as a family member. The term "family-employed substitute" was not further defined -- it could include the self-directed consumer or anyone they chose. The substitute could be taught and educated, be given information, and make decisions on what they wanted to do.

Nurses saw benefits to taking this approach in preference to changing the rules on delegation. At first, they had tried to get the state of New York to redefine the word family. However, for a lot of sociological and social political reasons, the state was unwilling to do so. And, although nurses saw a need for delegation, they saw huge legal and other problems in changing delegation legislation directly. So the option to amend the exemption clause turned out to be the most feasible compromise. But it wasn't easy. There was a lot of objection to changing, and many of the nursing groups received a lot of hot criticism for being willing to expand the definition of family and the exempt clause.

There are really two sections in that amendment to the Practice Act. One is a family substitute section, where the legislation says that, "In 1992 we amended the Nurse Practice Act to allow family members, household members, friends or household employees, to provide nursing services as long as they are not paid for the services and do not hold themselves out as trained nurses to anyone else." Then there is a family-employed substitute section. It goes on to say, "If the family member, household member, friend, or household employee is chosen by the patient to be the employee under the Patient Managed Home Care Program, they can be paid for the services provided." (The Patient Managed Home Care Program was later renamed the Consumer-directed Personal Assistance Services Program.)

It remains unprofessional conduct in our regulations to violate the state's delegation definition, which is very strict. Anyone who does not qualify as a family-employed substitute is governed by fairly strict rules on delegation that apply to licensed personnel. The State Health Department regulates activities performed in a traditional home care setting, so that it's very clear what home health aides can do and what they can't do. Rules were developed by the State Department of Social Services, the Health Department and the State Nursing Board that list permissible tasks for level one and level two personal care workers, and a matrix for home health services. The matrix for home health services allows certain kinds of tasks to be done under permissible conditions -- determined by setting, provider competency, and other factors.

The exemption to the Nurse Practice Act was amended and went into legislation in 1992. It appears to be working. Under this approach, the responsibility of ensuring that tasks are performed appropriately is transferred to the consumer. However, the legislation clearly states that first, a nursing assessment must be performed by a registered professional nurse. This assessment determines whether the consumer or the surrogate is capable of overseeing the substitute and whether the setting is appropriate. (As of the most recent set of legislation, the 1995 legislation, surrogates can now take on the responsibility of directing substitutes.) If these conditions are met, the family-employed substitutes can do anything an RN can do with the appropriate instruction and under the supervision of the nurse.

It is important to note that the discussion has been very setting specific -- the issue is seen differently in home and community-based settings than it is in institutional settings. The mantra is, "the right person, the right place, the right setting." There are different expectations regarding the level of care people should receive, depending on the setting. The nurse must make an evaluation and assessment about the ability of the consumer or their surrogate to self-direct in home and community-based service settings.

The exemption approach applies only to the states' consumer-directed personal assistance program, which uses unlicensed personnel. Of course, the Concepts of Independence program had been in operation since 1980 and the state, as regulator knew that delegation was likely occurring in that program. But the state was committed to seeing that the consumer-directed program work and, really, ignored what was going on. Although Concepts was the only such program for a long time, statute set in 1995 requires that the consumer-directed program be available to every consumer across the state. This means that everyone in New York State's personal care program, which serves over 65,000 people, can participate in the program.

The consumer-directed program has worked very well. It began with a group of consumers who were very concerned about the changes that were proposed in the city of New York. The state was going from a dual payment system, where they were having independent contractors providing the services, to a vendor system, a more traditional framework of service provision. Consumers presented an idea for an alternative program where they could do their own hiring, training, and supervision of their own home care workers. Consumers would use an intermediary support organization -- Concepts -- to handle benefits, payroll, and related tasks. Concepts would take on the job of ensuring workers' compliance with relevant employer responsibilities. It is estimated that the program has saved about \$11.5 million a year because of the savings associated with using family substitutes.

Concepts serves people who generally have stable conditions rather than acute illnesses. About 56 percent of them are over 55 years of age. A few are over 100 years of age -- they tend to ask a lot more questions and are very feisty. Consumers stay in the program for 5.4 years, on average -- and about one-third of the consumers have participated for more than nine years.

All consumers participate voluntarily. The whole key to the program is that the consumer accepts the responsibility and the liability for the services they direct; every time an attendant is hired the consumer must complete a form which confirms that they accept that responsibility.

Many of the 440 consumers of Concepts need fairly intensive services that are a routine part of their day-to-day life. Right now about 270 consumers receive high level services: 64 require some sort of ventilatory support, 130 are quadriplegic, and 188 receive more than 12 hours of service per day. Eleven people in the program require injections.

Some of the controls that go into this program are that every consumer must be certified by an RN and must be capable of handling the training and supervision associated with their high level service. That can mean that consumers could be approved for the program, but may have one particular task that the nurses from the Social Services Department may feel is inappropriate for them to manage individually. Consumers are monitored through at least two nursing assessment visits per year and one or two visits by the Social Service Department. In addition, consumers, various medical professionals, or personal assistants may alert Concepts if there are important changes in the consumer's situation.

Washington

Cheryl Allen, the Community Health Policy Coordinator for Aging and Adults Services Administration in the state of Washington, is responsible for the state-wide implementation of the nurse delegation services within aging and adult services administration. Washington State's effort is of particular interest because an evaluation component was mandated as part of program implementation.

Aging and Adult Services provides services to elderly and disabled individuals in community-based settings and in long-term care settings in nursing homes. There is a real disparity of services between individuals because of where they chose to live. A large percentage of people said "I don't want to live in a nursing home. I prefer to live in an in-home type care setting, in a community-based setting." However, it was very difficult to respond to these preferences because approximately one-third of the people being served by Aging and Adult Services were in nursing homes. And this one-third were getting three-quarters of the agency's money -- that's three-quarters of the budget going on nursing home placement. So the department began to look at ways of supporting community-based care.

Back in 1989-90, Aging and Adult Services began to look at unlicensed practice in cooperation with the Board of Nursing. Not much happened until the tax revolt took place and the state passed Initiative 601. In Initiative 601, the state taxpayers mandated that the state should limit its spending and growth, and they attached increases in spending.

This provided Aging and Adult Services with an opportunity to present some of the issues it was facing to the legislature. The primary issue was that, at the same time that the agency was restricted to a five percent increase in spending, the population it served was growing at two to three times that rate. The agency decided to propose legislation that totally revamped the community-based care system. Nurse delegation was an important part of that.

In 1995 the Washington state legislature passed legislation that amended the Nurse Practice Act. Washington State had attempted to model its delegation practice after Oregon's, because Aging and Adult Services Division thought highly of the way Oregon appeared to be working. However, the Washington state legislature took a very conservative approach to nurse delegation and limited it, by restricting the settings in which delegation can occur and by limiting the tasks that could be performed.

Settings were limited to three: our licensed adult family homes; our DD certified residential programs; and our licensed boarding homes that have assisted living contracts. It was also limited in tasks: oral and topical medications; eye, ear, nose drops; some real basic G-table feedings; clean catheterization; and clean dressing changes.

The Washington changes are looked at as a pilot project, because of the many concerns about delegation. To respond to the fear and apprehension expressed by many opponents of delegation, the legislature commissioned a study of nurse delegation as it is implemented. There appeared to be no real data about what nurse delegation was all about, who it impacted, what the cost was, how it affected satisfaction, or what the outcomes were.

The University of Washington School of Research was appointed by the legislature to do the research. This was a battle between the agency and the nursing commission -- and the University of Washington got pulled into this battle. There are many, many interested parties in this process. The legislature did something unique -- it continued to participate in the process by setting up a monitoring committee.

The study will sample each of the three different settings, focusing on some very specific issues -- the legislature was very specific in the statute about everything. First, it required that the Board of Nursing put nurse delegation protocols into rule -- which had never been done before. It was also very specific about the content of the study, which really tied the hands of the researchers in developing a research model. The legislature mandated that the study look at eight different issues:

- the patient, nurse, and nursing assistant satisfaction;
- medication errors, including those resulting in hospitalization;
- compliance with required training;
- compliance with nurse delegation protocols;
- incidents of harm to patients, including abuse and neglect;

- impact on access to care; impact on quality of life; and
- incidence of coercion in the nurse delegation process.

The legislature also placed restrictions on who could become a delegate. Anyone to whom tasks are delegated must be either a nursing assistant "registered" or nursing assistant "certified." One reason for the restriction was to ensure that there was a process for disciplinary action, if any problems arose.

In our state, to be "certified" as a nursing assistant, a person must have 85 hours or more of training. To be "registered" as a nursing assistant, all that is required is that the individual send \$10 to the Department of Health to be placed on a registry. The advantage is that these individuals then fall under the Uniform Disciplinary Act. Even though there's no required training for the registered nursing assistants, those who wish to work for the agency must take part in some training. They receive 22 hours of fundamentals of care-giving training. Both categories must undergo a nine-hour course of core delegation training, which was mandated in the legislation.

The study only got going this year (1996), although the legislation was passed in 1995. This delay was partly due to the nursing commission's task force, which finalized the protocols only last March. However, data are beginning to be collected from some of the existing data sources. Training sessions have also taken place for nurses, even though there was no mandatory training for registered nurses. There have also been workshops to bring some of the nurses up to speed on delegation. Also, there has been training for nursing assistants, the delegates.

The pre and post tests have also been set up. At the beginning of the training, nurses are given a questionnaire about how much they know about delegation, what do they feel about delegation, have they ever delegated. This is to get a feel for where they are at the beginning of the workshop or the training. Then at the end of that training, a post test is administered to see if there has been any change in their level of knowledge. These tests will be repeated.

In this study each of the state's six regions will be looked at, with at least one of the three identified settings being looked at within those regions. For the community-based setting, information will be obtained from assessments and other documentation. The study will begin with a pilot, and then move into focused interviews. Research assistants will choose individual facilities to focus on. Within those facilities, specific clients who are receiving delegation will be studied, along with everyone associated with that client, whether it's the delegating nurse, the nursing assistant doing the care, family members, or the case manager that placed them. They all will receive in-depth questionnaires and interviews. Because some of the individuals have problems with communication, researchers will have to use a lot of different ways of extracting information. Some of the other elements that will be looked at are the medication issue, compliance with training, nurse compliance with delegation protocols, and some other issues.

This whole process is voluntary. The nurse has to be willing to delegate, the nursing assistant has to be willing to receive the delegation. The client has to agree to the delegation, and want it. This applies to the study also.

It is important to note that the study is not going to determine whether delegation works or doesn't work, because of the lack of comparative data. There is nothing to compare it against. This study will provide baseline information on delegation in the state of Washington -- not whether it's good or bad, but information that will contribute to additional research and enable judgments to be made. It will help in making policy decisions, because it will address concerns regarding accountability, liability, and coercion. The study will provide data on whether consumers are getting the services, and the impact on those individuals.

The study is to run for approximately a year. By December of 1997, Aging and Adult Services is supposed to go back to the legislature with recommendations from the study to hopefully expand, modify, and improve this nurse delegation. However, because it has been such a time-consuming and complex process in getting this going and involving all the interested parties, Aging and Adult Services is going back to the legislature to request a one-year extension to this study.

The hope is that the study will produce some real concrete data. Delegation is too important to the state's efforts and it affects too many lives for the study to be halfhearted. Aging and Adult Services is very interested in what the outcomes are going to be. But remember, there will not be any clear decisions about what does and doesn't work -- the study will only provide a baseline to how we can make better policy decisions around community-based care and nurse delegation in Washington State.

C. Comparison of Nurse Delegation Provisions in Four States (October 1996)

Regulatory Feature	New York	Oregon	Texas	Washington
1. Delegation or Exemption? & Source of Authority	Exemption N.Y. Pub Health Law §3622, amended in 1992, establishing the "patient-managed home care program" -- now called the "consumer-directed personal assistance program." The nurse practice act, N.Y. Public Health Law §6908, was amended to carve out an exemption from the nurse practice act for this program.	Delegation State Board of Nursing regulations amended in 1987 (Oregon Administrative Regulation §851-47-000 to -030)	Delegation Bd. of Nurse Examiner regulations -- 25 Tex. Admin Code §§217.11 \$218. Changed in 1993 in conjunction with new category of service, "personal assistance services" recognized under Home and Community Support Services Act of 1993. Texas Dept of Health regulations and memo of understanding between Dept. of Health and the Bd. of Nurse Examiners provides guidelines.	Delegation 1995 amendment to regulatory statute governing "nursing assistants" (must be either certified or registered under Washington law) Rev. Code of Wash. Ann. §188.88A.210 to .240.

Regulatory Feature	New York	Oregon	Texas	Washington
2. Program Limitations on Delegation	Applies only to the state's consumer-directed personal assistance program	No limitations	Applies only to programs under the jurisdiction of the Texas Dept. of Health, providing home and community support services.	Applies only to individuals in community-based settings regulated by the Dept. of Social & Health Services, specifically: (1) community residential programs for the developmentally disabled; (2) adult family homes; and (3) boarding homes contracting with DSHS to provide assisted living services.
3. Personnel Limitations. Who may be a delegate?	Not applicable. Any person who provides care in the exempt program is exempt.	Unlicensed person.	Unlicensed person.	Certified or registered nursing assistant.
4. Setting Limitations	The program limitations, noted above, have effect of limiting the exemption to home care settings.	Only acute care and long-term care institutions are excluded from delegation option. [OAR §851-47-000(2)]	Any independent living environment, defined as a client's individual residence, which may include a group home or foster home, or other settings where a client participates in activities, including school, work or church [Bd of Nursing Examiners' regs (§218) and Dept. of Health regs]	Applies only to individuals in community-based settings regulated by the Department of Social & Health Services, specifically: (1) community residential programs for the developmentally disabled; (2) adult family homes; and (3) boarding homes contracting with DSHS to provide assisted living. [RCWA §18.88A.210(1)]
5. Task Limitations:				
<ul style="list-style-type: none"> • Tasks that can be delegated 	Not applicable -- no delegation permitted.	Provides list/criteria [OAR §851-47-000 to -030]	Provides list/criteria [25 Tex. Admin. Code §218]	Provides list/criteria [RCWA §18.88A.210 & WAC §246-840-910]
<ul style="list-style-type: none"> • Tasks that are permitted without delegation 	If eligible for the consumer-directed program, all tasks are consumer controlled with no nurse delegation required.	"Basic tasks of client/nursing care" -- include but not limited to ADLs. Assignment and supervision by RN is discretionary for these. [OAR §851-47-010(2) (1993)]	"Personal care" (feeding, preparing meals, transferring, toileting, ambulation and exercise, grooming, bathing, dressing, routine care of hair and skin, and assistance with medications that are normally self-administered) [25 TAC §115.26(c)]	None specified (so <i>presumably the definition of "registered nursing practice" [RCWA §18.79.040] must be consulted.</i>)
<ul style="list-style-type: none"> • Tasks that cannot be delegated at all (in addition to the task of delegation itself) 	Not applicable.	None specified, except that the R.N. may not "delegate the nursing process in its entirety to an unlicensed person." [OAR 851-47-030(2)]	The nursing task must not require the unlicensed person to exercise judgment or intervention except in emergency. [22 TAC §218.3(4) (1993)]. This is supplemented [at §218.7] with list of illustrative tasks that may not be delegated.	None specified (<i>But not clear whether the given list of delegable tasks, at RCWA §18.88A.210(4), is merely illustrative, or exclusive and thus limiting.</i>)

Regulatory Feature	New York	Oregon	Texas	Washington
6. Required procedures for delegation described?	Not applicable.	Yes, substantial detail.	Yes, substantial detail.	Yes, substantial detail.
7. Recognition of Surrogates for Consumers	Yes, guardian, or adult designated by consumer and who is able and willing to assist in making choices concerning the services the consumer is to receive and to carry out the consumer's responsibility in the exempt program. [§3622(7)]	Not addressed nor part of the criteria for delegation.	Yes, family member or significant other. [§218, Bd of Nursing regs]	Yes, authorized representative, i.e., person authorized to provide informed consent for health care on behalf of a patient who is not competent to consent. Must be a member of classes of person defined in RCWA 7.70.065 (spouse, adult children, parents, adult siblings). [WAC 246-840-920 (1996)].
8. Role of Consumer in Delegation	Individual must be given notice of eligibility and availability of consumer-directed personal assistance program. If determined to be eligible after assessment by an RN and consumer elects to participate, consumer controls recruiting, selecting, training, supervising and terminating workers. [N.Y. Pub. Health Law §3622]	No active role.	No active role.	RN must discuss delegation with consumer and obtain informed consent. [WAC 246-840-930(9) and 246-840-940(1)]
SOURCE: ABA Commission on Legal Problems of the Elderly, Charles P. Sabatino, October 1996.				

D. Consensus Topics and Recommendations of Conference Participants

Symposium participants were divided into four work groups to develop recommendations and to identify areas of consensus about delegation and exemption strategies. Participants were asked to assume that their group had the opportunity to design an "ideal" system and the authority to change any regulations that apply to professionals and/or service organizations. Participants were also asked to identify areas of consensus within the groups as well as areas of disagreement. Each group reported out to the full body during the final session of the symposium. Below are the highlights of each work group.

Areas of Consensus among Participants

Participants found several general areas in which there was consensus. These include the following areas:

1. The consumer is central to all discussions and decisions made around long-term care and should have the opportunity and right to independence and autonomy in care decisions.
2. Policy development affecting professional practice and consumer choice and directions should be designed with full participation of all stakeholders -- professionals, consumers, caregivers, and policymakers.
3. Decisions about care plan options should involve the individual consumer as well as the professionals and caregivers who are working with the consumer.
4. The fragmented funding for long-term care imposes barriers on consistent delegation and/or exemption policies affecting consumers of long-term care.
5. There should not be a federal standard for delegation.

Areas of Disagreement among Participants

1. Whether different standards regarding delegation were appropriate in different service settings.
2. Whether a team should make decisions regarding delegation and the tasks to be delegated or whether decisions should be made on the authority of one person -- a nurse or a consumer, for example.
3. Whether a list of tasks is the best way to limit or prescribe delegation.

In general, there is disagreement between professionals and consumers regarding the extent to which consumers should "control" the decision to delegate tasks and the level of professional involvement necessary to assure quality and evaluate progress on a regular basis.

Ideal Approaches to Delegation

There were three discrete approaches to delegation designed by the five work groups. Each work group had slightly different details and assumptions in its approach, but in general the approaches fell readily into the three groups described below.

1. Exemptions and site-specific delegation

This approach uses a combination of a "blanket" exemption and a delegation policy. Exemptions from any delegation act would be automatic for the family and friends of consumers as well as any personal attendant the consumer hires. Delegation, however, should be an available service option in all facility settings and within professional service organizations. When tasks are delegated, the nurse or other professional delegator would assess the consumer's situation, delegate any function

that they believe appropriate and determine how much, if any, supervision is required on an ongoing basis. In delegating tasks, the consumer is trained and must be competent to perform delegated tasks. If this criteria is met, the nurse or other delegator would not be liable for problems which arise as a result of the delegation.

2. **Right to least restrictive living options**

The second approach does not address delegation per se. Rather it suggests that the state adopt a policy for long-term care which ensures that each individual consumer has a right to live within the least restrictive living environment possible and to be independent in his or her functioning. This general policy would support a number of decisions on the part of the consumer including the extent to which he or she wants to be involved in receiving care from a professional or wants to perform tasks himself/herself or delegate to others. In order to foster this mission statement, participants suggested that the funding for needed services and support would follow the individual consumer and not be related to the environment or setting in which they live or receive services. Participants also envisioned a system with specifics designed by all stakeholders in long-term care: nurses, pharmacists, consumers, physicians, caregivers, etc.

3. **Delegation standards.**

The third approach relies more on "traditional" delegation models. In this model, as in practice in many parts of the country today, delegation is negotiated between the professional and the consumer. Delegation decisions would be based upon the extent to which the consumer and/or designee demonstrates competence in performing delegated tasks. Critical judgment functions such as assessment and evaluation could not be delegated. This group also agreed that delegation always involves teaching -- but teaching does not always involve delegation. And, finally this group (and others) strongly recommended that delegation activities be covered by any third-party funding available for services needed by the consumer.

General Recommendations

Because of the diversity of the symposium participants, a specific set of recommendations around which there was a consensus did not emerge. However, there were general themes around which recommendations could be articulated. These include:

1. The fragmentation of funding presents problems in long-term care and states should work to combine funding from the various sources into one funding pool in order to ensure continuity of care and policy. **Service dollars should follow the individual consumer rather than be articulated by and tied to different funding sources.**

2. Funding from third party sources should be available to support the delegation of tasks process -- evaluation, education, assessment, and monitoring.
3. Nurses or other delegators should be free from liability associated with negative outcomes resulting from delegation, provided they have performed the delegation correctly.
4. States should assume some responsibility for consumer protection in the area of personal attendants and assistants through the development of workers' registries and the facilitation of criminal background checks.
5. Policies and practices towards delegation should be applicable to all settings. However, the implementation of these policies and practices could vary according to setting.

III. SURVEY OF STATE BOARDS OF NURSING

As participants in the Symposium's planning committee, The National Council of State Boards of Nursing agreed to conduct a brief survey. This survey was designed to take a snapshot of activity related to delegation among state Boards over the last two years. It was administered via Internet in September 1996. Forty-seven of the 61 state Boards responded, resulting in a 77 percent response rate. Nearly all states, 94 percent of those responding, have language specifically addressing delegation in their Nurse Practice Acts, regulations, and/or other guidance they produce.

Do States Address Delegation?		
	Number	Percent
Language regarding delegation is included in State's Nurse Practice Act	28	60
Language regarding delegation is addressed by rules and regulation	34	72
Language regarding delegation is addressed by other forms of guidance	31	66
States that use one or more of these approaches to address delegation*	44	94
n=47		
* Numbers do not add up because states use multiple approaches.		

Findings indicate that Boards are very active on issues relating to delegation; although, lacking a baseline against which the survey findings can be compared, it is difficult to set the level of activity in historical context. Of the 47 Boards responding to the survey, 30 (64 percent) report that changes are planned or have been made over the last two years regarding the legislation, regulation, or other guidance relating to delegation. Of those states whose legislation, regulation, or other guidelines address delegation, 24 (55 percent) have experienced changes in the last two years. Six of those states made changes to the act itself, 17 made changes to their rules and regulations, and 12 made changes to other resources providing guidance on delegation. Thirty-two percent of Boards are aware of planned changes that will affect the ability of unlicensed personnel to perform nursing tasks.

How are States Changing Delegation Practice?		
	Number	Percent
States that made changes to Nurse Practice Acts in the last two years	6	13
States that made changes to rules and regulations in the last two years	17	36
States that made changes to other forms of guidance in the last two years	12	26
States that are aware of planned changes	15	32
States that have changed in the last two years or are planning changes*	30	64
n=47		
* Numbers do not add up because states use multiple approaches.		

The reported level of planned changes may be due to an increased recognition of issues associated with unlicensed personnel who provide services in the community. Eighty-one percent of Boards reported that such issues have been raised and discussed in Boards over the last two years.

It appears that few Boards formally recognize the relevance of differences among service settings in their regulation of delegation activities. Only six states (13 percent) interpret delegation differently for services provided in home and community-based settings than for those provided in hospital or other settings.

States interpreting delegation differently for home and community-based service settings: Hawaii, Montana, New York, Oregon, Texas and Washington.

On the other hand, Boards are more likely to recognize a responsibility for non-nurses who perform nursing tasks. Twenty-one percent have the authority to monitor or regulate unlicensed personnel providing services in the community. Other states, however, have an indirect authority through regulating the person who is doing the delegation.

This snapshot of activity related to delegation represents the first attempt to evaluate state practices on a national, comparative scale. Previous research (most notably, Kane et al, 1995) has evaluated only subsets of states. However, due to the brevity of this survey, it provides only a rough indication of the level and types of activities that have taken place over the last two years. Future research could usefully focus on providing more detail on the nature of guidance issued by Boards; on the direction of change (whether changes liberalize existing practice or regulate it more tightly); and on the types of issues relating to delegation that are dealt with by boards.

IV. NATIONAL STAKEHOLDER ASSOCIATION POSITIONS ON DELEGATION

A. Americans with Disabilities Attendant Programs Today (ADAPT)

When Are Medical Tasks Not Medical Tasks? A Call for Health Maintenance Services from Institutions to the Community!

The current federal funding for health care services, created over thirty years ago, was designed to provide services in acute and/or institutional settings.

However, the changing demographics of our country and advances in rehabilitation techniques and medical technology have reshaped the type of services needed and desired. Children born with disabilities are now living to adulthood. Traumatically disabled young adults who, not so long ago would have died, now live a normal life-span. The aging of America has meant more individuals acquiring disabilities later in life who need health and support services. The current health care debate, calls for Medicaid and Medicare reform, the rise of physician-assisted suicides, are all in reality a backhanded recognition of these dramatic changes.

These growing numbers of people with disabilities, old and young, are now demanding medical/health and support services in home and community settings. Institutional placement is no longer an option people accept without question. People want personal attendant services.

Personal attendant services (PAS) are defined as those health and support services, delivered in home and community settings, that assist a person with a mental and/or physical disability, regardless of age, in accomplishing activities of daily living, instrumental activities of daily living and health maintenance activities. Health maintenance activities are those, now defined as medical tasks, that can be done by or delegated to a qualified unlicensed personal attendant.

These demands for personal attendant services will require a rethinking of the philosophical underpinnings of our current long-term service delivery system.

First the system must recognize that long-term services should be delivered in the home and community. This means health services that were once only delivered to people with mental and physical disabilities in hospitals and congregate facilities must now be provided in home and community settings, wherever the person needs them.

A home and community support system requires flexibility to meet the varied needs of people of all ages and disabilities. It requires that the delivery of these services be done as non-medically and as unobtrusively as possible. People are questioning the "medical model" approach and the role the health professional has in that model.

In the current "medical model" system of service delivery, individuals are passive players who rely on health professionals for guidance and often for permission. In return, we as patients, are offered the hope of cure or some level of fixing. The balance of control lies with health professionals providing health and support services, rather than with the person requiring these services. There has only been token acknowledgment that the person receiving the services has anything to contribute to their own care.

People with disabilities of all ages are demanding more choice and control in these health and support services. The level of satisfaction in long-term services can be directly related to how much choice and control an individual has in their service delivery options.

As more and more individuals receiving health and support services gain more choice and control, a contentious debate is growing around the role of health professionals in this new system.

The major point of controversy between health professionals and the disability community arises when tasks now defined as "medical" are delivered in concert with non-medical support services in home and community settings. People with disabilities want these services delivered effectively and with as little medical intrusion as possible.

However, the medical community looks at these services differently than people with disabilities do. The debate over de-medicalization of health and support services raises the following questions:

- Which tasks are medical?
- Who should provide which services?
- What level of skill is needed to deliver services?
- Who is in control of the services?
- Who makes the decision as to what degree of risk is acceptable?
- Who is ultimately liable for mistakes and abuses?

There is a critical need to distinguish between "medical tasks" that need to be provided by or under the direct supervision of a health professional and "health maintenance tasks" which can be done by or delegated to a qualified unlicensed personal attendant.

Moving the locus of control from health professionals to the users of health and support services in home and community settings will have significant impact on whether any specific task is defined as medical or a health maintenance one.

These distinction between "medical" and "health maintenance" tasks should take account of the difference between short term acute illness, institutional placement and long-term maintenance needs.

The setting in which a task is provided has a major impact, not only on the way we define the task, but also on who and what level of skill that person needs to perform the task. A task performed in a nursing home, ICF-MR facility or hospital may be defined as medical while the exact same task performed in a person's home and community may be defined as a health maintenance task. The fact that the person is receiving health services in a non-institutional setting fundamentally makes them different than those in hospitals, ICF-MR facilities and nursing homes. The locus of control shifts to the person with a disability when health and support services are provide in the home and community.

When we distinguish between "medical" and health maintenance tasks, it allows us to think differently about the delivery of long-term services in the home and community. The focus would be on people with disabilities, living in the home and community, needing health maintenance and support services rather than being seen as people who are sick or broken in need of "medical" services and professional fixing. The distinction focuses on our needs as people to become as functional as possible rather than as "patients" needing to be cared for and cured.

Health maintenance tasks include not only, those tasks delegated, by a health professional to an unlicensed personal attendant, but also a category of tasks that need no health professional involvement. These are not activities of daily living in the traditional sense not are they medical tasks. Intermittent catherteization, bowel programs and tube feeding, are just a few examples.

These are tasks that are a routine on-going part of the lives of many people with disabilities and their families. These people are not "sick". Their health is "stable and predictable" and will not suddenly change. Provision of these tasks is essential for the person: to live in the home and community but does not necessarily involve health professionals. Currently many of the tasks are defined as medical tasks.

Factors can be identified that would allow the individual (guardian or family member in the case of children under 18 years) to be in total control of the tasks that are performed by a qualified personal attendant.

These could include: the choice of the consumer of services to direct services, level of experience of the personal attendant, the setting, in which the task is being provided, and the nature of the task. Priority should always be given to the choices of the individual receiving the health and support services.

Concerns by the health professional and home health community about health and safety of "vulnerable" individuals are often cited as explanations for the system as it is today. Protection of some individuals from abuse and neglect has led to a blanket system that doesn't give the recipient any choices to accept a level of risk that is necessary to live in the community. Ironically, we seem to be building an "institution without walls" mentality in the community because of liability concerns.

The fear of being sued, the concern about liability, is a more important factor than health concerns in explaining some of our over-medicalized, over-regulated home and community- based long-term service system. This fear continues even though in states where unlicensed personal attendants have been performing health maintenance tasks for years, there have been no reported abuses that have led to major legal actions.

The growing number of people with complex support needs challenges us to develop a home and community services system that has the flexibility to allow individuals to make choices. Risk management models must be instituted that give individuals with disabilities the ability to control their services and take acceptable risks. Health professionals and home health providers must work with the disability community to work out acceptable alternatives to the current system.

There is not total unanimity in the disability and older communities on all these issues. The differences expressed are ones of degree. Should there be any health professional involvement in the delivery of PAS? Are we setting ourselves up for massive complaints of abuse and neglect? What is the balance between no health professional involvement and medical intrusiveness? Are we in danger of winning the philosophical war over the non-medical nature of our service needs, and then potentially losing the dollars needed to fund this system because we have cut ourselves off from the strong medical lobby which got the money in the first place?

There are no easy answers. As resources become scarce, it will be necessary to deliver home and community long-term services differently. The design must come from the disability community, working with health professionals and home and community service providers on an equal basis. PAS must mean personal attendant services not physician assisted suicide.

FREE OUR PEOPLE!

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B. The American Nurses Association (ANA)

Registered Nurse Utilization of Unlicensed Assistive Personnel

Summary:

The American Nurses Association (ANA) recognizes that unlicensed assistive personnel provide support services to the RN which are required for the registered nurse to provide nursing care in the health care settings of today.

The current changes in the health care environment have and will continue to alter the scope of nursing practice and its relationship to the activities delegated to unlicensed assistive personnel (UAP). The concern is that in virtually all health care settings, UAPs are inappropriately performing functions which are within the legal practice of nursing. This is a violation of state nursing practice acts and a threat to public safety. Today, it is the nurse who must have a clear definition of what constitutes the scope of practice with the reconfiguration of practice settings, delivery sites and staff composition. Professional guidelines must be established to support the nurse in working effectively and collaboratively with other health care professionals and administrators in developing appropriate roles, job descriptions and responsibilities for UAPs.

The purpose of this position statement is to delineate ANA's beliefs about the utilization of unlicensed: assistive personnel in assisting in the provision of direct and indirect patient care under the direction of a registered nurse.

Unlicensed Assistive Personnel

The term unlicensed assistive personnel applies to an unlicensed individual who is trained to function in an assistive role to the licensed nurse in the provision of patient/client activities as delegated by the nurse. The activities can generally be categorized as either direct or indirect care.

Direct patient care activities are delegated by the registered nurse and assist the patient/client in meeting basic human needs. This includes activities related to feeding, drinking, positioning, ambulating, grooming, toileting, dressing and socializing and may involve the collecting, reporting, and documentation of data related to these activities.

Indirect patient care activities focus on maintaining the environment and systems in which nursing care is delivered and only incidentally involve direct patient contact. These activities assist in providing a clean, efficient, and safe patient care environment and typically encompass categories such as housekeeping and transporting, clerical, stocking, and maintenance supplies.

Utilization

Monitoring the regulation, education, and utilization of unlicensed assistive personnel to the registered nurse has been ongoing since the early 1950's. While the time frames and environmental factors that influence policy may have changed, the underlying principles have remained consistent:

- IT IS THE NURSING PROFESSION that determines the scope of nursing practice;

- IT IS THE NURSING PROFESSION that defines and supervises the education, training, and utilization for any unlicensed assistant roles involved in providing direct patient care;
- IT IS THE RN who is responsible and accountable for the provision of nursing practice;
- IT IS THE RN who supervises and determines the appropriate utilization of any unlicensed assistant involved in providing direct patient care; and
- IT IS THE PURPOSE of unlicensed assistive personnel to enable the professional nurse to provide nursing care for the patient.

It is the assumption of the ANA that the provision of safe, accessible and affordable nursing care for the public may include the appropriate utilization of unlicensed assistive personnel and that the changes in the health care environment have and will continue to alter the activities delegated to UAPs.

Therefore, it is the responsibility of the nursing profession to establish and the individual nurse to implement the standards for the practice and utilization of unlicensed assistive personnel involved in assisting the nurse in the direct patient care activities. This is accomplished through national standards of practice and the definitions of nursing in state nursing practice acts. In order to understand the roles and responsibilities between the RN and the UAP the ANA recognizes that the key to understanding is the clarification of professional nursing care delivery and the activities that can be delegated within the domain of nursing. The act of delegation is defined as "the transfer of responsibility for the performance of an activity from one person to another while retaining accountability for the outcome."

In delegating, it is the RN who uses professional judgment to determine the appropriate activities to delegate. The determination is based on the concept of protection of the public and includes consideration of the needs of patients, the education and training of the nursing and assistive staff, the extent of supervision required, and the staff workload. Any nursing intervention that requires independent, specialized, nursing knowledge, skill, or judgment cannot be delegated.

- Effective Date:** December 11, 1992
- Status:** New Position Statement
- Originated by:** Congress on Nursing Economics, Congress of Nursing Practice
- Adopted by:** ANA Board of Directors
- Related Past Action:** (1) Scope of Nursing Practice, House of Delegates, 1987; (2) ANA Opposition to the AMA proposal to Create Registered Care Technologists, House of Delegates, 1988.

Attachment I: Definitions Related to ANA 1992, Position Statements on Unlicensed Assistive Personnel

The ANA Task Force on Unlicensed Assistive Personnel developed the following definitions to clarify the ANA position statements on the role of the Registered Nurse in working with unlicensed assistive personnel. These definitions reflect a review of current regulatory, legal practice, and professional terminology and are intended to be used only in the context of these position statements.

1. Unlicensed Assistive Personnel:

An unlicensed individual who is trained to function in an assistive role to the licensed registered nurse in the provision of patient/client care activities as delegated by the nurse. The term includes, but is not limited to nurses aides, orderlies, assistants, attendants, or technicians.

2. Technician:

A technician is a skilled worker who has specialized training or education in a specific area, preferably with a technological interface. If the role provides direct care or supports the provision of direct care (Monitor tech, ER tech, GI tech) it should be under the supervision of a Registered Nurse.

3. Direct Patient Care Activities:

Direct patient care activities assist the patient/client in meeting basic human needs within the institution, at home or other health care settings. This includes activities such as assisting the patient with feeding, drinking, ambulating, grooming, toileting, dressing, and socializing. It may involve the collecting, reporting, and documentation of data related to the above activities. This data is reported to the RN who uses the information to make a clinical judgment about patient care. Delegated activities to the UAP do not include health counseling, teaching or require independent, specialized nursing knowledge, skill or judgment.²²

4. Indirect Patient Care Activities:

Indirect patient care activities are necessary to support the patient and their environment, and only incidentally involve direct patient contact. These activities assist in providing a clean, efficient, and safe patient care milieu and typically encompass chore services, companion care, housekeeping, transporting, clerical, stocking, and maintenance tasks.

²² Judgment as it relates to the above definitions is defined as the intellectual process that a nurse exercises in forming an opinion and reaching a clinical decision based upon an analysis of the evidence or data.

5. **Delegation:**

The transfer of responsibility for the performance of an activity from one individual to another while retaining accountability for the outcome. Example: the nurse, in delegating an activity to an unlicensed individual, transfers the responsibility for the performance of the activity but retains professional accountability for the overall care.

6. **Assignment:**

The downward or lateral transfer of both the responsibility and accountability of an activity from one individual to another. The lateral or downward transfer must be made to an individual of skill, knowledge and judgment. The activity must be within the individual's scope of practice.

7. **Supervision:**

The active process of directing, guiding and influencing the outcome of an individual's performance of an activity. Supervision is generally categorized as on-site (the nurse being physically present or immediately available while the activity is being performed) or off-site (the nurse has the ability to provide direction through various means of written and verbal communications).

C. Developmental Disabilities Nurses Association

Mission Statement: As nurses in the specialized field of Developmental Disabilities, our mission is to continually develop our expertise in order to assure the highest quality of life to the people we serve throughout their lifespan.

At this time, we in the Developmental Disabilities Nurses Association (DDNA) are in the process of developing a position statement on delegation. In preparation for this endeavor, the following concepts and views will be considered:

Nurses must know the legal scope of nursing practice within the state nurse practice act and any other regulations that are applicable. Additionally, as nurses with a specialized area of practice, we are professionally and ethically obligated to promote and support standards of practice in our specialty. These standards define our professional accountability to the public and the individual outcomes for which they are responsible. They also provide a direction and framework for the evaluation of our practice.

The purpose of the Standards of Developmental Disabilities Nursing Practice is to fulfill the profession's obligation to outline and delineate developmental disabilities nursing practice in order to determine levels of practice to achieve excellence in practice. (DDNA Standards of Practice, 1995).

The practice of developmental disabilities nursing endorses the promotion of wellness and normalization in the provision of services to individuals with developmental disabilities. The nursing profession focuses primarily on interventions which maximize the psychosocial, physical, affective, cognitive, and developmental strengths of individuals and their families.

In 1984, Congress enacted the Developmental Disabilities Act (PL 98-527) that stated that states must work to promote the values of independence, integration, and productivity for all citizens with developmental disabilities.

Capacity does not equal competency. Most people with developmental disabilities are capable of at least some informed decisions. This capacity may vary over time and may vary across different decisions. Therefore, except for those who are most profoundly impaired, the evaluation for capacity needs to be decision specific.

Society is now viewing the continual growth of a set of values with regard to individuals with developmental disabilities. With any aspect of a growing and changing system, standards and credentialing need to ultimately reflect changes in values. Nurses can be facilitators rather than inhibitors for this interactive evolutionary process for safe and respectful change.

As nurses we must ensure that adequate and sensitive services and flexible resources are cost-effective, the least intrusive, most normative as possible and are provided by qualified, trained personnel to meet individual needs and preferences.

Although living arrangements with less than full-time supervision permit people to enjoy their greatest possible liberty, it also reduces monitoring of their well-being, thus ensuring safety and well-being is a growing challenge.

Differing agendas and motives and conflicts among the stakeholders are inherent due to the nature of the work, requiring all stakeholders to be reliable, truthful, and scrupulous.

In human services there are a range of ethical dilemmas in which two desirable ends are in conflict, such as the drive to ensure an individual's autonomy and the pressure to "do no or protect from harm."

Historically, in this field there has been a "tension" between safety and risk, responsibility, and choice. The value of individual choice and empowerment must be balanced with the responsibility to protect individuals from risks they may not comprehend due to limited cognitive ability or life experiences.

No one lives risk free, for each of us "safety" is defined along a scale with a wide variance for risk tolerance.

Responding to the challenges of ensuring safety in an often dispersed service delivery system requires new ways of thinking about quality assurance and related quality-enhancement systems. While quality assurance will continue to focus attention on basic health and safety, it is increasingly being defined around quality-of-life outcomes, with health and safety being just one component.

Three methods used to safeguard health, safety, and basic comfort or well-being of persons with developmental disabilities include the education of family, staff, and other personal assistants; provision of technical assistance and implementation of a system for monitoring.

Well-defined standards and well-trained quality assurance monitors and other safeguards are essential for the balance of quality of care and quality of life.

The development of a Position Statement of Delegation must consider these key concepts and views to promote safety and well-being and quality of life for individuals with developmental disabilities.

D. National Association for Home Care

The statement has been contributed by the Home Care Aide Association of America, an affiliate of the National Association for Home Care.

Expanding Roles: Delegating Tasks to Home Care Aides

Should home care aides (HCAs) be permitted to administer medication? Adjust an IV flow rate? Monitor oxygen? Change a colostomy bag? Provide decubitus care? Change a simple dressing? Across the country HCAs are providing these services and performing other tasks that traditionally have been considered within the scope of nursing practice. Fueled by an aging population, hasty patient discharges, and an increasingly cost-focused health care environment, the home care industry has grown rapidly. Most notable of these trends, however, is the continued and projected growth in the number of paraprofessionals. The US Department of Labor projections indicate a growth rate of more than 100% in two home care paraprofessional positions. HCAs who perform a variety of housekeeping tasks for home care patients will increase from 179,000 positions in 1994 to 391,000 in 2005 (a 119% increase). HCAs who provide personal and physical care will see an increase from 420,000 in 1994 to 848,000 in 2005 (a 102% increase).

As the HCA ranks have expanded, so have their roles. The role of the paraprofessional caregiver has grown in some settings beyond the assistive realm into areas of significantly more independence. It is no longer unusual for HCAs to provide dressing and simple wound care, routine catheter care and irrigation, and administration of medication. These tasks are all being delegated to HCAs in many states. The

expanding scope of tasks for HCAs raises challenges and dilemmas for home care agencies, nurses, HCAs, and home care recipients.

Agencies are under great pressure to have aides provide care beyond basic activities of daily living (ADLs). As resources to pay for health care services shrink and costs increase, health care providers, insurers, and government entities seek less-expensive means to provide care. And people with disabilities have pushed for a more liberal and less medical view of the scope of work that can safely be provided by paraprofessional caregivers.

EXPANDING ROLES

For the past year the Home Care Aide Association of America (HCAAA), an affiliate of the National Association for Home Care (NAHC), has examined issues related to HCAs' expanding role and scope of practice. In response to numerous requests for guidance from members, HCAAA's Supervision and Delegation Task Force, comprised of home care nurses and administrators, examined delegation issues to develop a position on suitable tasks for appropriately trained HCAs.

The National Association for Home Care (NAHC) established the Home Care Aide Association of America (HCAAA) in 1990 to provide a forum for the discussion of issues related to the work of paraprofessionals in home care. Home care aide (HCA) is one of the fastest growing occupations in the country. As the HCA ranks have expanded, so have their roles. HCAAA has examined closely issues related to the expanding role and scope of task of HCAs in an effort to provide guidance to its members.

This issue analysis is designed to assist agencies in examining the myriad issues related to expanding the tasks of the HCAs, responding to requests from managed care companies, and addressing state or federal legislative initiatives. Despite urging from some agencies for a concrete list of acceptable HCA tasks, HCAAA has concluded that the broad and diverse range of practices at the state and agency level, the diversity in client needs and conditions, and variations in individual aides' abilities make it impractical to present a list of activities that can be delegated. HCAAA believes that an agency's decision to permit delegation of tasks to aides should be based on assessment of a number of variables, including existing laws and regulations, the complexity of client needs and stability, and the training and clinical competence of the HCA.

HCAAA found that policies and practices governing HCA duties are changing rapidly. The US Department of Health and Human Services provided funding for research on supervision and delegation. State Nurse Practice Acts are being revised to expand tasks that nurses may delegate to aides. Home care agencies report pressure from payor sources to expand the tasks HCAs currently provide. Home care agencies are forming coalitions to develop consensus on what is and is not appropriate. People with disabilities are seeking ways to expand the tasks that can be delegated as well as supervisory and training requirements.

Delegation of tasks to HCAs is governed primarily by state Nurse Practice Acts. These laws vary by state: some have fairly strict requirements while others are broadly drawn, leaving much to the discretion of registered nurses. Although some states have developed or are developing training and competency standards for aides, few rules and regulations provide a solid framework for agencies.

In 1995 HCAAA surveyed NAHC members to assess current agency practices in delegating tasks to HCAs that are traditionally considered beyond the aides' scope of tasks. The survey sought information in a broad range of clinical areas from monitoring to medication administration and invasive procedures.

More than half of respondents indicated that HCAs in their state or region were being assigned nontraditional tasks. More than 70% expected funding sources -- primarily managed care companies -- to request HCAs to perform nontraditional tasks. Most respondents believed expansion of tasks was appropriate for HCAs *with appropriate training*.

HCAAA has concluded that the broad and diverse range of practices at the state and agency level, the diversity in client needs and conditions, and variations in individual aides' abilities make it impractical to define a list of activities that can be delegated. There is insufficient information to draw hard conclusions about ideal approaches and little information about the consequences.

EXAMINING THE ISSUES

Two research reports have examined the implications of more extensive delegation of nursing tasks to unlicensed paraprofessionals and have reached similar conclusions.

"Liability Issues Affecting Consumer Directed Personal Assistance Services," published in 1995 by the World Institute on Disability and the American Bar Association Commission on Legal Problems of the Elderly, closely examines 50 state nurse practice acts and delegations practices in many states. The report states:

"Under nurse delegation, our experience is insufficient to draw any hard and fast conclusions about optimum approaches, legal ramifications. Existing law is quite varied and vague ... If any one theme has been consistent in home and community-based services, it is the reality that one size does not fit all. Detailed standards and procedures that must be applied to all consumers easily miss that reality."

A report published by the Public Policy Institute of the American Association of Retired Persons (1995) examines a range of delegation issues. The report, "Delegation of Nursing Activities: Implications for Patterns of Long-Term Care," was written under contract by the University of Minnesota's National Long-Term Care Resource Center. The report reviews nurse practice statutes, related regulations, and customary

professional practices to examine the circumstances by which nurses can delegate nursing tasks to unlicensed people. The goal of the report was to explore nurses' potential for playing an enhanced role as teachers and delegators of care to unlicensed persons. The report includes a case study of opinions about nurse delegation.

In support of nurse delegation, the following statements were made: "Delegation offers a way for nurses to assist patients to live in the settings of their choice because of general cost lowering"; "Delegation promotes equity between people with families (...give free care outside of nurse delegation prohibitions) and those who do not have families"; "Delegation offers nurses greater opportunities for leadership and use of their skills."

Views in opposition to expanded delegation included fears that "permission to delegate would glide into requirements to delegate"; concerns that "nurses' education about the why, how, and what of delegation was insufficient"; skepticism about the claims to efficiency made by proponents of delegation; liability concerns; concerns about risks of poor quality care.

The report concludes that nurse delegation is a feasible and promising approach to providing cost-effective, long-term care in community-based settings, including group residential settings.

IMPLICATIONS FOR AGENCIES

The home care industry is in a unique position in that it routinely teaches family members, friends, and neighbors to perform sophisticated and complex tasks to promote client independence. At the same time, agencies employ paraprofessional caregivers whose training and supervision become the agency's direct responsibility and liability. Some agencies are in contractual arrangements whereby another entity actually employs a paraprofessional caregiver with whom the agency staff works. Agencies must consider that they may be held liable for actions taken by aides who are inadequately trained or supervised. Within the context of delegation there are two directions of liability which agencies must understand and consider.

Under the doctrine of *respondeat superior* the agency is responsible for all the actions its employees take. Accordingly, negligence by an aide in the performance of delegated tasks leads to liability for the agency. The nurse who has delegated the responsibilities retains liability for the performance of the aide. This could mean personal professional liability. Liability in both of these instances can mean direct financial consequences as well as loss of license. As well, individual nurses whom the agency employs must consider the impact of inappropriate delegation, or improperly performed tasks, on their own licensure status.

Most Nurse Practice Acts are broad in their definition of what constitutes the practice of nursing, leaving nurses uncertain of the standards they must meet. Nurses make critical delegation decisions that must be consistent with safe and effective

nursing practice. As the nurses making these decisions will necessarily consider the appropriate training of aides, agencies must consider whether nurses have the skill to delegate.

A recent paper by the National Council of State Boards of Nursing (NCSBN), "Delegation: Concepts and Decision-Making Process," provides practical guidelines to direct the process for making decisions about delegation. NCSBN includes Five Rights of Delegation to facilitate decisions about delegation:

- Right Task -- one that is delegable for a specific patient
- Right Circumstances -- appropriate patient setting, available resources, and other relevant factors considered
- Right Persons -- delegating the right task to the right person to be performed on the right person
- Right Direction/Communication -- clear, concise description of the tasks, including their objectives, limits, and expectations
- Right Supervision -- appropriate monitoring, evaluation, intervention, as needed, and feedback.

The paper lists a number of premises as the basis for delegation. The first is: "All decisions related to delegation of nursing tasks must be based on the fundamental principle of protection of the health, safety, and welfare of the public."

Reimbursement issues are another concern for home care agencies. Often reimbursement is inadequate to cover the cost of essential training and supervision. Rates paid to home care agencies under Medicaid are often below the cost of providing care, which forces some home care agencies to subsidize patients. As the scope of tasks for aides expands, more extensive and costly training will be required. This cost will place an added burden on agencies. In addition, payors are demanding more for less, placing home care providers in a difficult situation.

DIFFICULT DECISIONS

Clearly, for home care agencies the primary concern is and must be the safety and well-being of the care recipient. However, every day home care agency staff must make difficult decisions concerning aide tasks with little guidance and under increased pressure for aides to do more. Established standards are minimal and are complicated by conflict among industry standards, federal and state governments, the nursing community, advocates, and people with disabilities, each of whom claims responsibility for determining appropriate standards in different circumstances.

Although some agencies and communities have developed operationalized lists of tasks that can and cannot be provided by aides, the HCAAA Advisory Board has opted not to create such a list. This paper was developed to help agencies examine issues related to expanding the tasks of the aides employed by the agency, responding to requests from managed care companies, and addressing state or federal legislative initiatives.

HCAAA believes that an agency's decisions to permit delegation of specific tasks to specific aides should be based on assessment of a number of variables, including existing laws and regulations, the complexity of client needs and stability, and the training and clinical competence of the home care aide.

V. INFORMATIONAL RESOURCES

American Nurses Association, Model practice act. Washington, DC: American Nurses Publishing, 64 pp., May 1996, \$14.95.

Burbach, Vicky, "Delegation in nursing". Issues, 15(3), 1994, Publisher: National Council of State Boards of Nursing, Inc., Chicago, IL.

California Board of Registered Nursing, "Board adopts position statement on RN supervision of medical assistants." BRN Report, 8(3): 6, Winter 1994, Publisher: California Board of Registered Nursing, Sacramento, CA.

California Board of Registered Nursing, "Board issues advisory statement on unlicensed assistive personnel." BRN Report, 8(3): 4-5, Winter 1994, Publisher: California Board of Registered Nursing, Sacramento, CA.

Developmental Disabilities Nurses Association, Standards of Developmental Disabilities Nursing Practice, Eugene, OR: Developmental Disabilities Nurses Association, 1995.

Harris, Marilyn D., "Competent, supervised, unlicensed personnel will contribute to high-quality, in-home health care." Home Healthcare Nurse, 11(6): 55-56, 1993, Publisher: J.B. Lippincott, Philadelphia, PA.

Home Care Aide Association of America, Guiding principles governing the delivery of long-term care. Washington, DC: National Association for Home Care, 2 pp.

Kane, Rosalie A., Colleen M. O'Connor, Mary Olsen Baker, Delegation of nursing activities: implications for patterns of long-term care. Washington, DC: American Association of Retired Persons, 73 pp., Nov. 1995.

Kafka, Bob, Stephanie Thomas, Discussion of the attendant services component of personal assistance services. Denver, CO: ADAPT, 30 pp., Sept. 1993.

Lakin, K.C., "Persons with developmental disabilities: Mental retardation as an exemplar." In R.J. Newcomer & A. E. Benjamin (eds.), Indicators of Chronic Health Conditions: Monitoring Community-Level Delivery Systems (pp.99-135). Baltimore: Johns Hopkins University Press. 1997.

McAlvanah, Margaret F., "A guide to delegation." Pediatric Nursing, 15(4): 379, July-Aug. 1989.

National Council of State Boards of Nursing, Inc., Model nursing practice act, Chicago, IL: National Council of State Boards of Nursing, Inc., 45 pp., August 1994, \$11.

National Council of State Boards of Nursing, Inc., Delegation: concepts and decision-making process. Chicago, IL: National Council of State Boards of Nursing, Inc., 4 pp., 1995.

National Council of State Boards of Nursing, Inc., Model nursing administrative rules. Chicago, IL: National Council of State Boards of Nursing, Inc., 77 pp., Aug. 1994, \$12.

Noon, Jody Ann. Legal issues in community-based care nursing practice. Portland, OR: Davis Wright Trenaime, 8 pp., 1994.

Sabatino, Charles P, Simi Litvak. Liability issues affecting consumer-directed personal assistance services. Oakland, CA: World Institute on Disability and ABA Commission on Legal Problems of the Elderly. 166 pp., 1995, \$20. Also published in *Elder Law Journal*, 4(2): 247368. Urbana, IL: College of Law, University of Illinois at Urbana-Champaign, Fall 1996.

Sundram, C.J. (ed.). Choice & Responsibility: Legal and Ethical Dilemmas in Services for Persons with Mental Disabilities. Albany, NY: New York State Commission on Quality of Care for the Mentally Disabled, 1994.

VI. APPENDIX A. QUESTION AND ANSWER SESSION: ISSUES RAISED BY THE STATE PRESENTATIONS

This section presents some of the discussion from the question and answer session following the states' presentations. The text below is an edited transcript of the actual event, organized into themes. Speakers have not been identified because we were unable to do so with any reliability; an attempt has been made to keep the text as true to the event as possible while retaining coherence.

Relevance of Service Setting and Acuity

Q: I hear general reluctance to delegate in an acute care setting, but there are people who have acute care needs in the home setting. How do we handle it when a patient is sick and also has long-term care needs?

A: All these states seemed to say acute care is off limits, except for Texas -- it seems to have broad delegation across all settings. Assistance with ADLs seems to be okay -- that seems to be an issue that people can embrace and feel pretty comfortable about. However, the health maintenance activities seem to be the gray area, such as medication administration related to injectables. What's medication administrations versus medication assistance? There seems to be a lot of disagreement over some of the skilled body issues, such as bowel and bladder, IVs and so forth.

A: The setting rather than the level of disability or acuity is the most important thing in determining whether delegation is appropriate. The question is, is the combination between the individual themselves and the unlicensed person right? I think there's a reason somebody's in a hospital, a nursing home, or an ICF/MR facility that calls for a little bit more oversight -- though admittedly some people have been inappropriately placed, both in the community or in an institution. But mostly, regardless of a person's severity, if they're out in the community the combination of the setting and the individual should allow a focus on delegation. Although obviously, it's a case-by-case situation.

A: Both people who are hospitalized and people using community-based long-term care are likely to have acute needs, but in both settings you can recognize and identify activities of daily living that are stable. And you may find that a person's condition is stable and everything is fine then the consumer has to be hospitalized for another situation. Though you may need to bring in a little more nursing at that point, it doesn't mean that the other situation is no longer stable.

The variability of people's conditions is my reason for keeping the nurse in the loop and for my concern about avoiding delegation by using other strategies. I think nurse

delegation makes it easier to determine when a consumer's situation changes and is better in ensuring that a nurse is accessible to address those needs.

A: In Oregon, in the licensed facilities -- the foster care homes, residential care, and assisted living -- the assumption is that delegation is appropriate for the basic stable ADL care. But there are folks who are predictably unstable. They have a course in their disease, terminal care, where there are ups and downs; things are going to happen. We expect the nursing presence to be there. Consultation and assessment will determine the degree of delegation and the degree of frequency. But it is not our position that people with unstable conditions are unsuitable for delegation. Perhaps if they are really unstable and need a lot of nursing oversight. But there are a lot of people who **really** are not that unstable -- there's a predictable course to how their condition progresses.

A: The other concern that we have is that the hospital industry thinks that delegation should occur in hospitals. Then you'll end up with one nurse for a 500-bed hospital -- where does that leave quality and safety? Although in Oregon delegation has worked well in the settings it's currently restricted to, there are concerns about whether or not it's a policy that should be applied to every setting.

Cost of Delegation

Q: The Texas folks stated that about 12 percent of the 73,000 people on the personal attendant services program would benefit from nursing delegation. You also stated the department decided they couldn't do it because of the costs associated with it. What do those estimated costs represent -- the cost of the nurse training the particular person or the cost of the assessment? What I'm getting at here is that if it wasn't a delegation situation, rather a transfer, like they do in New York, would those costs be manageable? Would they be reduced if you just acknowledge that a consumer is self directing, has the responsibility, and can teach their worker the tasks that are needed?

A: The cost for this was based on the cost of the registered nurse doing an assessment and training the unlicensed person. So the cost that we would incur was based on having an RN supervisor for those individuals who needed to have delegation. I'm very interested in pursuing this other model. I think that might be a real way to do it.

This other model is not a nurse delegation model. When the nurse assesses the client and determines that in this situation care can be provided by somebody else under the client's direction, the nurse isn't delegating to that care provider. So that's kind of important. Delegation is giving your authority to somebody else and supervising them and being accountable for that. It's just a little different mechanism.

Q: Exactly what is it that costs in nurse delegation? And doesn't the delegation process, or at least the process such as they have at Concepts of Independence, save a lot of money?

A: Once delegation has occurred, it costs about one-third as much, on a per hour basis, to provide care through a delegated setting. With more constant nursing monitoring, it would be more. It's all based on the desire of the client to be able to continue their own care and go from there.

A: In New York the costs are minimal for the whole process. The consumer has to receive initial training and they usually get it as part of their discharge process or from their own experience with their disability. The consumer's familiarity with their condition is really what runs the program. They are the ones that make the decision on what is necessary for them and how it should be done. So once that process is complete, the costs do not change for someone who needs a high level service versus a more conventional personal care level service.

A: In Texas adding a delegation function appears to add to the cost because you're actually expanding the services available in the Medicaid program. Under the personal care option, if you offered it to one, you offered it to everybody, which then potentially raises the cost. So, we toyed with the idea of a Medicaid waiver that would enable us to cap it at, say, 5,000 people, and control the potential costs. Most of the programs I've seen have been really fairly small.

Surrogate Decision-makers and Informed Consent

Q: How do you address the issue of surrogate decision makers? What about individuals who may want to direct their own care but may need some support: people with mental retardation, people with psychiatric disabilities, even older people who may be developing dementia? How does that play out in terms of the assessment in terms of what the nurse determines, and from a legal standpoint? Presumably for many of these people, the guardianship process has not been adjudicated? So they are technically competent to make their own decisions.

A: In New York the legislature provided for adult household members, guardians and family members to take on the responsibility. In the state consumer-directed program, it's really part of the Medicaid program, not a waiver but a mandated program. Every county must provide access to a program. As far as the people that are nonindependently self directing, each county must make their own determination, for that particular consumer.

They would look at such things as whether the delegate has a track record with the consumer. Is this person participating in an organization like the Alzheimer's Association, or SKIP, or another organization in New York called PICK, or something like that which would help with the case management process, to make sure that family members stay there and does what they say they are going to do? During the initial process, the country may decide that extra nursing assessment visits are necessary to make sure that that consumer is capable of receiving the appropriate services through the direction of this surrogate.

The county is responsible to make sure that process goes through and as such there really hasn't been a problem with that. We've only begun to work with the county to set up guidelines. We've occasionally dealt with consumers who really rely upon family members and others to work with them to provide their services and it's really worked very well -- if the family holds together and is supportive.

A: In Washington State we have an informed consent statute that says for delegation to occur, there must be written consent from the consumer who's receiving care. Then there is a hierarchy determining whether the surrogate is a family member, spouse, sibling, or a legal guardian. A problem that we've run into is that some people with developmental disabilities do not have family members, they do not have guardians, and they need this delegation. So our DD agency is looking at a limited guardianship for health care to get this delegation going.

So that's what we see already as an issue, especially written form consent. For an individual who does not have family members or someone in that hierarchy, it's a difficult process, because it's clear in our statute that the registered nurse has to get informed consent and has to be sure that the client is a willing participant. If there's a question, the nurse won't delegate. The limited guardianship has become an issue because it appears to take away some consumer rights -- Is it really worth it?

A: Let's just talk about the basic principles. If we go back to old public health nursing, for heaven sakes, nursing is a profession that has embraced working out in the community and helping neighbors. And I get frustrated, folks, when I hear the legal chains around the neck. In practice, the whole home health principle is one where if the consumer cannot direct the de facto surrogate, be they family or neighbors, then we step in to help that person stay at home.

But it is also the responsibility of the licensed facility setting. Licensing bodies have the responsibility to keep people in the community and hold their providers accountable. So in Oregon the regulations for licensing foster homes, residential care facilities, and assisted living ensure access to nursing. If you do that, then the issue of "Do we have a true surrogate?" becomes much less of an issue. The issue of "Do we have true consumer direction?" becomes much less of an issue because our standards of practice have been established within the care setting as well as with the nurse. Let's not get hung up here saying if all the /'s aren't dotted and all the t's aren't crossed, we aren't going to do it. Because we end up denying availability of services to people who really need them.

Risk Assessment

Q: I'm concerned from the perspective of education. A lot has been said about balancing the risk and the choices and the responsibility. To what degree are the nurses and the clients/consumers being educated about risk assessment and decision-making models? I kept hearing the word judgment -- To what degree are we helping the

consumers and the nurses judge risk? Is there a curriculum out there for the nurses and the consumers?

A: I think education may get too much into the process. We're talking about individuals with disabilities just trying to get a service delivery in a community. Though I agree that there needs to be some general education, the bottom line is that everybody is sort of like going through hoops, whistles, and everything else.

I get very fearful of somebody coming in with an assessment tool to say whether I can or can't direct. I mean it really scares me because someone might be judging me on whether I speak well -- or, if I'm brain injured and I have a little bizarre behavior, is someone going to say that's not appropriate? It sounds like Washington is balancing whether they're going to take the legal rights away from somebody just to give them a service. Just think of that! It is almost absurd, really. To even think that we're going to be taking rights from somebody to give them a service to live in the community -- and we're not even talking about people living in private homes, these are people in group facilities. This exactly illustrates the problem I think we have in the whole delivery of home and community-based services.

Nurse Education and Points of View

Q: Isn't part of the education that is needed, education of nurses in how to delegate?

A: Nurses need to recognize the potential of the people we are serving to actually direct their own care. I think in Oregon one of the reasons that there's not as much concern around the education from the disabilities community perspective is because there's been a chance to sit down at the table and really start to look at how roles need to change in order to better serve people. If consumers see a need for more information and education, we're going to demand it from the system. The majority of people in the program say "No, I really do know how to direct my own care and I'm comfortable with the risks that may be involved." One of the main reasons that the client-employed provider program continues to grow is because people are confident about being able to direct their own care -- I don't care if you're talking about an 83-year-old grandmother or 18-year-old quad, or somebody moving out into the community, out of an institution, where they've otherwise been labeled as mentally retarded.

We need to grapple with those perceptions through broader and broader based discussions in our states, so that the barriers to communication and understandings can come down in the future. One of the things I'm optimistic about is that, over time, things are going to change. Those of us who grew up so that we're tired of having services provided for us, are going to maintain that perspective as we grow older. APA, as the philosophy of the older generation changes because of having grown up with that intolerance for being done for, the environment through which the services are being provided will eventually change as well.

A: What all the states here have in common is they brought together the key stakeholders to discuss these issues. The disability advocates were very involved. The departments of health, nursing, boards of nursing, nurses associations, home care, were all involved. It's an interesting similarity across the states: the programs have been challenged to address consumerism.

A: There's a lot of concern about nurses being out of the loop if it's decided that nursing is only lists of tasks. Well nursing is a process. It's a profession of judgment. Now I agree that there are nurses that the disabled community loves to hate, who are very attached to the whole idea of clinical nursing. These people haven't been out in the community and can't understand how to adapt to people's living situations because they just don't have that kind of experience.

But there's another whole body of nursing that's very in tune with that. They understand that not every situation requires a nurse to visit every 60 days. But in other situations that does belong. I think therein lies the problem. The problem isn't one of this task or that task. The problem is one of providing a community where persons are able to make choices. They're able to choose for me to come and help them; or choose not -- that and they're able to do it based on good information.

A: I just want to share what's going on for me in the last 24 hours. When I hear the consumers get up and what I consider the clients get up and talk about wanting independence and control, I nod my head and I have an "aha" and remember yes, that's where it should lie. On the other hand, what I struggle with -- maybe some of this is because I'm a pediatric nurse -- is that what I see is that when, for example, kids aren't doing clean catheterization with the proper technique, I am seeing some bad outcomes. I have three teenagers right now who have lost their kidneys and who are on dialysis or have had to have transplant. Then when some of the kids I follow come in with large ulcers because their braces aren't fitting right -- there's no one being vigilant about getting them to come in and get their braces fixed.

What I struggle with is, yes, there should be control and autonomy. On the other hand as a nurse I am steeped in this, "I can help, I can make things better." So, it's hard for me to give up control and just turn my head. I'm all for giving control where it should be, but if I am to remain in the loop, if I have to continue to interface with my clients, then I feel a major pull to be an advocate and a nag and a nudge and all those things. Because I feel it's my responsibility and it's not just because I worry about my license, but when a bad outcome happens, when the kids end up on dialysis, or osteomyelitis, I feel awful because I come from a perspective of "where did I fail, what could I have done better?"

Monitoring Personal Assistants

Q: My question comes from anticipating my future as a consumer, wanting to make choices, and as the only daughter of aging parents. I want to avoid a Value Jet care situation where it looks good on takeoff, but feels like a swamp in outcome. Basically, I

wanted to know how, particularly in New York, you keep track of the individuals providing care? Does anybody provide discipline for a provider who abuses people? This has been a concern in Oregon about how we keep people informed. Consumers need to know there are people out there who should not be providing services. Second. Any suggestions for how institutions, state regulatory bodies can be kept on task for monitoring those care facilities they are supposed to monitor? In Oregon sometimes we've had to find out about abuse cases through the newspaper. And I don't want to wait that long.

A: I think that there are numerous way in which monitoring occurs. In New York State there is monitoring and surveillance of the personal care agencies because most of those are licensed home care agencies. Or there's monitoring and surveillance of the certified home health agencies. New York State does not have a licensure law or a registry law for aides. Attendants who are associated with agencies go through the agency's hiring process. Abuse has usually occurred outside of agency situations and usually in individual cases where Medicaid money was not in any way involved.

We've not seen major problems with the individual consumers who are involved in consumer- directed programs. Basically, I think it comes down to the interviewing. In New York City there is a roster that is maintained for home care workers. People can call to find out whether and where someone has worked and you can check the references just like you would in any other situation: you find out where they worked; you call; you ask for information about their employment; and you find out their employment history.

When it comes down to the consumer level, it's just like employing anyone else. If you were going to employ someone to come in to do something within your home, you'd look at people's references, you'd check. Those are consumers' responsibilities in a consumer-directed model: to ask the right kinds of questions.

A: Yes, there is a "central registry" which we are required (under our contract with the city of New York) to consult every time the consumer hires a new worker. The problem is that often, consumers have already identified the attendant they want. They don't make their decision on the basis of qualifications or schedules. They're looking at chemistry. They're looking at "Can I successfully work and survive with this person?" And usually during the consumer's first year in the program, there's a fairly good turnover because they don't know what works. But consumers don't have to apologize to the agency for being choosy. Concepts has no allegiance to the worker in that sense: we provide them with benefits and we put them back in the hiring system. If they have worked successfully with a consumer and they don't have a negative reference, we try to help them move to a new position, but the consumer rules the roost.

A: In the state of New York a piece of legislation was almost unanimously passed in both our Houses that addressed the disciplinary process for unlicensed persons. The legislation transferred this process from our state attorney general's office to the state education department. Currently, the only way you can discipline someone who is not

licensed to practice a profession is through our attorney general's office. However, someone who holds a license is prosecuted through our state education department. The attorney general's office and the state education department have spent many years looking at this issue and decided to transfer the authority to discipline unlicensed persons to our state education department. Unfortunately, for a variety of reasons, our governor just recently vetoed that legislation, but we will actively pursue that because our state education department believes controlling inappropriate, unlicensed practice is not best done through regulation, but through discipline.

A: Delegation works well where there is a stable situation. It works well in foster homes, particularly where there is a stable staff and low turnover, and staff have an ongoing relationship with the home so that they can consult before a crisis occurs. Where I think delegation does not work well is the flip side of that. In my clinical practice as an emergency room nurse, unfortunately I see the failures of our community-based care system, not just foster care, but home care. So I know that we have more roads to cover to ensure that services are available to people when they need them, so that the red flags can be noted and people can receive care before their blood sugar drops to 20, or before their potassium is 3.1 and they fall on the floor. I think Oregon has some more work to do.

Legal Mechanisms for Performance of Tasks

Q: Regarding the exemption for domestic servants -- it exists in several state Nurse Practice Acts. It always struck me as somewhat of an odd exemption because if you wash dishes, you can give the insulin, but if you have had any training and are called an aide, you can't do it. How did this happen?

A: I think it's a political expediency. Legislatures realized that we don't want to require domestic help to have to be licensed nurses. No matter what you do, they're going to help around the house. It's certainly not consistent. Just like the family exemptions aren't consistent. Education and training requirements should apply to everyone, but realistically it's not going to happen.

A: There's also the Department of Labor companionship exemption that addresses the role of the domestic employee. In that situation, if you do not perform more than 20 percent of your time in household duties and you are also assisting someone in their home who is able to self direct, you can be considered a companion for the purpose of minimum wage and overtime. They don't have to be paid; however, that exemption was passed by the Department of Labor, as a political response to people who are from the South who are used to having a lot of household employees and didn't want to have to pay minimum wage. It looks to me like somebody looked over the Department of Labor laws and the discussion of domestic servant and said "We don't want to complicate this, let's keep them in this group."

A: It's interesting to note that Washington wears two hats: delegation and also exemption. While there are a number of areas where they currently allow exemption, the

exemption applies only to unlicensed personnel who serve without compensation -- paid personal attendants would not be covered by the exemption. New York, on the other hand, doesn't delegate. It is better classed as an "exemption state." It also emphasizes the role of the nurse as the assessor, as the judgment person. Responsibility is really transferred rather than delegated.

Oregon seems to have a very broad-based delegation policy which really emphasizes nursing judgment, nursing assessment, and linking that with the care plan and the capabilities and the settings and judging appropriateness.

Relationship between Consumers and Professionals/Nurse Liability

Q: How many people here are in situations where it is presumed that the delegating nurse is responsible for everything that that individual does? It seems the sensible approach is not to treat this as an employer-employee type of situation where the doctrine of *respondeat superior* would kick in and make you liable for any negligent act that the delegate does within the course of their work.

A: From our perspective in California, we're always tied to a liability string. Was the delegation appropriate, was it legal, and did I evaluate and assess on an ongoing basis? An ongoing basis -sometimes that can be once every six months. It could be once a year. It's always an individual judgment based on whether the delegation was appropriate with this particular client, in this particular setting. Because there is no hard and fast rule, you're constantly evaluated on your judgment. That's okay because I feel like that's what we get paid for as nurses, to make that judgment.

A: But your liability would be based on whether or not you were negligent, not on the basis that you happened to delegate. The mere fact of delegation doesn't give rise to the liability. It's whether you were negligent in doing so.

A: Oregon is unique in its explicit limited liability for nurses -- that is, as long as they have performed their delegated and training tasks appropriately, they are not liable. This responds to one of nurses' strongest concerns about delegation. They ask "Well, if I train Mrs. Smith to do X today and three months from now she ends up in the hospital and someone questions that Mary didn't really know how to do that task, am I still liable?"

A: It makes a difference whether all parties are employed by the same employer. For instance, if I am in a home health agency and the aide that I'm delegating to is also working through my home health agency, then I think there are more complications about whether or not vicarious liability comes in for the agency, not for me as the delegating nurse. The Florida rules on delegation are designed to deal with acute facility settings and all of the language envisions the nurse holding on to the liability or accountability for a proper delegation. I'm not sure how that really fits when we talk about it in terms of doing delegation to someone that's not on the same facility and not on the same staff. If you are out in the community, I'd like to differentiate that.

A: Well, *respondeat superior* vicarious liability is liability that goes to you merely because of the relationship, an employer for its employees. For example, if an employee driving a car has an auto accident and kills some people, the employer is liable. If you are a nurse delegating, it's unlikely that *respondeat superior* would hold you liable for the negligence of the person you delegated to. However, you can also be liable if you were negligent in the delegation -- if you delegated to someone who wasn't qualified or didn't supervise properly. This type of liability is not automatic, it depends on what you did personally.

A: I think we're confusing some issues here. First of all there is no task that belongs to a nurse, meaning even injections. There are many people who can give injections besides a nurse. I as a consumer can give injections to myself and I do not need anybody's authority to give that injection. I need health care professionals to educate me and to teach me and consult with me, but I don't need their authority. So if I become disabled tomorrow, and I want to direct somebody to give my injections, provide my services that I would provide for myself, but I can't -- that's not nursing delegation. I am empowering that person to act upon my behalf to do for me what I would do for myself except for my disability.

I consult with health care professionals to help me make appropriate informed decisions. However, I could also, contract with Shirley, my colleague here, and say "you know, I don't want to manage my care, I want you to manage my care for me. I want you to take my input and use my holistic perspective and I want you to manage my care for me." Shirley then delegates to the unlicensed persons and then Shirley is practicing nursing and that unlicensed person is practicing nursing on Shirley's behalf to provide services to me.

But three, four months, maybe I get my energy level back. Maybe I now have knowledge of my own services and I don't need to contract with Shirley anymore. And I say "Shirley, will you just be there as a consultant, I will now take over directing my own care." That unlicensed person is now receiving my authority. Maybe I call Shirley on the phone and I say "This is happening, that is happening, what do you think?" Shirley's responsibility is to practice nursing in the standards of giving me accurate information, but Shirley is not accountable for that unlicensed person anymore because that person is going on my authority, not hers. So I think we need to keep the two things very separate. Personal care attendants, if they are practicing on my authority as a consumer, there is no nursing delegation involved.

A: The notion of delegation as a piece of consulting is very interesting. That is, we can conceive of the nurse as a consultant and the decision of whether to delegate is a piece of that consulting rather than a unique standalone entity.

A: That's not what the law is today. Although some laws are that way, it's not what you'd like it to be. We've got 50 different states and in some states your example is the practice of medicine and the practice of nursing. The law isn't where you want it to be.

A: You need to clarify the concepts and then you can create the law. It was that clarification that began the process about two years ago in Nebraska. Although we don't have a mechanism for surrogates, adult competent persons can direct their own health maintenance activities and there is absolutely no requirement for nursing delegation or medical delegation or anything else. The next step, of course, is to get the surrogate in there.

A: All of the Nurse Practice Acts, when they talk about delegation, they talk about authority flowing from the nurse to another provider. The consumer is not in the picture at all. There is an alternative pathway where the authority flows from the consumer to the assistant or the attendant, which really needs to be part of the puzzle.

A: I hear us all struggling with different ways you can define the relationship between the professional and the consumer. On the one hand, we have heard it described as a consultant kind of relationship or a teacher who is hired to teach and then to move out of the picture. On the other hand for people who have lesser ability to manage their own care, we've heard of the nurses remaining in the loop very closely as a supervisor or case manager who may delegate to other people. And somewhere in between perhaps the idea of the nudge is interesting.

Q: One observation was that if there's liability or if there's a problem, then the nurse gets the brunt of the fallout. The payer doesn't and the consumer doesn't. Two questions here: If a consumer directs and, by insistence or coercion or force of magnetic personality, the delegates or the personal assistant does something that wasn't delegated or in a manner that wasn't delegated, would the consumer in some way be liable for the damage? If so, or if not, is that a result of the way laws are currently written, or practices currently evaluated?

A: In terms of liability it's whether damages result. If we're talking about delegation that has lead to damages to the consumer, the consumer can't sue themselves, so it's probably not a damage issue. If a consumer convinces someone that's unlicensed to do something that only a licensed person is supposed to do, there might be a conspiracy and criminal allegation on that basis -- most states make the unauthorized practice of the profession a crime. You could have a conspiracy of yourself with the personal care attendant. But I don't think any prosecutor is going to worry about that. It's kind of theoretical. If we look at similar situations with the unauthorized practice of medicine, very often when a patient is successful in getting someone else to do something, the prosecution is against the person who did the unlawful act, not against the patient.

Q: Isn't this common behavior among individuals getting services, contracting or agreeing to have your attendant or assistant do things that the nurse under no circumstance would ever have allowed them to do?

A: There are instances where the agreement is, okay the nurse is here, we're going to do it her way, but the rest of the time we are going to do it my way. I don't tell and you don't tell and we'll all be fine.

Agency and Attendant Liability

Q: It seems to me that we've talked about nurse liability and there's a lot of representation from various disabled communities and perhaps some of the payers. But I'm a little concerned about the personal care assistant, who seems to be caught in the middle. There doesn't seem to be anyone here voicing the concerns of that person, who may be being forced to do things that she/he doesn't want to do and doesn't know how to do. Where do they fall into this picture?

A: Well, the personal care assistant to the extent that they would be engaged in the unlawful practice of a regulated profession could be criminally liable as well as civilly liable for any damages. State law will determine what the penalties would be. To the extent that the personal care assistant engaged in conduct or activities that they knew or should have known they weren't properly trained to do, there could be liability as well. It's the test, you have a duty, you have a duty to exercise reasonable care, not do things that you don't know how to do. Did you breach the duty? Did it cause damages? It's the same test for everything.

Q: I'm wondering what happens when not only is there consumer assumption of risk, but there is consumer assumption of risk and responsibility, i.e., the Concepts program in New York, where there is a fiscal intermediary agency, but the consumer has the power to hire, fire, screen, to train and supervise. What liability from your point of view would an agency which is basically administering benefits have in this case?

A: I intentionally did not address the employment issues since this is a seminar on delegation. Charlie Sabatino's works have summarized it as well. If you are simply what I would call a pay master -- you are cutting the checks, it's very clear that you are simply in that role of the paychecks and the tax deductions, things like that -- if it's clearly set up that way, that would be your only responsibility. The consumer bears a tremendous responsibility as an employer.

I want to emphasize that if it's clearly set up -- that is, there are clear documents or clear pamphlets, there doesn't have to be a big legalistic document -- but you can establish that your activities are restricted to payroll administration and withholding, then you're kind of like ADP or some of the payroll services. You can be in just that role as the agency. There may be some situations in which you become a joint employer, but in general I think you can stay clean.

Funding Issues

Q: There's been a whole lot of discussion about stable vs. unstable and the difference between long-term care and other kinds of acute needs. One of the problems that I've

seen is that, in most plans, you get this plan of care developed. Those are all costed out by someone representing the funding source. And then they are set.

Then something comes up to where you would like a little extra help with a judgment call, or maybe need a professional to come in and take a look, or even need a little extra help for a while. It stops the clock. You have to be reassessed by a state official, which unfortunately in my state is usually a social worker, as opposed to a nurse. It threatens your independence. So this explains a bit why attendants are pushed to do things by consumers. Because it's really scary when you ask for help that it starts this whole process that's complicated and does at a certain level threaten your independence. So one of the coping mechanisms is to stay quiet and not ask for any extra assessment.

What we do is we try to set the care plans way up high to cover the five days out of the year that you may need the extra stuff so that you won't have to ask again. So then your freedom is protected. But it's really inefficient because you are in fact using or wasting resources you don't really need most of the time, just so they are there when you do need them. So how does everyone else deal with that? Could that be something we could work together on with the nurses, on to figure out how to make that happen in all of our states so we can get that extra help with the judgment without threatening our independence and without having to do artificial things that make the cost of care artificially high to cover contingencies?

A: It's interesting how many of these delegation discussions raise funding issues and how many changes relating to delegation were actually initiated by funding issues.

A: At the Department of Veterans Affairs one of the neat things about the home care program that we have is that we don't have to worry about that. We have a budget that's sent to the facility and we all figure out how it's allocated, but I don't have to account for every little thing. So if something happened to you, I could come out and see and then I would call up and authorize a little more of home health attendant care, etc., for that particular limited period of time. I don't come under any kinds of Medicare-type restrictions or any of the other. I have complete freedom in order to be able to assess you and to be able to give you the support of care that you need without there being any incentives to give you more care or less care than you need.

A: Consumers are concerned that they can't get the services that they need because of the structure and design of funding. What Oregon has done well is to have the funding sources follow the form and the function of services. Most states have a terrible, terrible disadvantage to overcome because they have a whole bunch of little agencies with perhaps big budgets, but their own turf and their own parameters. If you are big payers, your Medicaid agencies will drive public policy because the government's worried about money. So in each state, we have to get the players, the agencies, to sit down and talk about the design of what we want. Hopefully that will lead to funding streams designed to accommodate the services. That's what waivers are about. That's what a whole lot of things are about. They can accommodate what consumers want, but there has to be collaboration to help government do what it needs to do.

A: I had a discussion with someone last evening about their mother and how she had come home from an acute episode with a drain and such. After one visit she had figured out how to manage the things that she needed to manage. She said to the visiting nurse "You don't need to come anymore. I can empty my drain. I can watch for it to turn clear, so I can call the secretary and say it's time to go in and have the drain removed." Well this person reported that the home care organization was just aghast that this elderly woman was sending them home. So the younger family member intervened and said "Look, my mother feels comfortable with what she's doing, she doesn't want you in her house any more, she feels comfortable. I know it's a Medicare- reimbursed visit, but get over it, let her be." So I think that's a good example and I thought it was very enlightening. It's not just the under 65-population.

A: There's a real challenge on a national level that we've got to look at. One of the underlying problems in the current law is that community-based care services is an optional service under Medicaid, where nursing continues to be the mandatory service. So as resources become more and more limited, we're not going to be able to improve the overall environment through which providers work and clients receive their services until we work collectively to make that change in the federal law.

Outcomes

A: In our personal care program, you're not supposed to do any health tasks. Well, then there are a whole bunch of quadriplegics that haven't gone to the bathroom for about five years. So, we have some really constipated people in Texas -- I think there's a lot being done that everybody's been covering their eyes about in terms of health-related tasks. Because obviously someone's doing a bowel program somewhere, and it's not allowed in the program.

We don't seem to know what we want out of any of these programs. From the consumer perspective, some of the things we do as a normal part of our "routines" would just be abominable to you and would be put down as a bad outcome. I think that 's the whole problem: health professionals, providers, and state agencies all interpret outcomes differently. Consumers just want the service to live our lives whether we're old or young -- and that's not getting through too well because you're looking at outcomes in terms of how clean the catheter is or was it done four times a day. So I think that the problem we have in talking to each other is that what we're looking for as outcomes is totally different and that's why it's so important to start talking about the same things in terms of changing the focus towards just living in the community.

Q: Isn't the counter argument that there is a connection between those kinds of outcomes, between the clean catheter and between you getting on with your life?

A: I think people have assumed that, but I'm not sure it's totally true. You know the assumption is that you're going to get infections and end up in the hospital. That may or may not happen.

I can hear all the nurses in the back. But I think this is something we talk a lot about in the community. Some of the things you get taught in rehab, you never would do in the real world, never. It just doesn't happen. What we're saying is the reality of our lives is the reality of our lives. Health professionals, rehabilitation professionals are there to cure us and fix us, but that's not what we want you to do. We just want you to provide us a service and get out of the way. You are taught that you've got to fix us and cure us and I think we have a whole different view of things. And I think a lot of older people feel the same way -- generationally they may just express it differently.

A: I would agree with you on that. I think perhaps the driving force behind the need for professionals to look at outcomes is because someone has to pay them, and that's what the payers are looking for.

A: I wanted to talk a bit about this issue of outcomes. Some of the most interesting and stimulating conversations about what outcomes are being measured. Some folks want to measure outcomes like "Is the water hot enough?" or "Was the bath given at a certain time," or "Did she comb my hair in a certain way?" or something like that. What's really more important to the consumer is "Did I get to work on time?" or "Did I miss the bus?" "Was I at the doctor when supposed to be there?" Getting together will be crucial to defining quality and outcomes and keeping out of a shouting war with each other.

A: I think that also illustrates the point that the outcomes for you may be very different outcomes than for the next person.