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A Special Call for Papers

This issue reflects our continuing commitment to cover the nursing crisis. The first two articles provide international and domestic data on the nursing shortage while the third article reports on a recent study that links nurse staffing with patient outcome data. All point to a complex crisis that will not yield to easy, quick-fix solutions. Aiken and her colleagues and Buerhaus, distinguished experts on the nursing shortage and lead contributors to this issue of Policy, Politics, & Nursing Practice, tell us that nursing workforce issues, especially the design of hospital work environments, are driving nurses out of nursing. Although this fact does not surprise many of us, the needed response appears to elude those inside and outside of the profession. Nursing leadership is conspicuously absent, and the voices one does hear are calling for marginal change, not the substantive changes needed to address the core of the crisis. Nursing education, research, and practice are being challenged as never before as ground shifts beneath the feet of the practicing professional nurse.

Tim Porter-O’Grady (1999, pp. 35-36) outlines a probable future for nursing if nurses do not seize this moment of the current crisis and transform it into a preferable future scenario. The predicted changes are

1. Departments of nursing will fold, leaving no organizational structure for the articulation and definition of nursing practice in health systems.
2. Nurse managers will continue to be eliminated, removing nurses from key management roles throughout the system.
3. Nurse executives will cease to function in that capacity, which will be eliminated as a key role in the organization’s leadership.
4. Increased use of case management will require a higher level of education than most nurses currently have, thus allowing diverse graduate school practitioners (e.g., social workers and health educators) to function as case managers.
5. The influx of more physicians into positions of leadership and management in many health systems will create supervisory relationships with nurses and others in clinical practice.
6. Payment and remuneration processes will slow the growth in nurses’ salaries, which will remain at the lower midline in health care salaries and will be consistent with salaries for functional rather than professional roles.

With this issue, I am issuing a Special Call for Papers in the area of the nursing shortage/crisis. Manuscripts that analyze federal, state and local proposals to address the shortage; educators’ strategies for restructuring nursing curricula to respond better to current practice realities, research studies that support the value of professional
nursing practice; individual institutional responses to the crisis; and nurses’ own personal perceptions and ideas for resolution of the present shortage are desired and encouraged. *PPNP* will be the seminal journal for the collection of articles and “best thinking,” inside and outside of the profession, about how to define and solve this problem.

Future issues of *PPNP* will also focus on the expanding impact of technology, particularly changes in information technology, on nursing practice, education, and research; insurance reform at the state and national levels, with an emphasis on patients’ rights and the movement from a defined benefit to defined contribution; Medicare reform; and the policy implications of medical errors. Submission of manuscripts in these areas is encouraged.

CAROLE P. JENNINGS, PhD, RN
Editor-in-Chief

REFERENCE
The past decade has witnessed pronounced changes in the organization of hospitals, many the direct result of restructuring and reengineering initiatives intended to reduce costs. In a recent survey, 57% of U.S. hospital chief executives reported that their hospitals had undergone restructuring (Aiken, Clarke, & Sloane, 2000). Personnel were reduced in nearly 90% of the restructured hospitals, and nursing skill–mix reductions occurred in about 70%. Moreover, deterioration in practice environments for nurses and concomitant increases in nurse dissatisfaction in restructured hospitals have been the current nursing shortage, high hospital-nurse job dissatisfaction, and reports of uneven quality of hospital care are not uniquely American phenomena. This article presents reports from 43,000 nurses at more than 700 hospitals in the United States, Canada, England, Scotland, and Germany during 1998 and 1999. Nurses in countries with distinctly different health care systems report similar shortcomings in their work environments and the quality of hospital care. Although nurse and physician competence and nurse-physician relationships appear satisfactory, core problems in work design and workforce management threaten care provision. Resolving these issues, which are amenable to managerial intervention, is essential to preserve patient safety and provide care of consistently high quality.

Authors’ Note: This research has been supported by the National Institute of Nursing Research, National Institutes of Health (NR04513); Commonwealth Fund of New York; Agency for Healthcare Quality and Research; Alberta Heritage Foundation for Medical Research; British Columbia Health Research Foundation; Federal Ministry of Education and Research (Germany); Nuffield Provincial Hospital Trust, London; and the Baxter Foundation. Further details on the survey methodology for each country is available from Dr. Sean P. Clarke, sclarke@nursing.upenn.edu. All other correspondence to Dr. Linda H. Aiken, director, Center for Health Outcomes and Policy Research, University of Pennsylvania, 420 Guardian Drive, Philadelphia, PA, 19104-6096. Tel: (215) 898-9759, Fax: (215) 573-2062, laiken@nursing.upenn.edu. This paper is based on analyses published in Health Affairs, 20(3), 43-53, May to June 2001, with permission of the editors of both journals.
observed (Aiken et al., 2000; Davidson, Folcarelli, Crawford, Duprat, & Clifford, 1997). Similar changes in hospitals have been reported in Canada and Europe (Aiken & Sochalski, 1997).

Concurrent with such changes in the organization of hospitals, an international shortage of nurses has emerged, the impacts of which are already being felt. Doctors in five countries recently ranked the shortage of nurses as a serious impediment to the provision of high-quality health care (Blendon et al., 2001). The shortage is generally associated with declining nursing school enrollments, aging of the nurse workforce, and increasing fiscal constraints on hospital budgets (Buerhaus & Staiger, 1999). Comparatively little attention has been given to how changes in the organizational climate of restructured hospitals and changing staffing patterns affect nurse retention and the emerging nursing shortage.

The International Hospital Research Consortium was formed in late 1996 to study the impact of hospital restructuring on the nurse workforce and patient outcomes. Consisting of seven interdisciplinary research teams led by the University of Pennsylvania School of Nursing’s Center for Health Outcomes and Policy Research, the consortium drew on a decade of research undertaken by the center to design a study of the effects of hospital organization and staffing on nurse and patient outcomes. The study is unique because of its sheer size—more than 700 hospitals, 43,000 nurses, and hundreds of thousands of patients—its cross-national design, and its focus on the organizational climate for nursing practice as well as nurse staffing.

THE RESEARCH BASE

The studies that form the basis for the design of the International Hospital Outcomes Study began with research on U.S. magnet hospitals, institutions that had been demonstrated to be successful in attracting and retaining nurses (McClure, Poulin, Sovie, & Wandelt, 1983). Research by Kramer and her associates suggested that magnet hospitals had many of the same leadership and organizational attributes as successful companies, such as competent managers, decentralized decision making, investment in workers and recognition of their contributions, and scheduling flexibility (Kramer & Schmalenberg, 1988a, 1988b). We extended Kramer’s work by demonstrating that these attributes resulted in higher levels of nurse autonomy, greater control by nurses over resources required to provide good care, and better relations between nurses and physicians. Magnet hospitals were also found to have significantly lower risk-adjusted mortality than matched hospitals (Aiken, Smith, & Lake, 1994; Aiken, Sochalski, & Lake, 1997).

Next, we took advantage of a natural experiment in hospital reform that took place in the late 1980s in U.S. urban hospitals faced with large numbers of AIDS patients. Because this period was also a time of nursing shortage, hospital management, fearing nurse recruitment problems in AIDS care, delegated unusual latitude to nurses in developing models for inpatient AIDS care. The most prominent new model was the dedicated AIDS unit, designed by nurses and incorporating elements of professional nursing practice long sought by hospital nurses (Fox, Aiken, & Messikomer, 1990). Indeed, when we studied dedicated AIDS units, we found that they had characteristics similar to those of magnet hospitals and substantially better nurse and patient outcomes than matched hospitals with conventionally organized inpatient services (Aiken, Sloane, Lake, Sochalski, & Weber, 1999).

The International Hospital Outcomes Study extends prior research on particular subtypes of hospitals to all hospitals within defined geographic areas: state, province, or country. It employs surveys of nurses, generally sampled using rosters obtained from their licensing bodies, to create measures of organizational climate in each hospital. The resulting database provides an unprecedented vehicle for studying how organizational climate affects nurses and patient care. In later articles, we will report on the effects of organizational features of hospitals, including staffing, on nurse and patient outcomes. In this article, we present survey findings from nurses within countries as a cross-national description of the state of hospital nursing in this time of substantial turbulence in hospital care.
STUDY DESIGN

The sample consists of 43,329 nurses from the United States (Pennsylvania, 13,471), Canada (17,450), England (5,006), Scotland (4,721), and Germany (2,681) who were working in adult acute care hospitals in 1998 and 1999. Consortium members agreed on a core nurse questionnaire that underwent minor adaptations following pilot testing to ensure that language and content were relevant to nurses in each site. Questions dealt with a variety of issues related to the nurses’ perceptions of their working environment and the quality of nursing care being delivered in their hospitals as well as their job satisfaction, career plans, and feelings of job burnout. All nurses sampled received self-administered questionnaires, which were anonymously returned by mail.

The sampling of nurses was designed to allow survey assessment of the working climate in a substantial share of hospitals in each country or geographic jurisdiction studied (Sochalski & Aiken, 1999). Nurse sampling designs were driven by the methods used to select target hospitals for the larger outcomes study. In the United States, all hospitals in Pennsylvania were studied. In Canada, all hospitals in the three provinces of Ontario, Alberta, and British Columbia were included. All hospital trusts in Scotland were targeted for study. Limitations in administrative patient discharge data in England and Germany necessitated the selection of hospitals participating in benchmarking organizations. In Pennsylvania, 50% of registered nurses living in the state were sampled. In Alberta, a complete census of registered nurses working in hospitals was undertaken. Representative samples were drawn of nurses employed in all acute care hospitals in Ontario, British Columbia, and Scotland. In England and Germany, representative samples of nurses were drawn from hospital employment records in target hospitals. Response rates ranged from 42% to 53% across geographic jurisdictions.

STUDY FINDINGS

Job Dissatisfaction, Burnout, and Intent to Leave

There is plenty of anecdotal evidence and numerous press accounts suggesting that nurses are dissatisfied with their jobs in hospitals (Appleby, 1999; Buchan, 1997; Driedger, 1997; Trafford, 2001). We have long been interested in nurse satisfaction, not only because it has ramifications for recruitment and retention of adequate numbers of nurses, but also because the same organizational deficiencies that produce nurse dissatisfaction also result in patient dissatisfaction and poorer patient outcomes (Aiken & Sloane, 1997; Aiken, Sloane, & Lake, 1997). Table 1 illuminates problems in the hospital nurse workforce and clearly demonstrates that low morale among hospital nurses is not unique to the United States. High proportions of registered nurses, ranging from roughly 30% to more than 40% across all countries studied except Germany, were dissatisfied with their jobs.

In the United States (Pennsylvania), more than 40% of nurses working in hospitals reported being

<table>
<thead>
<tr>
<th>Study Country</th>
<th>Percentage Dissatisfied with Present Job</th>
<th>Percentage with Scores in High Burnout Range</th>
<th>Percentage Age 30 or Younger</th>
<th>Percentage Planning to Leave Present Job in the Next Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>United States</td>
<td>41.0</td>
<td>43.2</td>
<td>19.0</td>
<td>22.7</td>
</tr>
<tr>
<td>Canada</td>
<td>32.9</td>
<td>36.0</td>
<td>10.3</td>
<td>16.6</td>
</tr>
<tr>
<td>England</td>
<td>36.1</td>
<td>36.2</td>
<td>40.6</td>
<td>38.9</td>
</tr>
<tr>
<td>Scotland</td>
<td>37.7</td>
<td>29.1</td>
<td>31.9</td>
<td>30.3</td>
</tr>
<tr>
<td>Germany</td>
<td>17.4</td>
<td>15.2</td>
<td>33.6</td>
<td>16.7</td>
</tr>
</tbody>
</table>

a. Published norms for emotional exhaustion were from Maslach and Jackson (1986, p. 3).
b. Numbers in parentheses are the percentages of nurses younger than age 30 who were planning to leave in the next year.
dissatisfied with their jobs. Job dissatisfaction is much higher among nurses, at least in the United States, than among other groups of workers. In the larger U.S. population, data from the General Social Survey of the National Opinion Research Center from 1986 to 1996 indicate that only 10% of professional workers and 15% of workers in general reported dissatisfaction with their jobs. This suggests that the nurses surveyed in Pennsylvania were three to four times more likely to be unhappy with their positions than the average U.S. worker (National Opinion Research Center, 2000).

Many nurses across the five countries are also experiencing considerable job-related strain. A standardized tool, the Maslach Burnout Inventory (MBI), was used to measure emotional exhaustion, the extent to which nurse respondents felt overwhelmed by their work. Significant percentages of nurses, ranging from just under 30% to more than 40% in all countries except Germany, had high scores relative to the norms for medical workers published by the developers of the MBI (Maslach & Jackson, 1986).

In the two North American countries, the percentages of nurses who were 30 years of age or younger, and thus had the potential to have extended careers in nursing, were quite low compared with the European samples. These data are consistent with findings of Buerhaus and Staiger (2000) that in the United States, fewer college-age youth, who have traditionally been the major base of conventional students in schools of nursing, are choosing careers in nursing. The low percentage of younger nurses in Canada may reflect a dual impact of hospital downsizing. New graduates there were, for a time, unable to find work in hospital settings, and the seniority rights negotiated by nurses’ unions led a high proportion of younger and relatively inexperienced nurses to lose their jobs when hospital staffs were cut several years ago.

The final row of Table 1 indicates that more than 3 in 10 nurses in England and Scotland and more than 2 in 10 nurses in the United States planned on leaving their hospital jobs within the next year. What is most striking, however, is that the percentages of nurses younger than 30 who plan on leaving their jobs within the next year is high in all countries. Among U.S. nurses, 1 out of every 3 nurses younger than 30 plan to leave their hospital jobs. As a whole, these data suggest greater problems for hospitals in future years unless these negative recruitment and retention trends are stemmed.

### Working Climate in Hospitals: Good News and Bad News

Although discontent among hospital nurses was high, the nurses surveyed did not perceive all aspects of hospital practice as unsatisfactory. As
the top panel of Table 2 shows, between 70% and 80% of the nurses in the five countries believe that they work with physicians who provide high-quality care, and between 85% and 95% of the nurses report that the nurses they work with are clinically competent. Furthermore, nurse-physician relationships do not appear to be as problematic as popular opinion might suggest. More than 80% of nurses in all five countries perceive that nurses and physicians work well together in their hospitals.

A different picture emerges when nurses’ perceptions of staffing adequacy and workforce management policies are considered, as shown in the middle and bottom panels of Table 2. Across the countries surveyed, only 30% to 40% of nurses report that there are enough registered nurses to provide quality care and enough staff to get the work done. The proportion of respondents who perceive that support services are adequate is only slightly higher. Moreover, fewer than half the nurses in each country reported that management in their hospitals is responsive to their concerns, provides opportunities for nurses to participate in decision making, and acknowledges nurses’ contributions to patient care. Nurse ratings of the presence of other aspects of their work potentially key to job satisfaction were more variable across countries. Nurses’ participation in developing their own schedules is a contentious issue in an industry that involves the provision of care 24 hours a day and 7 days a week, but it is important to the largely female nurse workforce. Survey results show that the proportion of nurses who have a say in scheduling ranges from less than a third of all nurses in Canada to more than two thirds in Germany. In four of the five countries, only a minority of nurses perceived that they have opportunities for advancement, although in Germany (where the percentages of nurses dissatisfied and planning to leave their job were low), this was true of nearly 7 in 10 nurses. Finally, whereas more than three fourths of the nurses in the United Kingdom felt that their salaries were inadequate, nearly 60% of U.S. nurses and 70% of Canadian nurses felt salaries were adequate. In the United States and Canada, at least, nurses were more likely to be dissatisfied with working conditions than with their wages.

**Changes in Workloads and Managerial Support**

Responses to a series of questions dealing with changes in workload and the structure of nursing leadership and management in hospitals in the previous year show that nurses are themselves observing the types of restructuring discussed in the literature and the press (Table 3). A clear majority of U.S. and Canadian nurses report that the number of patients assigned to them increased in the previous year, which is particularly troubling given the widely reported rise in patient acuity levels in both countries (these questions were not included on the United Kingdom surveys). The reports from nurses in North America indicate also that frontline nursing management (nurse manager) positions have been cut and that top nursing management positions (the chief nursing officer level of management) have been eliminated in a number of hospitals. These findings imply that in addition to having responsibility for more patients, staff nurses might also have to take on more responsibilities for managing services and personnel at the unit level, tasks that take time away from direct patient care. In addition, the loss of managers, particularly the chief nurse officer, makes communication between top management and nurses at the bedside more

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**TABLE 3: Nurse Reports of Changes in the Practice Setting in the United States, Canada, and Germany**

<table>
<thead>
<tr>
<th>Percentage of nurses reporting</th>
<th>United States</th>
<th>Canada</th>
<th>Germany</th>
</tr>
</thead>
<tbody>
<tr>
<td>An increase in the number of patients assigned to them</td>
<td>83.2</td>
<td>63.6</td>
<td>44.2</td>
</tr>
<tr>
<td>A decrease in the number of nurse managers</td>
<td>58.3</td>
<td>39.9</td>
<td>14.0</td>
</tr>
<tr>
<td>The loss of a chief nursing officer without replacement</td>
<td>16.8</td>
<td>25.0</td>
<td>22.9</td>
</tr>
</tbody>
</table>

**NOTE:** These questions were not asked in England and Scotland.
difficult at a time when there is clearly a need for greater communication between clinicians and management.

**Structure of Nurses’ Work: Non-Nursing Tasks and Omitted Nursing Care**

Nurses in the United States, Canada, and Germany were asked about the types of tasks they performed on their most recent shift. As Table 4 shows, in each country, many nurses reported spending time performing functions that did not call on their professional training, while care activities that rely on their skills and expertise were often left undone. For example, the percentage of nurses who reported engaging in housekeeping tasks or transporting food trays or patients ranged from roughly one third to more than two thirds of nurses in all three countries. At the same time, a number of tasks that are markers of good nursing care, such as oral hygiene and skin care, teaching, and comforting patients, were frequently reported as having been left undone, in some cases by as many as 40% or 50% of the nurses.

**Quality of Care and Adverse Events**

As Table 5 shows, only roughly 1 in 9 nurses in Germany and 1 in 3 nurses in the remaining countries rated the quality of nursing care provided on their nursing units as excellent. Moreover, in the United States and Canada, only about one third of the nurses were confident that their patients are adequately prepared to manage at home on discharge, and nearly one half of them believe that the quality of patient care in their institutions deteriorated in the previous year. Deterioration in the quality of care was less commonly reported in the European countries than in North America, which may reflect poorly on the extensive and widespread restructuring of Canadian and U.S. hospitals in the years preceding the survey (Brannon, 1996). The comparatively positive ratings of patient preparedness for discharge among European nurses may result directly from the longer hospital stays in those countries, particularly in Germany, and the more extensive home care services available to discharged patients. It may also result from the fact that, in Germany, hospital restructuring is more recent, and any ill effects of such initiatives may be still to come.

When nurses in North America and Germany were asked about the frequency of specific marker events that indicate potential problems in quality of care, for the most part, U.S. and Canadian nurses were considerably more likely to report that incidents like medication errors and patient falls occurred with regularity in the preceding year (Table 5, bottom section). A majority of U.S. and Canadian nurses indicated that patient and family complaints and verbal abuse directed

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**TABLE 4: Work Design: A Contrast of Non-Nursing Tasks Performed by Nurses and Nursing Care Left Undone in the United States, Canada, and Germany**

<table>
<thead>
<tr>
<th></th>
<th>United States</th>
<th>Canada</th>
<th>Germany</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage of nurses reporting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Performing the following non-nursing tasks on the most recent shift:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Delivering and retrieving food trays</td>
<td>42.5</td>
<td>39.7</td>
<td>71.8</td>
</tr>
<tr>
<td>Housekeeping duties (cleaning patient rooms, etc.)</td>
<td>34.3</td>
<td>42.9</td>
<td>n.a.</td>
</tr>
<tr>
<td>Transporting patients</td>
<td>45.7</td>
<td>33.3</td>
<td>53.7</td>
</tr>
<tr>
<td>Ordering, coordinating, or performing ancillary services</td>
<td>68.6</td>
<td>71.7</td>
<td>27.6</td>
</tr>
<tr>
<td>That the following nursing tasks were necessary but left undone on the most recent shift:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oral hygiene</td>
<td>20.1</td>
<td>21.7</td>
<td>10.0</td>
</tr>
<tr>
<td>Skin care</td>
<td>31.0</td>
<td>34.7</td>
<td>13.0</td>
</tr>
<tr>
<td>Teach patients or family</td>
<td>27.9</td>
<td>26.2</td>
<td>29.6</td>
</tr>
<tr>
<td>Talk with patients</td>
<td>39.5</td>
<td>43.6</td>
<td>53.6</td>
</tr>
<tr>
<td>Develop or update care plans</td>
<td>40.9</td>
<td>47.4</td>
<td>34.0</td>
</tr>
<tr>
<td>Prepare patients and families for discharge</td>
<td>12.7</td>
<td>13.7</td>
<td>13.4</td>
</tr>
</tbody>
</table>

**NOTE:** These questions were not asked in England and Scotland. In the other sites, nurses were asked whether these tasks were performed, or were necessary but left undone, on the previous shift; n.a. = not asked.
toward nurses had also occurred with regularity in the previous year. Our question about verbal abuse did not single out a specific source; we can assume that it reflects mistreatment of nurses from many quarters, including patients, families, visitors, and other staff. The high frequency of abuse and complaints suggests that the current climate of care in hospitals is as unsatisfying to patients and their families as it is to nurses. The resulting tensions are likely compromising the civility of the work environment and contributing to the high rates of nurse burnout reported earlier. We coined the term ward rage to depict the high levels of frustration apparent in today’s hospitals.

**DISCUSSION**

Consumers, health professionals, and hospital leaders concur that all is not well in hospitals. Consumer trust in hospitals is eroding, nurses feel under siege, and hospitals cannot find enough nurses willing to work under the present conditions in inpatient settings. The remarkable consistency of the findings across the five countries surveyed makes it clear that problems in hospital nursing are not uniquely American. It also suggests that there are fundamental flaws in the design of clinical care services and the management of the hospital workforce worldwide.

The current shortage of hospital nurses in Western countries appears destined to worsen over the long term. The trends pointing in this direction include high levels of nurse job dissatisfaction and intent to leave hospital positions, an aging workforce, an increased tendency for younger nurses to show greater willingness to leave their hospital jobs, and declining enrollments in nursing schools. Although nursing shortages have been cyclical for decades, generally, hospitals have acted as oligopsonies, conceding salary increases and other benefits begrudgingly (Aiken & Mullinix, 1987). But 21st-century health care has brought a myriad of opportunities, and hospitals are now ill-prepared to compete for and retain a workforce of professionals who have many employment options, both within and outside of traditional health care settings.

Hospitals, by all reports, are spending substantial amounts of money on short-term solutions to staffing problems that are not stemming high nurse-turnover rates. These include signing bonuses, use of per diem and traveling nurses at two to three times the pay rates for permanent staff, recruitment of nurses from other countries, and the substitution of unlicensed personnel for nurses. A recent report by the Advisory Board Company (2000) estimates that the turnover of each general medical–surgical nurse in U.S.
hospitals costs $42,000, and each specialty nurse costs $64,000. The report’s authors estimate the savings for a 500-bed hospital able to reduce RN turnover from 13% to 10% at $800,000.

Much recent hospital reengineering and restructuring were designed to emulate industrial models of productivity enhancement. Many of these approaches have had limited success in the industries where they originated (Micklethwait & Wooldridge, 1996) and, not surprisingly, have not been particularly successful in hospitals either (Aiken et al., 2000; Walston, Burns, & Kimberly, 2000). Meanwhile, hospitals have not looked to their own nurses to come up with solutions, despite very strong evidence that nurse-designed innovations in hospital care, such as intensive care units (Fairman & Lynaugh, 1998), dedicated AIDS units (Aiken et al., 1999), and magnet hospitals (Havens & Aiken, 1999), have been immensely successful. Nurses want more communication with their managers about the allocation of resources and the creation of an environment conducive to high-quality care. Yet, sadly, reengineering efforts have reduced frontline nurse leadership roles, thereby eliminating a key mechanism for connecting the hospital’s mission with the providers of bedside care, as well as a vehicle for communicating the responsiveness of administration to the concerns of frontline caregivers.

To retain a qualified nurse staff in a competitive labor market, hospitals will have to develop personnel policies and benefits comparable to those in other lines of work and business, including opportunities for career advancement, lifelong learning, flexible work schedules, and policies that promote institutional loyalty and retention. Moreover, staffing mix and work design must be reevaluated in light of the increasing severity of illness of hospitalized patients and their short lengths of stay. Although many hospitals have maintained or even increased employment of nurses to stay even with increasing complexity of case mix, substantial reductions in the employment of support personnel are common (Aiken, Sochalski, & Anderson, 1996). The end result can be a misuse of scarce nursing resources for tasks not requiring nursing expertise.

The ultimate objective of the study from which data are reported here is to examine the relationship between hospital nurse staffing and working conditions and variation in patient outcomes. Our previous research and that of others has already established that hospital working conditions and the adequacy of nurse staffing are important predictors of variation in hospital patient outcomes (Aiken et al., 1994, 1999; Kovner & Gergen, 1998). Hence, beyond concerns that inadequate hospital nurse staffing will become chronic, there is every reason to believe that the problems in work design and workforce management that are reflected in the responses of the 43,000 nurses in our study contribute to uneven quality of care, medical errors, and adverse patient outcomes.

NOTE
1. The authors represent the International Hospital Outcomes Research Consortium, which is led by the Center for Health Outcomes and Policy Research, School of Nursing, University of Pennsylvania, directed by Linda Aiken, and includes the following research teams: United States: Linda Aiken, Sean Clarke, Eileen Lake, Jeffrey Silber, Douglas Sloane, and Julie Sochalski (University of Pennsylvania); Alberta: Carole Estabrooks, Konrad Fassbender, and Phyllis Giovannetti (University of Alberta); British Columbia: Heather Clarke (Registered Nurses Association of British Columbia), Sonia Acorn, Arminee Kazanian, and Robert Reid (University of British Columbia); England: Jane Ball (Employment Research, Inc.), James Coles (CASPE Research, Inc.), Philip James (CHKS, Inc.), Martin McKee, and Anne Marie Rafferty (London School of Hygiene and Tropical Medicine); Germany: Reinhard Busse, Thorsten Koerner (Hannover University Medical School), and Gabriele Müller-Mundt (University of Bielerfeld); Ontario: Geoffrey Anderson, Jack Tu (Institute for Clinical Evaluative Sciences and University of Toronto), Judith Shamian (Health Canada-Santé Canada), and Donna Thomson (Mount Sinai Hospital); Scotland: Heather Baillie, Andrew Boddy, Alastair Leyland (University of Glasgow), James Buchan (Queen Margaret College), Jennifer Hunt, Suzanne Hagen, and Louisa Sheward (Nursing Research Initiative for Scotland).

REFERENCES


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Expected Near- and Long-Term Changes in the Registered Nurse Workforce

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On May 16, 2001, I gave a briefing to members of the U.S. Congress, their staffs, and others interested in policy making aimed at strengthening the nursing workforce. The briefing was organized by the Association of American Colleges of Nursing, Association of Academic Health Centers, and the Friends of the National Institute of Nursing Research. Following the presentation of results of a five-nation study of nursing given by Dr. Linda Aiken (see Aiken, Clarke, Sloane, & Sochalski, 2001 [this issue]), I offered brief remarks covering three areas: perspectives on the current nurse labor market, expectations for near- and long-term term changes in the registered nurse (RN) workforce, and a summary of policy options that lawmakers might wish to consider.

PERSPECTIVES ON THE NURSE LABOR MARKET

This article begins by providing some insight into key developments affecting the nurse labor market. Four areas were discussed: employment and earnings trends, explanations for the current RN shortage, new evidence on the relationship between nurse staffing and patient outcomes, and developments expected in the areas of collective bargaining and staffing legislation.

Employment and earnings trends. Data were shown describing trends in employment and earnings of RNs, licensed practical nurses (LPNs), and nursing
aides, orderlies, and assistants (aides) employed in hospitals and nursing homes during the period from 1993 through 1999, the latest years for which data were available at the time of the congressional briefing. Since 1995, colleagues from Dartmouth College and Harvard University have been determining and tracking employment and earnings trends using data from the U.S. Bureau of the Census Current Population Surveys (Buerhaus & Staiger, 1996, 1999). In the congressional briefing, the following points were emphasized:

- In hospitals, evidence suggests that despite some increases in employment of RNs in certain years during the 1990s, the overall employment picture is one of declining employment growth. In 1999, the number of RNs employed in hospitals was about the same as in 1993.
- After growing impressively between 3% and 6% annually since the early 1980s, inflation-adjusted hospital RN wages fell each year between 1994 and 1997; they have risen very little since then.
- LPN employment in hospitals has declined steadily over the past 15 years, but, surprisingly, inflation-adjusted wages for LPNs have risen in most years.
- Overall, hospital employment of aides has changed very little since 1983, although there have been years in which employment increased rapidly (100,000 over the 2-year period, 1995 and 1996) and years in which employment declined substantially (a decrease of 50,000 in 1997).
- Inflation-adjusted wages of aides have risen very little since 1983, increasing by no more than 4%, which is very similar to the cumulative increase in average real earnings of most Americans during the same period.
- Home health care has been the fastest growing sector of the nurse labor market, at least until 1997, when the Balanced Budget Amendment (BBA) of 1997 was enacted. Data from the U.S. Bureau of the Census show that the number of aides grew by about 250,000 full-time equivalents (FTEs) in home health care between 1990 and 1997. For RNs, employment grew by nearly 120,000 FTEs between 1990 and 1997 before declining in 1998 and 1999. Employment of LPNs grew somewhat in home health care during the same period. However, in the past few years, employment and earnings have declined for all nursing personnel in home health care.
- In states that have a high enrollment of their population in health maintenance organizations, there is lower employment growth for RNs than in states with low HMO enrollment. However, RN earnings are higher in high HMO enrollment states in both the hospital and nursing home sectors of the nurse labor market.

Explanations for the current shortage of RNs in hospitals. Since 1998, many hospitals have been reporting shortages of RNs, particularly in intensive care units (ICUs), operating rooms, and post-anesthesia recovery units. The development of this shortage can be explained by the interaction of at least five developments. First, although good data on annual hospital demand for RNs are not readily available, and despite steady reductions in the number of hospitals and beds over the past two decades, demand is likely to be rising due to the increase in the number of sicker and older inpatients. Because there is limited ability to substitute less skilled and less knowledgeable nursing personnel (LPNs and unlicensed aides) for more highly educated and skilled RNs, demand for RNs has been rising. Second, inflation-adjusted wages for RNs fell substantially for 4 years in the mid-1990s and have risen only slightly since 1997. As wages fall, holding all else constant, many (but not all) RNs are given an economic incentive to reduce the number of hours they work; some RNs may even withdraw from the workplace altogether. Third, the strong national economy of the past few years is likely to have reduced the supply of RNs in the workforce. Because the majority (about 70%) of RNs are married, changes in the incomes of their spouses (or in spouses’ perceptions of employment security) directly influence the decisions of RNs about whether they will participate in the labor market and how many hours they are willing to work. Because unemployment levels have been very low, consumer confidence has been rising, and personal earnings have been growing over the past 4 years, many RN spouses have experienced greater job and income security. In turn, this has reduced the economic pressure on some married RNs to spend their time working and may have even caused some RNs to withdraw from the labor market completely. A fourth reason for the development of the current shortage of RNs may be working conditions and dissatisfaction of hospital-employed RNs, as made clear in the study reported by Dr. Linda Aiken during the congressional
briefing (see Aiken, Clarke, Sloane, Sochalski, Reinhard, et al., 2001). Regardless of economic circumstance, for some RNs, problems in the workplace may be enough to cause them to reduce their willingness to participate in the labor market. The final explanation for the current shortage of hospital RNs concerns important changes in the demographics of the RN workforce. Buerhaus, Staiger, and Auerbach (2000b) showed that the decreasing number of RNs under the age of 30 may be partly responsible for the current shortage of RNs in hospital ICUs. This is because ICUs have traditionally attracted younger RNs, and today, there may simply be too few young RNs available for hospitals to attract into this setting. The Buerhaus et al. (2000b) analysis also showed that shortages in operating rooms and postanesthesia recovery units, where the oldest hospital-employed RNs work, are explained in part by the retirement of older RNs.

Nurse staffing and patient outcomes. The congressional briefing continued with a short discussion of the results of a recent study (Needleman & Buerhaus, 2001) on the relationship between nurse staffing in inpatient acute care hospitals and patient outcomes. Cosponsored by the Health Resources and Services Administration, Division of Nursing, the Health Care Financing Administration, the Agency for Healthcare Research and Quality, and the National Institute of Nursing Research of the National Institutes of Health, the study sought to develop the evidence base on patient outcomes potentially sensitive to nurse staffing in inpatient units in acute care hospitals. Of the 14 outcomes potentially sensitive to nursing that were examined in the study, results showed that both nurse staffing levels and mix of personnel, particularly RNs, are strongly and consistently associated with five patient outcomes in medical patients and one outcome in surgical patients. As perhaps the largest and most sophisticated effort to date aimed at assessing the relationship between nurse staffing and quality of patient care, the study has received considerable attention in the media and health policy community (e.g., nearly 4,000 downloads in the first 7 days the study was made available on the government Internet site http://bhpr.hrsa.gov/dn/staffstudy.htm).

Spotlight shining brightly on hospitals and nurses. Given the development of nursing shortages, evidence that nurse staffing is unequivocally related to patient outcomes and the quality of patient care in hospitals, and the significant dissatisfaction of nurses with their work in hospitals, policy makers and legislators can expect more attention focusing on hospitals and issues concerned with nurse staffing. Several studies assessing nursing’s contributions to patient care are in progress (Buerhaus & Needleman, 2000), and once results are published, public focus on the nursing workforce and problems nurses are experiencing is likely to capture still more interest among the media, government, policy makers, and special interest groups. One can expect this media attention to stimulate increased collective bargaining activity and calls for regulatory oversight of a variety of nurse staffing issues, particularly mandatory staffing and overtime hours. Hence, during the foreseeable future, Congress and the states can expect to be dealing with complex issues related to nurse staffing, shortages, and quality of care.

EXPECTED NEAR-TERM CHANGES IN THE RN WORKFORCE AND KEY UNCERTAINTIES

Over the next 6 years, a number of important changes are expected in the RN workforce. First, I expect RN shortages will continue and spread both geographically and by sector of the nurse labor market (i.e., developing in home health, in nursing homes, and perhaps even in physician offices). In addition, I expect that shortages will slowly increase in intensity and that more organizations will be unable to staff their facilities adequately. In response, wages are likely to rise and may even increase sharply, but I do not expect that the labor supply response of RNs (increasing the time they spend working) will be as large as that which occurred in the 1980s, when earnings were increasing substantially. This is because the RN workforce is older, the national economy is robust, there are not large numbers of RNs who are readily available to rejoin the workforce, and RNs are on average much older today than in earlier decades. Thus, even though RN earnings will probably rise with resulting increases in the amount of labor supplied by RNs, I do not expect
the response to rival the increases in labor activity experienced in previous years or cause shortages to go away. Over the near term, I also expect little if any increase in enrollment into nursing education programs; meanwhile the RN workforce will continue to age.

Near-term uncertainties. Whether these expectations materialize will depend largely on if and how three uncertainties develop. Should the national economy experience a recession, and result in stagnant or falling earnings, rising unemployment, growing concern about job security, and declining consumer confidence, then economic pressure on RNs, particularly married RNs, will grow. Consequently, many married RNs will be motivated to rejoin the nursing workforce if they are not working, and some of those who are working will increase the number of hours they work. The resulting increase in labor supply, however, could slow the development of further RN shortages. The magnitude of the increase in the supply of RN labor will be determined by how severe the recession is and how long it lasts, if it develops in the first place.

A second uncertainty is whether Congress and the states enact and fund comprehensive policies to address the forces driving the instability in the RN workforce. At the time of this writing, three pieces of legislation have been introduced in Congress and have gained bipartisan support. Current legislation contains provisions aimed at addressing many but by no means all of the pressing problems afflicting the RN workforce, the organizations that employ them, and the programs that educate new RNs. Moreover, the amount of dollars allotted in the proposed legislation is not impressive, suggesting that legislators and their staffs fail to grasp the depth and breadth of both current and projected shortages of RNs and their impact on society, employers, educators, and the public’s health. In addition, it is not clear when the various proposals are likely to be reconciled into one bill, whether the legislation will be funded adequately, when the legislation will be passed by Congress and signed into law, and how soon federal agencies will be able to write and implement regulations governing the distribution of funds and startup of new programs. Unfortunately, precious time has already been lost as the Government Accounting Office (GAO) was required to spend time determining if, in fact, a current RN shortage exists. Based on what has been demonstrated thus far, one cannot rely on Congress to play a timely role in enacting effective and decisive legislation that would prevent the large shortages projected for the future.

Whether the above expectations unfold over the next 6 years will also be influenced by yet another uncertainty: the politics of quality and regulation. It is not clear how the majority of nurses and the professional organizations and labor unions that represent them will react to current shortages and to the “new knowledge” that nurse staffing makes an important difference in the quality of care and patient outcomes. Shortages and growing concerns about quality are shifting economic power from employers to employees. Therefore, nurses and their representative organizations are in a strong position to take advantage of this shift in economic power by acting in either a contentious manner toward employers to obtain their various interests or in a synergistic manner. The latter means cooperatively rebuilding relationships with employers and engaging and working with employers to find constructive and decisive ways to deal with all the barriers blocking nurses ability to provide high quality, safe, and desirable patient outcomes. Thus, whether near-term conditions in nursing improve or worsen will depend not only on what happens to the economy and how soon and how effectively Congress acts but also on how the nursing community handles its newfound economic power and national media and policy spotlight.

EXPECTED LONG-TERM CHANGES IN THE RN WORKFORCE AND KEY UNCERTAINTIES

Long-term changes in the RN workforce over the next 6 to 15 years will be dominated by the rapid aging of RNs. Data from a study on the aging of the RN workforce (Buerhaus, Staiger, & Auerbach, 2000a) show: (a) the average age of the RN workforce is increasing more than twice as fast as the age in all other occupations in the U.S. workforce and (b) between 1983 and 1998, the number of RNs under 30 years of age decreased...
41%, whereas over the same period, the number of working people in the U.S. workforce in this age group dropped by only 1%. The implications of these trends have been described in considerable detail in a four-part series (Auerbach, Buerhaus, & Staiger, 2000; Buerhaus, Staiger, & Auerbach, 2000b, 2000c; Staiger, Buerhaus, & Auerbach, 2000) and are, therefore, not repeated here. Suffice it to say that the continuing failure to replace the large number of aging RNs who will reach retirement age in the relatively near future means that the largest age group in the RN workforce will be RNs in their fifties. Moreover, the total number of RNs will begin to shrink considerably as large numbers of RNs begin retiring after 2010. Both access to health care and the quality of care are likely to deteriorate as severe RN shortages develop.

Thus, over the long term, and assuming not much is done in the near term to strengthen the nursing workforce, I expect the following:

- Steadily rising demand for RNs driven by increased need for health care, greater use of technology and the Internet, general economic growth, policy changes that will expand access to health care, increases in the total size of the population, and expansion of the number of older people in the United States, who are living longer (particularly women) than their counterparts in previous generations.
- Steady increases in the average age of working RNs (workforce in the fifties) as fewer younger people choose nursing as a career compared with earlier decades, when nursing was a more socially desirable career and large numbers of people entered the profession.
- Accelerating reduction in the supply of RNs beginning around 2010 due to the large number of RNs of the baby boom generation (born between 1946 and 1960) reaching retirement age.
- Intensifying RN shortages, which will add pressure on policy makers to allow increased immigration of nurses educated in countries other than the United States.
- Deterioration in access to and quality of health care, particularly for the 78 million Americans born in the baby boom generation, who will begin enrolling in the Medicare program starting in 2010.

**Key long-term uncertainties.** Whether the long-term expectations about the composition and size of the RN workforce materialize will depend to a considerable degree on whether (a) the social status of the nursing profession improves or worsens, (b) ergonomic improvements in the nurse workplace are achieved rapidly, and (c) a better way is found to train and use nonprofessional personnel.

If the image of the nursing profession improves, it will be much easier to attract people into nursing. Large numbers of people will be needed (as much as a 40% increase in enrollment, beginning now) to avoid the RN shortfalls projected to develop after 2010. To improve the image of nursing will require sweeping changes throughout society, involving the media’s portrayal of nursing; RN’s portrayal of the profession to the media; hospitals and other employers’ making comprehensive changes to overall working conditions; and corporations, organizations, and individual citizens recognizing the value of a stable and increasingly educated nursing workforce. If private and public sector efforts can begin immediately to repair the image of the nursing profession by implementing a sustained and pervasive media campaign marked by significant increases in earnings, then there is a good chance that significant numbers of people will choose nursing as a career and the supply of future RNs will rise enough either to delay the onset or to reduce the size of the shortages projected for the future.

Whether the long-term expectations outlined above develop will also be influenced by how quickly ergonomic improvements in the nurse workplace are achieved. Because it is inevitable that the average age of the RN workforce will continue to increase, it is imperative that efforts be taken to improve workplace ergonomic conditions affecting nurses. Although older nurses have considerable knowledge and experience gained by years of nursing practice, the bodies of many RNs are wearing out due to sore and injured feet, ankles, knees, backs, shoulders, necks, and wrists, in addition to changes in vision and hearing. Because so many older RNs are expected to retire, if even a small proportion could be induced to remain employed and not retire, then the effect on maintaining the supply of working RNs could be substantial. Thus, organizations should move quickly to acquire equipment and technology that will reduce the physical and mental strain on RNs and thereby induce them to delay their retirement.
Improving the ergonomics of the nursing workplace will require considerable investment of dollars and effort, and it is doubtful that hospitals by themselves will embark on such a strategy in a timely manner. Federal and state governments should, therefore, consider providing financial help to stimulate these responses. In addition, corporations that manufacture patient-related equipment and devices and sell them to hospitals must recognize that without an adequate supply of RNs in the future, their sales will be negatively affected. Thus, corporations that make their living supplying goods and services to health care providers should recognize their self-interest and not only develop new products to improve the ergonomic conditions in nursing but also consider offering financial resources to help hospitals fund ergonomic and other needed changes aimed at retaining and strengthening the nursing workforce.

A final long-term uncertainty concerns whether a better way can be found to train and use nonprofessional personnel to support RNs in providing patient care. Over time, hospitals and the nursing profession have struggled to find a way to organize the delivery of nursing care that effectively uses nonlicensed nursing assistants. For one reason or another, tensions and difficulties have erupted at both the clinical and policy levels. Yet, I believe that it may not be possible to accomplish all the changes needed to rapidly increase the number of RNs in the future. Thus, nursing leaders and policy makers should focus on the way that nursing can be provided in health care delivery organizations in an environment characterized by fewer RNs than one would like and a workforce mostly in their fifties. Logically, more aides and non-RNs will be needed to provide adequate patient care. Thus, now is the time to begin new programs to better educate and train assistive personnel in a far more comprehensive manner than what is currently done. With both public and private sector support, training programs could be developed that are committed to supporting individuals as they acquire new skills and knowledge, advancing their careers, and retaining them in the health care workforce. Seeing these workers as a valued asset, employers can invest in long-term relationships with employees and, working cooperatively with RNs, determine proactively how nursing care can be organized and provided using more non-RNs in the future. Relying on more assistive personnel to provide nursing services may not be the outcome desired by the nursing profession or policy makers, but it would be irresponsible to fail to prepare for this highly likely scenario.

The congressional briefing concluded with some overall comments on policy options that could be considered by members of Congress in fashioning legislation. The options deal with actions that can be taken to cope with an aging workforce, to raise future supply, and to draw attention to the serious problems in nursing. Because these options have been described elsewhere in considerable detail, they are not discussed here (Buerhaus, Staiger, & Auerbach, 2000c).

CONCLUDING COMMENTS

That a congressional briefing on nursing was conducted indicates that the profession’s policy-influencing community is able to organize programs to reach members of Congress and their staffs. It also signifies that public awareness of the problems affecting the nursing profession and debate over how to resolve them have finally reached the point where Congress and the federal government are beginning to pay attention. Although these developments are clearly positive, much remains to be done to assure that comprehensive and adequately funded legislation is passed as soon as possible. Moreover, it is important to keep in mind that obtaining favorable legislation and public policies is only part of the solution needed to address the forces beleaguering the RN workforce and the employers who depend on it. In the end, the most effective change needed to deal with the nursing profession will come not from reshaping public policy and using government intervention but from changing the real world where markets and people interact daily, where media convey images of society and what is valued, where people form images of desirable careers, and where people with resources and connections make decisions that influence the market behavior of millions of other people. Unless and until the private sector values the contributions of nursing, not unlike the way the
teaching profession is valued, the nursing profession will be unable to respond effectively to the near- and long-term expectations projected for the RN workforce.

REFERENCES


Peter I. Buerhaus, PhD, RN, FAAN, is the Valere Potter Professor of Nursing at the Vanderbilt University School of Nursing and senior associate dean of research.
The results of a U.S. Department of Health and Human Services study entitled *Nurse Staffing and Patient Outcomes in Hospitals* (Needleman, Buerhaus, Mattke, Stewart, & Zelevinsky, 2001b), released on April 20, 2001, confirm what every registered nurse (RN) has always known: that nurses make a significant contribution to patient care and recovery. Based on 1997 data from more than 5 million patient discharges in 799 hospitals in 11 states, the study found a strong and consistent relationship between nurse staffing and five patient outcomes for medical patients and one for surgical patients (Press release, Health Resources Service Administration Press Office, Friday, April 20, 2001).

After an extensive review of the literature and discussion with members of a technical expert panel, the investigators developed 14 Outcomes Potentially Sensitive to Nursing (OPSNs). The OPSNs were in three categories: (a) patient complications, which there is some evidence are
sensitive to nursing care: urinary tract infection, skin pressure ulcers, hospital-acquired pneumonia, and deep vein thrombosis (DVT)/pulmonary embolism (PE); (b) exploratory measures, including upper gastrointestinal (UGI) bleeding, central nervous system complications, sepsis and shock/cardiac arrest, and complications among surgical patients, including surgical wound infection, pulmonary failure, and metabolic derangement; and (c) a group of outcomes consisting of mortality, two measures of patient length of stay, and failure to rescue, defined as death among patients who had experienced one to five complications: shock, sepsis, pneumonia, DVT/PE, or UGI bleeding (Needleman, Buerhaus, Mattke, Stewart, & Zelevinsky, 2001a).

The study used hospital patient discharge data to construct the OPSNs and state hospital financial reports or hospital staffing surveys to construct measures for nurse staffing. Data for the analysis were obtained from three samples: a sample of 799 hospitals from 11 states (Arizona, California, Massachusetts, Maryland, Missouri, Nevada, New York, South Carolina, Virginia, Wisconsin, and West Virginia) and Medicare data from these hospitals; a sample of 253 California hospitals, which were part of the 11-state sample but were used for service-level calculations; and a national sample of 3,357 hospitals that provided discharge abstracts for only Medicare patients (Needleman et al., 2001a).

Multiple regression analysis was used to analyze the relationship between the OPSNs and various models of inpatient nurse staffing. Separate regressions were run on each of the samples. Results from the 11-state all-patient sample showed a strong and consistent relationship between nurse staffing and five outcomes in medical patients: urinary tract infections, pneumonia, length of stay, UGI bleed, and shock. In surgery patients, only one strong OPSN, failure to rescue, was related to nurse staffing. Results of the service-level regression analysis of the California hospitals were consistent with the full 11-state all-patient sample. The results of the Medicare analysis showed that all of the OPSNs that were identified as strongly and consistently related to nurse staffing in the 11 state sample were comparable to the results of the 11-state Medicare sample, and all but UGI bleeding were strongly and consistently related to nurse staffing in the national Medicare sample. For surgical patients, however, inpatient differences were observed, as there were strong associations between nurse staffing and failure to rescue, pneumonia, UGI bleed, shock, and sepsis in the national Medicare sample (Needleman et al., 2001a).

In June 2001, I had the opportunity to hear Dr. Peter Buerhaus at the Maryland Hospital Association’s Annual Convention and subsequently conducted a telephone interview with him. As one of the major contributors to nursing workforce research, Dr. Buerhaus is a highly respected nurse researcher, and this study adds to an already illustrious research career. Dr. Buerhaus is currently the senior associate dean for research and the Valere Potter Professor at Vanderbilt University School of Nursing in Nashville, Tennessee. I followed up that telephone conversation with an interview with Judy Goldfarb, MA, RN, a nurse consultant with the Center for Medicare and Medicaid Services (abbreviated CMS, formerly the Health Care Financing Administration), who participated as a member of the government work group that oversaw the project, to get the agency perspective on the study. Ms. Goldfarb has made a significant contribution to nurse workforce data collection over her tenure at CMS.

Dr. White: What was the background/impetus for the study?

Ms. Goldfarb: In 1995-1996, the former administrator of CMS, Bruce Vladeck, was asked by Donna Shalala, the former secretary of the Department of Health and Human Services [DHHS], to conduct a study in response to a growing public and congressional concern over poor nursing care in hospitals. He called upon the department to address the growing concerns. Secretary Shalala sent out a departmental letter to put HRSA in the lead to address this concern. So, simultaneously, CMS promised to study the problem and HRSA was
given the assignment of looking at the deskilling of the nursing workforce. This caught my eye and that of several of my coworkers, and we reached out to HRSA to collaborate in the fall of 1996. Shortly preceding these events, and in response to an Institute of Medicine [IOM] study, a jointly sponsored HRSA, National Institute for Nursing Research [NINR], and Agency for Healthcare Research and Quality [AHRQ] summit was held. The timing was right for all these DHHS agencies to collaborate on a shared study.

Also, at the same time, CMS was looking for support for its new hospital conditions for participation in proposed rule published in the Federal Register on December 17, 1997. We received over 60,000 comments about the proposed rules that among other things called for an explicit method to determine nurse staffing based on patient needs. So this requested study would provide an evidence base for all the agencies working on the project, but for CMS it could also be used to support the proposed rules.

Dr. Buerhaus: The IOM report in 1996 on the adequacy of nurse staffing pointed out the paucity of information about the relationship between nurse staffing and patient outcomes. It reported that there was inadequate evidence linking nurse staffing and patient outcomes and recommended that a research agenda be formulated to identify areas of study that would fill in the gaps. Nurses at NINR, AHRQ, and HRSA worked together and developed a draft research agenda. After obtaining input from the field, the agenda was published in the Federal Register in 1997.

Dr. White: How did you get involved in this study?

Dr. Buerhaus: When I was at Harvard, Jack Needleman was a faculty colleague. We had a discussion about patient outcomes and nurse staffing that led to a decision to develop a grant application to AHRQ to study this relationship. Just before we learned that we were awarded the grant, HRSA put out a call for a contract study to develop the evidence base for the relationship between nurse staffing in hospitals and patient outcomes sensitive to nursing. We developed a detailed proposal for HRSA within 3 weeks. Oftentimes, HRSA provides contracts to research firms, but fortunately, we were awarded the contract.

Ms. Goldfarb: The DHHS work group was comprised of four members, one from each of the agencies involved. The initial project director was Evelyn Moses from CMS, who was given the lead by Secretary Shalala. After she left, Carole Gassert from HRSA became the project director. I was the project officer from CMS. Cheryl Jones was the first agency representative from AHRQ, and then, Peter Gergen replaced her after about 2 years. Carol Hudgings was the agency representative from NINR. Each of these people was intricately involved with the details of the work, an active part of the technical expert panel of the study based on their areas of expertise, and a representative from their respective agencies to keep the appropriate agency leadership informed.

Dr. White: What makes this study different from the other studies you’ve done?

Dr. Buerhaus: Since the late 1980s, I have felt that given the development of market pressures in health care, there would be rewards to organizations and professions that produce high quality. Thus, nurses would be well served the closer they connected nursing practice with high quality through solid research and broad dissemination of findings. But we needed to get good data, and I had never really done quality-of-care research. This was a new branch of research for me, closely built on my previous work.

This study makes a number of important contributions. First, we tested a larger number of outcomes than has been done by other researchers. We were very careful in constructing the outcomes, and rigorously tested them. We carefully laid out and identified our approach to show exactly what we did. This should make it much easier for future researchers attempting to develop outcome measures based on hospital discharge abstract data, or to replicate or follow up on this research.

Second, the study included nursing aides. There are two other large studies of nurse staffing
and patient outcomes, and neither included the impact of nursing aides in the staffing mix. A third strength of this study is that we pushed the analytic methods for this kind of work beyond where they have been before. In addition to the development of patient outcomes, we struggled to develop good measures for nurse staffing variables. Hospitals don’t report clean data on nurse staffing, nor do they separate staffing into inpatient and outpatient settings. We examined how previous researchers allocated nurses into the inpatient setting using formulas based on hospital revenues. We used data from California hospitals that separated nurses into inpatient and outpatient settings and found that these formulas were way off the mark. We developed a better method to allocate nurses into the appropriate setting.

Another big accomplishment is that we modeled nurse staffing in 10 different ways to reflect different levels and mix of RNs, LPNs, and nursing aides. We wanted to see if the relationship was statistically significant, if it was in the right direction, and if the relationship existed in several models. This way, results would be more convincing. We also studied the impact of different levels and mix of staffing on patient outcomes. For example, when a hospital had low staffing levels and then increased the staffing level or mix, we examined the impact on the rates for all of the patient outcomes. For the OPSNs for which we found a relationship with nurse staffing, higher RN staffing was associated with a 3% to 12% reduction in the rates of OPSNs, depending on the OPSN tested and the regression model examined. Moving from low to high levels for all of the nurse staffing variables was associated with a 2% to 25% reduction in OPSN rates, depending on the OPSN and the regression model. A final strength is that we examined the relationship using three large and different samples of discharge data.

Dr. White: Please comment further on the three samples.

Dr. Buerhaus: The 11-state hospital sample provided data on all patients and provided a general representation of the country. Using this 11-state hospital sample also enabled us to analyze only the Medicare patients in this sample and compare results to all hospitalized patients.

The second sample was 253 California hospitals that were a part of the 11-state all-patient hospital sample. We used this sample to do an analysis of the data at the hospital and what we called the service level to approximate a unit-level analysis. We wanted to determine if the same results were found using data at the service versus the hospital level. We found that the results are comparable.

The third sample, the national Medicare sample, was important because we wanted to see if you could use Medicare data for studies like this and whether the data would be a good proxy for all patients. This is important because CMS has data available, and if we obtained comparable results, then it would be possible to use CMS data to monitor the relationship between nurse staffing and patient outcomes.

Dr. White: What were the major results?

Dr. Buerhaus: To obtain a detailed picture of the results, I would suggest readers go to the Web site and download the study results, at least the Executive Summary. But to summarize, the results from the 11-hospital sample showed a strong and consistent relationship between nurse staffing and five of the patient outcomes, specifically urinary tract infections, pneumonia, length of stay, UGI bleed, and shock in medical patients. This 11-hospital sample analysis showed a strong and consistent relationship between staffing and failure to rescue in surgical patients, and there was a weaker relationship for urinary tract infections and pneumonia.

When we simulated the effects of different staffing levels by introducing higher RN staffing levels, there was a 3% to 12% further reduction in the rates of the above OPSNs.

The results of the analysis of the California hospital sample showed that the relationships at the service level were generally consistent with those based on hospital-level analysis. This result is important because it suggests that using service-level data, rather than the larger sample data, does not result in a greater number of outcomes associated with staffing.

Finally, the results of the analysis of the national Medicare sample were comparable to the 11-state sample for medical patients. The Medicare analysis for the 11-state sample showed all
but UGI bleed as strongly and consistently related to staffing. For surgical patients, the results were different between the 11-state Medicare sample and the 11-state all-patient sample. Failure to rescue was not strongly and consistently related to nurse staffing. However, failure to rescue was strongly and consistently associated with staffing in the national Medicare sample, as was UGI bleed, shock, and sepsis. Thus, we need to be cautious about using the Medicare data when examining surgical patients and relationships to nurse staffing. We need further study to determine what accounts for this discrepancy.

**Dr. White:** What was the most important outcome of the study?

**Dr. Buerhaus:** The fact that across three different samples, using less than ideal data, we found evidence that certain patient outcomes are related to nursing. From this point forward, policy makers and others concerned with improving the quality of care in hospitals can no longer ignore the contributions of nurses nor the issues that are causing so much trouble in the nursing profession and jeopardizing adequate nurse staffing. We were given a set of goals for the study, and to achieve them, we had to use certain kinds and sources of data. The staffing data come from administrative databases. They are generated for payment reasons, not for quality monitoring or clinical outcomes. Nurse staffing data are poorly reported and require considerable effort to develop measures that were comparable across hospitals and across the three samples. In the end, the data analysis revealed relationships between several but not all patient outcomes that we analyzed. However, I think our data only reveal the tip of the iceberg. If we had better data on nurse staffing, I believe we would observe more outcomes related to staffing, and we would have a better quantification of the strength of the relationships.

There are reasons that the patient outcomes that we were interested in for the study are underreported in hospital discharge abstracts. Additionally, we were only able to measure adverse patient outcomes using these data, and thus, we were unable to test the contributions of nurses to positive patient outcomes.

Ms. Goldfarb: I think there were two important things. The first is the very important finding that there was a consistent relationship between RN staffing and outcomes, among both medical and surgical patients, even when we varied the levels of RN staffing. Specifically, with surgical patients, we saw the outcome of failure to rescue (defined as a mortality that was related to patient shock, sepsis, pneumonia, DVT, PE, GI bleed) was strongly associated with RN numbers. This study gave us the data to support what most of us in the profession already knew—that judgment and critical thinking skills are needed by an RN to identify the potential complications, to intervene and evaluate the response. It is the nursing process, and the key is the RN. With higher RN staffing, the reduction was 4% to 6% for failure to rescue, and with higher nurse staffing overall, there was a 2% to 12% reduction in failure to rescue.

The other thing that sets this study apart is that there is no single database in existence that can give us these findings. We were limited by using existing databases because of financial reasons. And the use of modeling and simulation techniques by Jack Needleman was a big contribution. Using the models, they were able to ask the “what ifs” if we had this number of RNs and make predictions.

**Dr. White:** What are the recommendations for the future?

**Dr. Buerhaus:** The most important recommendations for the future involve the need for better data collection. I would recommend that any future studies, even at the service level, at a minimum track the five outcomes that showed a strong relationship for the medical patients. We also need to think about the failure-to-rescue outcome and the ability of nurses to pick up errors and complications acquired in the hospital. We need to continue to show that staffing does matter. The data collection can’t end here.

We also need to develop more outcomes that are potentially sensitive to nursing care, including outcome measures that are positive, that show that patients are well cared for, that their functional status has improved, that they are educated well to care for themselves and their significant
others and are prepared for discharge. These types of positive outcome need to be developed, measured, and documented.

Last, I enjoyed the opportunity to talk to CMS. I made a presentation to CMS, and for me, that completed the process. It was perfect timing. CMS is aware of shortages and future shortages of nursing staff. The antennae at CMS are up because of this, and it is a pretty credible study using their data. They have a new administrator, Tom Scully, who is listening, and now, others are paying attention. He spent an hour talking with us. This is an important issue politically and for both providers and beneficiaries. We know now that nurses do matter and that we need them for quality and access. He demonstrated in front of CMS that this will be an important policy agenda for CMS.

Dr. White: Where do we go from here?

Ms. Goldfarb: CMS really embraced the value of this study. They budgeted for the report of this study, and with all the balanced budget constraints, that was important. They supported this study from its inception because of their commitment to this work. They were pleased to have the evidence demonstrating that nurses do make a difference and that there was a strong and consistent relationship between nurse staffing and patient outcomes. CMS wanted to stay focused on the results of the study. They presented it CMS-wide in a formal rollout of the results on June 18. The presentation was videotaped, and these videotapes have already been made available nationwide to all the regional offices (10) and to the four regional PRO offices (Boston, Kansas City, Dallas, and Seattle). The goal is that hospitals will review this with their PRO and use it as a focal point for improving nurse staffing and, subsequently, patient outcomes. The new administrator at CMS, Tom Scully, has embraced the results, praised the work, and made a renewed commitment for CMS in collaborations with other stakeholders to work to find a solution to relieve the nursing workforce shortage.

Another important result could be related to the hospital conditions of participation with Medicare. Although they are not yet published in their final form, if the rules require performance measures for hospitals, they could use the identified outcome measures and track these outcomes. Since these outcomes are linked with nurse staffing, they could monitor their nurse staffing, look for trends in nurse staffing contributing to negative patterns of outcomes, and do a root cause analysis.

Third, JCAHO is about to introduce a new standard on staffing effectiveness related to outcomes. It will be a human resource standard. I have had some input into the evaluation of this proposed standard. The JCAHO used the results of the study to support how you might substantiate a link between staffing and outcomes. The standard will require hospitals to evaluate the effectiveness of staffing and relate it to patient outcomes.

Last, I just want to comment that, OK, we have this information, what can we do with it? The dissemination of the videotapes will give us an opportunity to show the results nationwide and focus discussions on quality improvement. I also feel that anyone who wants to improve and reverse the nursing shortage needs to look at the evolving evidence base, this work, and also Linda Aiken’s work on magnet hospitals and their ability to recruit and retain nurses. Looking at these studies together, a local dialogue needs to be developed. The dialogue needs to emphasize that nurses do affect quality care, that they make a strong and consistent difference in improving patient outcomes. I am proud to have been a part of this contribution. It is no longer just anecdote—now, there is evidence!

NOTE

REFERENCE
The development and sustainability of a nursing center within the chaotic health care system of the last decade has required skill, experience, commitment, and the willingness to be flexible and responsive to the changing environment. The University of Maryland School of Nursing has been successful over the last several years in the development of Open Gates Health Center, a storefront clinic in inner-city Baltimore. Valuable lessons are shared that can support the development of new centers and the enhancement of existing ones. As nursing centers mature into the mainstream health care delivery system, they must maintain the capacity to preserve their fundamental commitment to meeting community needs. To better position themselves, nursing centers must demonstrate that they provide comprehensive quality health care in an efficient and effective manner. Moreover, nurse practitioners must work to be on the panels of both medical assistance and commercial health maintenance organizations to secure reimbursement for their services.

While nurses are essential providers of health care in nearly every clinical setting, only in the last few decades have nurses assumed autonomous roles in nurse-managed centers. Most nursing centers are designed in partnership with a community, providing public health services, education, and acute treatment to vulnerable populations. The Henry Street Settlement, founded by Lillian Ward in 1893 to provide care to...
the poor in New York City, is an early example of a community-driven nursing center. The focus was not merely on disease and public health but on disease prevention, education, safety, and advocacy for health reforms (Buhler-Wilkerson, 1993).

With the establishment of the nurse practitioner role in 1965, increasing opportunities arose for independent practice. The early nursing centers most often were developed as part of academic nursing programs to meet community needs while providing faculty with practice opportunities and student learning experiences. Supported by special project grants from the Division of Nursing, U.S. Department of Health and Human Services, academic-based nursing centers grew in number. In the last decade, nursing centers have developed outside of academia with support from community organizations and philanthropic groups. Regardless of their structure and support, nursing centers focus on meeting community needs by establishing access to nursing and other health care services. Further details on development and different models can be found in Nursing Centers: The Time is Now (Murphy, 1995) and proceedings from the American Association of Colleges of Nursing’s 2000 Faculty Practice Conference.

The development and sustainability of a nursing center within the chaotic health care system of the last decade has required skill, experience, commitment, and willingness to be flexible and responsive to the changing environment. The University of Maryland School of Nursing has been extremely successful over the last 6 years in the development of its clinical enterprise. The Open Gates Health Center (OGHC) was the prototype nurse-managed community-based model. It has provided valuable lessons and experience to support the success of other centers, including five mobile treatment units, 15 school-based health centers, a nursing center for frail seniors, a teen parent education and support center, a large interdisciplinary pediatric ambulatory practice, and a statewide consultation and training program for child care providers.

The lessons learned in the development of the OGHC are instructive to other academic institutions and organizations interested in starting nursing centers. This article will present the following: (a) a description of the development of OGHC and (b) a discussion of the challenges and opportunities of operating the center, particularly as they relate to sustainability in the health care environment.

OPEN GATES HEALTH CENTER

Center Development

The University of Maryland School of Nursing established the OGHC in the fall of 1993. The mission is to provide quality health care to individuals and families who are uninsured, underinsured, or who are having difficulty accessing the traditional health care system. The center originated from work being performed by faculty and students at Paul’s Place, a soup kitchen for the homeless located in the Pigtown/Washington Village community of southwest Baltimore City, Maryland. Neighborhood residents without access to health care became aware of the services available at the soup kitchen, and the “homeless” clinic evolved into a health care access point for medically underserved residents of the area.

A nonprofit organization, Open Gates, Inc., was formed with board representation from the community, the Episcopal Diocese (sponsors of Paul’s Place), and the School of Nursing. The new entity was envisioned as a community-based health center that would be nurse managed and responsive to the health care needs of the surrounding community. An initial grant of $250,000 from the Middendorf Foundation allowed Open Gates, Inc., to purchase, renovate, and equip two row homes.

A special projects grant from the Division of Nursing, U.S. Department of Health and Human Services, facilitated the rapid transition from startup to fully operational clinic. Policies were developed, staff was hired, assessment tools were created, supplies and equipment were purchased, and the center was marketed to the community. As the demand for service grew, the staff modified the hours of operation and the range of services.

From the beginning, the School of Nursing was committed to the goal of making the clinic self-sustaining. One key to success was the ability to obtain reimbursement for services from third-party payers, such as medical assistance and
commercial health plans. Successful strategies included increasing the rate of reimbursement from insurance and Medicaid, implementing a sliding fee scale, and increasing the number of patients served. The School of Nursing sought affiliation with a primary care network, thus enabling OGHC to serve Medicaid recipients in a manner consistent with 1996 state legislation that required all Medicaid recipients to be enrolled in a managed care organization. During its third year of operation, the School of Nursing formally affiliated with UniversityCARE, L.L.C., an organization created for the purpose of developing and operating an integrated delivery system of patient care services in underserved areas of Baltimore City and throughout Maryland. Thus, OGHC became the first nursing center in Maryland to seek certification as a primary care provider by managed care organizations.

With OGHC successfully positioned within the UniversityCARE network, the School of Nursing had the unique opportunity to demonstrate the value-added benefits of a community-based, nurse-managed primary care model. Thanks to a second 3-year grant from the Division of Nursing, U.S. Department of Health and Human Services, the school was able to demonstrate through measurable clinical and cost data the effectiveness of using this model. The grant also enabled the school to expand the geographical area served and improve access to care for residents of this medically underserved neighborhood by adding the services of community health workers (CHWs) and neighborhood volunteers. The project facilitated innovation of a new disease-management model of care.

Community Needs

The target population for OGHC is the southwest Baltimore community of Baltimore City, with a focus on the Pigtown/Washington Village neighborhood. OGHC was developed with a mission to respond to the health care needs of the following target populations:

- Uninsured individuals and families, including children not eligible for traditional Medicaid or the Maryland Children’s Health Program
- Underinsured individuals and families with limited insurance coverage and limited financial means to purchase additional benefits
- Individuals living in areas of southwest Baltimore City that are classified as Medically Underserved Areas
- Other individuals in the community who face significant access-to-care barriers.

Access to care is a major problem for inner-city residents. Financial impediments, lack of health care providers, and personal inhibitors such as cultural differences, limited education, mistrust, and poor knowledge of the health care system severely impede the ability of many citizens to take full advantage of medical advances. Baltimore’s west-side communities are no exception. In Pigtown/Washington Village alone, 17% of residents live in poverty. Among residents ages 18 to 64, 10% are unemployed despite the nation’s strong economy, and 16% live in poverty. Current trends indicate increasing unemployment and poverty. Health problems abound, with a high incidence of cancer, hypertension, and diabetes; only 58.9% of babies are considered “healthy” at birth (Maryland Department of Health and Mental Hygiene, 1998).

Despite the significant health problems in the community, service options are relatively limited. The Maryland Primary Care directory, published by the Maryland Department of Health and Mental Hygiene, lists 36 clinics serving uninsured or underinsured low-income adults. However, only 3 are in proximity to the targeted neighborhoods, and only 1 is within walking distance. At the time that OGHC was started, there were even fewer health care providers available to provide health care to the neighborhood. Recognized as a federally designated Health Manpower Shortage Area and Medically Underserved Area, the Pigtown/ Washington Village community has historically been neglected as a location for health providers to practice.

Student Needs

Although students in baccalaureate nursing programs take required courses in community health nursing, much of the emphasis has been on traditional public health models rather than community- and population-based care. Significant change in the health care environment over the last decade has shifted care to the community, with an emphasis on primary care, health promotion, disease management, and care management.
Consequently, curriculum change was needed to prepare nurses for new roles in the health care delivery system.

In 1994, the School of Nursing entered into a zero-based curriculum development process to radically redefine the entire undergraduate and graduate curriculum to be responsive to the needs of nurses who would be practicing in the new managed care, community-focused health care environment. As a major component of this strategic thinking, the school identified that faculty practice was a vital component of the education of nursing students for the future. This launched the school’s early development of new models of clinical practice and education that showcased faculty in leadership and practice roles while offering innovative learning laboratories for research and clinical instruction of students. Curriculum evaluation and revision has been ongoing.

Clinical learning experiences are an essential component of nursing education. Yet, in a health care environment where nurses are faced with increasing opportunities to play important clinical and leadership roles in the community setting, a new model of clinical learning that shifts the service mission of the university into a practice mission is critical to successfully prepare students for these new roles. Unlike schools of medicine, which have historically incorporated clinical practice as an integral component of the faculty role, schools of nursing have only recently seen this role as central to their mission, as well as that of clinical instruction of nursing students.

OGHC was the first faculty practice program developed by the School of Nursing and represents the foundation for the emergence of the Evidence-Based Clinical Practice Model, which is the framework used for development of all of the school’s nursing centers (see Figure 1). This model uses systems theory to define the set of relationships between community and student needs, the clinical practice program, and student and community outcomes.

The Evidence-Based Practice Model starts with the understanding that all faculty clinical practice programs are developed based on identified needs within a target community and in response to student needs for enhanced and sustained clinical instruction. These needs form the foundation for the development of a clinical practice program that includes a primary health care approach using advanced-practice nursing faculty and students, a structured and customized health education and promotion program that responds to the unique health care needs in the target community, and a community outreach strategy to communicate the services to local residents and provide in-home follow-up to health care plans. Clinical education of students is an integral component of the care delivery model. Student community experiences include hands-on primary care, health promotion, and community outreach. Research to document and understand the model’s process and outcomes is embedded in the entire delivery approach. The results of the service program produce changes in community and student outcomes that continue to inform the clinical education and practice model.

**Open Gates Health Center Care Delivery Model**

Using the Evidence-Based Practice Model as the framework, the care delivery system that has evolved at OGHC is described below.

**Primary Health Care**

The OGHC is a nurse-managed center that relies on faculty advanced-practice nurses from the School of Nursing to provide comprehensive health care to residents of all ages. The center believes in a family-focused service model and therefore provides a full spectrum of primary care services to meet the needs across family members.

Staffed with family nurse practitioners, adult
nurse practitioners, women’s health practitioners, nurse midwives, and nurse psychotherapists, OGHC is well positioned to provide the breadth of services required by residents in the community. A partnership with the University of Maryland Medical System allows for collaboration with consulting physicians and referrals for specialty medical and diagnostic services. The Medical System also provides a social worker for the center, who provides community resource referrals and mental health counseling. The Medical System also serves as the center’s network partner (through UniversityCARE, L.L.C.), facilitating contracting for managed care organizations, third-party billing, and JCAHO accreditation.

Services provided at OGHC include:

- Comprehensive medical/psychosocial histories and physical examinations per Maryland State regulations
- Immunizations
- Developmental assessments
- Vision and hearing screenings
- Diagnosis and treatment of acute medical problems
- Management of chronic medical problems
- Prescription of medications for acute and chronic medical problems
- Sports physicals
- Laboratory collection
- Family planning
- Gynecological examinations
- Sexually transmitted disease diagnosis and treatment
- Individual patient education
- Referrals for dental care

Essential to the successful nursing center is an on-site director who is knowledgeable in business practices and community relations. Although faculty who provide primary care may shoulder some of the administrative responsibility, the director acts to manage day-to-day operations as well as the long-term strategic planning.

Faculty Practice and Student Education

Advanced-practice nurse providers at OGHC are faculty in the School of Nursing. In addition to providing primary care, many teach in the classroom, participate in community health initiatives, and contribute to research and evaluation activities. Equally important, these faculty are the “real life” role models for the advanced-practice nursing role that the school is striving to inculcate in students. All faculty practitioners at OGHC view nursing students as a central part of their role at the center and offer an unparalleled learning opportunity for students to participate in this innovative community-based nurse-managed model of care.

The clinical instruction program at OGHC continues to build on the School of Nursing’s 7 years of experience in advancing community-based nurse-managed primary care models that are responsive to the challenge of caring for medically underserved communities. As described earlier, the school understands that as public entitlement health programs shift to managed care, a nursing model that responds to the comprehensive health and social service needs of the poor in a culturally competent way will prove to be the most appropriate and cost-effective delivery mechanism. The University of Maryland is committed to demonstrate through measurable clinical and cost data the effectiveness of this community-based nurse-managed model. OGHC offers faculty and students an unprecedented setting to do this work.

The evolution in the health care delivery continuum from bedside care to home- and community-based care also requires dynamic, flexible curricula. As described earlier, the School of Nursing has reengineered both undergraduate and graduate curricula to infuse concepts of community-based care throughout all programs. OGHC was the first setting and continues to be one of the most exceptional clinical sites for the provision of community-based learning experiences while also influencing the curriculum for future nursing students.

A broad range of learning experiences is organized through OGHC. Undergraduate community health students are involved in health promotion activities at schools and community sites, home visits, immunization clinics, physical assessments and referrals, health fairs, health education programs for residents, community assessments, observations, evaluations, and a variety of primary care clinical experiences. Students develop disease management programs, which have become critical to the goal of reducing health disparities in the target community. Both undergraduate and graduate students learn case management skills in working with OGHC patients;
they develop plans of care for individuals with long-term and ongoing health care needs. They also learn an interdisciplinary approach to care, because the needs of the residents are many and multifaceted.

On the graduate level, OGHC provides clinical practice for graduate students in numerous specialty areas, including advanced-practice pediatric nursing, women’s health, advanced-practice adult nursing, community addictions and substance abuse, and community health. Family nurse practitioner and pediatric nurse practitioner students have a required rotation in urban health, so many of those students practice at OGHC. This rotation provides graduate students a distinctive opportunity to be precepted by nurse practitioners of the 21st century—skilled nursing professionals working within a community-based, nurse-managed primary care model of operation—rather than being precepted only by doctors, as is the practice in many graduate programs.

Doctoral students are also involved with faculty in evaluating and conducting research studies related to the multitude of health issues confronting the target community. Studies related to the effectiveness of the nurse-managed model and evaluations of various new service delivery approaches are being conducted at OGHC to discern new findings related to the care of medically underserved populations.

Health Promotion

A major goal in developing OGHC was to demonstrate that the nursing model of care could effectively reduce the health disparities experienced by the medically underserved, particularly minority populations living in urban centers of poverty. The center serves people most affected by the health disparities identified in Healthy People 2010 (heart disease, diabetes, obesity, elevated blood levels, and low birth weight among infants) as prevalent among predominantly African American, low-income, poorly educated individuals who face significant access-to-quality-care barriers. Healthy People 2010 defines quality health insurance, higher incomes, and regular sources of ongoing health care as key indicators of quality health care. Residents of communities served by OGHC clearly lack that access to quality health care.

OGHC has tried to address these health disparities by implementing a nurse-managed, community-based model that takes a holistic, multidisciplinary approach to health promotion and disease prevention. The primary care services and health education programs delivered by staff, faculty, and students of the School of Nursing are fundamental to improving the health status of patients affected by the targeted disease areas.

Community Outreach

The health promotion services delivered through the center by faculty and students are complemented by a corps of community outreach workers participating as members of the health care team. These workers are paraprofessional staff who live in the center’s service area and proactively identify fellow residents who need care, help link patients to community services, reduce the cultural barriers between residents and health care professionals, and ensure that residents have ongoing, regular care. By working intensively within the target communities, nurse practitioners, students, and CHWs can address community health problems through a systematic, proactive approach.

Although community outreach workers have been an important part of the team, many felt that they could be better integrated into the disease management programs. Literature review revealed that although CHWs were shown to help link residents to community resources and bridge cultural barriers, few programs could demonstrate their success in improving health status indicators for targeted chronic diseases. As a result, the center sought to extend traditional outreach worker roles to foster increased patient participation in disease management and to improve adherence with mutually agreed-on treatment plans. Four areas were targeted for this expanded CHW role: hypertension, diabetes, child health, and prenatal care.

For each targeted area, a clinical pathway was created consisting of a series of health education topics to be reviewed by the CHW during home visits, thus supplementing the education provided by the nurse practitioner. CHWs participate in
education sessions designed and implemented by center staff. Documentation forms cue the CHW to address all topic components. The OGHC model is attempting to demonstrate that a more structured and targeted home visiting program will be effective in improving health outcomes. In addition, faculty hope to demonstrate the efficacy and cost effectiveness of CHWs as members of a disease management team in a managed care model.

In addition to the CHW disease management program, extensive community outreach is also conducted by the outreach staff and students to churches, schools, and community organizations to promote increased awareness of the center’s services and to continually assess community needs.

Research

Considering the strong ties with the community, OGHC provides a unique opportunity to contribute expertise in research and evaluation activities. Many of the faculty who provide primary care at OGHC, and some who practice in the community, are doctoral prepared. Although individuals in the community often identify needs well, the faculty can help clarify questions and propose appropriate methods to conduct evaluation and research. Because many community groups have limited research knowledge and limited resources to devote to research and evaluation, the School of Nursing also provides much of the support.

Much of the research could not be carried out without students. Undergraduate students help by conducting community needs assessments. Master’s students often participate in data collection, interviews, and analyses through their research and theory coursework. Doctoral students may conduct pilot studies in the community as they work toward dissertation. Faculty preceptors who are familiar with the community and with research methods are essential.

The importance of good documentation tools and the establishment of electronic databases cannot be overstated. The registration and billing software of the UniversityCARE network captures demographic, clinical, and service utilization data. Although aggregate data reports are provided periodically, accessing these electronic enrollment and claims data to examine utilization patterns has also been a challenge. The clinical data are limited, but they do provide valuable utilization and productivity information. Educational sessions were conducted to emphasize accurate coding and to improve capture of important nursing activities that are unique to the nurse-managed model. These types of data can also be used to help researchers identify subsamples for more in-depth study.

As a UniversityCARE clinic, OGHC must also meet JCAHO accreditation requirements. The center was accredited in 1999, and changes are under way to enhance safety and access issues. As a member of UniversityCARE, the center must comply with additional documentation, information systems, and quality assurance standards. Studies have been conducted to demonstrate compliance with documentation standards, to compare documentation with codes submitted for reimbursement, and to examine variation in adherence to recommended standardized guidelines for targeted disease areas, such as cancer prevention and hypertension diagnosis and management.

CHALLENGES AND OPPORTUNITIES

OGHC has grown tremendously since 1993, and there is continual reassessment as needs change for the community, for students, and for faculty. Changes in health policy and the market have necessitated the development of new organizational structures and models to position the center for long-term success in the dynamic and turbulent health care environment. Management of the center within the domain of the academic institution presents ongoing challenges to balancing community needs and accountability, which at times conflict with sound business and public health practices.

Practice Management/Clinical Operations Challenges

The development and sustainability of a nurse-managed center such as OGHC is demanding from both a management and operations perspective. The needs of the community, coupled with the demands of working within an academic
A major challenge for clinical operations is the staffing of the center. Committed to the faculty practice model, OGHC has been confronted by the often-disparate objectives of faculty—who are required to teach, conduct research, and practice—and the business of running a primary care clinic. Faculty practice is a relatively new phenomenon for schools of nursing, and traditional, seasoned faculty may not have incorporated independent practice as a central part of their faculty role. The director must work with faculty to help them develop their practice role while meeting the demands of practicing in a busy clinic.

OGHC has made tremendous strides in shifting the paradigm within the School of Nursing to embrace and understand faculty practice as instrumental to the mission of the university. Working relationships have been established between the associate dean of clinical affairs and the academic department chairs to facilitate joint planning for faculty recruitment, assignment, and evaluation. Faculty who have teaching and practice assignments understand that their accountability in their practice role is to the center manager and that in their teaching/research role they are accountable to their department chairs. This requires consistent and open communication and joint planning between academic departments, the Office of Clinical and External Affairs, and the center. This has taken years to develop and must be constantly nurtured to remain effective.

Related to the staffing, it is important to assure an appropriate fit of the faculty with the center's practice in a community-based inner-city clinic. Many faculty are not experienced in care to underserved populations and need to acquire a level of cultural sensitivity to successfully provide quality services. Administrators have learned that primary care experience alone does not satisfy the job requirements for a practitioner at OGHC. Faculty practitioners should have prior experience working with underserved patients and demonstrate a career interest and commitment to working with the target population. Again, good working relationships between the clinical practice faculty and the academic chairs is required to assure that the center administration is involved in faculty recruitment and appointment activities, as well as faculty evaluation.

Operating a full-time primary care nursing center with a staff that has the level of clinical skill and experience to meet the productivity demands of a busy managed care practice has also been challenging. Policies and procedures that meet the center's needs while accommodating academic institutional and individual faculty needs have developed over several years. Everyone understands that OGHC must remain open 5 days per week all year, except for major holidays, if it is to generate the volume and provide the level of patient continuity required for successful practice. This means that faculty are required to work during academic breaks and certain academic meetings and that significant coordination is again required with the department chairs to allow for flexible scheduling of faculty.

Faculty productivity is often an issue with the increasing market demands to generate enough patient visit volume to support the practice. Many faculty advanced-practice nurses are inexperienced with these "real life" practice requirements and need to be supported in their clinical growth to adapt to these business realities. Patient documentation forms have been revised to reduce excessive charting, while preserving the content required for billing and documentation of the primary care and nursing process. Support staff, such as medical assistants and the community health outreach workers, have been added to the practice to assist in the patient flow. Opportunities for observation by faculty in other busy primary care practices have been arranged to expose faculty to other academic practices that operate within the same business realities as OGHC and to offer peer recommendations for enhancing productivity.

The business management challenges related to operating a nurse-managed center like OGHC cannot be underestimated, especially in the current uncertain health care environment. The organizational structure has been reinvented over the last several years to be well positioned for long-term success in the evolving health care system. The School of Nursing has been successful in sustaining its nurse-managed services through integration within the UniversityCARE network. Working closely with this large, prominent,
primary care network, OGHC has been able to secure third-party reimbursements and to develop strong relationships with government health care funding initiatives.

Although third-party reimbursement is in place, many of the OGHC patients are medically uninsured and generate little revenue to contribute to the operation. Therefore, the School of Nursing is constantly challenged with raising funds through grants and contracts to support the uncompensated care mission of the center and to fund innovative health promotion and community outreach initiatives. These services distinguish the center as a nursing center.

Community Challenges

While nursing has been attentive to community needs, the sometimes negative reputation of a university within an underserved community is one that must be overcome to successfully develop and sustain a nurse-managed center. Significant attention has been devoted to this issue to cultivate a mutually respectful and productive working relationship. This was accomplished by first grounding the development of the center in a history of work in the target neighborhood. As indicated, OGHC grew out of years of work that had been conducted by faculty and students at the School of Nursing, which represented a strong foundation of a community relationship on which to build.

The center was started based on identified needs expressed by the community and not solely the faculty. This is a fundamental construct incorporated in the Evidence-Based Practice Model. However, it is a concept that many well-intentioned health care programs do not adopt when starting new initiatives. Underserved communities feel that they have suffered under the whims and desires of some universities and other large institutions that come into the community with their ideas for research and service programs and that take advantage of residents to achieve their institutional goals rather than the expressed community goals.

OGHC continues to regularly assess the community and has established mechanisms to become aware of current issues. Regular meetings are held with key community organizations, and a community advisory board exists to provide ongoing feedback and input into center services in response to priority community needs. Establishing these community processes is challenging to operating a practice and is often in conflict with academic interests, which must be negotiated and balanced for the center to be successful.

Research Challenges

In light of the need to balance community, education, and health service needs, the center must review proposed faculty research programs. Based on priorities, modification or delay may be necessary. Center management and School of Nursing clinical practice administrators must be experienced enough in both the community health and academic environments to be able to translate needs on both sides to achieve balance and advance mutual goals.

Although not unique to community settings, a major challenge to faculty is how to balance the competing demands of practice, education, and research. Faculty successful at this integration often conduct research as part of their practice and involve their students in varied aspects of the research process. This necessitates expert organization and targeted student guidance; faculty who are successful are able to actively conduct research, present findings, and publish. Delaying research until summer or mid-semester when classroom demands are lighter is rarely effective.

For faculty to be successful at integrating practice, education, and research, other supports are necessary. Access to updated computer hardware, software, and Internet communication must be assured. Although the School of Nursing’s Computer Services Department offers a limited level of support to OGHC, obstacles have included geographical distance from the school, confidentiality restrictions, and security barriers. Faculty who are in community practice may also feel somewhat disconnected from the school’s research resources. The recently expanded Office of Research at the School of Nursing provides assistance in identifying potential funding sources, educational sessions, and methodological and statistical consultation. Working in multidisciplinary, collaborative groups has been most successful.

Like many other nurse-managed centers, OGHC has been challenged to demonstrate its effectiveness. Identifying the uniqueness of the nurse-
managed model and isolating the influence is crucial. Continual efforts are directed to optimizing the documentation systems to facilitate efficiency while capturing essential information that is unique to advanced nursing practice. With the refocus to a disease management model that better uses CHWs, a longitudinal study comparing processes and outcomes of matched samples from OGH C and a similar UniversityCARE clinic is under way.

IMPLICATIONS

As health care continues to evolve with an increased focus on quality of care and consumer involvement, nursing centers can play an important and distinctive role. The core nursing center competencies of primary care, health promotion, and community outreach are essential services that will be needed to achieve a healthier, well-educated, and self-directed future population. Nursing centers like OGH C, which have the ability to traverse the complicated business demands of operating a successful community-based health care program, can capitalize on their core competencies.

Nursing centers need to mature into the mainstream health care delivery system while maintaining the capacity to preserve their fundamental commitment to meeting community needs and health promotion. Nursing centers have come and gone due to their inability to successfully integrate themselves within traditional health care models. OGH C’s success is, in part, due to its affiliation with a larger, established health care network that has provided the structure, business systems, and contracts to allow for acceptance by third-party payers, regulators, government agencies, and other institutions. Yet, the University CARE partnership has not diminished the commitment of OGH C to innovatively address community needs, which ultimately will lead to health improvement within the target population.

A major part of positioning centers is demonstrating that nursing centers provide comprehensive quality health care. More outcomes research is needed to substantiate the efficiency and effectiveness of nursing centers. Nurses must compete for the grant dollars that have been made available to study health quality. With clinical experience and research credentials, nurses are in a unique position to study health care quality.

Reimbursement for advanced-practice nurses by third-party payers continues to be a policy obstacle in many states around the country. The School of Nursing has been successful in this arena over the last 7 years by establishing nurse practitioners as independent practitioners on the panels of medical assistance health maintenance organizations (HMOs).

Consumers are increasingly educated and are demanding a role in their health care. Nurse-managed centers have an unprecedented opportunity to capitalize on their commitment to community and family by forwarding their core competencies in primary care, health promotion, and community outreach to pioneer new and innovative models for health education, disease management, and care management. Nurses understand more than any other health discipline the relationship between an individual’s health and the influences of family, the community, and the environment. Nurses have a great opportunity and responsibility to advocate for communities. If nursing centers are to be sustainable, they need to develop the level of business sophistication required to adapt to the evolving health care delivery system.

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SUGGESTED READINGS


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Quality Outcome Measures at an Academic Rural Nurse-Managed Center: A Core Safety Net Provider

Laura Anderko, RN, PhD
Mary Uscian, RN, MS, CS

With the former Clinton administration’s plan to reform our nation’s health care system now a distant memory, a growing number of people have fallen into the ranks of the uninsured or underinsured. A variety of strategies and policies have been introduced to tackle this growing need, none of which have included a comprehensive plan to address the burgeoning need for affordable health services. Our nation continues to rely on an “institutional safety net system,” consisting of a hodgepodge of agencies and programs that vary dramatically by region, to meet the growing needs of underserved populations. Within this institutional safety net system are core safety net providers, who adopt a mission that offers access to services regardless of ability to pay; these core providers report that a substantial share of their patient mix are uninsured, Medicaid, and other vulnerable populations (Hegner, 2001; Institute of Medicine [IOM], 2000).

Although nursing centers have historically served as core safety net providers, they have not routinely been recognized in national discussions for their unique and substantial efforts in meeting

As the number of medically underserved people continues to swell, core safety net providers, such as nursing centers, are finding it increasingly difficult to provide quality care and remain financially viable. The purpose of this article is to highlight the successful implementation of a quality improvement plan at one rural nursing center. Outcome measurement has been conducted since 1994 in several areas, including client, nursing, and student satisfaction, as well as a variety of measures to evaluate access to health care and its effectiveness in improving client health. The need for nursing centers to measure and publish quality outcome data is discussed, including recommendations for national health policy initiatives to support nursing centers as one of the few options remaining for the underserved in our nation.
the special needs of low-income and uninsured populations. This may be due in part to the fact that little has been published on nursing centers and their contributions as core safety net providers, namely quality outcome data (Kerekes, Jenkins, & Torrisi, 1996; Lundeen, 1997; Ramsey, Edwards, Lenz, East-Odom, & Brown, 1993). Under-scoring the need for core safety net providers to be actively involved in the quality improvement process, the IOM (2000) recently stated, “The commit-tee was struck by the paucity of reliable and con-sistent data available to accurately assess, measure, or compare the changing status of safety net providers nationally.” Future funding and related policy initiatives have been and will con-continue to be directly tied to outcomes, making out-come measurement and reporting essential for the survival of nursing centers. This article will pro-vide a brief history of one core safety net provider, the TriCounty Community Health Center, includ-ing reimbursement information, and describe quality measures and processes employed to determine its effectiveness in addressing community needs.

HISTORY OF NURSING CENTER

Recent federal welfare reform, together with the insurance industry’s efforts to control health care costs, have reduced access to health care for the underserved, particularly in rural areas. In many rural communities, core safety net provid-ers may be the only available source of primary health care services for vulnerable populations. In addition, the proportion of people living in pov-erty, in itself a significant health hazard, has increased. The Agency for Health Care Policy and Research (1997) estimated that the rate of uninsured people is 20% higher in rural than in urban populations and that many of these people are the working poor, unable to qualify for Medicaid (Hjelm, 1995).

These national trends are reflected in the rural, medically underserved, three-county area that the TriCounty Community Health Center serves. The majority of those living at poverty level are work-ing, and they, along with many near poverty-level families, hold jobs with few or no health ben-etits. The center is an academic nursing center and is certified as a rural health clinic, acting as the sole core safety net provider for residents living in this northwestern Illinois three-county area who seek primary care services (Anderko & Uscian, 2001).

The Northern Illinois University (NIU) School of Nursing established the center in 1993. Care provided is holistic, client-centered, and focused on health promotion and disease prevention. The mission of the center is three-fold: (a) to increase access to affordable primary health care for residents in the three-county area, (b) to provide outreach to high-risk populations, and (c) to educate nursing students in community-based primary care (Barger, Uscian, & Chilton, 1993).

In 1992, the NIU School of Nursing conducted a needs assessment to identify community health problems, gaps in service, and the need for the nursing center. A total of 1,172 surveys were com-pleted and analyzed (Barger et al., 1993).

The needs assessment identified a typical set of rural health problems. Although 10% of the popu-lation lived in poverty, only 4.8% of the popula-tion received public aid benefits. The majority of the poor were working and held low-paying jobs with few or no health benefits. About 22% of those surveyed lacked health insurance. A rapidly growing Hispanic population in all three counties had no access to health care providers who spoke Spanish. Uninsured community residents were turning to hospital emergency rooms for primary health care services because there was no clinic that would provide care for the medically indi-gent. About 35% indicated they faced a barrier to receiving health care at least once in the previous year (Barger et al., 1993).

These problems, although very important, affected small populations (a typical occurrence in rural communities) and therefore went unad-dressed until the center opened its doors in April 1994. The primary health care services it provides range from health promotion interventions (e.g., health education classes) to illness care. Outreach has been provided at a variety of sites, including homeless and domestic violence shelters, elemen-tary schools, and day care centers. An important objective of all outreach programs is to identify community residents with no ongoing source of primary care and connect them with the center.
As an academic nursing center, the center employs and educates associate-, baccalaureate- and master's-prepared nurses to provide and manage health care services. Associate-prepared nurses and students practice as clinic nurses, providing health education and standard treatments and procedures for individuals according to established protocols. Baccalaureate-prepared nurses and students work as community health outreach nurses, providing health education, screening, and case management for families and others in the community. Master's-prepared nurses and students work in two different roles. These include nurse practitioners, who provide primary care, and community health nurse specialists, who conduct community health assessments, develop programs, and intervene on the aggregate and community client level. The clinic director also holds a master's degree in nursing and is responsible for the overall administration of the center (Anderko & Uscian, 2001).

REIMBURSEMENT HISTORY

Financial self-sufficiency has remained a challenge for the center, requiring creative financing strategies to offset costs over the 7 years the center has been operational. Sources of income have consistently fallen into the following categories: (a) client fees, insurance, and cash; (b) contracts with community agencies and businesses; (c) Medicaid and Medicare; and (d) grants, awards, donations, and in-kind contributions (Anderko & Uscian, 2001).

During the first 5 years of the project, about one third of services were funded with monies provided by a grant from the U.S. Department of Health and Human Services, Public Health Service, Health Resources and Services Administration (Barger et al., 1993). In addition, the center became certified by the Illinois Department of Public Health as a rural health clinic in its first year of operation, which allowed the center to be reimbursed at cost for services provided.

The mix between client fees, insurance, and cash payments has varied, with the trend indicating a growing number of clients that qualify for the sliding scale (50% in 1993, compared to 95% in 2000). About 25% of operating costs are reimbursed through a mix of this revenue.

Contracts with community agencies and businesses have included fee-for-service agreements with a variety of agencies, including a county jail, prenatal clinic, schools, and day care center. Although the type and number of contracts have varied, about 15% of revenue has come from contracts over the 7-year time period.

Few of our clients have Medicare benefits because the center was designed to address those without any other source of health care, and rural physicians were amenable to payment from this provider source. Although small, the percentage of Medicaid clients has gradually increased, with about 15% of patients eligible for Medicaid benefits.

Grants, awards, donations, and in-kind funding has varied from year to year, with a greater emphasis on in-kind funding and donations occurring since the grant concluded in 1998. Major contributions include the facility used as the primary site for the nursing center. This building was donated by the community college. Funding for center operations has been provided since Year 6 of the project by the NIU School of Nursing, College, and University and has been integral to maintaining operations. About 45% of revenue comes from this source of funding.

SIGNIFICANT CHALLENGES ENCOUNTERED IN CARRYING OUT THE PROJECT

The center has experienced threats that mirror what other core safety net providers have experienced, in particular, serving a disproportionate share of low-income and uninsured patients. The most significant challenge encountered in carrying out the project has been financial viability, which is related to the uncompensated care provided to a growing number of uninsured people. In fiscal year 2000, more than 95% of clients registered for center services were eligible for the sliding scale for payment of services. Of this population, 15% qualified for Medicaid coverage, and more than 80% used the sliding scale option (Anderko & Uscian, 2001).

Financial viability of the center is the result of a number of strategic efforts, including (a) the procurement of new contracts in partnership with local health departments, (b) improved Medicaid
reimbursements, and (c) increased donations from public and private foundations. New contracts with existing community agencies have increased the number of clients seen who have some level of reimbursement. For example, the center is being reimbursed at full fee for providing pap smears and breast exams for medically indigent women through a partnership with the DeKalb County Health Department, which is a recipient of Illinois Breast and Cervical Cancer Grant funding. Another benefit from these collaborative partnerships is the reduction in the duplication of services and enhanced efficiency in delivering these services to the underserved.

Improved Medicaid reimbursements have resulted from two major strategies, including timelier billing practices and the linking of eligible clients with the medical assistance program. The last strategy has reduced the number of clients needing sliding scale adjustments and improved overall reimbursement of costs.

The need to recover revenue lost when the grant ended has required the clinic director and chair of the School of Nursing to develop and implement a strategic plan with the university development office to attain endowments and other donations. These efforts have been successful, with a substantial increase in donations noted for fiscal years 1999 and 2000.

Although many nursing centers do not survive beyond the first 5-year grant funding period, the center has been able to survive financially because of creative strategies employed in the area of personnel management and because of financial support from the university. As we enter the 21st century, the center will need to seek more creative ways to attain funding, which will enable us to serve the increasing numbers of people who are becoming uninsured. Funding has been procured in large part using the quality improvement data that has been collected and reported.

QUALITY ASSESSMENT AND PERFORMANCE IMPROVEMENT PROCESS

The center has an established ongoing quality improvement program in place, known as Quality Assessment and Performance Improvement (QAPI), which is required for all certified rural health clinics. It is a systematic program that was developed at the inception of the center with overall objectives designed to improve health care access. In the first year of operation, the center developed tools to measure utilization patterns as well as client satisfaction and began the data collection process (Anderko, Robertson, & Uscian, 2000).

Quality improvement reports are prepared monthly, quarterly, and/or annually. The clinic director, faculty, nursing staff, graduate assistants, and students are actively involved in data collection efforts. Data entry is performed by the clinic nurse and by graduate students, as appropriate. Data retrieval and analysis are the joint responsibility of the project director and the clinic director and graduate assistant. Participants in the quality improvement process include the community advisory group, the medical advisory committee, the faculty advisory committee, clinic director, nursing staff, peer review committee, and medical consultant. Each has a specific responsibility in the quality improvement process. The clinic director is responsible for coordinating all quality improvement activities.

The QAPI plan uses (a) structure, (b) process, and (c) outcome measures to assess for quality. Structure refers to the setting in which care is provided and resources used. Process refers to activities involved in giving the care. Outcomes refer to the effects of those nursing interventions.

Several structural components are measured on an ongoing basis and include a review of (a) the mission, (b) human resources, and (c) policies and procedures. Other structural components include identifying the client profile and reviewing job descriptions, which are evaluated annually.

Process components are evaluated quarterly and annually and include (a) competency testing for lab procedures, (b) personnel performance evaluations, and (c) documentation of care evaluated for adherence to clinic protocols and professional standards of care.

Outcome evaluation activities include the measurement of (a) client utilization patterns, (b) client health outcomes using the Omaha Classification System, (c) client satisfaction, (d) nursing job satisfaction, and (e) student satisfaction. These
outcome measures will be described in greater detail.

Utilization Patterns

Data on utilization patterns are collected on an ongoing basis and reported quarterly and annually. Both qualitative and quantitative measures are collected and reported. Components influencing access, such as availability, accommodation, affordability, and acceptability, have been measured using information collected on client satisfaction surveys and clinic registration forms (Anderko, Robertson, et al., 2000). The center has made dramatic strides in improving access and providing health care to residents. The number of new clients who reported not having a primary care provider has consistently increased from 58% in 1997 to 62% in 2000. Since the center opened its doors, a total of 11,949 unduplicated clients have been served for a total of 27,542 visits.

More than 95% of these individuals qualified for the sliding fee scale by having incomes at or below 200% of the federal poverty level, and 70% of new clients reported having no regular source of primary care in the previous year (Uscian, 2000).

Client Health Outcomes

Outcomes are measured for changes in client status and are conducted for selected diagnostic groups, using the Omaha Classification System (Martin & Sheet, 1992). The clinic director, in collaboration with nursing staff, develops diagnosis-specific data collection tools. The center has previously reported positive client outcomes at the individual, family, and aggregate levels of intervention for knowledge, behavior, and status (Anderko, Robertson, & Uscian, 1999; Anderko & Uscian, 2000). Recent data collected on hypertensive clients (tool reliability = 0.93) indicated significant differences between pre- and postintervention scores (knowledge, \( P = 0.004 \); behavior, \( P = 0.000 \); status, \( P = 0.052 \)), using paired \( T \)-test analysis. A surprising finding beyond the hypertension diagnosis revealed that of the total number of hypertensive clients registered at the center \((N = 48)\), 29% suffered from mental illness and thus needed to be excluded from the study. The high prevalence of mental illness in this population necessitates a reexamination of strategies necessary to effectively manage chronic diseases in this rural population (Anderko, Uscian, & DeWaters, 2000).

Client Satisfaction

Client satisfaction surveys have been conducted annually since 1995. Findings consistently reflect a high level of client satisfaction. In the 2000 fiscal year, 98% of clients stated that the “clinic hours are convenient”, 100% agreed with the statement “I would use the center again,” and 100% stated that their appointment was scheduled soon enough to meet their work, family, and personal needs. These and other indicators point to the center’s success in addressing the needs of the underserved (Anderko, Robertson, et al., 2000).

Job Satisfaction

Nursing job satisfaction has been conducted annually since 1996. Job satisfaction is measured both qualitatively and quantitatively using the Brayfield Job Satisfaction Questionnaire, the McCloskey/Mueller Satisfaction Survey, and the Job Descriptive Index. A high level of job satisfaction has been found using all three tools (Anderko, Robertson, & Lewis, 1999). One example includes overall job satisfaction, measured from 1996 to 1998 using the Brayfield questionnaire, resulting in a mean score that exceeded the neutral score of 54 for each of the study years: 76.8 (1996), 75.3 (1997), and 75.0 (1998), with mean scores ranging from 65 to 86 (Anderko, Robertson, & Lewis, et al., 1999).

Student Satisfaction

Student satisfaction levels (for associate, bachelor’s, and master’s students) have been measured each semester since 1994. Both qualitative and quantitative measures are reported, including the level of satisfaction with the learning experience and comments regarding the student’s experience in a nursing center compared to a traditional inpatient or community-based setting. Recent data indicate that students’ satisfaction with their learning experiences is high. All students stated that they were satisfied with the overall clinical experience at the center, with 95% reporting that the
clinic increased their knowledge of rural primary health care (Robertson, Anderko, & Uscian, 2000).

FINDINGS

The center has been able to address the unique needs of this three-county rural area. Data from fiscal years 1995 through 2000 show high levels of client, staff, and student satisfaction. Results also show consistently positive client outcomes for several high-risk populations, suggesting that interventions implemented within a nursing center are an effective model for delivering quality health care for populations that have traditionally been denied health care. Seven years after its beginning, funding remains as the primary threat to the center, especially as the number of uninsured rises.

IMPLICATIONS FOR NURSING

The loss of core safety net providers, especially nursing centers, has the potential to become a national crisis and calls for stronger federal direction and financial support. Currently, no agency in the federal government has the sole responsibility for monitoring the effectiveness and status of nursing centers. Although efforts to organize nursing centers regionally have met with success in some areas of the country (e.g., Regional Nursing Centers Consortium in Philadelphia), there is an urgency to link nursing centers nationally and provide a forum that will promote a collective voice that will affect policy initiatives. Development of a central database could provide consistent outcome data and reveal the impact that nursing centers have on our nation’s health, particularly for the underserved.

The funding of nursing centers should be a key consideration for inclusion in the national health policy agenda. Although some authors have recommended that competitive 3-year grants be made available to core safety net providers to support efforts financially, supplemental funding is not the answer (IOM, 2000). This forces neighboring safety net providers to compete with each other for limited dollars. There is a need for a comprehensive funding plan, addressing the underlying problems that make the health care safety net system necessary for so many people. Failure to support nursing centers financially could have a devastating impact not only on the populations who depend on them for care but also on other providers that rely on the safety net to care for patients whom they are unable or unwilling to serve (Hegner, 2001; IOM, 2000; Moy, Bartman, Clancy, & Cornelius, 1998).

CONCLUSION

Despite overwhelming odds against survival, nursing centers have been able to provide quality care to vulnerable populations, including those without adequate health insurance coverage. Nursing centers must begin collecting and reporting outcomes that will provide important information for future health policy funding and reimbursement initiatives.

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Mary Uscian, RN, MS, CS, is cofounder and clinic director of the TriCounty Community Health Center. Her research interests include outcome measurement of primary, secondary, and tertiary nursing interventions conducted at the center and service-learning strategies for improving health care access in rural areas. She also teaches at the Northern Illinois University School of Nursing.
Speaking With a Unified Voice: Recommendations for the Collection of Aggregated Outcome Data in Nurse-Managed Centers

Laura Anderko, RN, PhD
Elizabeth Kinion, RN, EdD, CNP

Nurse-managed centers have historically served as core safety net providers, that is, serving populations regardless of their ability to pay (Institute of Medicine, 2000). Since Lillian Wald developed the Henry Street Settlement to address poor health conditions in New York City’s tenements in the late 1800s, nurse-managed centers have provided quality care targeted to the unique needs of the populations and communities they serve (Estabrooks, 1995). Despite these longstanding contributions, nurse-managed centers continue to be overlooked in many national policy discussions and health policy initiatives (Hegner, 2001; Institute of Medicine, 2000).

The relative anonymity of nurse-managed centers as effective providers of primary health care can be attributed, in part, to the paucity of literature about their impact on improving health care access to those most vulnerable in the United States. Although the positive impact of nurse-managed centers on client health outcomes and improved access has been increasingly documented in the literature, efforts have typically focused on isolated case studies rather than
multicenter efforts (Benkert, Bucholz, & Poole, 2001; Helvie, 1999; Lindsey, Henly, & Tyree, 1997; Matas, Brown, & Holman, 1996; Robertson, Anderko, & Uscian, 2000; Verhey & Ferretti, 1996). Beyond these isolated case studies, however, is a larger problem. Although some attempts have been made in the past, there has been a lack of strong leadership from any one specific nursing organization or federal agency, committed to organizing nurse-managed centers into a collective political voice.

Although the care provided by each nurse-managed center is uniquely targeted to its specific community and population, missions that focus on serving the underserved unite them. There is an urgent need for nurse-managed centers to develop a unified voice that will convey to policy makers the impact that they make in the health care delivery system. One way to accomplish this is through the establishment of a uniform data collection process to obtain aggregate outcome data from multiple centers nationally. Even simple data, such as number of client encounters, when reported nationally can provide a significant perspective on health care utilization trends and nurse-managed centers’ role.

The Health Resources and Services Administration’s (HRSA’s) mission to improve the health status of the nation’s people by assuring equitable access to comprehensive quality health care is consistent with the mission of nurse-managed centers. Ensuring the ability of safety net providers to care for poor, uninsured, and other vulnerable populations is critical to the HRSA’s FY 2001 goal of 100% access and zero health disparities. Evaluation plays an integral role in helping HRSA assess both its progress in accomplishing this mission and the performance of its programs. It is critical that HRSA programs, in particular nurse-managed centers, measure health outcomes and how they affect HRSA’s mission of eliminating health disparities. Many of the groups that suffer from health disparities are unable to access needed health care services due to low socioeconomic status. As core safety net providers, nurse-managed centers can help HRSA accomplish this goal by improving health care access and targeting clinical interventions to populations in most need. Access-related activities accounted for a significant portion of HRSA’s $4.8 billion budget in FY 2000 (U.S. Department of Health and Human Services, 2000). Clearly articulated outcomes resulting from nurse-managed center interventions are essential to procure some portion of this funding.

Improved access can also result when nurses are educated to serve vulnerable populations. Academic nurse-managed centers provide a variety of clinical learning opportunities for nursing students, with a focus on (a) providing community-based health care, (b) serving vulnerable populations, and (c) developing cultural competency. The current nursing shortage and the increasing number of uninsured people underscores the need for nurse-managed centers to document their successes in preparing a nursing workforce that can meet the increasing demands placed on an already fragile health care system.

Although many challenges exist that prevent easy assessment of health outcomes and impact on access to health care, the participants in the National Data Workgroup (see Appendix for list of participants) began the daunting task of developing a uniform list of data elements necessary to assess outcomes for nurse-managed centers nationally. This article will provide an overview of this historic event, describing the purpose, process, and recommendations made for outcome data collection as a result of discussions held.

**OVERVIEW OF THE DATA WORKGROUP MEETING**

The purpose of the meeting was to identify uniform data elements that could be feasibly collected from funded Division of Nursing nurse-managed centers. Discussion related to data collection and reporting centered around two key issues: improving access to health care for vulnerable populations and educating the nursing workforce to be culturally competent, with a particular focus on community-based learning experiences. Several areas associated with data collection were considered and discussed, including (a) purposes (e.g., evaluation), (b) resources (e.g., human resources), (c) barriers (e.g., software compatibility), (d) limitations (e.g., reliability of data collection tools), and (e) costs of implementation. To develop an understanding of the steps necessary when integrating data systems, representa-
tives from the Regional Nursing Centers Consortium (RNCC)/Independence Foundation described their recent work in establishing a database project that shares common data elements among several nursing centers that are members of the RNCC.

**REGIONAL NURSING CENTERS CONSORTIUM (RNCC)**

The RNCC includes nurse-managed health centers in Pennsylvania, Delaware, and New Jersey, as well as California. This consortium was founded in 1996 with monies procured from the Independence Foundation. Currently, the RNCC has 33 members. The RNCC’s mission is to foster growth and sustainability of member organizations. It serves as an advocate for nurse-managed centers at the state and federal levels (Hansen-Turton, 2001).

The RNCC has developed a quality care plan for member centers. RNCC/Independence Foundation representatives shared experiences from their data project, which was designed to establish a common database at the RNCC and, ultimately, demonstrate the RNCC’s impact on outcomes. Purposes of this project are to ensure standard collection of common data elements, document services, guide RNCC advocacy, guide planning and programming decisions, and facilitate centers’ operations (E. King and B. Tornberg, personal communication, January 30, 2001).

Information on the various data systems and the type of data collected was shared with the data workgroup participants. Client demographics and encounter information are the data elements included in this common data set. A database sharing common outcome data elements has been piloted with four health centers. Centers have collected the following data: (a) client demographics, (b) ICD-9 codes, (c) CPT codes, (d) patient satisfaction forms, (e) and SF-12 forms (Hansen-Turton, 2001).

The representatives made suggestions for workgroup participants to consider when developing a uniform data collection instrument or process, the most important of which was the need to agree on clearly defined goals for the project and devise an implementation strategy. Questions to ask during the development phase that were posed to the work-group included (a) What are we trying to measure? (b) What is the value of the data? and (c) Why do we need the data? (E. King and B. Tornberg, personal communication, January 30, 2001). Work-group participants considered these questions during later discussions on instrument development.

**DATA ELEMENTS AND REPORTS: PARTICIPANT NURSE-MANAGED CENTERS**

Workgroup participants were selected based on past or current funding from the Division of Nursing and represented a variety of services, populations, and geographic service areas. All participating nurse-managed centers can be described as core safety net providers, serving a wide range of ages (birth center to geriatric center) and providing a wide range of services (health promotion to acute care) for culturally diverse populations. Both rural and urban centers were represented. Centers represented a variety of geographical areas in the United States, with participants from Utah, Maryland, Illinois, Texas, Tennessee, Minnesota, California, Ohio, and Pennsylvania.

Prior to the meeting, participants were asked to submit (a) a list of data currently collected, (b) copies of data collection tools/data reports, (c) purpose for the data being collected, and (d) a brief description of the participant’s current work with quality improvement. Finally, participants were asked to consider what minimum data should be collected that would clearly communicate nurse-managed centers’ impact on improving health care access for vulnerable populations. Data elements considered included (a) client demographics, (b) client enrollment, (c) utilization patterns, (d) types of services offered, (e) student characteristics, and (f) students’ involvement in using the nurse-managed center as a learning environment. The following summaries, although brief, will reflect the unique characteristics of the populations served by the respective nurse-managed centers.

**East Tennessee State University**

The Johnson City Downtown Clinic is a rural nurse-managed center that provides services to
the homeless and indigent. Nursing services that are provided include case management and advanced-practice interventions for acute care, chronic care, and preventive health care. Services are also provided for physical and behavioral illnesses and socialization needs.

The client encounter form serves as both a billing form and a data collection form and is completed for each client encounter in the clinic. Data collected on an ongoing basis include (a) type of referral made (ER, physician, mental health, dental, and other), (b) sex, (c) age, (d) race, (e) housing (non-homeless, homeless, unknown), (f) education, (g) marital status, (h) number of personal hygiene packets distributed, (i) reason for encounter, and (j) various billing information indicators. Client outcomes can be evaluated by grouping diagnoses, so that characteristics of certain populations can be examined more completely. The database is also used for a variety of other purposes, including reports, statistics and comparative data for grant applications, and selected research purposes (C. Macnee, personal communication, January 30, 2001).

Lamar University

A faith-based nursing center, Ubi Caritas (meaning “where mercy dwells”) provides case management and primary health care services to residents of medically underserved people in the southeast region of Texas. Case management was a key service provided during the establishment of this center, and therefore, a great deal of emphasis is placed on quality assurance activities. Monthly case manager reports provide information on the case manager’s or community health worker’s activities, including (a) referral for care or resources, (b) teaching performed, (c) telephone follow-up, (d) clinical pathways, (e) home visit, (f) letter/card sent, (g) psychotherapy, (h) prescription assistance program, (i) chart review, and (j) consultation. Patient satisfaction surveys are conducted routinely, as are service needs assessments.

Data are also collected on patient demographics and services provided, including (a) census tract, (b) geographic, (c) race, (d) well-child visits, (e) adult well visits, and (f) payer source. Also measured are volunteer hours, student supervision, and the number and type of community and education programs and health fairs (C. Esperat, personal communication, January 30, 2001).

Minnesota Public Health Department

The need to enroll more nursing students into a community-based curriculum is essential to the overall goal of improving access to vulnerable populations. In addition, evaluating competencies of nurses in areas related to community-based care requires methods that can measure effectiveness of nursing interventions. Although not involved with a nursing center, the Minnesota Department of Health (Section of Public Health Nursing) has worked extensively with data collection, most recently with self-identified competencies of the public health nurse’s pre- and post-training. The public health section, in collaboration with and through its contractual relationship with the University of Minnesota, School of Nursing, developed the Public Health Nursing Practice for the 21st Century competency evaluation tool. This tool contains the following categories for evaluating public health nurse competencies: (a) population-based process, (b) individual/family-focused interventions, (c) community-focused interventions, and (d) systems-focused interventions. Workgroup participants reviewed the competencies to assist in the process of developing measures to evaluate competencies of nursing students educated in nursing centers (M. J. Rippke, personal communication, January 30, 2001).

Northern Illinois University

The TriCounty Community Health Center is an academic nursing center that is certified as a rural health clinic serving a three-county area in northwestern Illinois. Care provided is holistic, client-centered, and focused on health promotion and disease prevention. Primary health care is provided at the center’s main site, as well as various outreach sites throughout the three-county area, including homeless shelters, domestic violence shelters, and schools.

A Quality Assessment and Performance Improvement Plan was developed that specifically outlines a variety of evaluation measures, which include structure, process, and outcome
components. Outcomes that are measured include (a) client satisfaction, (b) nurse job satisfaction, (c) student satisfaction, (d) perceived health status, (e) utilization patterns, and (f) client health outcomes for selected diagnoses, using the Omaha Classification System. In addition to outcome measures, several process (e.g., chart audits) and structure (e.g., review of policies and procedures) measures are evaluated.

Data are collected using a variety of tools, including the client sign-in sheet, encounter forms, progress notes, and surveys. Using specialized computer software, a textual search of progress notes can be accomplished to identify patient characteristics, concerns, and procedures (e.g., Beck Depression Inventory, mammogram referral) (L. Anderko, personal communication, January 30, 2001). Past studies have consistently reported positive client outcomes and improved health care access (Anderko, Robertson, & Uscian, 1999, 2000; Anderko & Uscian, 2000).

Rutgers–The State University of New Jersey

The E-Port Community Health Center located in Elizabeth, New Jersey, provides primary health care to medically underserved residents, 90% of them minorities who live at or below the poverty level. The systematic collection of client outcome data began with the development of a Quality Performance and Improvement Plan. The plan is reviewed and revised annually based on evaluation of its usefulness and effectiveness. General outcomes measures include (a) resource utilization (number of visits, ER visits, hospitalizations, and length of stay), (b) SF-36 for physical role, (c) functional status, (d) general mental health and vitality (energy and fatigue), (e) the effectiveness/usefulness of HEDIS 3.0 data with minority populations, (f) client satisfaction, and (g) diagnostic specific clinical audits (e.g., hypertension). Evaluation methods include peer review, supervisory evaluation, chart review, various audits, and surveys to clients. Outcome research planned for the future includes disease management such as intervention studies of asthma management, hypertension/cardiovascular disease prevention, and diabetes management (P. Hurley, personal communication, January 30, 2001).
Service forms. These data will provide information on the effectiveness of interventions in improving health outcomes of disadvantaged populations (Chen, 2001).

**University of Akron**

The University of Akron Center for Nursing Clinic was established in the 1980s as one of the first nursing centers with a tripartite mission of education, service, and research. This center provides primary health care to vulnerable people who reside in an urban environment. The target populations are older adults on a fixed income, homeless women and children, and people who do not have health insurance. The ethnic makeup of people served is African American, Caucasian, and urban Native American. Health education, case management, and surveillance are the most frequent interventions.

In addition to providing primary health care, the Center for Nursing serves as a clinical education site for graduate and undergraduate nursing students, medical students, medical residents, dietetic students, and students in psychology.

The Omaha Classification System for clinical documentation is used, and the following patient data are obtained for each visit, following that framework: (a) type of visit (clinic appointment, walk-in, non-clinic appointment, home visit, telephone call, or group), (b) domain (environmental, psychosocial, physiological, or health-related behavior), (c) intervention (health teaching, treatment and procedures, case management, or surveillance), (d) modifiers (health promotion, potential problem, or actual problem), and (e) outcome (knowledge, behavior, and status). Each of these categories has standardized unique descriptors, which allow further description of data. A relational data program is used at the Center for Nursing, and the Omaha Classification System is part of this relational database application (E. Kinion, personal communication, January 30, 2001).

**University of Maryland**

Several different centers are described, along with their quality improvement measures, including the Senior Care Center, Open Gates Health Center, and Governor’s Wellmobile.

The Senior Care Center seeks to improve access to care for elderly residents of an inner-city, medically underserved neighborhood. Services offered include comprehensive geriatric assessment, geriatric primary care, and geriatric wellness programs. A relational database is used to document demographic, encounter, and billing information. Data are extracted from this database to reflect the geriatric nurse-practitioner activities, and information is added to nurse practitioner assessments. This is then used for both evaluation and patient follow-up (M. Oros, personal communication, January 30, 2001).

The Open Gates Health Center is a community-based nurse-managed center in the Pigtown community of Baltimore. In addition to primary care provided by nurse practitioners, community health workers provide outreach to the neighborhood.

UniversityCARE, the center’s partner, established standards for documentation and provides billing services through an online link. Outreach worker activities are documented on separate logs, with additional information collected for targeted populations (hypertensive patients). UniversityCARE’s computing facilities provide activity summaries, productivity reports, and accounting information. This information contributes to day-to-day management, patient and staff scheduling, and patient recruitment (M. Oros, personal communication, January 30, 2001).

The Governor’s Wellmobile consists of two mobile health units that deliver direct services and health education programs to families in medically underserved communities throughout Maryland. Partnering with health resources and schools in communities, nurse practitioners provide acute care, screening services, and linkages to other community services. Encounter forms document required billing information, whereas clinical data are recorded in the client’s medical record. The staff maintains a relational database that can link ICD-9 codes and client outcomes. The relational database provides the majority of the information needed for management, operations, and evaluation. Outcomes and trends can be examined to identify areas requiring more in-depth medical record review (M. Oros, personal communication, January 30, 2001).
BirthCare HealthCare (BCHC) is a multidisciplinary health care clinic and freestanding birth center in Salt Lake City, Utah. Multiple demographic, antepartum, intrapartum, postpartum, health history, and personal and family history data points are collected. Use of prescribed, over-the-counter, and illicit drugs, and alcohol (smoking included) are also reported. Clinical morbidity and mortality are documented, as well as 6-week postpartum functional health status and client satisfaction.

Birth center outcomes are reported through automated technology. This automated log will transition to any birthing practice and is a relational database, providing the capability of running multiple queries and reports. Primary clinical outcome measures include (a) the number of deliveries at the birth center; (b) the percentage of intrapartum, postpartum, and newborn transfers to the inpatient hospital setting; (c) cause-specific transfer rates; (d) medication in labor; (e) low and high birth weights; (f) percentage of low Apgar scores; and (g) average times from admission to birth and birth to discharge (L. Roberts, personal communication, 2001). Clinical outcomes reported have been consistent with previous studies, exhibiting that birth centers are a safe alternative site for delivery (Roberts & Seward, 2001).

**DATA WORKGROUP DISCUSSIONS AND RECOMMENDATIONS**

Participants had the option to participate in one of two workgroups to discuss a variety of questions posed by the Division of Nursing (HRSA) on issues affecting (a) the delivery of health care (client profile/primary care/health promotion) and (b) the education of nursing students (student/faculty profile). Questions that were discussed by the workgroups can be found in Table 1. Discussion centered primarily on issues involving the feasibility of data collection and reporting of findings. Following the initial discussion, the two workgroups reconvened as one workgroup to discuss recommendations for each of the two data collection tools.

Using the recommendations provided by the workgroup, the Division of Nursing staff drafted data collection instruments to obtain aggregate outcome data for the nurse-managed centers funded by the Division of Nursing. Use of these data collection tools will be voluntary. It is anticipated that the selected data elements will demonstrate (a) nurse-managed centers’ capacity to provide primary health care services to vulnerable populations, as well as their role as core providers in America’s health care safety net; and (b) the critical role nurse-managed centers play in

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<tr>
<th><strong>TABLE 1: Questions Discussed by Workgroups</strong></th>
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<tr>
<td><strong>Instrument I: Client Profile/Primary Care/Health Promotion</strong></td>
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<tr>
<td>What are the primary care health services that are offered by this nurse-managed clinic?</td>
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<tr>
<td>What is the total number of clients served by this nurse-managed clinic?</td>
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<tr>
<td>What percentage of patients served are women? What percentage of the patients served are men?</td>
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<tr>
<td>What percentage of patients served are adolescents? What percentage of that population served are girls? Boys?</td>
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<tr>
<td>What percentage served are children? Are population-specific services provided? Pregnancy counseling for teens?</td>
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<tr>
<td>What percentage of patients are members of minority groups?</td>
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<tr>
<td>Does this nurse-managed clinic provide a range of services?</td>
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educating nurses to effectively provide primary health care to vulnerable populations.

Workgroup participants are currently piloting the proposed data collection instruments, which include three data tables intended to profile each nurse-managed center’s activities. The data collection material includes information related to (a) client encounter by type of visit (e.g., health promotion), (b) patient demographics (e.g., age), and (c) students and faculty at the center (e.g., number of undergraduate and graduate students rotating through the nurse-managed center). Ongoing refinement of the data tables will occur during the next fiscal year.

ISSUES AND CHALLENGES

A variety of issues and challenges will affect the feasibility of implementing a uniform data collection instrument to obtain aggregate outcome data for nurse-managed centers. First, there are generally few common characteristics among various automated data medical record systems, making standardization of the data collection process difficult. Second, limited financial resources for many nurse-managed centers restrict their ability to develop and implement a well-integrated uniform data collection system, which often requires expensive computer technology. Finally, the communities in which nurse-managed centers operate have widely varying characteristics, as do the clientele. Therefore, in evaluating programs, there is no “one size fits all” (Wells & Conviser, 1998). The need for anecdotes and qualitative data to more clearly express success stories of improved health care access will still be needed, despite a well-integrated uniform data collection system used for quantitative data analysis.

The current focus of the Bush administration on the underserved and expanded access to health services provides a tremendous opportunity for nursing centers to develop and refine appropriately targeted health interventions for vulnerable populations, with an emphasis on improving access to quality health care. The large number of nursing centers with which HRSA works provides an opportunity to conduct large, consortium-based, multicenter assessment and evaluation. The systematic collection of a uniform data set among this multicenter consortium can result in the effective use of results in policy decision making and program management.

FUTURE DIRECTIONS

A standardized multicenter national data set, one that provides a minimum set of aggregate outcome data, is paramount as nursing centers begin to convey to policy makers their contributions as core safety net providers. One specific federal agency, responsible for overseeing and providing direction for these efforts, is needed. Policy initiatives that provide for financial support to mobilize these efforts on a national level will also be needed to establish consistent, reliable databases. These databases are obviously important to nursing, but other providers will also benefit from efforts to integrate a national database to measure outcomes. Nursing centers can provide other health care providers with valuable information on the logistics of establishing and implementing such a system.

Understanding the contribution of nurse-managed centers to the health of the nation is more important now than ever before. Nurse-managed centers provide care to people who are often forgotten by the larger health care system. Access to health care affects not only the individual but also the nation as a whole. Developing and maintaining political power is critical for organizations to be successful. Although nurses have high credibility, their visibility is often obscure. As a profession, we must take credit for our essential role in the health care arena. Visibility goes hand in hand with data. As Dodd (1997) noted, “visibility is never offered, it must be asked for and negotiated” (p. 426). Nurses must seize the opportunity not only to become visible, but also to gain respect as key players in the health care arena.

APPENDIX

Participants in Data Workgroup Meeting for Nurse-Managed Centers

(in alphabetical order):
Laura Anderko, RN, PhD, associate professor, Northern Illinois University.
Christina Esperat, RN, PhD, CSFN, professor and associate dean for research and practice, Texas Tech University, HSC
Charlotte Ferretti, RN, EdD, professor, San Francisco State University.
Patricia Hurley, RN, PhD, FAAN, director of research, Rutgers–The State University of New Jersey.
Eunice King, RN, PhD, senior project officer, Independence Foundation, Regional Nursing Centers Consortium.
Elizabeth Kinion, RN, EdD, CNP, professor, University of Akron.
Carol Macnee, RN, PhD, professor, East Tennessee State University.
Marla Oros, RN, MS, assistant dean of clinical practice and services, University of Maryland at Baltimore.
Mary Rippke, RN, MS, director, Section of Public Health Nursing, Minnesota Department of Public Health.
Leissa Roberts, RN, CNM, MS, clinical director of OB Care Now, University of Utah
Brad Tornberg, chief technical officer, Independence Foundation, Regional Nursing Centers Consortium

REFERENCES
Laura Anderko, RN, PhD, is an associate professor at Northern Illinois University School of Nursing in DeKalb, Illinois, and is past project director for the TriCounty Community Health Center’s originating grant, A Rural Nursing Center Model for Differentiated Practice (CFDA 93.359). Her research interests include investigating factors that influence health outcomes of the poor and underserved, quality improvement strategies for health care delivery in rural areas, and environmental influences on the health of children.
Elizabeth Kinion, RN, EdD, CNP, is the director of professional practice and director of the Center for Nursing at the University of Akron. She is a professor of nursing and teaches advanced clinical pharmacology. She is an advocate for university-community partnerships. Her research interest is access to health care for vulnerable people. In 2000, she and her colleagues Mary Agnes Kendra, PhD, and Marlene Huff, PhD, received $340,384 in funding for a 3-year project, Nurse’s Oral Health Initiative for the Underserved, from HRSA, Bureau of Health Professions, Division of Nursing.
In your opinion, what constitutes high-quality (good) primary health care? The question more easily leads to dialogue about what is not good care rather than what constitutes high-quality health care. Frequently, responses to this question are based on personal experiences and biases. The question serves as a vehicle for consumers and providers alike to air frustrations with the overall health care system, share what they think needs to be fixed, and reflect on what is needed to keep themselves and their families healthy over time.

Often, respondents describe models of managed care that fragment services, undermine positive provider-client relationships, and contribute to burdensome work to ensure the availability of accessible and affordable preventive health care. People relate that what they want is accessible, available, affordable, and trusted health care providers in their neighborhoods. They do not want

Authors’ Note: Visit www.rncc.org for more information about nurse-managed health centers and the Regional Nursing Centers Consortium. Please feel free to contact Tine Hansen-Turton at (215) 951-0330, extension 147, if you have any questions with regard to this article or how to support the nurse-managed health center movement.

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to use emergency rooms as the first line of defense for primary care. They do not want to wait hours and hours to be seen by a provider for 5 minutes or wait weeks for an appointment. They do not want to be denied care because of lack of or inadequate health insurance. They want to be treated with respect, they want their information to be held confidential, and they want to be informed consumers with the power to make appropriate health care decisions. Health care consumers know what they do not want or like and, from their own personal perspective, describe what constitutes good health care. Respondents state they no longer want to deal with a health care system that spawns health care horror stories, revealing a system that is broken and dysfunctional.

This article describes an evolving nurse-managed health center model that does work. The authors outline current challenges to the sustainability of this health care model and call for increased activism and public policy change to move this model forward in this new century.

NURSE-MANAGED HEALTH CENTER MOVEMENT

Nurse-managed health centers, also known as nursing centers and nurse-run clinics, are managed and operated by professional nurses. Professional nurses have the chief management positions and often function as both clinical and executive directors of the health centers. The majority of nurse-managed health centers are located in distressed urban areas or sparsely settled rural areas. The recent evolution of nurse-managed health centers has been supported by the work of visionary educators, clinicians, and researchers in a variety of academic and nonprofit settings. The current emphasis of the nurse-managed model is prevention and early intervention services, targeting individuals, families, and the communities where they live and work.

The centers have built unique and productive relationships with their community colleagues and members. Health center sites are sponsored by faith-based organizations, public housing developments, schools, community and recreation centers, strip malls, homeless and domestic violence shelters, and academic health centers in large universities. Advance-practice nurses, nurse practitioners, public health nurses, and mental health specialists work with collaborating physicians to provide comprehensive primary care to vulnerable populations. Nurse-managed centers integrate community resources and personnel to address pressing local health care needs. Most important, nurse-managed centers exist at the invitation of the communities they serve and are embedded in the core of community life.

Most member centers of the Regional Nursing Centers Consortium (RNCC) are affiliated with schools of nursing or independent, nonprofit organizations, and they are classified by ownership as either academic or community-based (for a complete, up-to-date list of members, please visit the RNCC Web site, www.rncc.org). They provide comprehensive primary health care and/or health promotion/disease prevention services. Current funding sources include the federal government, in the form of special project grants from the U.S. Department of Health and Human Services, Division of Nursing; state and local governments, in the form of contracts for public health services; and private foundations. Nurse-managed health centers have been recognized by the U.S. Department of Health and Human Services with its Models That Work award and Community Service award, as well as numerous other state and local awards.

Academic-based nurse-managed health centers have been recipients of Division of Nursing special projects grants and have demonstrated their capacity and commitment to prepare a workforce with the skills to serve the medically underserved. In addition to serving underserved populations, nurse-managed health centers play a vital role in addressing nursing shortages as they prepare nursing students with the necessary clinical education experiences to move from the role of student to that of nursing professional. Nurse-managed health centers, as members of the RNCC, possess data from Medicaid managed care providers to document that the clients they serve have fewer emergency room visits, fewer hospital inpatient days, higher rates of timely pediatric immunizations, and less use of specialists. These outcomes have been achieved despite devastating living conditions, low socioeconomic status, and significant chronic and acute health problems of enrolled clients.
Public health nursing history documents that ongoing funding of community-based and directed programs is critical. Just as the century-old public health nursing model established by Lillian Wald faced fiscal challenges, so does the 21st-century nurse-managed health center model. Nurse-managed health centers, regardless of their setting, must piece together diverse funding sources to remain in the primary care and public health business. Although nurse-managed health centers in many states have been granted credentials by managed care organizations and receive reimbursement, many continue to confront the fiscal challenge of providing services to the uninsured and underinsured. In any given day, nurse-managed centers may provide services to 40% to 60% of the uninsured clients in a community. The economic status of the majority of clients, their complex health problems, and the center’s lack of access to disproportionate share payments result in constant financial struggles which require senior administrators and staff to reach out regularly to a variety of funders and philanthropists. About 80% to 90% of nurse-managed health center budgets are supported by private or public grants, gifts, and contributions, with the remainder coming from managed care or fee-for-service allocations. Current scarce funding sources require that the RNCC hold dialogues with national organizations and elected officials for alternative fiscal strategies, such as inclusion in the Consolidated Health Centers Program to promote long-term sustainability.

**EVOLUTION OF THE REGIONAL NURSING CENTERS CONSORTIUM (RNCC)**

The RNCC is the first organization of its kind to support the growing movement of committed nursing professionals responsible for the oversight and operation of nurse-managed health centers. In fact, the RNCC has assumed a pioneering role in representing health care consortia dedicated to nurse-managed health care center models. In 1996, 11 nurse-managed health center leaders from the tri-state area of Pennsylvania, New Jersey, and Delaware came together to increase their collective capacity to provide services to vulnerable people, promote their model of care to the public, and advance the nurse-managed health center model into mainstream health care services. After a year-long series of planning/strategy meetings and development of the bylaws, an additional seven centers joined to form the core membership group. During the first 2 years of RNCC’s existence, volunteers from its member centers ran the consortium. In 1998, the RNCC governing board hired two full-time staff. Membership has expanded to more than 33 members in the Northeast corridor, the South and the West Coast. Collectively, the members serve more than 50,000 clients annually for primary care services, with a total of 500,000 health encounters recorded annually.

The RNCC’s vision is to improve community health through neighborhood-based primary health care services that are accessible, acceptable, available, and affordable. The RNCC’s mission is to serve its neighborhood-based health center members by enhancing their potential for sustainability, thus ensuring their growth. More specific purposes include to foster understanding, recognition, and use of nursing centers; to promote nursing centers as essential primary health care providers, emphasizing health promotion, disease prevention, health education, and outreach services; to provide a forum for communication and collaboration among consortium members; and to offer services that enhance members’ management capabilities and health care program offerings.

The RNCC members reflect the future of nursing in the 21st century. MarieAnn North, senior vice president of the Hunter Group recently commented, “The nurse-managed health centers are five years ahead. . . . The model represents a growing movement and a player in the mainstream health care arena.” In addition, nurse-managed health centers enable students and faculty to receive rotational experiences and observations in non-traditional, out-of-hospital settings. In a recent poll, nursing students who participated in an RNCC training program said that nurse-managed health centers made it more attractive for them on graduation to work with underserved rural and urban populations. Nurse-managed health centers are entities that allow nurses at all levels of
educational preparation to come together and create opportunities for clients to self-determine their health care destinies. These health centers and related community practice settings represent the current and future multidisciplinary configuration of health care in this country. The progressive teaching and learning environment allows students, faculty, and staff to confront complex social, environmental, educational, and funding issues that challenge nursing practice and may undermine positive client outcomes on a daily basis.

2001 SUSTAINABILITY CHALLENGES AND OPPORTUNITIES

Because the overall mission of the RNCC is to ensure long-term sustainability of nurse-managed health centers, it has worked to develop strategies that bring about long-term sustainability. Many of these solutions involve policy change. One partner is the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA). RNCC senior staff are actively exploring opportunities for nurse-managed health centers (nursing centers) to become Federally Qualified Health Centers (FQHCs) or look-alike models. By becoming FQHCs, approved nurse-managed health centers would have the fiscal advantage of cost-based Medicare and Medicaid reimbursement rates for covered clients, grant opportunities and access to discounted pharmaceuticals. The pressing dilemma, however, is that the majority of existing nurse-managed health centers cannot qualify for FQHC status under current law and regulations. Therefore, the RNCC is working with HRSA senior staff at the regional and national level to address and resolve statutory limitations.

The statutory and regulatory requirements include board composition; also, the nurse-managed health center must stand alone with its own non-profit status. HRSA and its Bureau of Primary Care require that FQHCs and look-alikes have community boards. The community board must include 51% community users of the health center and possess governance authority. Governance authority includes control over the budget as well as the hiring and dismissal of the executive director. At present, many of the nurse-managed health centers receive grant funding support from HRSA’s Bureau of Health Professions, Division of Nursing. Division of Nursing grants require the director of the nursing center to be a faculty member of the sponsoring school of nursing and to have the fiscal, managerial, and administrative responsibility for the nurse-managed health center model.

The Division of Nursing requirements place academic-based nurse-managed health centers in direct conflict with the FQHCs or look-alike requirements relative to the community board composition. Interestingly, RNCC’s member organizations have constructed community advisory boards representative of their target communities and committed to the nurse-managed health center model; however, the community advisory boards do not have fiduciary or hiring/firing responsibilities. The inconsistencies between Division of Nursing requirements and the composition of the FQHC look-alike organization is of increasing concern to the RNCC. Nurse-managed health centers provide cost-effective, high-quality services to vulnerable clients and their families. This dilemma, indeed, is jeopardizing the long-term sustainability of nurse-managed health centers across the nation. The additional stipulation of the Balanced Budget Act (BBA) of 1997 (P.L. 105-33)—that an entity may not be owned, controlled, or operated by another entity—presents an overwhelming political obstacle to any school of nursing’s nurse-managed health center located in a private university setting. These stipulations mean nurse-managed health centers in private universities may not take advantage of cost-based reimbursement or select grant opportunities.

Currently, two RNCC nurse-managed health center members are federally qualified. Another one has just received status as a FQHC look-alike. These health centers provide the same services as other member primary care nurse-managed health centers; however, because of their FQHC status, each center is able to receive an additional $400,000 a year for services to Medicaid and Medicare and uninsured clients. These monies come directly from state departments of health and welfare or other appropriate agencies who administer Medicaid programs. Such enhanced
financial support enables the nurse-managed health centers to be fiscally solvent and sustainable over time.

Through the process of working with HRSA representatives, the RNCC staff has become expert in identifying the challenges, regulations, policies, and related issues that influence the long-term viability of nurse-managed centers and has proposed several viable solutions to the current dilemma. These solutions include adding a new class of service settings to include nurse-managed health centers located in medically underserved urban and/or rural communities. Currently, the Health Center Consolidation Act of 1996 allows for the following four community health center populations and service settings: community-based, migrant, public housing, and health care for the homeless. By definition, these entities are automatically granted FQHC or look-alike status.

Other solutions include allowing all nursing centers to apply for look-alike status, whether they are in public or private university-based settings, or mirroring current Bureau of Primary Health Care requirements. (These requirements currently allow public entities, such as Schools of Nursing in public universities, to apply for FQHC or look-alike status and amend the current regulations to include an exception to nursing centers that are administered by private universities.) Another solution is for nurse-managed health centers to team up with existing community health centers and expand their service network arrangements. Although this may be an immediate solution, the potential problem here is that most community health centers have a different model of care and use the traditional medical model. There is a significant concern that nurse-managed health centers will not be able to maintain their unique model of care in these types of network arrangements. Although these solutions address the immediate sustainability issue of nurse-managed health centers, it is very likely that there will be unforeseen obstacles, despite the nurse-managed health centers’ comparability to community health centers both in terms of mission and services.

As part of its broad-based strategy, the RNCC has solicited the support of the Tri-Council for Nursing, which consists of the American Association of Colleges of Nursing, American Nurses Association, American Organization of Nurse Executives, and National League for Nursing. The Tri-Council for Nursing has recognized that nurse-managed health centers provide a valuable service to underserved populations and serve as clinical training sites for faculty and undergraduate and graduate students.

The RNCC has also been in dialogue with the National Association of Community Health Centers regarding this unique model of care and the challenges it faces. In addition, President George W. Bush has pledged to increase funding for the Consolidated Health Centers Program, which includes community, migrant, homeless, and public housing community health centers. RNCC and national nursing organizations, such as the American Association of Colleges of Nursing, American Nurses Association, American Organization of Nurse Executives, National Organization of Nurse Practitioner Faculties, American College of Nurse-Midwives, American College of Nurse Practitioners, National Association of Pediatric Nurse Practitioners, and Michigan Academic Consortium: Nurse Managed Primary Care have educated President Bush and his administration about the need to include nurse-managed health centers in this funding expansion. The President has pledged to start 1,200 new community health center sites over the next 5 years; nursing groups believe that a minimum of 100 of these new sites should go to existing nurse-managed health centers.

CONCLUSION

The challenges and opportunities for nurse-managed health centers and their long-term sustainability are enormous and ongoing. This article represents a small sampling of issues that advanced-practice nurses in nurse-managed health centers have to struggle with on a daily basis. Other major sustainability issues include business practices, managed care credentials, and prescriptive authority. Despite these challenges, there is no doubt that nurse-managed health centers are here to stay. They work because they focus on a neighborhood where national policy and social reality meet. They build community and promote wellness from a holistic perspective that integrates preventive care and primary care.
Patients know and trust nurse providers because they take time to listen and to learn about their problems and they treat their whole family. In conclusion, nurse-managed health centers are ideal models for present and future primary health care service delivery.

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**Recommended Readings**


Public Policy Decisions Related to Disability and Rehabilitation: Is It Time for a New Paradigm?

Mary Ann Schroeder DNSc, RN
Kathleen M. Buckley, PhD, RN
Annette Tyree Debisette, DNSc, RN

According to the National Organization on Disability (2000), there are 54 million Americans with disabilities. There have been several legislative approaches to help these individuals attain a level playing field. The Americans with Disabilities Act of 1990 has been a major influence on the treatment of people with disabilities. This act’s major thrust has been to make it illegal to discriminate in employment or access to public accommodations against those who are disabled. Still other approaches have included governmental appropriations for research and rehabilitation. It is important for nurses and other health professionals who care for people with disabilities to understand what influences public policy.

Nurses are frequently called on to advocate for specific vulnerable populations. People with disabilities form a large cohort of those in need of rehabilitation or other health and social services. Availability of these services is greatly influenced by politics, price, and principles that culminate in public policy. Currently, it is difficult to discern a rationale that underpins some public policy decisions regarding disability and rehabilitation. The allocation of government resources appears to be inconsistent. When nurses advocate for specific groups, such as those with disabilities, it is important for them to understand the political context of their actions. This article identifies the major factors that influence the present system and suggests a new paradigm to use in making decisions about allocation of certain health care resources.

Editor’s Note: The opinions expressed here are those of the authors and do not necessarily reflect the official positions or opinions of the U.S. Department of Health and Human Services.

Authors’ Note: The development of this article was supported by the National Institute on Disability and Rehabilitation Research (NIDRR) at the U.S. Department of Education under the RERC on Telerehabilitation, award number H133E990007-00A. This paper was presented in part at the RESNA 2000: Technology for the Millenium annual conference, Orlando, Florida, July 1, 2000.
Public policy is the culmination of decisions regarding allocation of resources. Generally, resources mean money. It is especially vital for nurses who are interested in rehabilitation to understand how policy and funding decisions are made.

Because of the increase in the percentage and number of older Americans, there will be an increased demand for new technology to help those with chronic illness. For example, by 2020, the Centers for Disease Control and Prevention predicts that 60 million Americans (baby boomers) will have arthritis (National Center for Chronic Disease Prevention and Health Promotion, 2000). It is critical to consider now how to pay for the increased demand.

Past federal regulations have been inconsistent in regard to disability. Consider two examples of public policy decisions affecting people with disabilities: (a) those with blindness receive an extra deduction on their federal income tax and (b) those with end-stage renal disease receive government-compensated care.

In a perfect world, it would seem that all citizens would receive benefits related to their needs. However, resources are not infinite. The factors that influence policy decisions related to disability and rehabilitation offer insight into how many health policy decisions are developed. Why do individuals with blindness deserve $1,050 more in income tax credit each April 15, but those with deafness do not? Why do those with kidney failure receive completely subsidized treatment, but those with liver disease do not? In these and many other policy decisions, a critical influence is politics.

POLITICS

Politics is frequently defined as the process of influencing the allocation of scarce resources. In other words, politics is part of the process that determines policy, and it is not a neutral term. Politics involves competing and conflicting values and views. Different points of view are the result of many things.

Vested interests, compassion, and public opinion influence the politics of policy formulation, including decisions involving people with disabilities. These concepts are interwoven with the political process. How are interest groups successful in winning economic advantages and political support? Frequently, through lobbying. Lobbying may involve efforts by those affected by the specific condition or by professional lobbyists.

When becoming involved in the policy-making process, nurses should be aware of what the missions and goals of interest groups are. Is it the rehabilitation hospitals or centers that are lobbying? Is it a specific disability group? Or is it “mothers of” people with a specific condition who offer testimony at legislative hearings and provide an emotional appeal?

Public opinion, a powerful and important tool in our information-age democracy, also helps shape policy. The mass media may initiate the process of policy development by bringing an issue to the public’s attention and creating a sense of urgency or a demand for action. But, then, they often move on to the next issue, contributing little to the difficult process of working through the problem. However, once public awareness has been raised, individuals or special interest groups may develop advocacy campaigns to continue to help raise public awareness or rally support behind proposed solutions. At this stage, mass communication often continues to shape the issue by governing relationships and attitudes within the general population and imparting specific information to the public. This affects the way individuals in society behave and moves elected policy makers toward getting the issue on the public and governmental agenda, with the goal of policy formation and allocation of needed resources.

The saga of the televised Spin City’s star Michael J. Fox and his personal struggle for 10 years with Parkinson’s disease left television viewers with a humanized view about the tragic effects of disease and disability. Fox announced to millions of viewers that he had Parkinson’s disease. During his testimony to Congress in 1999, Fox, then 37 years old, described to lawmakers the effects of his crippling disease (Lehrer, 1999). He generated worldwide interest in Parkinson’s disease because he is a national celebrity, young at age of onset, and courageous in coming out publicly with his appeal. Fox pleaded with Congress to provide more federal appropriations for research about the disease, and staunch advocates for Parkinson’s research could not have been...
happier. Fox’s pleas were heard loud and clear, probably even more so as comrades in both the House of Representatives and the Senate were mourning the loss of Congressman Morris K. Udall of Arizona, who died of Parkinson’s disease in 1998.

Emerging from public appeals and opinion were two important developments. The House Working Group on Parkinson’s Disease was formed to push for federal appropriations and funding for the disease to be included in the federal budget of 2001 (Parkinson’s Action Network, 2000). Also included was the Morris K. Udall Parkinson’s Disease Research Act of 1997, a bill authorizing funding of at least $100 million to the National Institutes of Health (NIH) for scientific research on Parkinson’s disease (Department of Labor, Health and Human Services, and Education and Related Agencies Appropriations Act, 1998, Public Law 105-78).

Public opinion does count, and political action does effect change. Advocacy groups are pressing forward, responding to public outcries and public mourning. Public opinion and public advocacy groups are bringing together a firm agenda for action. For example, the Parkinson’s Action Network (2000) has called for “the advocacy community to ensure NIH pursues an aggressive and thorough agenda and that Congress provides sufficient funding for a cure to be developed as soon as possible.” Lawmakers have no other option than to listen to the concerns of their constituencies. Through Fox’s efforts and posthumous sympathy for Congressman Udall, widespread public attention has been drawn to study seeking a cure for Parkinson’s disease. Through NIH, the National Institute of Neurological Disorders and Stroke (2000) has funded 11 Morris K. Udall Parkinson’s Disease Research Centers of Excellence.

PRINCIPLES

Principles are the rules or truths that influence reasoning or a code of conduct. The principles underlying policy decisions may be lofty or base. Lofty ones may be rooted in ideas of social justice. Social justice is defined as “the entitlement of all persons to basic necessities, such as adequate income and health protection, and the acceptance of collective action and obligations to make such possible” (Hitchcock, Schuber, & Thomas, 1999, p. 899). Even in discussing social justice, competing and conflicting values loom. Should policy be based on egalitarianism, where everyone is treated the same, or should distributive justice be given greater importance, whereby vulnerable populations deserve more? Should the greatest good for the greatest number, the major tenet of utilitarianism, dictate policy? As a society, we have never decided which theory of justice should have the most weight.

Campaign finance reform has failed. Money influences elections, issues, and public policy. Money talks, and people listen. The appeals made by celebrities in the media are tremendously powerful when it comes to private citizens’ responding to the call. Michael J. Fox, sports legend Muhammad Ali, and former U.S. Attorney General Janet Reno all have been diagnosed with Parkinson’s disease, and sympathizers are generous in their donations. The Parkinson’s Disease Foundation (1999) reported income totaling $6.6 million in gifts from living individuals, bequests, and income from investments for 1999. Corporate support has been received from numerous medical technology, financial investment, and pharmaceutical companies (Parkinson’s Disease Foundation, 2000).

Another factor that influences politicians is votes. The elderly are known to vote in greater numbers than any other segment of society. They are courted by all officer holders and seekers. Is there a danger that a generational battle might emerge over which disabilities receive preferential treatment by legislators? Should the elderly have more influence because of their greater numbers or because of their voting power?

Costs associated with rehabilitation have risen at a phenomenal rate. This has led policy makers to debate whether care for those with disabilities is a right or a privilege. This debate has focused on what constitutes the common good. Perhaps nowhere is this seen as more influential than in policy surrounding the financing of care for vulnerable populations. Is the benefit worth the price?

PRICE

For more than a decade, the rallying cry for delivery of all services has been cost containment. As every budding economist knows, price is not
the same as cost. Price is considered to be an amount of money that is paid for something. It does not include all the costs. If one spends money on one item, that same money cannot be spent for something else—it’s gone. For example, the price of doing hearing screening in a school amounts to the per hour rental of the equipment plus the per hour salary of the person who does the screening. However, the price does not include the cost to the students who, while waiting in line for the screening, are not being instructed in the classroom; thus, they are losing educational time. Furthermore, the person who is doing the screening cannot at the same time do health teaching regarding the prevention of hearing problems. In evaluating hearing screening, it costs more than the price. So, too, if professionals spend time engaged in one activity, they cannot spend that same time doing something else. This is loss of opportunity costs. Opportunity cost means that certain goods and services “are forgone in order to obtain something else” (Schiller, 1993, p. 30). If money is spent on rehabilitation of the elderly cardiac patient who smokes, will there be enough for an adolescent with cerebral palsy?

Another important aspect of price is that rehabilitation care has become a lucrative business in the health care industry. Hospitals and rehabilitation centers are actively marketing their services for patients who are either insured or have the ability to pay. Insurers are being courted by centers offering rehabilitation services because they have the financial capital to pay and reimburse providers for rehabilitation services. The health care market can be termed an insurer’s market because of its leverage in being able to pick and choose where patients receive care or to refer or refuse care. This practice is a combination of politics and economics. Because of these issues, rehabilitation services are not available to all Americans (National Center for Injury Prevention and Control, 2000).

Rehabilitation and assisting technologies have been scrutinized by cost-benefit analysis. But many times, the benefit has not been considered for its necessity but rather for its desirability. Perhaps what is desirable for one specific cohort is not good for the whole society.

How is this decision about what is good to be made? The difficulty lies in balancing the medical ethics of providing rehabilitation services and technologies with the newer ethics of cost-benefit analysis. In cost-benefit analysis, we compare the health value of a rehabilitative program or assisting device with the monetary cost, projecting the number of individuals to benefit from the skill or technology. The health benefit should be greater than or equal to the marginal monetary cost. This new ethic ensures that balance occurs and that whatever we get is worth the resources it costs. This is not an easy process, as many may feel uncomfortable in making decisions for others in choosing between health and money. Although cost-benefit studies are routinely done by economists in and out of government in every policy field, very few programs are actually run on the basis of such analyses. The reason is that politics generally interferes.

NEW PARADIGM

In the 1986 classic *Theoretical Foundations of Nursing*, Gertrude Torres defined paradigm as “the integration of multiple theories in understanding phenomena” (p. 30). The suggestion that a new paradigm is needed results because in the past, nurses have used advocacy as the overriding concept in dealing with issues about disability. In realizing that resources are finite, nurses currently require a more complex thrust; thus, a new paradigm is proposed.

Plato, quoting Socrates, declared that an unexamined life is not worth living. To extend that thinking to the topic at hand, unexamined policies may not be worth implementing. As a nation, we must examine how policies affecting those with disabilities are made. That examination should include revisiting the following questions.

- How is disability defined? (Albrecht, 1997)
- What policies are currently in place?
- What was the rationale behind these policies?

and, perhaps most important,

- Is that rationale still valid?

Answering these questions is most difficult to do, as other equally probing questions result, such as
Is there not danger of going backward in time to when those with disabilities were invisible and/or mistreated?
Is there not a chance that profound beliefs as well as livelihoods might be compromised?

Even with these dangers, one must admit that the present system is not fair to all. Why one group receives more resources than another should not be based on skill in lobbying or promise of votes.

There are several major thrusts in proposing a new paradigm. First, there must be an open discussion of current laws, regulations, and funding related to disability and rehabilitation. A public interest group without ties to any specific organization or rights group should gather specific information about the past and present status of disabilities and rehabilitation. This must include costs and consequences of the current state of affairs.

Second, once this discussion takes place, a decision must be made about what, and subsequently who, should receive resources. This decision can be made through democratic processes. An excellent prototype is the methodology used by the state of Oregon in deciding which health care procedures and diseases would be subsidized by citizens. In the 1990s, Oregon, like other states, was reeling from skyrocketing health care expenses and embarked on a systematic rational approach to ranking what treatments the state would fund. This process involved the collaboration of the health care community and citizens to set priorities. The state needed to control its Medicaid budget and wanted a basis to justify the allocation of monies. Officials turned to the health care community to provide advice about what treatments were useful and what procedures had little actual value.

This evidence-based approach should be the third thrust, and it is especially crucial to the new paradigm. Approaches to allocation of resources must be based on research findings that these approaches work. Part of the problem of the old paradigm has been a dramatic increase in the number of older people who, with chronic conditions, are considered disabled. Another aspect is the increasing use of technology in treatment of those with disabilities. Technology, like all treatments, must be scrutinized as to effectiveness and cost. Even though technology is presented as a way to reduce the amount of money spent, only rarely do innovations live up to cost-saving expectations (Bodenheimer & Grumbach, 1995).

**IMPLICATIONS FOR NURSING**

How can and should nursing contribute to a new policy-making paradigm? The unique role of nursing revolves around the specific and special function of patient advocate. This role is an essential part of professional nursing practice. As patient advocates, nurses are concerned with supporting and safeguarding the rights and interests of people with disabilities. However, in their pursuit of advocacy, nurses have an unfortunate tendency through their caring nature to reduce patient autonomy. Nurses need to be careful to respect the right of disabled people to be their own advocates and not assume a role that might inadvertently reduce client autonomy. When clients are clearly incapacitated by severe disabilities, unwilling or afraid to pursue their own rights, or simply unable to grasp the complexity of functioning in the role of self-advocacy, the nurse's position becomes more clear as a basic moral obligation and professional duty. Nevertheless, patient advocacy should empower people with disabilities to develop autonomy and self-determination.

Beyond rights lie the interests or preferences of specific groups of people with disabilities. These should not be confused with basic rights. The nurse's role as patient advocate becomes less clear in supporting and advocating specific interests. Clearly, rights of people with disabilities are something nurses should promote and preserve. However, a group of clients may have other pursuits regarding their health care that are based entirely on their own specific needs, without consideration of the needs of society as a whole. In an effort to demonstrate caring and compassion, nurses may become involved in supporting and advocating for these interests. Although caring and compassion are basic values of professional nursing, nurses must be careful not to allow these values to cloud their vision as patient advocates. To make a decision about the direction of advocacy, nurses have the advantage of a knowledge
base about health and illness as well as evidenced-based outcomes.

In summary, nurses are obligated to use their expertise to defend and promote patient rights, to support client autonomy in the pursuit of rights, and to make an informed choice of supporting and representing particular interests.

CONCLUSION

The purpose of this article has been three-fold: (a) to provide an overview of some of the problems with the current state of disability and rehabilitation, (b) to propose a different approach to deciding on how resources should be allocated, and (c) to suggest that nurses reconsider their advocacy role. With no end in sight for cost containment, it becomes most important to engage in discussion about the issues raised.

It is hoped that discussion might center on a somewhat different approach than the one used historically or traditionally as the basis for determining policy. A new paradigm has been proposed on which to base decisions. Is it perfect? Of course not—nothing is—but it would seem that a paradigm based not on mere politics but rather on enlightened outcome measures would be fairer and more rational.

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Many states in America will be receiving tobacco settlement money as a result of the $246 billion settlement in response to the civil lawsuits filed by the states against the tobacco industry (Campaign for Tobacco-Free Kids, 2000b). These civil lawsuits were an attempt to recoup billions of taxpayer dollars spent on tobacco-related illnesses. According to Pierce and colleagues (1998), states such as California, Florida, Oregon, Massachusetts, and Arizona have established and implemented smoking-prevention and smoking-cessation programs using tobacco settlement funding. Indiana has not allocated specific settlement funds to establish a statewide policy on smoking prevention and cessation.

Tobacco use among children continues to increase in America, where “every day 3,000 kids become regular smokers” (Campaign for Tobacco-Free Kids, 2000a). It is predicted that one third of these children will die prematurely from lung cancer, emphysema, heart disease, and other tobacco-related diseases. An estimated 4.5 million children between the ages of 12 and 17 are smoking. Whereas adult smoking has been on the decline, youth smoking habits have increased at an alarming rate (Campaign for Tobacco-Free Kids, 2000c). In Indiana high schools, 36% of all students smoke, 20% of all males use smokeless tobacco, and more than 30,000 youths under 18 years old smoke cigarettes. African American and
Hispanic adolescents have also increased their cigarette smoking habits (Indiana State Department of Health, 2000). It is projected that 140,000 children who are now under 18 will eventually die from smoking, should current trends continue.

According to the Campaign for Tobacco-Free Kids (2000c), smoking kills more people in Indiana than alcohol, AIDS, car crashes, illegal drugs, murders, and suicides combined. Smoking or tobacco use is the single greatest factor in preventable illnesses and premature deaths (Percival, 1999). Smoking-cessation and prevention programs have decreased the number of adolescent and adult smokers (Manfredi, Crittenden, Cho, Engler, & Warnecke, 2000; Noland et al., 1998; Phillips & Kelly, 1999; Pierce et al., 1998; Tilashalski, Rodu, & Cole, 1998). Incorporation of smoking-cessation and prevention programs into regular health care visits could promote better overall health for the residents of Indiana.

Tobacco-related health care expenditures in Indiana are about $1.5 billion (Campaign for Tobacco-Free Kids, 2000c). The state and federal tax burden caused by tobacco-related health costs is estimated at $730 million to Indiana residents. Indiana Medicaid payments directly related to tobacco use equal $250 million. The Indiana State Department of Health (2000) estimates that direct medical costs associated with smoking are about $50 billion per year. Medicare will spend $800 billion over the next 20 years caring for people with smoking-related illnesses. Lost productivity and lost earnings because of smoking-related illnesses and premature deaths cost an additional $50 billion a year and “smoking costs every man, woman, and child in Indiana $548 per year for health-related costs” (Indiana State Department of Health, 2000, p. 1).

Implementation of smoking prevention and cessation programs into the health care of Indiana could decrease the amount of money spent for tobacco-related illnesses. There is strong evidence that when health care providers take time to teach and reinforce healthful choices for patients, they can influence patient behavior patterns for the better (Lai & Cohen, 1999). With a healthier population, medical spending can be reduced.

Health education, prevention, and smoking cessation are honorable and easily implemented tools to promote wellness and good health. Ethical battles in the courts with the tobacco companies resulted in the deliverance of the tobacco settlement funding (Modisett, 1997). It is reported that tobacco companies may still be targeting the youth of our society with marketing ploys (Benjamin, 2000). Thus, it is fair practice to use tobacco settlement funding to formulate and implement smoking-cessation and preventive programs to improve the health of Indiana communities and to discredit the myths of tobacco advertisements aimed toward the younger population, depicting smoking as glamorous (Sarna, 1999).

The Indiana government has received a significant amount of tobacco settlement money. Legislators are currently addressing the issue of how to use this money. The governor of Indiana has supported legislation that will allocate 50% of the first year of settlement payment to the Children's Health Insurance Program (CHIP) and additional funding to support public health, including smoking cessation and prevention programs (Campaign for Tobacco-Free Kids, 2000b). Senate and House bills currently before the Indiana General Assembly, as identified by the Indiana Commission for Women, would establish health services trust funding, distribute the settlement funds, institute an endowment fund, enforce youth tobacco laws, and create funding for rural health care and agricultural enterprises (Campaign for Tobacco-Free Kids, 2000b). Although legislators have budgeted $47 million for CHIP out of the initial tobacco settlement, no other policies have become law. Health care and smoking prevention and cessation are mentioned in a few of the bills. Specific program details or dollar amounts have not been allocated for the development and implementation of other related programs.

**Issue statement.** The issue statement surrounding this health care concern is: How can the State of Indiana use the settlement money to implement smoking cessation and prevention programs? State policy makers have a responsibility to protect public health (Pulcini & Mahoney, 1998). Tobacco settlement funds could provide a cost-effective avenue to improve the health of Indiana residents.
Stakeholders. Policy formation consists of the choices of a society, parts of that society, or organizations within that society regarding goals and priorities and allocation of resources to create principles that govern action to meet a given end (Leavitt & Mason, 1998). Stakeholders with a potential interest in this issue and a stake in the development of specific legislation on this topic would be the Indiana Nurses’ Association, Indiana Medical Association, Indiana Primary Health Care Association, American Heart Association, American Cancer Society, American Lung Association, Indiana State Department of Health, Parent-Teachers Associations, Public Health Association, and Home Health Association. Coalitions such as the Campaign for Tobacco-Free Kids could be considered, as well as legislators who could champion this issue. The development committee composed of stakeholders and volunteers with an interest in this issue would devise recommendations for the formal legislative policy. The goal would be to receive tobacco settlement funding specifically for development and implementation of a mandated statewide smoking-cessation and prevention program included with health care provision.

Policy objectives. The policy objectives would be to

1. Decrease tobacco use in the state of Indiana.
2. Decrease the occurrence of tobacco-related illnesses.
3. Ensure cost-effectiveness of smoking cessation and prevention programs.
4. Provide effective and useful evaluation of smoking cessation and prevention programs.

POLICY ALTERNATIVES

Policy alternatives provide policymakers with a variety of choices based on research, background literature reviews, and governmental data. The authors examined three possible policy alternatives that could be considered by tobacco settlement policymakers. These include

1. A legislative mandate to require smoking prevention and cessation programs in primary health care–provider practices.
2. A legislative mandate to require school-based smoking cessation and prevention education.
3. A legislative mandate to implement a statewide smoking cessation and prevention public health awareness campaign.

Evaluation of Policy Alternatives

The legislative process consists of two phases, the policy formation phase and the policy implementation phase (Longest, 1998). During the policy formation phase, policy alternatives are compared, reviewed, and evaluated. Mason and Leavitt (1998) and Longest (1998) outlined a process of evaluating policy alternatives based on selected criteria. Each policy alternative is evaluated to assess the positive and negative aspects of implementation, using the criteria of cost containment, political feasibility, quality, and measurable outcomes. Research and prior findings from other successful state programs can also be used to assist with this process. According to Hanley (1998), an evaluation of cost containment provides information to support cost-effectiveness of the policy. When evaluating political feasibility, one is determining the possibility of enactment of the policy, taking into consideration opposing and supporting stakeholders. Quality refers to worth or value of the program (Longest, 1998). When evaluating measurable outcomes, one can provide policymakers with documentation of the end results and effectiveness of the policy (Polit & Hungler, 1999).

Smoking prevention and cessation program in primary care settings. In the evaluation of the legislative mandate to require smoking prevention and cessation programs in primary health care–provider practice, there would be initial costs. These costs could be kept to a minimum, using research to locate existing universal, successful, and recognizable smoking prevention and cessation programs. Education and implementation costs of these programs to primary providers would be outlined. With necessary documentation of utilization and evaluation, further costs would be minimal, as the responsibility would be placed on primary health care providers to include the smoking cessation and prevention programs in routine care. One negative aspect to ponder is that primary health care providers may object to the mandated additional responsibility without financial compensation, which may necessitate
negotiations for governmental financial assistance. The existence of several tobacco settlement funding allocations that have been included in Senate and House bills and are now under committee review provides political feasibility (Indiana General Assembly, 2000). Legislative mandates may offer increased quality of care in the areas of prevention and cessation, as documented community- and practice-based smoking-cessation programs do work (Phillips & Kelly, 1999; Rice, 1999; Tilashalski et al., 1998). More liberal legislators tend to support regulation of health care issues (Hanley, 1998), whereas some legislators may believe the tobacco funding money should be allocated to other needs of state government besides health care. Measurable outcomes from other successful programs can be presented and then used to document effectiveness and success of the statewide implementation.

School-based smoking cessation and prevention programs. In assessing the legislative mandate to require school-based smoking cessation and prevention education, cost for this program would be limited to education of school boards and teachers responsible for implementation of requirements in the school curriculum. A possible disadvantage could occur, as school systems may request additional funding to cover costs of additional staffing and program supplies. Although specific policy formulation has not addressed the education of school-age children, tobacco settlement funding has already been allocated to the CHIP program. Legislators may feel this program is sufficient to benefit the younger population. The Kessler-Koop Advisory Committee (1997) recommends that schools implement the Centers for Disease Control and Prevention guidelines to provide quality care with the prevention of tobacco use and addiction. Noland et al. (1998) has documented that preventive programs work when started early in childhood and continued. Legislative mandates could improve the health of Indiana children. Documentation of end results and information on the effectiveness of the policy would be provided by the measurable outcomes (Polit & Hungler, 1999).

Statewide smoking cessation and prevention program. Legislative mandate for tobacco settlement fund-

ing to be provided for a statewide public health awareness campaign is the final policy alternative to be reviewed. A large number of individuals could be reached through public awareness activities funded by the tobacco settlement to Indiana. Depending on the route of awareness chosen, some sources could be more expensive than others, for example, television and radio media versus individual mailings or pamphlet development. Political feasibility is high with this alternative, as tobacco settlement allocation is currently an active topic with Indiana legislators. Informed consumers are better prepared to make choices and seek assistance for healthier living (Lai & Cohen, 1999). A legislative mandate allocating funding for public education could increase the educational and awareness levels of this population and lead to decreased use of tobacco products. In reviewing the negative aspect of this mandate, education and awareness are but one part of implementing healthy lifestyle habits. Many variables are involved with individual lifestyle choices, and measurement tools of these may be limited. Without consistent follow-up and consideration of other numerous variables, awareness of the hazards of tobacco use may be increased, but development of behavioral changes to discontinue use may not occur. As more legislators are elected who are economically conservative, more focus in politics may be centered on getting the most outcomes out of programs offered.

RECOMMENDED POLICY

The authors recommend a legislative mandate to require smoking prevention and cessation programs in primary health care–provider practice. The positive aspects surpass the negative ones. Outcomes can be easily measured, and the population is not limited to one age group. There is a large body of research supporting the successful implementation of smoking-cessation and prevention programs in the primary care setting in other states.

SUMMARY

Policy formation is a process that requires knowledge of several different matters. One must
understand the issue at hand, the political climate, the opposing and supporting stakeholders and policy makers, the informal and formal community leaders, and the legislative process (Mason & Leavitt, 1998). Knowing when to speak up, keep quiet, assemble support, form coalitions or task forces, and design strategies and plans of action are also important aspects of policy development. The tobacco settlement fund in Indiana is currently an active legislative issue, as are health care issues in general. Recommendations from the Kessler-Koop Advisory Committee (1997) stress the importance of reducing the health care issues caused by tobacco use, and the Indiana Primary Health Care Association (1999) continues to speak out about including tobacco control at the provider level. Along with the efforts of concerned individuals, these activities mean policy development and implementation could occur soon. Health care providers, including the nursing profession, must stay active in the legislative process to achieve this goal.

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Title V-CSHCN: A Closer Look at the Shaping of the National Agenda for Children With Special Health Care Needs

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Public health and/or maternal and child health nurses who manage or deliver services to children with special health care needs (CSHCN) in the community work within the policy context of state Title V programs. Those of us who become absorbed at state and local levels sometimes can lose sight of the broader perspective—of the forest for the trees—until something compels us to ask “What led to this change?” or “Who is behind the decisions that are being made?” or “Where are we going?” This article provides a brief historical background of the broader perspective of Title V-CSHCN programs. Kingdon’s multiple streams approach to policy formation is used as a conceptual framework to explore how policy was transformed in the 1980s to shape the national agenda for CSHCN. The article also discusses the effect of internal and external forces on the refinement of that agenda during the 1990s. Relevance for nursing practice is discussed, with validation that nurses can influence future policy development and implementation—in partnership with families.

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(b) how we help families and providers to interpret that policy at the community level, and
(c) how we may reinterpret it at the level of service provision to best meet the priorities of families.

**TITLE V-CSHCN: THE FIRST 45 YEARS**

The Title V Program of the Social Security Act of 1935, currently known as the Maternal and Child Health Block Grant, authorizes federal funds to states for maternal and child health services. This includes services to CSHCN. About 85% of the funds are distributed to each state through a block grant under a formula that corresponds to the percentage of the nation’s low-income children residing in each state. States are required to match federal funds at a minimum of three state dollars for every four federal dollars. Of the funds received by each state, 30% must be used to support CSHCN. The remaining funds are used to support Maternal and Child Health Bureau (MCHB) innovations and special projects (MCHB, 2000b).

Title V has its roots in the Children’s Bureau of 1912, whose mission was to study the economic and social factors affecting maternal and child health. A consequence was the enactment of the Sheppard-Towner (Maternity and Infancy Protection) Act in 1921. States were to develop health services for mothers and children in partnership with the federal government, which would provide, for the first time, grants-in-aid to each state (Schlesinger, 1967). This act was allowed to lapse in 1929 due to strong opposition from leaders in the Catholic Church, the Public Health Service, and the American Medical Association (Hutchins, 1994; McPherson, 1987). The act was criticized as being derived from socialistic philosophies and requiring that services be available to all residents, including immigrants and minorities, a revolutionary concept during that era. Nonetheless, the advent of the Great Depression and continued data collection efforts by the Children’s Bureau provided the basis for a new plan for children’s health and welfare programs. This plan for maternal and child health services, including those to “crippled” children, was implemented through the Social Security Act of 1935 as Title V (i.e., Part 5) of this legislation. This enabling legislation (i.e., the Social Security Act) was intentionally placed within an economic or social security framework versus a health framework (i.e., Public Health Services Act) because these measures were envisioned as protecting the home and consequently children (Schmidt & Wallace, 1988). Thus, a major role of government to address the needs of women, infants, children, and crippled children was established within states as part of a social policy that “conveyed greater respect for the dignity of individuals and families” (Zimmerman, 1995, p. 43). Nurses became involved as direct service providers in well-baby and crippled children’s program clinics, which emphasized health promotion, case finding, diagnosis, and treatment (Hoeman & Repetto, 1992).

Subsequent legislation provided additional supports to CSHCN. The enactment of Medicaid (Title XIX) in 1965 had a large impact on Title V programs because it broadened the funding base for the economic burden of payment of direct care services for low-income families and children. The Developmental Disabilities Act was enacted in the 1970s under the umbrella of mental health to meet the community-based needs of children and adults who were deinstitutionalized from state hospitals. A priority service under this act was case management (Linz, McAnally, & Wieck, 1989). The Social Security Amendments of 1972, meanwhile, created the Supplemental Security Income program (SSI) to assist families by providing monthly cash payments to low-income children with disabilities. This allowed families to pay for related services (transportation, respite, etc.) that are generally not covered by medical insurance. In 1976, funds were appropriated through the SSI/Disabled Children’s Program (SSI/DCP) to link low-income disabled children under the age of 7 to community-based services through a referral to the Title V agency, which provided care and service coordination. The *Sullivan v. Zebley* Supreme Court decision in 1990 expanded enrollment in the program by ruling that in the 1972 legislation, Congress intended that age-appropriate functional status should be taken into consideration when determining a child’s eligibility for SSI. In 1996, Congress changed its intent by adopting a narrower definition of childhood disability and implementing more restrictive eligibility criteria. This change in definition stopped the rapid expansion of the
program, which started in 1990 (Farel, 1997; see Doolittle, 1998, for discussion of SSI and the Personal Responsibility and Work Opportunity Reconciliation Act of 1996).

The Education for All Handicapped Children Act of 1975, later amended as the Individuals with Disabilities Education Act of 1990 (IDEA), guaranteed a free and appropriate education for all school-age children with disabilities. This required assessment of children who may need special education services through a multidisciplinary team of educators and health personnel, which culminated in an individualized education plan for each child. Amendments expanded special education to children between the ages of 3 and 5 years, and Part H addressed the needs of infants and toddlers. An important component of these efforts was the provision of related services (transportation, case management, etc.) to assure that the child would benefit from special education. The Part H legislation also provided a critical systems-change initiative, which required each state to develop a plan for statewide services integration with agencies serving this population. Health and education agencies with programmatic mandates to serve young children were required to collaborate on their efforts (Farel, 1997; Hutchins, 1994). Part H is now known as Part C in the reauthorization of IDEA.

In the early 1980s, the Title V-CSHCN program underwent changes in policy framework and implementation mechanisms. It is somewhat paradoxical that these implementation changes occurred during the politically conservative Reagan administration, which was intent on decreasing the size of federal government, containing federal spending, and returning control (devolution) of federally funded programs to the states. A consequence was the creation of the Maternal and Child Block Grant in 1981, which consolidated seven programs, including Crippled Children's Services and the SSI/DCP, under one grant. This meant that states had more discretion in the administration of this grant. At the same time, the national agenda for CSHCN emerged at the federal level during this decade of devolution and resulted in major enhancements of the original statutes. Kingdon's (1995) policy formation framework is used as an explanatory mechanism to discuss the elements of this transformation.

THE EMERGENCE OF THE NATIONAL AGENDA FOR CSHCN: THE 1980s

Kingdon (1995) uses a multiple streams or lens approach to explain the policy-making process under conditions of ambiguity. The three streams are composed of problems, policies, and politics. Problems are the issues and how policymakers learn about them. Policies are the ideas or proposals for how to deal with the issues. Politics is composed of the national mood or special interests that converge or interact at moments in time. These moments in time are referred to as policy windows within Kingdon's framework. Policy outcomes are multiply determined. They are influenced by the actions of individuals or groups, the timing or coincidence, and the political process. Policy entrepreneurs, meanwhile, are the individuals willing to invest “time, energy, reputation, money to promote a position for anticipated future gain” (Kingdon, 1995, p. 179). The job of the entrepreneurs is to use their influential position, recognize these windows of opportunity, and initiate action by creating strategies for bringing these three process streams together.

The Problems

The ambiguity in the early 1980s was a lack of clarity about the issues surrounding all CSHCN and their families, and therefore the extent of the problems and how best to address them. The lens was directed at identifying the concerns of families and their children who were ventilator assisted and technology dependent. This target population was chosen due to the complexity of their condition; the goals were to determine how best to allocate funds and to learn how to better support families (Koop, 1983). The strategy was that by targeting the most complex children, who used the most costly services, solutions would be identified for this population and those solutions would have applicability to all children with disabilities. Haas (1992) noted that “the problem’s scope needed to be defined so that regional systems of care that would safeguard quality and minimize abuse in or of the system could be developed and financed . . . standards of care needed to be developed” (p. 8). She also described changes in pediatric health care such as developments in neonatal technology, deinstitutionaliza-
tion, change in hospital policies regarding parental involvement, and mainstreaming and normalization concepts as concurrent influences on changes in the health care system. This first problem stream focused on clearly articulating the problem for an identifiable subpopulation of CSHCN, gauging the responsiveness of the service delivery system, and funding community-based services to raise awareness and give voice to family issues (Kirkhart & Gates, 1988).

The Policies

The policy stream consists of the general ideas that are generated, discussed, and revised in relation to the identified issues. Sometimes, these ideas are not connected to discrete issues until a compelling reason attracts them together. The strategic mechanism for bringing the ideas together with the issues or problems was to convene meetings with interested stakeholders. The notion of inviting stakeholders to discuss a topical area of concern with policy makers is credited to the collaboration of the MCHB with Julius Richmond, the Surgeon General and assistant secretary of health and human services during the Carter administration (V. Hutchins, personal communication, November 28, 2000). The initial Surgeon General meetings were directed at maternal and child health issues and resulted in a report released in December 1980 that became a precursor for the national Healthy Mothers, Healthy Babies campaign. Subsequently, three Surgeon General Conferences were held on behalf of CSHCN, and these became recognized as landmark events during the 1980s. The first Surgeon General Conference resulted in a series of specific issues and ideas, translated into concrete recommendations that led to funding of studies and demonstration projects. These initial projects involved research to define the issues and solutions, develop models, identify standards of care and regionalized systems of care, improve financing, identify and incorporate principles of care, and train health professionals (Koop, 1984). One of the results of these initial projects was a philosophical reorientation of CSHCN programs away from professional-directed, tertiary care-delivery systems toward family-centered care, parent-professional collaboration, and community-based systems of care (see Bishop, Woll, & Arango, 1993; Hobbs, Perrin, & Ireys, 1985; Hutchins & McPherson, 1991; Shelton, Jeppson, & Johnson, 1987). Another reconceptualization of thinking and working with families and their children was to retire the historical language of “crippled children.” The Omnibus Budget Reconciliation Act of 1985 changed the language of crippled children to the broader children with special health care needs, which emphasizes the child first and the disability second.

The Politics

The political stream encompasses the key changes in legislative or administrative leadership, the voices of special interests, the public mood, and the actions of the entrepreneurs. A number of forces and factors converged in the mid-1980s to bring CSHCN issues into the foreground. The first was the incoming Reagan administration’s recommendation to appoint Dr. C. Everett Koop as Surgeon General. Opposition to his appointment created a delay in his confirmation, and during that interim period, he became situated in the MCHB. Dr. Koop had lengthy experience as a pediatric surgeon in Philadelphia and a special interest in this population of children and families. Dr. Vince Hutchins, the director of the then–Office of Maternal Child Health (later the Bureau), had crossed paths with Dr. Koop in Philadelphia. Their opportunity to discuss mutual concerns about CSHCN and interest in replicating the success of prior maternal and child health policy meetings led to the first (1981) of three Surgeon General Conferences for CSHCN during the 1980s. The second factor that encouraged the events that were to unfold was that the Reagan administration had an interest in disabilities. Finally, other critical policy leaders (Dr. Merle McPherson and Kathy Bishop) within the MCHB corroborated the need to spotlight CSHCN. They supported the need to develop interdisciplinary teams, championed the inclusion of parents in the discussion, and acknowledged the overall need for “things to change” for this population (V. Hutchins, personal communication, November 28, 2000).

The national mood in relationship to this group of children and families mirrored the developing
consumer movement in the country. This move-
ment was evidenced by an increasing focus on the
rights of families, encouraged through the Educa-
tion for All Handicapped Children Act of 1975
and the Rehabilitation Act of 1973 (Section 504), as
well as individual advocacy by parents on behalf
of their children. Parents of CSHCN were com-
manding attention on local, state, and federal lev-
els. One of the initial and well-known grassroots
parent advocacy groups was formed in response
to state and federal education reform for children
with disabilities in 1974. This group, the Federa-
tion for Children With Special Needs in Boston,
remains composed of a broad coalition of disabil-
ity advocacy groups that have expanded their
focus beyond education (Robinson, 1999). Parents
were also involved at the executive level, where a
small conference of parents was convened to
advise President Reagan in the area of disabilities.
The federal authorization of “Katie Beckett
Waivers” in 1981 allowed thousands of children
to return home with technological support funded
by Medicaid in lieu of living their lives in institu-
tions. This endorsement of home and community
as the preferred site of care was the direct result of
advocacy by Julie Beckett, the mother of Katie
(Roberts & Considine, 1997). The family-centered
values of the policy entrepreneurs and the advo-
cacy of parents on behalf of their children and
families precipitated an invitation to the policy
table during the first Surgeon General Conference
in 1982. “It was serendipity . . . the timing was
right . . . it was natural to include families” (M.
McPherson, personal communication, November
28, 2000). Later in the decade, at the 1987 Surgeon
General’s Conference, another parent network
developed and matured into a national organiz-
a tion now known as Family Voices (Arango, 1997).

The Policy Window

In the late 1980s, the policy window described
by Kingdon (1995) opened, and the problem, pol-
icy, and political streams converged. Issues were
clarified, solutions were sought and applied, and
policy emerged. The national agenda for CSHCN
was unveiled in Campaign ’87—the third Surgeon
Generals conference for CSHCN. Conference par-
ticipants included pediatricians, parents, and rep-
resentatives from health care administration,
third-party reimbursement, health planning, and
health care financing (Koop, 1983, 1984). In other
words, many of the potential stakeholders had a
role in defining the issues and developing
solutions.

The national agenda sought to create systems of
care for all CSHCN. Most significant, this agenda
was enforced in amendments to the Title V legisla-
tion that were included in the Omnibus Budget
and Reconciliation Act (OBRA) of 1989. Through
these amendments, the Title V-CSHCN mandate
was broadened (a) to provide and promote family-
centered, community-based, coordinated care,
including care coordination; (b) to facilitate develop-
ment of community-based systems of care; and
(c) to provide rehabilitation services for blind and
disabled individuals under the age of 16 who
received benefits under SSI, to the extent these ser-
vice s were not covered by Medicaid. Koop sums
up the paradigm change over the decade as

moving our nation’s child health care system
from a categorical to a noncategorical paradigm
of service delivery; from medical to more
functional definitions of disability; from deficit
perspectives to strengths perspectives; from
clinical to family-centered philosophies; and
from isolated to integrated models of providing
services. (MCHB, 1997b)

This call to action, including the language of “sys-
tems of care” was later incorporated into Healthy
People 2000 and later updated in Healthy People
2010 (U.S. Department of Health & Human Ser-
sices, 2000).

One of the original concerns regarding block
granting, devolution to the states, and relaxation
of government oversight of state programs was
that great variability among states in eligibility
and program benefits could occur in the absence
of federal standards and monitoring (Wallace &
Gittler, 1997). This was remedied in the 1981 legis-
lation by requiring states to produce an annual
report of their intended expenditures and in the
1989 legislation by requiring a portion of block
grant funds to be specifically directed to CSHCN
programs. Furthermore, the culmination of a
decade of gradual shifts mobilized and reener-
gized a national constituency for maternal and
child health programs (Hutchins, 1994). The
transformation in Title V-CSHCN programs was official.

A REVISED NATIONAL AGENDA FOR CSHCN: THE 1990s

The policy process does not conclude with the articulation of a specific policy. It continues to be shaped through implementation activities and responses to emerging internal and external forces. This discussion briefly reviews four of the internal and external influences that followed OBRA 1989 and necessitated some modification to the national agenda for CSHCN. These include a new conceptual framework, government accountability, the growth of managed care, and the enactment of the State Children’s Health Insurance Program (SCHIP).

A New Conceptual Framework

The landmark report The Future of Public Health (Institute of Medicine, 1988) resulted in universal acceptance that public health has three core functions: assessment, policy development, and assurance. In keeping with this model of public health, maternal and child health leaders sought to “define the elements of personal and public health systems and services necessary to assure appropriate focus on the needs of women, children, and youth” (Dievler, Grason, & Guyer, 1997, p. 6). This framework serves as a consensus umbrella and strategic planning process for federal, state, and local partners (Grason & Guyer, 1995). It directly affects state Title V-CSHCN programs by emphasizing a focus on prevention and population-oriented health services and decreasing emphasis on the provision of direct care services, which has been a traditional function of state Title V-CSHCN programs.

Government Accountability

The impetus for accountability in the federal government, on performance and results, was codified in the Government Performance and Results Act (GPRA) of 1993. This was preceded in 1992 by then-Vice President Gore’s National Performance Review to redesign and reinvent government and make it more entrepreneurial, customer driven, and results oriented. Meanwhile, the November 1994 election resulted in a Republican majority in both houses of Congress, with their reform agenda, a Contract with America. Bingman and Pitsvada (1998) note that these two programs represented an almost “unprecedented coincidence of political initiative—one presidential and one congressional—to reform federal government operations” (p. 763). The GPRA was a powerful initiative that was intended to hold federal agencies accountable for spending taxpayer dollars. It included Congress and involved stakeholders in the planning and review process, and it strengthened the federal-state partnership. Consequently, the MCHB developed a 5-year plan to evaluate state Title V agency performance. The 1998 to 2003 strategic plan identifies three major goals that are consistent with those of its parent agency, the Health Resources and Services Administration (HRSA) and Healthy People 2010 (U.S. Department of Health & Human Services, 2000). These goals are (a) to eliminate barriers and health disparities, (b) to assure quality of care, and (c) to improve the health infrastructure and system (MCHB, 1999). The long-range strategic goal of HRSA and the MCHB is to assure 100% access to care and 0% health disparities for all Americans.

The CSHCN specific block grant performance measures, which complement Healthy People 2010 objectives, are directly related to the 1999 OBRA legislative mandates, as well as state-selected measures. States are required to report progress in meeting performance measures on an annual basis. The measures identify four types of agency activities, which are represented in a pyramid. The base or foundation of this pyramid is composed of population-based and infrastructure-building activities. The tip or smallest surface area of the pyramid contains direct service delivery, whereas enabling services are sandwiched in between the top and bottom. This visual presentation of population-based preventive services at the base is consistent with the core functions and essential services identified for public health and maternal and child health services. The performance of the activities at the different levels of the pyramid is measured by three dimensions of agency performance, which are the resources, the results and outcomes, and the impact on the
population (MCHB, 1997a). In addition, the development of an electronic information system in 1999 provides accessibility of information to the general public regarding state progress in achieving these measures (MCHB, 2000b).

Managed Care

The research regarding the effects of managed care on CSHCN is ambivalent. This population of children is particularly vulnerable because they may not receive the broad range of services they may need under managed care arrangements. On the other hand, CSHCN benefit from primary care and preventive services that were not accessible in the past through the fee-for-service system (Grossman, Rich, Michelson, & Hagerty, 1999; Mele & Flowers, 2000; Newacheck et al., 1996; Simpson & Fraser, 1999; Szilagyi, 1998). Of current concern is the increasing practice of state Medicaid programs to enroll CSHCN in mandatory capitated managed care or prepaid health plans, where use and cost are strictly monitored. This may imply restriction to a broad range of services that these children require on a daily basis. This has precipitated the development of certain safeguards for CSHCN enrolled in Medicaid managed care. The criteria require states to define these children, identify them within the plan, assure provider capacity, provide case management/care coordination, measure quality, develop risk adjustment methods, and monitor access (Health Care Financing Administration, 2000).

State Children’s Health Insurance Program

The enactment of the State Children’s Health Insurance Program (SCHIP), Title XXI of the Social Security Act, allows states to initiate and expand the provision of child health insurance to uninsured, targeted, low-income children. A targeted, low-income child is defined as a child under the age of 19 who is not Medicaid (Title XIX) eligible or covered through some other health insurance and whose family income does not exceed the state Medicaid income level by more than 50 percentage points (Mayer, Kavanagh, & Carpenter, 1998). This legislation has provided additional economic support to Title V-CSHCN programs by filling the health insurance gap between private insurance providers and Medicaid. It also provides opportunities and challenges to CSHCN programs to determine how to maximize their resources and coordinate their activities around children funded through SCHIP and Medicaid and have access to family-centered, community-based, coordinated systems of care (Association of Maternal and Child Health Programs, 2000).

The Revised National Agenda for CSHCN

Three policy briefs were disseminated by the MCHB in the late 1990s. These reemphasize the values and priorities of family-centered, community-based, coordinated, comprehensive, and culturally competent care (MCHB, 1997b, 1998, 2000a). Cultural competence, although not included in the language of either the 1987 Surgeon General’s Conference or in the OBRA 1989, was promoted through the efforts of a small work group in 1990 (Roberts & Evans, 1997). As a result of this and subsequent formation of a National Resource Center on Cultural Competency, the value of cultural competency was incorporated into policy. The changes in the external environment—the emphasis on population-based and enabling activities versus direct care, concern with managed care, implementation of SCHIP, and government accountability—are creating challenges for the future of Title V-CSHCN. The following revisions in the national agenda, as stated in the policy briefs, reflect these influences and challenges: (a) focus on models of service delivery that resolve cost and utilization issues and include family participation, develop quality assurance mechanisms, improve data and evaluation activities, and integrate managed care programs within a system of community services (MCHB, 1997b); (b) identification of outcome indicators: screening, access to a medical home, insurance, services organized in ways that families can use them, family participation in decision making at all levels of care, transition of youth to adult health care, work, and independence (MCHB, 1998); and (c) a 10-year state-gic plan to direct the work of the MCHB in partnership with Family Voices, the American Academy of Pediatrics, and other partners to focus on sustainable development of service systems and direct attention to assisting state agencies (MCHB, 2000a).
RELEVANCE FOR NURSING PRACTICE

Reflection on the past, present, and future of Title V-CSHCN policy allows nurses to gain a perspective that can be instructive and refreshing. Givens and Carpenter (2000) and Arango (1997) acknowledge the contribution of nurses on behalf of mothers and children and offer a few ways in which nurses can continue to make a difference. These include advocating for the needs of one child at a time, increasing the visibility of what nurses do, networking with those who can influence the system (particularly professional organizations), learning how to influence the legislative process, and becoming active in the political process.

Nurses must also look toward the horizon and be sensitive to changes in their external environment. A potential policy, the Family Opportunity Act, known as the Dylan Lee James Act, was initially introduced into the U.S. Senate in March 2000 and reintroduced into both houses on February 13, 2001. Nurses should be keenly interested in this bill. Its major provisions are concerned with expanding Medicaid to middle-income families with children who have severe disabilities to assure that families can continue to work and receive health insurance coverage for their children. It includes home- and community-based options for psychiatric services for children currently in hospital settings. It provides for state innovation in determining how best to prevent the development of severe disability as a result of lack of health care access. Finally, it establishes state family-to-family health information centers staffed by parents and professionals to assist families in accessing the broad range of services they need. Family Voices, the parent group born of the Title V-CSHCN transformation, has spent the past 7 years building and developing networks and partnerships to help move this legislation forward. State and community nurses should be particularly involved in the development and staffing of the resource centers with families.


CONCLUSION

Nursing practice and policy are inextricably linked. Nursing practice reflects policy through implementation, and concurrently, nursing practice re-creates the meaning of that policy. Nurses at state and local levels of practice are employing methods to remove obstacles, find and take alternative routes, use political skills to negotiate for what families need, and create child- and family-friendly policy. These innovations need to be shared. Families already acknowledge the importance of nurses:

"The information that our children’s nurses provide us... community health resources, innovative procedures, helpful organizations, and pitfalls in managed care or fee-for-service systems can affect how we families take care of our children... But we can’t do it alone." (Arango, 1997, p. 402)

Systems of care are being built at the place where families live and nurses practice—in the community. Let us continue to contribute our voice and expertise to the development and implementation of the national agenda for CSHCN.

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