Assuring the Effective Development of A Family Resource Center: Advanced Degree Nurse as Clinical Education Program Manager

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Citation

Abstract
Since the 1970's, the Advanced Degree Nurse's (ADN) role has evolved and expanded to include clinical, consultative, administrative, research and evaluation, and program planning responsibilities. This paper describes the Advanced Degree Nurse's (ADN) contribution to the design and execution of two program activities to assure the effective development of a resource center for persons with disabilities and their families. Program activities were: a) gather information from professional staff on the resource needs of persons with disabilities, helpful resources, barriers to accessing resources, and how needs changed over time and b) to review web site information and interview administrator's from exemplar centers around the United States. Findings corroborate those found in the literature and expand to include the focus on resource needs as a holistic and life long process, capitalize on existing helpful resources, confront barriers as opportunities to acquire new resources, realize that persons with disabilities and their families evolve through developmental stages that correspond to persons and families without disabilities, and recognize the array of human and technological resources required to establish a resource center.

INTRODUCTION AND PROBLEM STATEMENT
According to the data from the Analysis of the Survey of Income and Program Participation (SIPP), an estimated 54 million (20%) of all non-institutionalized American adults live with some type of disability. This study also indicates that this 20% experiences some activity limitation due to a chronic health condition or impairment (1). Furthermore, data from the 1994 National Health Interview Survey [NHIS] reveal that an estimated 4.4 million (6.5%) children under 18 years of age who are in the non-institutionalized population have activity limitations due to an acquired or congenital chronic condition (2).

A rehabilitation facility (RF) in a large Midwestern city has been at the forefront of medical rehabilitation for over 40 years. Over 80% of patients from this RF are discharged back to their communities. Professionals at FR are dedicated to delivering comprehensive, state-of-the-art, and fiscally responsible health care. However, the current health care environment presents with shorter lengths of hospital stay, a nursing shortage, a managed-care environment (3,4,5,6,7,8,9,10). Thus, the growing volume and needs of persons with disabilities and RF staff's dedication to this population coupled with the health care environment created the need to develop a centralized and accessible patient and family resource center that would assist staff with meeting consumer health care needs. The RC was projected to be a patient and consumer learning resource center dedicated to providing information and support for people with disabilities and families in response to life events.

Programmatic innovations often emerge from those directly involved with the issues at hand and the success of such programs is often dependent on the process of obtaining stakeholder participation, guidance, and perspectives from the onset (11,12). The process used to obtain stakeholder participation can vary from hiring marketing consultants or hiring professionals with expertise and knowledge in project development. Advanced Degree nurses (ADN) have formal education and training to be program innovators and collaborators.

With this in mind, the RF administration initially hired an ADN who functions as a clinical education program manager (CEPM) in collaboration with the program director to develop the Resource Center (RC). At the time the CEPM was hired, the director had designed a preliminary framework for the Center. This framework centered on providing resources in eight categories: medical information,
care and treatment, recreation, employment, community living, healthy living, and renewal. The initial goal was to identify and obtain appropriate resources.

Funding for the Center came from philanthropic endeavors and private donors who assumed that funds would be used judiciously. To ensure that the Center was fiscally responsible and provided up-to-date and appropriate consumer health and patient education resources, it was required that development activities take place. This paper describes the contributions of two initial program development activities: discussion groups with medical rehabilitation staff at the RF and data reviews of exemplary libraries around the country initiated and directed by the Advanced Degree Nurse ADN clinical education program manager CEPM.

LITERATURE REVIEW

ROLE OF THE ADVANCED DEGREE NURSE

Since the 1970s, ADN's have been widely used within the health care arena in a variety of roles (14; 15; 16; 17; 18; 19). Some of these roles include administrative, educator, researcher, clinician or primary provider in community, acute, rehabilitative, or long-term care to name a few. As a result, the ADNs' primary focus may be the client or patient(s), student or staff nurse, and/or organization. Regardless, ADN's are prepared to demonstrate clinical expertise across the continuum of care, consult with other professionals, promote effective and efficient health care, conduct or participate in research, and act as a mentor or role to other staff (20).

Within each role, the ADN has the ability to create a setting for health care discourse (21; 22). The purpose of the discourse involves decision-making and systematic and inclusive problem solving within the broad scope of advanced practice. The nursing process provides a framework for discourse that includes assessment, planning, implementation, and evaluation phases and promotes interdependence and collaboration among participants and systems of health care. Consequently, discourse often leads to maximized resources, cost-effective and efficient programming, and successful collaborations (23; 24; 25).

Conversely, health care innovations frequently originate from anecdotal or clinical experience. In order to substantiate innovations as well as minimize the risk of duplicating services and inefficient programming, the ADN draws on knowledge and expertise in formative evaluation, organizational development, and communication skills (26; 27; 28; 29). Based upon the aforementioned reasons, ADNs implement health care innovations to address the identified or target populations, utilize current resources, address barriers, and cultivate new resources.

PERSONS WITH DISABILITIES

Disabilities, also known as activity limitations, restrict a person's ability to perform activities of daily living (ADLS): e.g., toileting, bathing, mobility, or instrumental activities of daily living (IADLS): e.g., attending school, working, or socializing. Activity limitations can be the result of either a congenital disease, e.g., cerebral palsy, or an acquired disease, e.g., multiple sclerosis, arthritis, or a traumatic event, e.g., spinal cord injury or traumatic brain injury (30). The range and depth of services needed by persons with disabilities (PWD) result in higher costs of health care than for the general population (31; 32). The current integrated health care system is not designed to serve the needs of PWDs. Persons with disabilities receive services from an array of public and privately funded programs that provide single services such as health care, social, and income services. As a result, PWDs and their families are forced to navigate through a complex service delivery system. As advances in medicine increase the life expectancy for persons with chronic diseases and disabilities, the number of disabled increases along with their life-long needs (33).

Progressing from one developmental life-stage to the next and participating in society regardless of having an activity limitation is a fundamental right for all individuals. Research indicates that people with disabilities and their families have a myriad of needs that require resources to promote and support their successful development and participation in society (34; 35; 36; 37; 38; 39; 40). These needs include ongoing medical education, vocational and/or post-secondary education and training, patient and family support, health care coverage, and advocacy to name a few.

Furthermore, PWDs and their families experience similar needs as persons without disabilities that coincide with the developmental life-stages. These stages and need include: infancy—separation, autonomy, mobility skills; latency/school-age—peer and school relationships; adolescence and young adulthood—maturing body, sexuality, intimacy, career and post-secondary education, separation from family, peer relationships; adulthood and middle age—marriage, family, career; and older adulthood
- family, career and contemplating about retirement, affects of aging process on health status. However, the difference between these two groups is that the intensity for need is heightened, the available resources are often fewer, and the societal barriers are often greater (41:42). Throughout the lifespan, PWDs and their families require social, psychological, financial, and emotional support (43:44:45), integration and reintegration into the community, health information (46:47:48); and caregiving (49:50:51:52:53).

In 1998, Louis Harris and Associates conducted the National Organization on Disabilities (N.O.D.)/ Harris Survey (54). One thousand Americans with disabilities age 16 years and over were interviewed over the telephone. Based on all respondents data show the following were problems that they “sometimes face” are: not having enough money, (68%); inadequate health insurance, (40%); inadequate work opportunities, (34%); not having a full social life, (51%); inadequate transportation, (27%); negative public attitudes, (31%), and poor access to public facilities, (25%)-55.

Literature highlights the prevalence of persons living with disabilities and their comprehensive unmet needs that pose limitations in their ability to access resources and participate in society to their fullest capability (56;57). Innovative programs can strengthen and promote access to the necessary resources and establish collaborations that cultivate stakeholder participation. Advanced Degree nurses have the formal education to conduct activities to assure effective programming occurs.

PROGRAM DEVELOPMENT METHODS

To ensure that resources would be efficiently dedicated and procured, the clinical education program manager, along with the director and administrative coordinator, initiated and guided conducting discussion groups with medical rehabilitation staff at the RF and interviewing administrators of resource centers around the county. These two activities are referred to as program development activities. Each activity is described separately. Descriptions include the purpose of the activity, procedures, analysis, and findings.

PROGRAM DEVELOPMENT ACTIVITY ONE: DISCUSSION GROUPS WITH MEDICAL REHABILITATION STAFF

The overall purpose of conducting discussion groups with medical rehabilitation staff was to identify their perspectives on consumer resource needs, helpful resources, barriers to accessing resources, and how need change over time. Data were collected from medical rehabilitation RF staff by holding discussions at their monthly staff meetings around the following questions: (a) What are the resource needs for persons and families with disabilities? (b) What resources have been helpful? (c) What are some of the difficulties in accessing resources? and (d) How does the need for resources change over time? The CEPM and Director interviewed a total of 123 who participated in one of 17 discussion groups. The participants were self-selected, cross-sectional and included physicians, care managers, nurses, occupational, physical, recreation, speech, sports, and vocational therapists, psychologists, social workers, administrative coordinators, environmental, security, food services, and ancillary professionals associated with the system of care. Each group lasted approximately one-hour. Notes were taken on directly entered into the computer and evaluated by content analysis technique.

The unit of analysis was the groups and not the individuals within the group. Descriptive statistics were used to describe the demographics as shown in Table 1. The researchers, the CEPM and the Program Director used alphabetical codes to maintain the confidentiality of information associated with each group. Responses to the open-ended assessment questions were analyzed by transforming qualitative data into quantitative data by coding based on defined categories. Data transformation occurred according to the Center staff and researcher adhering to the following process: (a) reviewed the content of transcript notes for each discussion group and each comment was assigned to a category that emerged from the data, (b) clarified categories and content for inter-rater reliability and consistency, (c) quantified the number of comments per category, totaled these comments, and (d) identified whether a group had a comment within that specific category. What was important was whether there was a comment within that group, NOT the number of comments within that group that became important. The researchers, the CEPM and the Program Director did not assign a separate weight based on the number of comments that fell into each category.

FINDINGS

All groups ranged in size from 4 to 13 members (M= 7; mdn = 7) except for one group that had two members. Key findings for this activity are presented by assessment question.

Most pressing needs for resources. Participants were asked,
“Based on your experience, what are your patients’/families’ most pressing needs for resources?” Table 1 shows the need for resources by group. Participants identified 11 pressing needs for resources, which are listed in order of highest percent shown among groups.

(a) Housing. A place to live that is accessible and affordable, having reasonable modifications and accommodations, intended to foster independent living in the least restrictive setting. Housing may be a group home, small apartment, and single-room occupancy.

(b) Psychosocial support, emotional, mental, spiritual, cognitive support to promote and or enhance coping, self-acceptance, and personal and family adjustment.

(c) Caregiver assistance and respite, family members that provide direct care to the PWD so that they can remain at home. Respite is temporary relief of providing caregiving.

(d) Finance, monetary resources including money, capital, and credit in order to pay for services necessary to function as independently as possible. Problems defined as insufficient funds and/or difficulty with access information regarding coverage.

(e) Transportation, the ability to locate and secure affordable and accessible transportation that would enable participation in daily life activities, including being able to assess one's ability to continue to drive.

(f) Recreation and socialization, Activities engaged in for pleasure that support building relationships, decreasing social isolation and providing the opportunity to develop new skills and/or interests.

(g) Medical information, Knowledge regarding preventive, restorative, curative facts/tips pertinent to patient teaching. Information on the symptoms, diagnosis and treatment of disease to help patients and their families better understand what has happened to them and the outcomes they can expect to achieve (58).

(h) Equipment, any devices necessary to increase independence and functioning; e.g., wheelchairs, adaptive clothing, or scooters.

(i) Education, the primary, secondary, post-secondary, or vocational training offered in a formal setting that provides the individual with the skills and knowledge relating to choosing a career, getting and keeping a job, and making job and career changes.

(j) Care and treatment, trained and licensed professionals providing “tip sheets” and basic education for patients and families in order to maintain activities of daily living (ADL’s) and to promote functioning.

(k) Employment, having a paying job either full-time or part-time that ultimately increases the individual's level of independence.

Figure 1
Table 1. Most Pressing Resource Needs

<table>
<thead>
<tr>
<th>Resource Needs</th>
<th>Number of Groups</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housing</td>
<td>12</td>
<td>71%</td>
</tr>
<tr>
<td>Psychological Support</td>
<td>11</td>
<td>65%</td>
</tr>
<tr>
<td>Caregiver Assistance</td>
<td>11</td>
<td>65%</td>
</tr>
<tr>
<td>Finance</td>
<td>11</td>
<td>65%</td>
</tr>
<tr>
<td>Transportation</td>
<td>10</td>
<td>59%</td>
</tr>
<tr>
<td>Recreation &amp; Socialization</td>
<td>10</td>
<td>59%</td>
</tr>
<tr>
<td>Medical Information</td>
<td>10</td>
<td>59%</td>
</tr>
<tr>
<td>Equipment</td>
<td>10</td>
<td>59%</td>
</tr>
<tr>
<td>Education</td>
<td>9</td>
<td>53%</td>
</tr>
<tr>
<td>Care &amp; Treatment</td>
<td>8</td>
<td>47%</td>
</tr>
<tr>
<td>Employment</td>
<td>6</td>
<td>35%</td>
</tr>
</tbody>
</table>

Includes one group that mentioned spiritual needs

Helpful resources. Participants were asked, “What are some of the [most helpful] best resources you've found to be useful in assisting your patients and their families?” The five most helpful resources identified were:

(a) Condition-related societies, Organizations whose mission are to provide services to those with specific conditions: i.e. Multiple Sclerosis Society, Spinal Cord Injury Association, and Brain Injury Association. Services include peer support groups, equipment lending closets, and up-dated information about their respective conditions.

(b) Not-for-profit community organizations, assistance offered by not-for-profit organizations to individuals with specific conditions in a particular locale: i.e., Access Living,
community centers in general/places of public gathering.

(c) City, state, or federal government organizations, Public services delivered to the community and funded through government monies. For example, the local school system and/or personnel within the school system that enable all eligible children with disabilities a public education in an appropriate environment. In this case, special education services, guidance counseling, special therapies supplied by the school system.

(d) Educational materials, Resources designed either by RF staff: i.e., tracheotomy care, or purchased from an outside vendor; i.e., transferring to a wheelchair, with the aim at providing a wide-array of health information to the patient and/or family. Participants did not make a distinction between patient education and consumer health education materials. However, all groups mentioned that technology, as a medium to transfer information, improved access to resources via the Internet or other telecommunications.

Difficulties in getting resources or barriers. Participants were asked, “What are some of the difficulties that your patients and/or their families experience in getting resources?” Participants cited that limited or no resources available, which included lack of financial resources and transportation or support, and the patient’s lack of knowledge about resources, were the main barriers. Participants expressed that the demand for resources is greater than the supply of resources needed. Examples of limited or no resources available are: the inability to find a suitable caregiver to hire, accessible housing, timely transportation, employment (there are more jobs available than qualified people to fill the positions), or being single parent who is hospitalized and has no one to provide childcare. Meanwhile, examples of the patient’s lack of knowledge about resources are not knowing about specific government entitlements, or implications of public laws such as the American with Disabilities Act.

How patient needs change over time? Participants were asked, “We understand that a patient’s need for resources may change over time. In what way, if any, have the needs of your patients/families changed over time?” Participants said that natural changes related to aging and normal development across the life span are impacted by or impact the person with a disability can be attributed to age-related changes; the change from a physical emphasis to a psychosocial emphasis, moving from physical to psychosocial/fuller life/ learning self-acceptance/new you

—Initial focus was on walking, ADL’s, being as physically independent as possible, but then focusing on emotional, mental, cognitive, recreational, social, and educational adjustments in order to live life fully; and a change in functional status, moving from a dependent level of functioning (needing an assistive device or hands-on assistance) to a more independent level of functioning, i.e., relying on a person for assistance to ambulate, to using a walker, then to a cane, or not needing any assistive devices or a decrease in function, in a person’s level of independence due to a new symptom or new illness.

PROGRAM DEVELOPMENT ACTIVITY TWO: INTERVIEWS WITH RESOURCE CENTERS/LIBRARIES

A second program development activity was to conduct interviews with administrative representatives from rehabilitation resource centers and libraries across the country. The purpose of this activity was to learn from colleagues’ experiences and to begin to establish organizational linkages. The CEPM interviewed representatives from 16 resource centers throughout the United States. Centers were identified via a snowball technique. The CEPM identified the top 20 Rehabilitation hospitals in the County and contacted them via email and telephone. Some respondents could then suggest to the CEPM to contact a particular representative from a library not included on the initial list. Due to time and staffing constraints, we had to limit the number of centers interviewed to 16. Administrators were contacted either by e-mail or telephone and asked if they would be willing to answer a few questions in regard to their respective centers or libraries. The subsequent six questions were asked: (a) Please describe the library (population served, location, and type of resources available in your library:. (b) What hours is the library open? (c) What are the human resources used to operate the library, e.g., paid staff, use of volunteers? (d) Do you have a web site? (e) Do you provide Internet access for public use? If so, how many computers do you have available for public use? And, (f) What, if any, suggestions do you have for us as we develop our resource center?

Information was typed or transferred from e-mail directly into the computer file. Since information regarding the library is public knowledge, informed consents were not obtained. However, we used alphabetical and numeric codes to maintain the confidentiality of the information associated with each center. Responses were analyzed by descriptive
techniques and open-ended responses were analyzed by content analysis.

**FINDINGS**

A total 16 centers were interviewed. Key demographic findings are shown in Table 2. Eight centers provide primarily consumer health education, five provide consumer health and patient education information, and three provide patient education, consumer health information, and professional health education. Eleven centers were located in acute care hospitals; four were in solo rehabilitation hospitals and one was off-campus from a university. The population served varied from eight centers primarily serving all age groups across the life span, five serving pediatrics (birth through age 21 years), and three serving solely adults (over 21 years).

**Figure 2**  
Table 2. Demographic Information

<table>
<thead>
<tr>
<th>Location of Library</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute care hospital</td>
<td>11</td>
</tr>
<tr>
<td>Rehabilitation</td>
<td>4</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Type of Information Available</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consumer Health</td>
<td>8</td>
</tr>
<tr>
<td>Patient Education</td>
<td>5</td>
</tr>
<tr>
<td>Professional Education</td>
<td>3</td>
</tr>
<tr>
<td>Consumer Health &amp; Patient Education</td>
<td>8</td>
</tr>
<tr>
<td>Professional Education, Consumer Health &amp; Patient Education</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Target Population</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Ages</td>
<td>8</td>
</tr>
<tr>
<td>Adults</td>
<td>3</td>
</tr>
<tr>
<td>Pediatrics</td>
<td>5</td>
</tr>
</tbody>
</table>

**AVAILABILITY AND HUMAN AND TECHNOLOGICAL RESOURCES.**

All libraries are open five days a week during regular business hours (Monday through Friday, 8 am through 5:30 pm; three libraries have some type of weekend hours with staff or volunteers); two libraries are open one evening per week; and two libraries are open, but not staffed 24 hours a day (refer to Table 3). Several libraries had hot lines or call-in lines in which people could leave a message with a question and receive a response within a designated time frame.

<table>
<thead>
<tr>
<th>Library</th>
<th>Hours Open</th>
<th>Additional Standard Monday-Friday Dependent on AM/PM</th>
<th>Web Site</th>
<th>Number of Computers Available</th>
<th>Availability and Human and Technological Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>8:00 AM</td>
<td>5:30 PM, 7:00 PM, 8:00 PM, 8:30 PM, 9:00 PM, 10:00 PM</td>
<td>1</td>
<td>2</td>
<td>Full-time Equivalent (FTE) Staff.</td>
</tr>
<tr>
<td>B</td>
<td>9:00 AM</td>
<td>5:00 PM, 6:00 PM, 7:00 PM, 8:00 PM, 9:00 PM, 10:00 PM</td>
<td>1</td>
<td>3</td>
<td>Full-time Equivalent (FTE) Staff.</td>
</tr>
<tr>
<td>C</td>
<td>8:00 AM</td>
<td>5:00 PM, 6:00 PM, 7:00 PM, 8:00 PM, 9:00 PM, 10:00 PM</td>
<td>1</td>
<td>4</td>
<td>Full-time Equivalent (FTE) Staff.</td>
</tr>
<tr>
<td>D</td>
<td>9:00 AM</td>
<td>5:00 PM, 6:00 PM, 7:00 PM, 8:00 PM, 9:00 PM, 10:00 PM</td>
<td>1</td>
<td>5</td>
<td>Full-time Equivalent (FTE) Staff.</td>
</tr>
<tr>
<td>E</td>
<td>8:00 AM</td>
<td>5:00 PM, 6:00 PM, 7:00 PM, 8:00 PM, 9:00 PM, 10:00 PM</td>
<td>1</td>
<td>6</td>
<td>Full-time Equivalent (FTE) Staff.</td>
</tr>
<tr>
<td>F</td>
<td>9:00 AM</td>
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<td>1</td>
<td>7</td>
<td>Full-time Equivalent (FTE) Staff.</td>
</tr>
<tr>
<td>G</td>
<td>9:00 AM</td>
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<td>1</td>
<td>8</td>
<td>Full-time Equivalent (FTE) Staff.</td>
</tr>
<tr>
<td>H</td>
<td>9:00 AM</td>
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<td>1</td>
<td>9</td>
<td>Full-time Equivalent (FTE) Staff.</td>
</tr>
<tr>
<td>I</td>
<td>9:00 AM</td>
<td>5:00 PM, 6:00 PM, 7:00 PM, 8:00 PM, 9:00 PM, 10:00 PM</td>
<td>1</td>
<td>10</td>
<td>Full-time Equivalent (FTE) Staff.</td>
</tr>
<tr>
<td>J</td>
<td>9:00 AM</td>
<td>5:00 PM, 6:00 PM, 7:00 PM, 8:00 PM, 9:00 PM, 10:00 PM</td>
<td>1</td>
<td>11</td>
<td>Full-time Equivalent (FTE) Staff.</td>
</tr>
<tr>
<td>K</td>
<td>9:00 AM</td>
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<td>1</td>
<td>12</td>
<td>Full-time Equivalent (FTE) Staff.</td>
</tr>
<tr>
<td>L</td>
<td>9:00 AM</td>
<td>5:00 PM, 6:00 PM, 7:00 PM, 8:00 PM, 9:00 PM, 10:00 PM</td>
<td>1</td>
<td>13</td>
<td>Full-time Equivalent (FTE) Staff.</td>
</tr>
<tr>
<td>M</td>
<td>9:00 AM</td>
<td>5:00 PM, 6:00 PM, 7:00 PM, 8:00 PM, 9:00 PM, 10:00 PM</td>
<td>1</td>
<td>14</td>
<td>Full-time Equivalent (FTE) Staff.</td>
</tr>
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<td>9:00 AM</td>
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<td>15</td>
<td>Full-time Equivalent (FTE) Staff.</td>
</tr>
<tr>
<td>O</td>
<td>9:00 AM</td>
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<td>1</td>
<td>17</td>
<td>Full-time Equivalent (FTE) Staff.</td>
</tr>
</tbody>
</table>

1 Only one-page description of library on the home organization’s web site.  
2 Resource information integrated throughout hospital web site.  
3 Full-time equivalents.

Eleven libraries have a web site of information that can be reached either through their home organization’s web address or by their direct web address. The information on the web sites varies and includes: listing upcoming educational programs offered at the library or in the local community, patient education and consumer health education materials housed in the library, and links to government resources or national organizations. Four of the libraries have a one-page advertisement on their home organizations’ web site and one library does not have a link to their home organization’s web site or an advertisement on the home page.

Each library has at least one computer for public access, with the exception of one center, which plans to purchase a computer for public access. The number of computers available for public access ranged from 2 to 20. The majority of libraries have between two and five computers available to the public.

Human resources included hired staff and volunteers. The number of full-time equivalents (FTE’s) ranged from .0 FTE
Eleven libraries have at least one part-time librarian on staff and additional staff included registered nurses (RN), Master's Social Workers (MSW), life specialists, and information specialists. In addition to paid staff, eight libraries rely on volunteers to operate the library.

SUGGESTIONS

Responses to the open-ended question regarding suggestions centered on the selection of materials and the distinction between patient education and consumer health education.

Selection of Materials. Consumer health and patient education are seen as two distinct entities. Although they may overlap, the type of information and staff that is responsible for reviewing and compiling information have distinct skills and roles. Furthermore, materials selected are based on consumer needs, professional staff requests, literature reviews, web searches, and recommendations from Consumer Health Guides and they are consistent with the mission of the organization and its standards of care. All libraries fall into one of three Models/Types: (a) Consumer Health, (b) Consumer Health and Patient Education, and (c) Consumer Health, Patient Education, and Professional Education. With the exception of one center that houses both consumer and patient education materials, all patient education materials are produced and reviewed by a patient education committee set outside the center. A representative from the center may or may not sit on this committee.

Make distinction between patient education and consumer health education. Representatives suggested that the skills needed to locate, monitor, and disseminate consumer health information differ from skills needed to locate, monitor, and disseminate patient education information. Furthermore, almost all of the representatives referred me to the Consumer Health and Patient Health Information Section of Medical Library Association website to better understand the distinction between the two.

Patient education/information. Planned activity initiated by a health professional, whose aim is to impart knowledge, attitudes, and skills with the specific goal of changing behavior, increasing compliance with therapy and, thereby, improving health (61).

Consumer education/health information. Is information on health and medical topics provided in response to requests from the general public, including patients, and their families.... In addition, CHI encompasses information on health promotion, prevention medicine, the determinants of health and accessing the health care system (58).

LIMITATIONS OF PROGRAM DEVELOPMENT ACTIVITIES

The element of time and manpower dictated the need to limit the number of libraries interviewed and the time and method of collecting information from medical rehabilitation staff. Hence, participants and/or respondents may not have had enough time to thoroughly cover each question and therefore meaningful information may have been unnoted.

DISCUSSION OF CONTRIBUTIONS AND NURSING IMPLICATIONS

Discussion groups contributed to the Resource Center's development in four ways. The first is that findings corroborate that persons with disabilities contend with problems highlighted in the literature; i.e., finance, transportation, employment, and recreation and socialization. The second is that findings highlight the need to appreciate that the life expectancy of persons with disabilities is increasing due to medical advances and therefore, they face similar issues associated with developmental life stages as persons without disabilities. Albeit, moving through life-stages may be complicated as a result of disability, but not unrealistic or unattainable. Perhaps, complications can be minimized with a framework that addresses the holistic needs of all persons and the many realms of life that are encountered day to day; e.g., food, shelter, and mobility. Third, findings suggest that the initial eight categories for the Center be refined to coincide with categories cited in the literature and from this activity. For example, instead of listing “community living” as a category, be more specific and list housing, transportation, and finance. Finally, findings contribute to establishing a foundation for gathering resources and establishing capacity building activities to address barriers. Thus, the center staff establishes solid connections and develops collaborations with those resources deemed “helpful”. Nonetheless, the Center staff will need to ensure that resource information is accessible to all PWDs and their families and providers. Furthermore, where there is a dearth of resources it should be brought to the attention of key stakeholders. For example, the lack of information about resources is a barrier to obtaining them. Therefore it is necessary to create a network or cadre of organizations to disseminate service delivery information and hire PWDs to use their talents to disseminate information.
Interviews, web site reviews, and/or e-mail correspondence with 16 resource libraries contributed to the program’s development by capturing three models of Consumer Resource Libraries or Libraries and clearly making the distinction between consumer health and patient education. These models are Consumer Health, Consumer Health and Patient Education, and Consumer Health, Patient Education, and Professional Education. These models dictate the process to be used to select resource materials, acquire human and technological resources necessary to have in the Center, determine hours of operation, and create the type of setting or atmosphere that coincides with the center’s mission. For instance, a consumer health and patient education center might be an informal area creating a space for customers to socialize, gather ideas and share issues whereas a professional library might provide a traditional/formal setting that is quiet providing a place to think, read and study.

Consumer health and patient education are two distinct entities that may require a varied level of investigation. Although they may overlap in some areas, the type of information and the staff responsible for reviewing and compiling information have distinct skills and roles. As a result of these findings, it was confirmed that there was a need to hire professionally trained staff in order to provide accurate and efficient response and referral to a broad array of resource requests from patients and consumers. Professional staff included a consumer health librarian and resource staff with clinical backgrounds.

CONCLUSION

Advanced Degree Nurses function in a variety of roles. One such role is a clinical education program manager. In this role, the ADN is in a unique position to be able to use his/her knowledge to understand, appreciate, and initiate program development activities rather than to forge ahead with inadequate information. The ADN recognizes that she/he is in a fluid role of teacher and learner and that every new contact is a potential resource and collaborator.

Although the essence of time becomes a critical factor in program development, the ADN is equipped to efficiently review the literature and gather information to use in refining program plans. New connections and information increase knowledge assisting the ADN with program innovation and organizational collaboration. For example, the two program activities described in this paper led to further validating the categories with consumers, establishing criteria and a process to evaluate resources that rely on consumer input, and subscribing to a patient education list serve. As a result, the program has legitimacy in the Consumer and Professional groups which increases the likelihood that both groups will utilize and benefit from the resources.

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References

13. Advanced Degree Nurses is defined as RN with Master, Post-Masters and/or doctoral degrees. It includes Clinical Nurse Specialist and Nurse Practitioner.
15. Cannon MT. Clinical and administrative issues of a child
55. Based on N.O.D. data. Percentages include those who rated this as minor or major issue that they sometimes face.
58. Block JM, Matassarin, EJ. Luckman & Sorenson's medical surgical nursing: A psychophysiological approach.

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