

Monitoring the Resource Requests of an Innovative Health Resource Center for Patients and Families with Disabilities and Professionals: The First Six Months

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Abstract

Disability is a public health concern. An estimated 68 million Americans have activity limitations and an estimated 4.4 million (6.5%) of children under 18 years of age who are non-institutionalized have activity limitations due to acquired or congenital conditions. As advances in medicine continue to offer treatment options, the number of persons with disabilities increases along with their life-long needs. A large Rehabilitation Facility in the Midwest opened a Health Resource Center to help address the resource needs for persons and families with disabilities and rehabilitation professionals in August 2003. The advanced degree nurse, as the clinical education program manager, collaborates with the director and staff to monitor the implementation of the HRC and assist with fine-tuning and re-defining programmatic needs. With this in mind, this paper presents findings from resource data for the first six months of the program's inception. The objectives are to describe: a) Who is accessing the HRC? b) What are their resource needs? c) What are the actions taken to address these needs? and d) What are the time elements necessary to address these needs?

INTRODUCTION AND PROBLEM STATEMENT

Disability and chronic illness are public health concerns. An estimated 68 million Americans have activity limitations(₁) and an estimated 4.4 million (6.5%) of children under 18 years of age who are non-institutionalized have activity limitations due to acquired or congenital conditions(₂). It is predicated that by 2020, 134 million people will suffer from a chronic medical condition(₃). Meanwhile, as a result of advances in medicine that offer new treatment options, the number of persons with disabilities increases along with their life-long needs(₄).

A rehabilitation facility (RF) in a large Midwestern city has been at the forefront of medical rehabilitation for almost 50 years. The majority (80%) of its patients are discharged back to their homes and communities. In 2000, findings from a hospital-wide satisfaction survey indicated a decline in patient and family satisfaction in preparation for discharge/in-patient education. This coupled with the current health care environment of shorter lengths of stay, a nursing shortage, and a complex health care system led to the development of the Health Resource Center (HRC) (₅ ; ₆). After 2 ½ years of planning, the HRC opened in August

2003.

The HRC provides patient, family, consumer, and professional health information. Based on findings from a Resource Needs Assessment Study(₇) and the expertise of the Program Director, the framework for the HRC provides resources in eight topic areas: medical information, caregiving and equipment, finance and law, education and employment, housing and transportation, support and wellness, recreation and leisure, and inspiration and hope. Funding for the HRC comes from philanthropic endeavors and from donors who assume that the HRC targets the education and resource needs of the target populations (patients and families with disabilities and the healthcare professionals that serve them).

Monitoring the implementation of a new program provides information that leads to fine-tuning and re-defining programmatic needs as well as revising data collection strategies. Often times, program-monitoring activities are not conducted. Thus, the reasons for programmatic failures are vague. With this in mind, the overall purpose of this paper is to understand program coverage as it relates to resource requests. Objectives are to describe: a) Who is accessing the

HRC? b) What are their resource needs? c) What are the actions taken to address these needs? and d) What are the time elements necessary to address these needs?

LITERATURE REVIEW

NEEDS OF PERSONS WITH DISABILITIES

Disabilities, also known as activity limitations, are restrictions in the 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 as a result of impairments, which are the result of either a congenital, e.g., cerebral palsy, or acquired disease, e.g., multiple sclerosis, arthritis, or traumatic event, e.g., spinal cord injury or traumatic brain injury (8; 9). The range and depth of services needed by persons with disabilities (PWD) result in higher costs of healthcare than the general population (10; 11). Currently, there is not an integrated healthcare system 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 healthcare, 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 (12).

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 (13; 14; 15; 16). These needs include on-going medical education, vocational and/or post-secondary education and training, patient and family support, healthcare 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 (17; 18). Throughout the lifespan PWDs and their families require social, psychological, financial, and emotional support (19; 20; 21; 22; 23), integration and reintegration into the community, health information (24; 25; 26) and caregiving (27; 28; 29; 30).

Moreover, research has shown that persons with disabilities and their caregivers are at risk for a variety of emotional, behavioral, and physiological morbidities (31; 32; 33; 34). As a matter of fact, having a disability, being socially isolated and/or having experienced a traumatic event are all risk factors for adolescent suicide in the United States (35; 36). The Centers for Disease Control and Prevention redefines the function of public health in the field of disability to include preventing co-morbidities as a result of the primary disability (37; 38). Creating programs that can address the resource needs of persons with disabilities and their families is essential to responsible public policy and program implementation. As a result, program planning and monitoring efforts that take an ecological approach (focus on transportation, housing, school, employment, community life, and socialization) may have a greater contribution to secondary prevention and early intervention than programs that focus on one component, e.g., physical limitations.

In 2001 the HRC conducted a Resource Needs Assessment Study by collecting data from 123 key informant interviews with persons with disabilities and their families and professionals. Specifically, collection occurred from the following four sources: (a) standardized consumer telephone interviews, (b) professional group interviews, (c) consumer discussion group interviews, and (d) telephone interviews with directors or representatives from consumer health resource centers throughout the country. Findings from the HRC's Resource Needs Assessment revealed that the top most pressing needs for persons with disabilities were:

- Psychological Support
- Recreation/Socialization
- Caregiver Assistance
- Transportation

- Care/Treatment Information
- Equipment
- Medical Information
- Housing
- Financial
- Employment
- Education.

Similarly, Louis Harris and Associates conducted the National Organization on Disabilities (N.O.D.)/ Harris Survey (1998). 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%³⁹ (40).

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 (41; 42; 43). Innovative programs can strengthen and promote access to the necessary resources, highlight opportunities, and create attention to public policy issues affecting vulnerable populations, i.e., lack of accessible and affordable housing. Program evaluation activities assure that effective programming occurs.

PROGRAM EVALUATION

Program evaluation often evokes a variety of responses that include fear, excitement, and apprehension. It is rare that grantors do not require some type of program evaluation to monitor the process and intended deliverables and/or outcomes. The definition of the practice of evaluation research is:

The systematic collection of information about the activities, characteristics, and outcomes of programs for use by specific people to reduce uncertainties, improve effectiveness, and make decisions with regard to what those programs are doing and affecting, (44).

For the past decade, there has been a shift of emphasis on

moving away from outcomes to looking at implementation and development and to use the evaluation as opportunity to make programmatic changes during implementation rather than waiting until the conclusion of the program (45). Specifically, evaluators are actively involved in creating more successful programs by providing input along the way and examining key variables. Variables commonly defined in most types of evaluation research include:

- Target population: The unit at which the program is directed.
- Specificity: The extent that you exclude persons not at risk.
- Stakeholders: Individuals and or groups directly or indirectly affected by the program. For example, grantors, policy makers, target population, consumers, patients, staff, family members, etc.
- Program Coverage: The extent to which the program is reaching its target population.
- Intervention: Any program or effort that was designed to produce changes in a target population.
- Delivery System: The program services, materials, space, human resources, time, procedures, and anything else that influences the program.

Moreover, the key to program evaluation is keeping the big picture in mind. Thinking about what you want to do with the data directs you to develop user-friendly data collection systems and to develop an appropriate evaluation design. Evaluation researchers (46; 47) describe various common types of program evaluation: cost/benefit analyses, cost/effectiveness, impact assessment efficiency, program monitoring, needs assessment, formative, and naturalistic or fourth evaluation. As shown in Table 1, each type of design addresses a specific type of evaluation question. A process/program monitoring evaluation design best uncovers the information necessary to understand program coverage as it relates to resource requests.

Figure 1

Table 1: Descriptions and Examples of Common Type of Program Evaluation Design

Type	Description	Example
Cost/benefit Analysis	Examines the relationship between the costs of the intervention and the benefits. Expressed in monetary form.	Economic rewarding of smoking cessation facilitating drugs - a comparison of over-the-counter and prescribed nicotine replacement therapy ⁽⁴⁷⁾ .
Cost/Effectiveness	Examines the relationship between the cost of the intervention and the outcomes delivered. Benefits are measured in terms of changes in behavior or conditions. Essentially, it estimates the effects of the program.	Regional variation in the cost effectiveness of childhood hepatitis A immunization ⁽⁴⁸⁾ .
Impact Assessment Efficiency Assessment	Evaluates whether the program causes desired change in target population.	Impact of Services, Met Needs, and Service Empowerment on Consumer Outcomes ⁽⁴⁹⁾ .
Program Monitoring or Process Studies Program Implementation Studies	Assesses whether or not the program is reaching the target population, is consistent with its original design, and what resources are being used to conduct the program.	Assuring Effective Outcomes in Cancer Screening through Academic and Agency Collaboration ⁽⁵⁰⁾ .
Needs Assessment Study	Reviews the type, depth and extent of the problem.	The natural history of adolescents with sickle cell disease: A need for case management ⁽⁵¹⁾ .
Formative Evaluation	Conducts the pre-testing of the intervention during the design. The information is used to guide the program's final design.	Mental Health Link: The Development and Formative Evaluation of a Complex Intervention to Improve Shared Care for Patients with Long-term Mental Illness ⁽⁵²⁾ .
Naturalistic or Fourth Evaluation ⁽⁵³⁾	Uses multi-methodology that relies on the constructivist approach whereby truth is shaped and reshaped through negotiation.	Mixed methods, mixed methodology health services research in practice ⁽⁵⁴⁾ .

METHODOLOGY

The Advanced Degree Nurse (ADN), an Education Program Manager, uses a non-experimental design to describe: a) Who is accessing the HRC? b) What are their resource needs? c) What are the actions taken to address these needs? and d) What are the time elements necessary to address these needs? Historical data were obtained from the data collection tool referred to as the Resource Request Log (RRL).

The data collection tool, the RRL, is an excel spreadsheet that is maintained by the HRC staff which are the Education Program Managers (EPM) the website librarian, and program director. It is kept on a secure computer file only accessible by HRC staff. Resource requests are entered and contain the following:

- Date: When the person submitted a resource request to the Center.
- Name: Name of caller and number if necessary to return call. 56
- Visitor Type: Is the person requesting a resource an inpatient, outpatient, general public, or an RF staff member.

- Contact method: Refers to how the person submitted their request: phone, in-person, e-mail, mail, or website.
- Referral Source: Refers to how the person came to the LC: family/friend/self, RF staff, community agency, printed materials, or RF website.
- Type of request: Refers to the Life topic area for which the request falls: medical information, caregiving and equipment, recreation and leisure, support and wellness, housing and transportation, education and employment, inspiration and hope, or finance and law (refer to Table 2. for Definitions).
- Sub-topic Area: Sub-topics according to LC web database under each of the above topic areas.
- Action Taken: A description of the resource provided.
- Time: The amount of time in minutes spent on the request.
- Whether or not the person was referred to RF System of Care.
- City and State that person calling resides.
- Initials of staff member responding to the request:

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Figure 2

Table 2: Definition of Life Topics (57)

Life Topic	Definition
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, i.e., stem research as it relates to spinal cord regeneration. (26)
Caregiving	Person or place that provides direct care to the person with a disability regarding living.
Equipment	Any materials used in providing specific care including having access to adaptive devices to increase independence, i.e., accessible van.
Recreation and Leisure	Activities engaged in for pleasure that support building relationships, decreasing social isolation and providing the opportunity to develop new skills and/or interests thereby increasing quality of life including daily living and community functioning, i.e., accessible swimming pools. (26)
Support and Wellness	Emotional, mental, cognitive support to promote and or enhance coping, self-acceptance, and personal and family adjustment, i.e., domestic violence. (26)
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. It may be a group home, small apartment, etc. (26)
Transportation	The ability to locate and secure affordable and accessible transportation that would enable participation in daily life activities, i.e., placard for disabled parking. (26)
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.
Law	Information on various laws, i.e., the Americans with Disabilities Act (ADA), life planning, and guardianship issues that applies to persons with disabilities and their families.
Education	Formal training (primary, secondary, post-secondary, or vocational) provided 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.
Employment	Having an occupation either full-time or part-time for which a person receives reimbursement for his/her skills and ultimately increasing the individual's level of independence.
Inspiration and Hope	A pleasure made for the soul suitable to its spirituality, a higher power or religious belief, i.e., books on poetry, personal success stories.
Multiple	Represents that a request was made on more than one topic area. For example, a person needs to find accessible housing (housing) because tenants are harassing them (law).

PROGRAM DESIGN

Figure 1 illustrates the condensed conceptual model for this Health Resource Center. It is based on the following problem statement: a) the majority (80%) of this hospital's patients are discharged back to their homes and communities; b) a hospital-wide satisfaction survey indicated a decline in patient and family satisfaction in preparation for discharge/in-patient education; and c) the current health care environment of shorter lengths of stay, a nursing shortage, and the absence of a centralized and up-to-date health resource center.

Figure 3

Figure 1: Conceptual Model

Lack of coordinated, up-to-date, centralized and standardized patient, consumer and professional education →	• Decreased pt. satisfaction & preparation for d/c
Shorter Length of Stay (LOS) →	• Increased demand for pt & consumer education
Nursing Vacancies →	• Increase demand to provide efficient mechanism to rehabilitation staff's efforts for pt., consumer, and professional education

The intervention developed and implemented is the Health Resource Center (HRC). In Figure 2, the simplified intervention model illustrates that the HRC is a primary space within the RF based on an ecological framework that encompasses standardized, up-to-date patient education,

consumer health and professional resources related to disabilities. Process outcomes include the target population and delivery system. The target population requesting resources represents persons with disabilities, their families, & rehabilitation staff. The delivery system includes the human resources necessary to deliver services (respond to requests, host programs, events, etc.). There are 3.0 FTEs; technological resources are the five on-site computers, the website and database; and space to host events, supports groups, and programs. Finally, the intermediate and long-term outcomes are likely consequences of the HRC.

Figure 4

Figure 2: Intervention Model

Health Resource Center	Process Outcomes	Intermediate Outcomes	Long-Term Outcome
<ul style="list-style-type: none"> Centralized Holistic Standardized Up-to-date 	<p>Target Population³ <i>Who are requesting resources?</i></p> <ul style="list-style-type: none"> Patients, families & consumers with disabilities & rehabilitation staff 	<ul style="list-style-type: none"> Efficient response to resource requests 	
	<p>Delivery of Services <i>Who provides resource assistance? Human resources: 3.0 FTEs + 15 volunteers³</i></p> <ul style="list-style-type: none"> Respond to resource requests made via phone, in-person, e-mail, website, or mail <p><i>How to access service?</i></p> <ul style="list-style-type: none"> Provide internet access to 5 computers 	<ul style="list-style-type: none"> Improved access to resources 	<ul style="list-style-type: none"> Increased patient satisfaction with preparation for discharge
	<ul style="list-style-type: none"> Maintain a database of resource collection & website specific to life topics related to disabilities 		<ul style="list-style-type: none"> Increased access to resources
	<ul style="list-style-type: none"> House programs, special events, & supports groups. <p><i>How much time does it take to respond to request?</i></p> <ul style="list-style-type: none"> Minutes per request. 		

³Due to the sensitive nature of requests and to protect callers' confidentiality, volunteers do not respond to request or have access to the request log.

SAMPLE SELECTION

The ADN took the first six months of the program's cases entered in the request log (August 4, 2003 to February 3, 2004) for an N=287 cases. Each case represents a request and NOT a new person. For example, one person could call several times with different requests and each request counts as a separate case. Any identifying information was deleted prior to the ADN cleaning and analyzing data.

PROCEDURE

Any identifying information for each request was deleted prior to being entered into SPSS and analyzed. Data included for analyses were: visitor type, contact method, referral source, Life Topic, time spent, and action taken. All data variables were nominal with the exception of time in minutes, an interval measure. The qualitative variable “action taken” was transformed into a quantitative variable by coding the data using the categories from the original Resource Needs Assessment (refer to Table 3.). For example, one entry read, “...Printed out the new Access Living list.” This would be coded as “community organization.”

Figure 5

Table 3: Definition of Action Taken

Action Taken	Definition
RF System	Referred to resources within the RIC System, i.e., Arthritis Center.
Condition Specific Society	Referred to an organization whose mission is to provide services to those with specific conditions, i.e. Multiple Sclerosis Society, Spinal Cord Injury Association, Brain Injury Association.
Community Agency	Referred to or given information from a not-for-profit organization, i.e., Access Living, Club House in Park Ridge.
Government Agency	Referred to or given information from government agency, i.e., Office of Rehabilitation Services.
Hospital	Referred to a healthcare organization comprised of healthcare providers who deliver primary, secondary or tertiary care, i.e., Northwestern Memorial Hospital.
Consumer Health Education	Provided information on health and medical topics 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 (18).
Support provided by staff	Provided emotional support through listening to caller, e.g., visitor's husband just died and she "needed to cry."
Professional Organization	Referred to a group of people with specific knowledge who work together in a structured way for a shared purpose, i.e., American Nurses Association.
Technology	Provided technical assistance on using the computer, adaptive equipment, access to e-mail system, etc.
Patient Education Material	Provided information on a 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 (19).
Vendor List	Provided a list of retailers for a specific topic areas, i.e., durable medical equipment.
Combination	Any combination of the above.
Other	Provided a tour without any request for resources.

ANALYSES AND FINDINGS

Data were analyzed by descriptive technique and non-parametric test statistics secondary to a lack of a normal distribution and not having a randomized sample. Time spent, an interval variable, was converted to minutes; and also made into a new ordinal variable called Time1. Findings are presented by evaluation question.

WHO IS ACCESSING THE HRC?

Demographic data show that the highest user group is the general public for 39.8% followed by the out-patient group at 34.9%. Thus, outpatients and general public comprise 75% of persons requesting resources during the first six months (refer to Table 4.). This finding may be due to the HRC being located at the first floor entry for which the outpatients and the public enter. People who are waiting for

transportation or appointments are more likely to roam into the HRC rather than inpatients and staff who are on the units and busy with therapy schedules.

Figure 6

Table 4: Visitor Type

Visitor Type	Number	Percent
General Public	113	39.8
Out Patient	99	34.9
RF Staff	38	13.4
In patient	34	12.0
Total valid cases	284	100.0

As shown in Table 5, the predominant method of contact was made in-person (56.8%), while 95% of persons made resource requests either in-person or by phone. Given technology, the use of the Internet, and access to HRC website, it is notable that more persons do not use the computer to contact the HRC.

Figure 7

Table 5: Contact Method

Contact Method	Number	Percent
In-person	162	56.8
Phone	110	38.6
E-mail	9	4.6
Website	4	1.4
Total valid cases	285	100.0

Self referrals or referrals from a family member or friend account for 61% of contacts. Combine this figure with referrals by RF staff for a total of 88.3% (refer to Table 6.).

Figure 8

Table 6: Referral Source

Referral Source	Number	Percent
Family/friend/self	172	61.0
RF Staff	77	27.3
Website/Written Material	29	10.3
Community Agency	4	1.4
Total valid cases	282	100.0

Table 7 illustrates that the majority of visitors contact the RF by phone or in-person; therefore, it is not surprising that inpatients and outpatients made requests via in-person and that public made requests via phone. This finding emphasizes an opportunity to appeal to the patients by building in a formal mechanism, i.e., a prescription to the HRC from their healthcare provider, to access to this target population. Meanwhile, the RF staff mostly contact the HRC via phone or in-person (81.5%). By having human contact with the RF staff, HRC staff can build relationships and demonstrate the utility of having the Center.

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Figure 9

Table 7: Contact Method by Visitor Type

Visitor Type	Phone	Contact In-Person	Method E-Mail	Website	Total
In Patient	N= 3 8.8%	N=31 91.2%	N=0	N=0	34
Out Patient	N=12 12.1%	N=87 87.9%	N=0	N=0	99
Public	N= 78 69.0%	N=29 25.7%	N=3 2.7%	N= 3 2.7%	113
RF Staff	N=17 44.7%	N=14 36.8%	N=6 15.8%	N=1 2.6%	38
Total	N=110 38.7%	N=161 56.7%	N=9 3.2%	N=4 1.4%	284

Data in Table 8. again show that most contacts are made through self referral, etc. In examining referral by visitor type, the most common source of referral for both patient groups and public still remains self, family, or friend. Again, this data emphasizes an opportunity to market to healthcare providers and build in a formal mechanism for referrals.

Figure 10

Table 8: Referral Source by Visitor Type

Visitor Type	Family/Friend/Self	Referral RF Staff	Source Agency	Website	Total
In Patient	N= 20 60.6%	N=13 39.4%	N=0	N=0	33
Out Patient	N= 63 63.6%	N= 26 26.3%	N=0	N=10 10.1%	99
Public	N=85 75.9%	N= 8 7.1%	N= 4 3.6%	N=15 13.4%	112
RF Staff	N=4 10.5%	N=30 78.9%	N=0	N=4 10.5%	38
Total	N=172 61.0%	N=77 27.3%	N=4 1.4%	N=29 10.3%	282

WHAT ARE THEIR RESOURCE NEEDS?

Definitions for topics are listed in Table 2. Table 9. shows that the top five resource needs are: medical information, equipment, housing, multiple topics, and support (refer to Table 9).

Figure 11

Table 9: HRC Topics

Topic	Number	Percent
Medical Information	90	31.4%
Equipment	34	11.8%
Housing	29	10.1%
Multiple Topics	27	9.4%
Support	22	7.7%
Employment	16	5.6%
Transportation	15	5.2%
Caregiving	13	4.5%
Recreation and Leisure	12	4.2%
Law	9	3.1%
Inspiration and Hope	8	2.8%
Finance	6	2.1%
Education	6	2.1%
Total	287	100%

When exploring topics by visitor type, descriptive data show that medical information is the top need for all types of visitors. Moreover, two-thirds of RF staff is for medical

information. These findings demonstrate the opportunity for patient education, consumer health, and professional education as it relates to physical health. However, the top needs change as you look across visitor types. For example, out-patient and public need resource assistance with equipment, while the requests are more varied across types with many empty cells. Findings are supported by the Resource Needs Assessment Study (2001), which reveals that resource needs change as persons with disabilities move through the process of recovery.

Figure 12

Table 10: Topics by Visitor Type

Topics	Visitor Type (N=284)				Total
	In patient N=34	Out Patient N=99	Public N=113	RF Staff N=38	
Medical Information	11 32.4%	24 24.2%	29 25.7%	25 65.8%	89 31.3%
Equipment	4 11.8%	13 13.1%	13 11.5%	4 10.5%	34 12.0%
Housing	5 14.7%	7 7.1%	17 15.0%	0	29 10.2%
Multiple Topics	3 8.8%	15 15.2%	8 7.1%	0	26 9.2%
Support	0	8 8.1%	9 8.0%	5 13.2%	22 7.7%
Employment	0	10 10.1%	6 5.3%	0	16 5.5%
Transportation	4 11.8%	6 6.1%	4 3.5%	1 2.6%	15 5.3%
Caregiving	3 8.8%	3 3.0%	6 5.3%	1 2.6%	13 4.6%
Recreation and Leisure	1 2.9%	5 5.1%	6 5.3%	0	12 4.2%
Law	0	1 1.0%	6 5.3%	1 2.6%	8 2.8%
Inspiration and Hope	3 8.8%	0	4 3.5%	1 2.6%	8 2.8%
Finance	0	4 4.0%	2 1.8%	0	6 2.1%
Education	0	3 3.0%	3 2.7%	0	6 2.1%
Total	34	99	113	38	284

WHAT ARE THE ACTIONS TAKEN TO ADDRESS THESE NEEDS?

Remarkably, the top action taken to assist in meeting the resource requests is referral to the RF system of care. Two-thirds of all requests were addressed within the RF System, technology, government, consumer education, or a community agency. The ADN used a selective random sampling technique of 28 cases to determine if the website provided access to action taken/resources. Findings show that 68.0% (N=19) were retrieved from the website. This finding recognizes the benefit of using the website as an efficient method to meet the needs of resource requests. Thus, this finding presents an opportunity to continue to build on website collection for efficient response to requests. Furthermore, program-planning efforts, i.e., the Resource Needs Assessment Study, directed staff to identify appropriate resources.

Figure 13

Table 11: Action Taken

Topic	Number	Percent
RF System	46	16.0
Technology	40	13.9
Government	33	11.5
Consumer Education	32	11.1
Community Agency	26	9.1
Combination	21	7.3
Vendor List	21	7.3
Support	16	5.6
Patient Education	15	5.2
Other	15	5.2
Condition Specific Society	11	3.8
Professional Organization	9	3.1
Hospital	2	.7
Total	287	100%

WHAT ARE THE TIME ELEMENTS NECESSARY TO ADDRESS THESE NEEDS?

Table 12 shows descriptive data on the time spent to respond to a resource request. Data show that on average it takes 18.10 minutes for a request with a mode of 10 and median of 15. Due to outliers, the range is from 5 minutes to 120 minutes. Over 94.3% of the requests were handled in 30 minutes or less (refer to Table 13.). The majority of outliers occurred with medical information (N=6) and multiple topics requests (N=3) and with one request in each of the following: housing, education, employment, inspiration and hope, and caregiving. Having a knowledgeable staff who are familiar with conducting Internet searches and using the HRC website are probable factors that contribute to the seemingly efficient time it takes to respond to the resource requests.

Figure 14

Table 12: Descriptive Statistics: Time Spent to Respond to Requests (N=282)

Statistics	Minutes
Mean	18.10
Median	15.00
Mode	10
Range	115
Minimum	5
Maximum	120
Percentiles 25	10.00
50	15.00
75	20.00

In further non-parametric analyses, a Spearman's rho test statistic was computed to see if there was a correlation between time spent and life topics. There was a not significant correlation at the $p < .05$ level. Kruskal-Wallis

test statistic showed a significant difference at the $p < .05$ level among visitor type (independent nominal variable) and time spent (dependent interval variable) with in-patient having a higher rank (higher ranking indicates more time spent).

Figure 15

Table 13: Time Spent Responding to Requests

Minutes	Frequency	Percent
5	39	13.6
10	69	24.5
15	52	18.4
20	67	23.8
25	9	3.2
30	30	10.6
35	2	.7
45	2	.7
60	9	3.2
65	1	.4
90	1	.4
120	1	.4
Total	282	100.0

LIMITATIONS

Limitations with monitoring the resource requests for the first six months of the program's existence include: a) a new data collection method with initial variations in logging information; b) a non-experimental evaluation design; and c) a lack of estimated number for target population which may lead to over coverage.

RECOMMENDATIONS

Public health policy recognizes persons with disabilities and chronic conditions are a growing population in need and underserved. Policy interests are directed toward: a) developing innovative programs that minimize gaps in access to care and information; b) minimizing secondary and tertiary complications; and c) reducing the healthcare chasm between persons with disabilities and those without. The HRC, as an innovative program, attempts to address the gap in accessing health information so that persons with disabilities can learn to self-manage their chronic illness and/or disability. There are four recommendations as a result of evaluating the resource requests.

A) Address Externalities. The technology center at the RF formerly provided computer-training programs to persons with disabilities. Due to funding cuts, the technology center lost its grant and no longer provides these classes. As a

result, many of the clients at the RF do not have access to a computer class. The HRC has on its website a list of free classes in the area, but few clients take advantage of these classes. It would be advantageous if the technology center or RF could offer these classes via the HRC. It is one thing to have access to the computer and Internet, but if one does not know how to use technology then they cannot independently access knowledge and resources.

B) Discover New Resources. The creation of knowledge occurs at a fast pace. HRC 's mandate is to keep up-to-date information. As a result, staff are required to discover new resources for the HRC and website. Access to resource information allows staff to efficiently respond to resource requests and foster a system that empowers persons with disabilities and their families and equips professionals with the latest data on evidence-based practice guidelines. Consequently, it is essential that the HRC have an intact delivery system comprised of human and technological resources to achieve its mandate.

C) Capitalize on Opportunities. Program monitoring often leads to recognizing opportunities. Thus, program refining includes efficiently capitalizing on the opportunities. Findings emphasize the opportunity to market to healthcare providers and build in a formal mechanism for referrals, i.e., prescriptions, and to develop relationships with staff through informal mechanisms, i.e., assisting with a resource request, discussing a case, and/or sending e-mail on a new resource or link. In addition, the HRC staff has an opportunity to contribute to clinical practice and be recognized as a key component to the patient care team by disseminating best practice guidelines on key topics.

D) Refine Data Collection Tools. As with any new program, data collection tools require refining and staff requires re-training on using the tools. In order to capture an accurate picture or snapshot of the requests made every six months, data entry needs to occur in a timely fashion. Each variable requires clear and meaningful definitions for consistent and reliable documentation. In addition, data collection and analyses should result in information that holds the program accountable to diverse stakeholder groups, leads to future funding, and creates awareness of public health policy issues for persons with disabilities. For example, it might be useful to document the need for computer training classes by logging the time spent providing technical assistance to patients and families. Administration could use this data to advocate for funding computer-training programs.

IMPLICATIONS FOR FUTURE RESEARCH

Findings from this process monitoring evaluation led to understanding program coverage as it relates to resource requests and suggest four potential research areas and questions. There areas are: a) quality of life, e.g., Does the information that persons with disabilities receive via the HRC impact their quality of life?; b) health services, e.g., Does having access to health information improve persons with disabilities self-efficacy?; c) management, e.g., What are the human and technological resources necessary to efficiently administer the HRC?; and d) social psychology, e.g., Does offering computer-training programs and access to computers increase persons with disabilities sense of empowerment? Each of these areas and research questions could potentially provide information that leads to future funding and informs public health policy.

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