Community Health Needs Assessment Report
RML Specialty Hospital

May 2013

Prepared by Illinois Public Health Institute
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Executive Summary

RML Specialty Hospital conducted comprehensive a Community Health Needs Assessment (CHNA) from January to May 2013 for both of its two hospital campuses – RML Specialty Hospital Hinsdale and RML Specialty Hospital Chicago – in accordance with IRS requirements for nonprofit hospitals.

Input and guidance were provided by a CHNA Advisory Committee made up of leaders from a cross-section of RML departments across both campuses, physicians, and representatives from several key partner organizations that refer to and/or receive patients from RML.

Based on its specialized focus and understanding of the population it serves, RML defined its CHNA community as people, particularly elderly and low-income, who have suffered a severe, life-changing, debilitating illness and that require extensive psycho-social and health support services when they return home. For RML Hinsdale, this community’s needs were assessed for the geography of Chicago, Suburban Cook County, DuPage County and Will County. For RML Chicago, the CHNA geography includes Chicago and Suburban Cook County.

2010 census data indicates 789,538 seniors over 65 live in the region of Chicago, Suburban Cook County, DuPage County and Will County, and about 620,000 of those seniors are in Chicago and Suburban Cook County. Seniors living in poverty and living alone may have a more difficult time accessing the resources they need to adapt to a changed home life with a severe, life-changing illness. There are approximately 230,000 seniors living alone in the service area. According to the Census, there are already an estimated 360,000 seniors in the service area having difficulty living independently. Almost 78,000 seniors 65 and older in the service area are living in poverty.

As part of this CHNA, RML gathered community input through interviews with former patients and family members, staff focus groups, and interviews with community service providers. Key themes that arose out of the community input were: communication, transition and continuity between sites of care, education and knowledge of disease process for patients and family members, caregiver stress, and cost and coverage of services. Transportation was also raised as an important issue in Chicago.

The CHNA Advisory Committee engaged in a process to identify priority health issues based on the assessment data and using the following criteria: prevalence and seriousness of the problem, disparities, importance to the community, available expertise, feasibility, and alignment with RML’s mission.

The priority issues are: patient/family knowledge of disease process, palliative care and hospice, communication around transitions and hand-offs, cost of accessing medicine and supplies, and caregiver stress. RML is now working to develop an implementation plan and move forward with strategies to address these issues.
The CHNA process provided RML with opportunities to better understand the quality-of-life issues that are important to our community, engage with former patients and family members to better understand their struggles and hear their ideas, and build stronger relationships with other service providers. We look forward to continued collaborative work to begin to address some of the priority needs of the community we serve.
Introduction

Description of RML

RML Specialty Hospital (RML) operates two campuses: an 87-bed hospital in Hinsdale (RML Specialty Hospital Hinsdale) and a 69-bed hospital on the near-west side of Chicago (RML Specialty Hospital Chicago).

RML is a long-term acute care hospital (LTCH). LTCHs are defined by Medicare as hospitals that have an average length-of-stay greater than 25 days.

LTCHs are much like short-stay acute care hospitals (i.e., community hospitals and university hospitals) except for some unique characteristics. LTCHs typically admit only elective referrals from short-stay acute care hospitals and are treatment-based rather than diagnosis-based. LTCHs focus on a patient population that is recovering from critical illness; this population has a long length-of-stay, is largely geriatric, and is very ill. Patients in an LTCH face intricate and delicate family issues, often involving end-of-life decisions. Also, they operate on a much smaller scale and have few, if any, outpatient services.

LTCHs provide a specialized role in the overall continuum of care. LTCHs are the first stop in what is known as "post-acute care". About 1% of the patients admitted to a short-stay acute care hospital are eventually referred to an LTCH. An LTCH's role in the continuum of care can be represented as follows:

Figure 1. LTCH's Role in Continuum of Care

RML Specialty Hospital Hinsdale and Chicago admit patients from over 65 hospitals across Northeast Illinois as well as from out-of-state. The overwhelming majority of our patients are admitted directly from the intensive care unit at the referring hospital and have been in the hospital for three weeks or longer.

RML specializes in the interdisciplinary physician-led treatment of patients with catastrophic or acute illnesses and injuries complicated by complex or multiple illnesses or conditions. RML has three major programs. About 65% of our patients come to RML to be weaned from a ventilator. These patients have failed to wean from the ventilator at the short-stay acute care hospital in spite of repeated attempts following a major surgery or a severe illness.
About 25% of our patients are admitted to the medically complex program. These patients are critically ill and suffer from multiple debilitating conditions and are just starting to take very small steps toward their rehabilitation.

The remainder of our patients come to us with severe, possibly infected wounds, including pressure ulcers, surgical wounds, and burns. In fact, as all of our patients have been in the hospital for a long time, many of the patients in our other two programs are also suffering from pressure ulcers.

RML Specialty Hospital Hinsdale was started in 1987 as the Ventilator Support Center within Suburban Hospital. It began as a partnership between Rush University Medical Center, MacNeal Hospital, and Suburban Hospital. In 1997, Suburban Hospital ceased operations. At that time the Ventilator Support Center assumed operations of the entire hospital and was recognized as an LTCH by CMS. Loyola University Medical Center replaced Suburban Hospital in the partnership in 1998 and the operation became known as RML. MacNeal Hospital left the Partnership in 2001. In 2010, RML Chicago (the former Advocate Bethany Hospital) was added and Advocate Health and Hospital System replaced Rush in the partnership. Loyola and Advocate are the current partners/owners of RML.

RML’s vision is to be a national center of excellence for long-term acute care, recognized for superior clinical outcomes and patient satisfaction, and for valued contributions to the advancement of medical care. Indeed, over the past 25-plus years, RML has established a national reputation for high quality, positive outcomes. RML is the only LTCH recognized by US News and World Reports (2011) and is the only LTCH to participate in research funded by the National Institutes of Health (NIH).

Overview of CHNA Law and Guidance

Under the Patient Protection and Affordable Care Act of 2010, nonprofit 501(c)(3) hospitals are now required to perform a Community Health Needs Assessment (CHNA) every three years in order to maintain nonprofit status. The CHNA must include a description of the community served by the hospital, input from people who “represent broad interests of the community served”, engagement of public health experts, public access to the CHNA results, and subsequent development of an implementation plan. RML is conducting this CHNA to meet the existing IRS guidance on CHNA for nonprofit hospitals.
Description of the CHNA process

RML Specialty Hospital conducted a comprehensive Community Health Needs Assessment (CHNA) from January to May 2013 for both of its two hospital campuses – RML Specialty Hospital Hinsdale and RML Specialty Hospital Chicago.

RML’s CHNA process was grounded in the organization’s mission and values.

**RML Mission**

To provide quality, compassionate care to patients from our referring community who suffer from prolonged, severe illness.

**RML Values**

*Integrity* - We are ethical, fair, and honest in all our actions.

*Service* - We are committed to achieving service excellence in all that we do.

*Respect* - We respect the individual rights, dignity, and confidentiality of others.

*Stewardship* - We strive at all times to be good financial stewards of the resources entrusted to us.

*Teamwork* - We value each staff member’s contribution to our Mission and believe that collaborative effort is essential to realizing our Vision.

*Accountability* - We hold ourselves accountable for our actions and for the achievement of results.

The CHNA process was led by RML’s Chief Operating Officer. Input and guidance were provided by a CHNA Advisory Committee. The entire effort was supported and facilitated by the Illinois Public Health Institute (IPHI).

The CHNA Advisory Committee was made up of leaders from a cross-section of RML departments across both campuses, physicians, and representatives from several key partner organizations that refer to and/or receive patients from RML. The committee met three times. The core of the committee’s work was to review the health and community data and contribute to identification of priority community health needs for the CHNA community.
Figure 2. CHNA Process Diagram

Define Community for CHNA
- Determine geographical boundaries and population demographics

Form CHNA Advisory Committee
- Orient advisory committee to CHNA Process

January 2013 – Advisory Committee Mtg. 1

Develop Vision and Values for CHNA
- Review RML Mission, Vision, and Values and Integrate into CHNA Visioning

Gather Assessment Data
- Develop Community Health Profile to report secondary data
- Gather Community Input through Focus Groups and Key Informant Interviews

March 2013 – Advisory Committee Mtg. 2

Synthesize and Analyze Assessment Data
- Develop Charts and Graphs to Communicate Findings
- Write Narrative Reports

April 2013 – Advisory Committee Mtg. 3

Identify Key Issues and Prioritize Needs
- Apply Prioritization Criteria
- Develop high-level objectives and strategies

Create CHNA Report
- Disseminate Findings of CHNA within the Community

Develop Implementation Plan
- Develop Measurable Goals and Objectives for Priorities
- Plan Community Benefit Activities
RML’s Approach to CHNA / Community Benefit

Challenges

As an LTCH, performing a CHNA and meeting the requirements of the Affordable Care Act and the guidance established by the Internal Revenue Service presented a set of challenges.

First, RML does not fit the mold of the typical community hospital as RML’s market is not its local community. Patients come to RML from over 65 hospitals in the nine counties within Northeast Illinois. Very few patients live in the same zip codes in which our two campuses are located. Instead, RML has traditionally defined its community broadly rather than locally, that is, as consisting of the patients in the entire Northeast Illinois region with severe, life-changing, debilitating illnesses. As might be expected given the focus on a specific patient type rather than a local community, there is very little detailed, informative secondary data available on this small, limited community of patients with severe, life-changing, debilitating illnesses.

RML’s operating structure also presents a challenge. RML’s focus has typically been on the treatment of patients with severe and complex illnesses in the inpatient setting. As a result, RML has limited vehicles for interacting with the local geographic community. In fact, RML has no outpatient services and no emergency department at either campus.

Finally, given its small size, limited focus, and diffuse community, it would be difficult for RML to develop a set of initiatives that would have a meaningful impact on the health status of the community.

Conceptual Framework

Community hospitals are ideally suited to address the health needs of their community. They have outpatient services designed to meet the needs of their local market and have local physicians providing care. Although large, university hospitals tend to focus on tertiary care and have regionally-based programs, they also serve a significant number of the patients in their local communities with basic outpatient and emergency services. In general, the community hospitals and university hospitals in the Chicago area are also much larger than RML with more resources at their disposal.

In summary, these acute care hospitals have the wherewithal, scope, delivery mechanisms, and focus to address public health issues that result in people in the community being admitted to the hospital. This includes issues like access to care, community violence, lack of prenatal care, and obesity as well as major chronic diseases like diabetes, mental health, and cardiovascular illnesses. Anything RML did in these areas would likely be duplicative and on such a small scale that the effort would not result in much of an impact.
We realized however that what you see depends on where you sit. In other words, the health needs that an organization is best positioned to address depends on its location in the health care continuum. As the first stop in the post-acute care continuum, RML was well-positioned to address the needs of the community after they left the hospital. These needs include quality-of-life, access to home care needs, end-of-life care, and chronic illness care.

**Figure 3. Community Needs Addressed by LTCH**

Community needs addressed by community hospital:
- Access to care
- Diabetes
- Asthma
- Obesity / Nutrition
- Prenatal care
- Mental health
- Community violence

Community needs addressed by LTCH:
- Quality of life
- Access to home care needs
- End of life care
- Chronic illness care

**Opportunities**

This approach presents unique opportunities to RML to advance our mission by enhancing the care we provide to the unique patient population we serve. We anticipated that the CHNA process would allow us to identify the quality-of-life issues that are important to this patient population and better understand and empathize with the struggles and hardships faced by these patients after they return to the community. In addition, we are looking forward to building stronger relationships with other service providers working with similar populations.
Community Definition

Analysis of RML Specialty Hospital's FY2012 patient data shows that the vast majority of RML's patients come from the region that includes Chicago, Suburban Cook County, DuPage County and Will County. The source of RML Chicago's patients is relatively concentrated with 83% living in Chicago and 13% in Suburban Cook County. The source of RML Hinsdale's patients is more widely distributed: 39% live in Suburban Cook County and 15% in Chicago, and an additional 17% live in DuPage County and 15% in Will County.

U.S. Internal Revenue Service (IRS) guidance (notice 2011-52) explains: "Generally, Treasury and the IRS expect that a hospital's community will be defined by geographic location (e.g., a particular city, county, or metropolitan region). However, in some cases, the definition of a hospital's community may also take into account target populations served (e.g., children, women, or the aged) and/or the hospital facility’s principal functions (e.g., focus on a particular specialty area or targeted disease). Notwithstanding the foregoing, a community may not be defined in a manner that circumvents the requirement to assess the health needs of (or consult with persons who represent the broad interests of) the community served by a hospital facility by excluding, for example, medically underserved populations, low-income persons, minority groups, or those with chronic disease needs."

Given RML's specialty in serving medically complex patients and patients with long term care needs, we define the CHNA communities in the following way:

RML Hinsdale’s community: People in Chicago, Suburban Cook County, DuPage County and Will County who have suffered a severe, life-changing, debilitating illness requiring extensive psycho-social and health support services when they return home. As the elderly and low-income are least likely to have the resources to adapt well to these circumstances, we will focus on these populations.

RML Chicago’s community: People in Chicago and Suburban Cook County who have suffered a severe, life-changing, debilitating illness requiring extensive psycho-social and health support services when they return home. As the elderly and low-income are least likely to have the resources to adapt well to these circumstances, we will focus on these populations.
**Data Collection Approaches/Methods**

In accordance with U.S. Internal Revenue Service (IRS) guidance, RML pursued two avenues of data collection for this assessment: (1) compilation and analysis of secondary data to create a Community Health Profile and (2) gathering community input through focus groups and interviews. For all data collection, data was collected and analyzed both for Chicago and suburbs to coincide with the geographic service areas identified for RML Hinsdale and RML Chicago.

**Secondary Data Analysis**

For the Community Health Profile, RML collected data from a range of secondary sources. RML was fortunate to be able to access data from local health departments (Chicago, Cook County, DuPage County, Will County) for many demographic and health status indicators. Other sources include the Decennial Census, American Communities Survey, Behavioral Risk Factor Surveillance System (BRFSS), Centers for Disease Control and Prevention (CDC), Illinois Department of Public Health, Illinois Department of Economic Security, Illinois Department of Healthcare and Family Services, and RML Internal Records.

The community input process for the RML CHNA was carried out between February and April 2013. RML used three methods for collecting community input: interviews with former patients and family members, focus groups with RML staff, and key informant interviews with service provider organizations. The Age Options Community Assessment was also reviewed.

**Interviews with Former Patients and Family Members**

RML, IPHI and the CHNA Advisory Committee collaborated to develop interview questions for former patients and family members. The original plan was to conduct focus groups with patients and families; however, because of the medical complexities and care needs of patients who are discharged from RML, individual interviews were a more appropriate method for collecting input from patients and families. A total of 14 patients and families were contacted (nine Hinsdale and five Chicago); seven agreed to provide phone interviews (five Hinsdale and two Chicago). The phone interviews were conducted by IPHI and followed a semi-structured format. (Questions listed in Appendix D.)

**Focus Groups – RML Staff**

Two focus groups were held with RML staff, one in Hinsdale and one in Chicago. Each of the focus groups consisted of one of each of the following: Care Coordinator, Chaplain, Intake Liaison, Nurse, Patient Ambassador, Physician, Rehabilitation Therapist, and Respiratory Therapist. The focus groups were conducted by IPHI and followed a
semi-structured format, using the same eight questions in each focus group. (Questions listed in Appendix C.)

Key Informant Interviews

IPHI and RML also conducted nine key informant interviews with community service providers to understand the services they provide and gather their input and expertise on issues faced by the community that RML serves. Interviewees included: Skilled Nursing Facility (serving both Chicago and suburbs), Rehabilitation Facility in suburbs, two home health providers (serving both Chicago and suburbs), hospice and palliative care provider (serving both Chicago and suburbs), Age Options (Suburban Cook County Agency on Aging), and the Chicago Department of Aging. The interviews followed a semi-structured format and questions were personalized for each interview based on the specific services provided and population served by each service provider.
Findings from Community Health Profile

Target Community for this CHNA

As detailed in the Community Definition section on page 11, RML’s CHNA community of focus is people with severe, life-changing, debilitating illness, particularly elderly and low-income individuals.

The Community Health Profiles for the two campuses (Appendix B) summarize the conclusions gathered from the data collected on demographic, socioeconomic, and health indicators for RML’s community. As mentioned in a preceding section, the geographic community covered by RML Hinsdale is Chicago, Suburban Cook County, DuPage County and Will County. The geographic community covered by RML Chicago is Chicago and Suburban Cook County. Citywide data is presented for Chicago and county data is presented for Cook County, DuPage County and Will County. State and federal comparison data are presented where available.

The total regional population, as of the 2010 Census, is 6,789,159 (approximately 2.5 million in the city of Chicago, 2.7 million in Suburban Cook County, 915,000 in DuPage County, and 675,000 in Will County). The total population of seniors over the age of 65 in the RML Chicago Community Area is 789,538, with 620,326 of those seniors living in Chicago and Suburban Cook County. The population of seniors increased by 4% between 2000 and 2010.

Figure 4. Population 65 and Older, 2000 and 2010

Source: US Decennial Census
Poverty Among the Senior Population (65+)

A large number of seniors are living in poverty in the community areas served by RML Hinsdale and RML Chicago. Overall, approximately 10% or 77,000 seniors (65+) are living below the federal poverty level in the area (the federal poverty level is defined as an annual income less than $11,490 for a one-person household or less than $15,510 for a two-person household).

Data is not specifically available about seniors living below 200% poverty (annual income less than $22,980 for a one-person household or less than $31,020 for a two-person household). However, as senior poverty rates are very similar to poverty rates of the general population, we can assume that the number of seniors living between 100% and 200% of the poverty level is about twice as many (or about 155,000 people) as the number living under the poverty level. This means that one-third or more of the seniors in RML Chicago's community live under 200% of the federal poverty level.

Figure 5. Poverty rates, 2010

<table>
<thead>
<tr>
<th>Poverty Rates (65+)</th>
<th>Chicago</th>
<th>Cook County</th>
<th>DuPage County</th>
<th>Will County</th>
<th>Illinois</th>
<th>US</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poverty Rates, 65+</td>
<td>16.7%</td>
<td>11.2%</td>
<td>4.9%</td>
<td>5.0%</td>
<td>8.3%</td>
<td>9.3%</td>
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</table>

Source: American Communities Survey, US Census Bureau
RML patient data

The majority of RML’s patients are seniors, which supports the CHNA’s focus on the elderly population. 60% of RML Chicago’s and 66% of RML Hinsdale’s patients are over 60 years old.

Figure 6. Age Distribution of RML Patients, FY2012

![Age Distribution Chart]

Source: RML data

The racial and ethnic makeup at the two RML hospitals is very different. Over 90% of the patients at RML Chicago are non-white while 75% of the patients at RML Hinsdale are white. The implementation plan needs to take into account the inherent cultural differences between the two populations.

Figure 7. Race/Ethnic Make-up of RML Patients, FY2012

![Race/Ethnic Make-up Chart]

Source: RML data
Most patients stay at RML for over three weeks. As most patients come to RML after over three weeks in a short-stay hospital as well, the total length-of-stay in a hospital is usually six weeks or longer, not including the time spent in a rehabilitation or skilling nursing facility after discharge from RML. This emphasizes how debilitated RML's patients are and is indicative of the challenges they will face when returning home.

**Figure 8. Length of Stay of RML Patients, FY2012**

<table>
<thead>
<tr>
<th></th>
<th>RML Chicago</th>
<th>RML Hinsdale</th>
<th>Total RML Patients</th>
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<tr>
<td>&lt; 3 weeks</td>
<td>29%</td>
<td>36%</td>
<td>33%</td>
</tr>
<tr>
<td>3-6 weeks</td>
<td>48%</td>
<td>43%</td>
<td>45%</td>
</tr>
<tr>
<td>6-9 weeks</td>
<td>17%</td>
<td>14%</td>
<td>15%</td>
</tr>
<tr>
<td>9-11 weeks</td>
<td>4%</td>
<td>4%</td>
<td>4%</td>
</tr>
<tr>
<td>12+ weeks</td>
<td>2%</td>
<td>3%</td>
<td>3%</td>
</tr>
</tbody>
</table>

Source: RML data

In 2012, discharge profiles were similar for RML Chicago and Hinsdale. At both RML Chicago and RML Hinsdale approximately 12% of the patients were discharged directly to home. Also at both facilities, 55% of patients were discharged to other post-acute facilities, either a Skilled Nursing Facility (SNF) or Inpatient Rehabilitation Center (IRF). The principle difference in discharges was the proportion of SNF and IRF discharges. At RML Chicago, 46% were discharged to a SNF and 9% to an IRF, while at RML Hinsdale, 37% were discharged to a SNF and 18% to an IRF. With over one-half of the patients having at least one intermediate stop before going home, it will be challenging for RML to follow and assist patients at home.

**Figure 9. Discharge Data for RML Patients, FY2012**

Source: RML data
The number of seniors living alone and/or with independent living difficulty highlights the great need for support for this population from the community. It is often not possible for patients returning home after a long-term illness to live independently.

**Figure 10. Population Living Alone, 2009-2011**

<table>
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<tr>
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<th>Population Living Alone, 65-74</th>
<th>Population Living Alone, 75+</th>
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<tbody>
<tr>
<td></td>
<td>Chicago</td>
<td>Cook County</td>
</tr>
<tr>
<td>Renters</td>
<td>23,494</td>
<td>33,104</td>
</tr>
<tr>
<td>Homeowners</td>
<td>19,683</td>
<td>48,059</td>
</tr>
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**Figure 11. Population with Independent Living Difficulty**

<table>
<thead>
<tr>
<th></th>
<th>Chicago</th>
<th>Cook County</th>
<th>DuPage County</th>
<th>Will County</th>
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<tbody>
<tr>
<td>75+</td>
<td>38,301</td>
<td>129,923</td>
<td>7,885</td>
<td>6,757</td>
</tr>
<tr>
<td>65-74 years old</td>
<td>17,953</td>
<td>11,029</td>
<td>6,294</td>
<td></td>
</tr>
<tr>
<td>35-64 years old</td>
<td>44,184</td>
<td>2,798</td>
<td>2,383</td>
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Seniors are nearly universally covered by Medicare. About 14% also have Medicaid to assist with payment of deductibles and co-payments. As a result, seniors are likely to be very sensitive to lack of coverage, especially for home-based services, provided by the major government programs.

**Figure 12. Medicare Enrollment, 2011**

<table>
<thead>
<tr>
<th></th>
<th>Cook County</th>
<th>DuPage County</th>
<th>Will County</th>
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<tbody>
<tr>
<td>Total 65+ Population</td>
<td>620,329</td>
<td>106,398</td>
<td>62,814</td>
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<tr>
<td>Part D Enrolled</td>
<td>235,630</td>
<td>38,063</td>
<td>20,368</td>
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<tr>
<td>Advantage Plan</td>
<td>76,166</td>
<td>7,361</td>
<td>5,163</td>
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<tr>
<td>Medicaid and Medicare</td>
<td>93,681</td>
<td>9,929</td>
<td>4,609</td>
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<tr>
<td>(dual eligibles)</td>
<td></td>
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Findings from Community Input

The Community Input Reports (Appendix C) analyze all community data collected during the CHNAs. As described in the Data Collection section above, the community input consisted of seven phone interviews with former patients and family members (five from Hinsdale and two from Chicago), two focus groups with RML staff (one in Hinsdale and one in Chicago), and nine key informant interviews with community service providers.

Former Patient / Family Interviews

In general, patients and family members expressed happiness with the quality of care provided by the staff at both RML campuses.

Top issues raised by former RML patients and family members included:

- Need for additional communication and education of patients and families.
- Difficulty transitioning to a new assisted-living facility or back to home.
- Gaps in insurance coverage and high out-of-pocket costs.
- Overwhelming care needs after discharge and particularly upon return to home.
- Need for additional caregiver training.

Former patients and family members from RML Hinsdale specifically highlighted:

- A disconnect in communication and education between RML and other facilities and community resources.

Former patients and family members from RML Chicago specifically highlighted:

- Need for additional communication and education of patients and families.
- Overwhelming care needs after discharge and particularly upon return home.

RML Staff Focus Groups

The top issues that were raised in the RML Hinsdale staff focus group were:

- Inability of patients and families to manage the patient's care needs.
- Gaps in insurance coverage and high out-of-pocket costs.
- Need to assist families in accepting patient's condition and developing realistic expectations.
- Need for additional education about home care and the disease process.
- Support for transitioning to next site of care and to home.

The top issues that were raised in the RML Chicago staff focus group were:

- Inability of patients and families to manage the patient's care needs.
- Gaps in insurance coverage and high out-of-pocket costs.
- Need to assist families in accepting patient’s condition and developing realistic expectations.
- Need for additional education about home care and the disease process.
- Support for transitioning to next site of care and to home.
- Ensuring that cultural differences are taken into account when developing education and support services for patients and families.
- Lack of transportation for physician and therapy visits.

Key Informant Interviews with Community Service Providers

Issues identified by community service providers echoed those raised by former patients and family members as well as RML staff. The most commonly raised issues included:

- Lack of social support and education for family members.
- Caregiver stress.
- Gaps in insurance coverage and high out-of-pocket costs.
- Need for effective communication and the importance of cultural competency.
- Support for transitioning to next site of care and to home.

Many of the community service providers emphasized the importance of social support and education for the client’s family members. The specific concerns brought up included:

- The family’s lack of coping strategies and expectations for unrealistic outcomes.
- Need for repeat and continued education for family members regarding their loved one’s condition and for services to process what is happening.
- Confusion regarding the differences between and the use of palliative care, hospice services, and end-of-life care.
- The lack of understanding and acceptance of the adjustment to the heightened and complex needs that these patients and families will need to go through.

It was noted that an emphasis needs to be placed on providing resources for caregivers. Specific issues related to caregiver stress included:

- Physical and mental strains of dealing with medically complex patients.
- Lack of understanding about the responsibility and expectations of being a 24 hour a day caregiver.
- Initial stress, shock, emotional strain, and anxiety for family members serving as the primary caregiver.

Cost and insurance-related concerns included:

- Medicare and Medicaid landscapes are changing, frequently leading to higher out-of-pocket costs.
- Transitioning to hospice can be financially complicated.
- Case managers can assist in working through insurance coverage issues.
• Some seniors do not have good insurance coverage beyond basic Medicare Part A.
• Many home services and some home health care services and equipment are not covered by public or private insurance.
• Young patients with severe health problems have challenges with insurance coverage and referrals to community resources.

Key informants emphasized the challenges related to communication, including:
• Expected outcomes and severity of medical conditions may be difficult to convey to clients and their families.
• Case management and care coordination would help with follow-up and improving communication across facilities.
• Lack of patient and family knowledge of disease process and possible outcomes.
• Need for more utilization of communication between social workers at different facilities.
• Family caregivers are shocked and overwhelmed by the patient's needs upon arrival back home.
• Stigma and loss of independence associated with accepting help, either physical or mental.

In summary, key themes across the community input were: communication, transition and continuity between sites of care, education and knowledge of disease process for patients and family members, caregiver stress, and cost and coverage of services. In Chicago, transportation was also raised as an important need and barrier. (Transportation was not raised as an issue for the RML Hinsdale community.)

The community input results are consistent with findings in Age Options’ Needs Assessment for Older Adults in Suburban Cook County from 2012.

Continuing to gather community input during planning and implementation will help RML to best design activities that meet community-specific needs, address barriers and leverage existing community assets in order to effectively address priority issues and improve health for the community that RML serves.
Priority Issues

Following data collection and presentation of findings, the CHNA Advisory Committee worked to identify priority health issues for the communities RML serves. IPHI facilitated a process at the second Advisory Committee meeting to guide the Advisory Committee in prioritizing community health issues. First, Advisory Committee members created a list of important issues based on the assessment data.

The Advisory Committee’s discussion yielded the following issues: caregiver stress, communication around transitions and hand offs, cost of accessing medicine and supplies, follow-up upon return home, home health care and access, gaps for Medicaid and Medicare (especially for younger people and low income), need for emotional support and mental health services, palliative care and hospice services, patient/family knowledge of disease process, and transportation. As part of the discussion, the Advisory Committee considered similarities and differences between RML Hinsdale and RML Chicago communities.

IPHI then facilitated a multi-voting process where each Advisory Committee member at the meeting voted for his or her top three priorities for RML Hinsdale and top three priorities for RML Chicago. IPHI provided a set of prioritization criteria to help guide each individual in deciding their priorities.

Figure 13. Prioritization Criteria

Population Characteristics
**Prevalence of the problem:** Is this a common occurrence in our communities?
**Seriousness of the problem:** What is the severity of the impact on individual, family and community?
**Disparities:** Is one or more population disproportionately affected, particularly the low income and most vulnerable members of the community?
**Important to the community:** Is there evidence that the issue is important to diverse community stakeholders?

Internal and External Resources
**Available expertise:** Can we make an important contribution?
**Feasibility:** Do we have the internal resources, including money, people, and expertise? Alternatively, are there potential external resources that we can partner with? What time constraints do we need to be aware of?
**Alignment with RML mission and strategic priorities:** Is this consistent with our mission and who we are as an organization?
The prioritization exercise yielded the following top issues:

**Figure 14. Priority Issues Identified through this CHNA**

- Patient/family knowledge of disease process
- Palliative care and hospice
- Communication around transitions and hand offs
- Cost of accessing medicine and supplies
- Caregiver stress

It is important to note that the top issues identified by the Advisory Committee were the same for RML Hinsdale and RML Chicago communities. The results of the Advisory Committee’s voting are displayed below:

**Figure 15. Advisory Committee Voting Results**

<table>
<thead>
<tr>
<th></th>
<th>Hinsdale</th>
<th>Chicago</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Top issues:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient/family knowledge of disease process</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Palliative care and hospice</td>
<td>11</td>
<td>9</td>
</tr>
<tr>
<td>Communication around transitions and hand offs</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Cost of accessing medicine and supplies</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Caregiver stress</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td><strong>Other issues:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follow up</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Home health help and access</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Need for emotional support and mental health services</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Gaps for Medicaid and Medicare (younger people and low income)</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Transportation</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Following the Advisory Committee’s discussion and prioritization exercise, the RML Administrative Council and Management Team reviewed the priorities and generally agreed they reflected the issues facing the community served by RML. Their feedback and ideas for approaches to address the issues were incorporated into discussion at the third Advisory Committee meeting.
At the third meeting, the Advisory Committee also started brainstorming potential approaches to address these issues. For each idea, RML has compiled more detail from the discussion on:

- whether it would be an opportunity for partnership and with whom
- whether it helps current patients, former patients and/or the broader community
- whether it is a long term or ‘quick hit’ approach

RML will incorporate some of these approaches into the CHNA and Community Benefit implementation plan.

**Patient/Family Knowledge of Disease Process -- Potential Approaches**

- Provide demonstrations and educational sessions
- Develop videos on respiratory care, wound care, etc. for viewing at home (could be opened to broader community via YouTube, other)
- Make follow-up calls to discharged patients and offer to answer questions and give guidance.

**Hospice and Palliative Care -- Potential Approaches**

- Deliver presentations for families about hospice/palliative care services in partnership with hospice company.
- Partner with other providers in RML’s existing post-acute network to provide “Quality of Life after LTCH” sessions.
- Hold education sessions on advance directives for patients and community residents.
- Offer palliative care consultations for patients and families.
- Convene a meeting with experts on advancing the acceptance of palliative care in the community.
### Communication around transitions and hand offs

- Send discharge planning reports to next level of care.
- Offer information hotline for family members before coming to RML.
- Incorporate information regarding the transition process into RML tours. Develop better ability to respond to questions about the transition process.
- Long term care coordination and patient tracking.
- Keep Primary Care Physician informed of patient progress during stay and after discharge from hospital.

### Cost of Accessing Medicine and Supplies

- Walk patients and families through existing software programs and on-line resources that identify discounts on medications and evaluate Medicare program offerings.
- Identify and consolidate resources on medication/ pharmacy discounts.
- Help individuals make informed decisions regarding their Medicare Part D options.

### Caregiver Stress

- Provide education on 24-7 care giving for families.
- Develop method to better prepare caregivers to provide care at home.
- Make discharge follow-up calls to offer information and support.
- Connect caregivers to existing community resources.
Implementation Plan

To be developed by September 15, 2013

Reflections on CHNA

The Community Health Needs Assessment (CHNA) process provided a unique opportunity to engage a cross-section of RML departments and several partner agencies. RML acquired significant knowledge about the needs of the communities it serves through the process. RML’s Chief Operating Officer worked diligently to put together a committed Advisory Committee. The Advisory Committee provided a chance for people working in different RML departments to think collaboratively about the needs of the community served by RML. Representatives of the partner agencies brought invaluable insights and ideas to the table for the Advisory Committee. For future processes, RML would like to build on that strength by inviting former patients or family members and representatives of community groups to participate on the CHNA Advisory Committee.

RML identified several keys to the successful completion of its CHNA that can be of use for other LTCHs and post-acute providers:

- Define a community that makes sense for the LTCH;
- Put together a committed Advisory Committee;
- Establish clear roles and expectations for advisory committee and internal stakeholders for their participation in the CHNA process.
- Ensure that meetings are well-planned and professionally facilitated in a focused and interactive manner for maximum effectiveness as the participants are usually volunteers and often have limited time to contribute to the process.
- Be flexible in designing community input processes from a community that is dealing with severe medical conditions and is extremely limited in its ability to participate.

A few lessons learned in compiling the Community Health Profile:

- The local health departments and area agencies on aging are good partners for accessing data.
- Advisory Committee members are important resources in identifying relevant health indicators and data sources.
- RML recognizes that the Community Health Profiles will be of interest and utility for many community groups, and the reports were designed to be accessible to a public audience.

A few lessons learned in gathering **Community Input:**

- There is minimal existing secondary data for RML’s community which makes community input data crucial for identifying needs and assets and arriving at priority issues.
- Gathering community input from LTCH patients and family members is challenging, which makes flexibility in designing the methods for gathering community input essential.

The CHNA process and the community input data that was gathered reinforced and brought into a stark light the struggles faced by the patient population and community served by RML. Of particular note are the struggles they face when they finally make it back home after a prolonged, debilitating illness. It is also apparent that the community resources available to support patients and families are disjointed, not well publicized, and not universally available due to budget cuts, cost, coverage and geographic constraints.

Engaging in this comprehensive CHNA process has opened the door for RML to develop partnerships to begin to address the needs faced by the communities we serve. RML embraces the opportunity before us.

**Approval**

The RML Board of Directors approved this document by unanimous vote at its meeting on May 28, 2013.
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</tr>
<tr>
<td></td>
<td>RML Chicago</td>
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# Appendix A: List of Advisory Committee Members

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
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<tbody>
<tr>
<td>Julie Ames</td>
<td>Chief Information Officer, RML</td>
</tr>
<tr>
<td>John Brofman, M.D.</td>
<td>Medical Director, RML</td>
</tr>
<tr>
<td>Carl Burdinie</td>
<td>Manager, Rehab, RML</td>
</tr>
<tr>
<td>Mary Clark</td>
<td>Manager, Care Management, Advocate Christ Medical Center</td>
</tr>
<tr>
<td>Nahlah Daddino</td>
<td>Community Benefits Manager, Loyola University Health System</td>
</tr>
<tr>
<td>Diane D’Antonio</td>
<td>Manager, Marketing Development, Manor Care</td>
</tr>
<tr>
<td>Menai Edwards</td>
<td>Supervisor, Recruitment and Retention, RML</td>
</tr>
<tr>
<td>Karen Finerty</td>
<td>Director, Performance Improvement</td>
</tr>
<tr>
<td>Collins Fitzpatrick, M.D.</td>
<td>Medical Director, Medically Complex Program, RML</td>
</tr>
<tr>
<td>Maxine Greene</td>
<td>Manager, Respiratory Therapy, RML</td>
</tr>
<tr>
<td>Steve Klikas</td>
<td>Manager, Biomedical Engineering, RML</td>
</tr>
<tr>
<td>James Liadis</td>
<td>Manager, Finance, RML</td>
</tr>
<tr>
<td>Cathy McBride</td>
<td>Regional Manager Social Service, Manor Care</td>
</tr>
<tr>
<td>Kathleen Mikrut</td>
<td>Director, Pharmacy, RML</td>
</tr>
<tr>
<td>Kate Olipra</td>
<td>Branch Office Director, Advocate Home Health</td>
</tr>
<tr>
<td>Ken Pawola</td>
<td>Chief Operating Officer, RML</td>
</tr>
<tr>
<td>Joann Shanahan</td>
<td>Employee Health Nurse, RML</td>
</tr>
<tr>
<td>Vicky Socha</td>
<td>Director, Care Coordination, RML</td>
</tr>
<tr>
<td>Sharon Troike</td>
<td>Liaison, Marionjoy</td>
</tr>
<tr>
<td>Nora Zolen</td>
<td>Liaison, Manor Care</td>
</tr>
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Appendix B: Community Health Profiles

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Community Health Profile

RML Hinsdale

Chicago, Suburban Cook County, DuPage County, and Will County

Prepared by the Illinois Public Health Institute and

RML Specialty Hospital
Community Health Profile - RML Hinsdale

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RML Hinsdale CHNA Community

RML Hinsdale’s Community: People in Chicago, Suburban Cook County, DuPage County and Will County who have suffered a severe, life-changing, debilitating illness requiring extensive psycho-social and health support services when they return home. As the elderly and low-income are most unlikely to have the resources to adapt well to these circumstances, we will focus on these populations.
Methods & Data

For the Community Health Profile, RML collected data from a range of secondary sources. The Illinois Public Health Institute helped in identifying the data sources, collecting, analyzing and presenting the data. RML was fortunate to be able to access data from local health departments (Chicago, Cook County, DuPage County, Will County) for many demographic and health status indicators. Other sources include the Decennial Census, American Communities Survey, Behavioral Risk Factor Surveillance System (BRFSS), Centers for Disease Control and Prevention (CDC), Illinois Department of Public Health, Illinois Department of Economic Security, Illinois Department of Healthcare and Family Services, and RML Internal Records.

Notes on data:

- While the Decennial Census is taken every 10 years, the American Community Survey (ACS) is a more detailed instrument given by the Census Bureau every year to a smaller sample of the population. In order to provide more accurate population data from a smaller sample, ACS data is averaged over a period of years. In this community health profile, we report data from the 2007-2011 ACS.

- To the greatest extent possible, all data for a given indicator are presented for the same time period. However, in some cases data at the local, county and national level are not reported for the same time period. In cases where the time periods on a graph do not exactly match up, a note clearly indicates the different years. These variations should be considered when making comparisons.

- The focus of the data indicators is on RML Hinsdale’s community, defined as: People in Chicago, Suburban Cook County, DuPage County and Will County who have suffered a severe, life-changing, debilitating illness requiring extensive psycho-social and health support services when they return home. As the elderly and low-income are most unlikely to have the resources to adapt well to these circumstances, we will focus on these populations.
Demographic Indicators

Total Population

As of 2010, the total population of the communities outlined in the Community Health Needs Assessment is 6,789,159. The most populous county served is Cook County (5,194,675), which includes the city of Chicago (2,695,598) and many other Suburban Cook communities (2,499,077). DuPage County has a population of 916,924 and Will County has a population of 677,560.

Sources: Decennial Census 2010, DP-1; *Cook County Department of Public Health, "Suburban Cook County Community Profile 2006-2008"
Age Distribution

The age distribution of the overall RML Hinsdale CHNA service area and the individual county locations (Cook, DuPage and Will County) are very similar. Will County and DuPage County both have slightly larger proportions of youth population. DuPage and Cook Counties have higher proportions of older adult population than the City of Chicago and Will County.

Source: Decennial Census 2010, DP-1

Age Distribution in RML Hinsdale Service Area

Source: Decennial Census 2010, DP-1
Cook County

Source: Decennial Census 2010, DP-1

Suburban Cook

Source: Decennial Census 2010, DP-1

Chicago, IL

Source: Decennial Census 2010, DP-1
DuPage County

Source: Decennial Census 2010, DP-1

Will County

Source: Decennial Census 2010, DP-1
Population Under 20

The total population in the service area is 6,789,159 and the total number of people under 20 is 1,839,792. Individuals under the age of 20 account for 27.1% of the population in the RML Hinsdale service area.

Sources: Decennial Census 2010, DP-1; *Cook County Department of Public Health, "Suburban Cook County Community Profile 2006-2008"

Source: Decennial Census 2010, DP-1
Population 65 and Older

Seniors 65 years or older account for 11.63% of the total population in the RML Hinsdale service area. Seventy-eight percent of the total senior population lives in suburban Cook County and Chicago.

Sources: Decennial Census 2000, SF-1; Decennial Census 2010, DP-1; *Cook County Department of Public Health, "Suburban Cook County Community Profile 2006-2008"

Population Aged 65+ (%) (2010)

Sources: Decennial Census 2010, DP-1; *Cook County Department of Public Health, "Suburban Cook County Community Profile 2006-2008"
Population 65+, 2000 and 2010

![Population bar chart]

Source: Decennial Census 2000, SF-1; Decennial Census 2010, DP-1

Households with Individuals 65+, 2009-2011

![Households bar chart]

Source: 2009-2011 American Community Survey 3-year Estimate
Race/Ethnicity

The biggest shift in terms of race/ethnicity between 2000 and 2010 was in the Hispanic/Latino population. In Will County, the Hispanic population increased by 6 percentage points to 14.3%.

**Cook County**

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>Population, White: 51.3%</td>
<td>Population, Hispanic: 49.1%</td>
</tr>
<tr>
<td>Population, Black: 23.8%</td>
<td>Population, Asian: 5.5%</td>
</tr>
<tr>
<td>Population, 2 or more races: 4.4%</td>
<td>Population, 2 or more races: 2.2%</td>
</tr>
<tr>
<td>Population, Hispanic: 18.2%</td>
<td>Population, Hispanic: 21.2%</td>
</tr>
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</table>

Sources: Decennial Census 2000, SF-1; Decennial Census 2010, DP-1

**Suburban Cook County**

<table>
<thead>
<tr>
<th>Ethnic Distribution of Suburban Cook County (2000)</th>
<th>Ethnic Distribution of Suburban Cook County (2010)</th>
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</thead>
<tbody>
<tr>
<td>Population, White: 67.5%</td>
<td>Population, Hispanic: 57.7%</td>
</tr>
<tr>
<td>Population, Black: 13.9%</td>
<td>Population, Asian: 7.1%</td>
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<tr>
<td>Population, 2 or more races: 5.5%</td>
<td>Population, 2 or more races: 16.2%</td>
</tr>
<tr>
<td>Population, Hispanic: 13.0%</td>
<td>Population, Hispanic: 18.9%</td>
</tr>
</tbody>
</table>

Sources: Decennial Census 2000, SF-1; Decennial Census 2010, DP-1

Suburban Cook County experienced larger changes than did Cook County as a whole. The percent of individuals who identify as white decreased by nearly 10%. The Hispanic/Latino, population increased by approximately 6% and the population who identified as black increased slightly as well. The Asian population experienced an increase of 2% between 2000 and 2010 in Suburban Cook County.
The race/ethnic make-up of the City of Chicago did not change substantially from 2000 to 2010. The proportion of white and Hispanic populations increased slightly while the population of people who identified as black decreased. The proportion of Asian population increased slightly.

DuPage County

The proportion of White population in DuPage County decreased slightly from 2000 to 2010, but the County still has a large majority of white residents (72.1%). The proportions of Hispanic, Black and Asian residents all increased slightly between 2000 and 2010, with the largest increase in Hispanic population.
Sources: Decennial Census 2000, SF-1; Decennial Census 2010, DP-1
Ability to Live Independently

Adults Living Alone

According to the 2007-2011 American Community Survey Cook County has a higher population of adults who either have independent living difficulties or self-care difficulties. The full service area has 443,473 citizens that have either an independent living difficulty or a self-care difficulty. 87.2% of the individuals who have some sort of living difficulty live within Cook County.

Adults with Independent Living Difficulty

Source: 2007-2011 American Community Survey 5-year Estimate
Adults with Self-Care Difficulty

Source: 2007-2011 American Community Survey 5-year Estimate
Socioeconomic Indicators

Overall, DuPage and Will County have the highest median household income. Cook County, as a whole (including Chicago and Suburban Cook County), is slightly more than the national median. Chicago has a median income ($47,371) slightly below the national median ($52,762). The highest rate of poverty is found in Cook County (12.9%). DuPage County (4.8%) and Will County (6.2%) had much lower rates of poverty. Seniors who live in Cook County also experience higher rates of poverty than the surrounding counties (11.2% in Cook, 4.9% in DuPage and 5% in Will). Overall residents of the city of Chicago also have higher rates of 200% poverty. The 200% of federal poverty means that a single person who makes $22,278 is making 200% of the federal poverty line.

Note: In 2010, the poverty line was set at $11,139 for a single person and $22,113 for a family of four with two children.

*Sources: 2007-2011 American Community Survey 5-year Estimate; *Cook County Department of Public Health, "Suburban Cook County Community Profile 2006-2008"
Percent Living Below Poverty Line

Poverty Rates (<100%)

Source: Decennial Census 2000, SF-1, Decennial Census 2010, DP-1; *2009-2011 American Community Survey 3-year Estimates

Poverty (<100%) Among Older Adults (65+)

Source: 2009-2011 American Community Survey 3-year Estimates
Poverty (<200%) (Individuals)


Population over 16 Unemployed, 2000 to 2010

Health Indicators

Medicare Enrollment, 2011

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<tr>
<th></th>
<th>Cook County</th>
<th>DuPage County</th>
<th>Will County</th>
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<tbody>
<tr>
<td>Total 65+ Population</td>
<td>620,329</td>
<td>106,398</td>
<td>62,814</td>
</tr>
<tr>
<td>Part D Enrolled</td>
<td>235,630</td>
<td>38,063</td>
<td>20,368</td>
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<tr>
<td>Advantage Plan</td>
<td>76,166</td>
<td>7,361</td>
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<tr>
<td>Medicaid/Medicare</td>
<td>93,681</td>
<td>9,929</td>
<td>4,609</td>
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</table>

Leading Causes of Death, 65+, 2011

City of Chicago

Heart Disease
Cancer
Stroke
Chronic Lower Respiratory Disease
Flu/Pneumonia

Illinois

Heart Disease
Cancer
Stroke
Chronic Lower Respiratory Disease
Alzheimer’s
RML Patient Data

Age Distribution of RML Patients, FY2012

Race/Ethnic Make-up of RML Patients, FY2012

Length of Stay of RML Patients, FY2012

<table>
<thead>
<tr>
<th></th>
<th>RML Chicago</th>
<th>RML Hinsdale</th>
<th>Total RML Patients</th>
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</thead>
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<tr>
<td>&lt; 3 weeks</td>
<td>29%</td>
<td>36%</td>
<td>33%</td>
</tr>
<tr>
<td>3-6 weeks</td>
<td>48%</td>
<td>43%</td>
<td>45%</td>
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<tr>
<td>6-9 weeks</td>
<td>17%</td>
<td>14%</td>
<td>15%</td>
</tr>
<tr>
<td>9-11 weeks</td>
<td>4%</td>
<td>4%</td>
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<tr>
<td>12+ weeks</td>
<td>2%</td>
<td>3%</td>
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Discharge Data for RML Hinsdale Patients, FY2012

Patient Diagnoses, RML (Both Campuses)

Ventilator Weaning
(65% of patients)
• Neurological dysfunction
• Chronic and acute lung disease
• Post-operative complications
• Coronary artery disease
• West Nile Virus & other infectious

Wound Management
(10% of patients)
• Complex pressure ulcers
• Surgical wounds
• Vascular ulcer
• Burns
• Osteomyelitis
• Fistula Management

Medically Complex
(25% of patients)
• CVA
• Head injury
• Pre-rehabilitation
  o Orthopedics
  o Neurology
• Deconditioned
• Organ Transplant
• Ventricular Assist Devices
Community Health Profile

RML Chicago

Chicago and Suburban Cook County

Prepared by the Illinois Public Health Institute and

RML Specialty Hospital
Community Health Profile - RML Chicago

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RML Chicago CHNA Community

**RML Chicago’s Community:** People in Chicago and Suburban Cook County who have suffered a severe, life-changing, debilitating illness requiring extensive psycho-social and health support services when they return home. As the elderly and low-income are most unlikely to have the resources to adapt well to these circumstances, we will focus on these populations.
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For the Community Health Profile, RML collected data from a range of secondary sources. The Illinois Public Health Institute helped in identifying the data sources, collecting, analyzing and presenting the data. RML was fortunate to be able to access data from local health departments (Chicago, Cook County) for many demographic and health status indicators. Other sources include the Decennial Census, American Communities Survey, Behavioral Risk Factor Surveillance System (BRFSS), Centers for Disease Control and Prevention (CDC), Illinois Department of Public Health, Illinois Department of Economic Security, Illinois Department of Healthcare and Family Services, and RML Internal Records.

Notes on data:

- While the Decennial Census is taken every 10 years, the American Community Survey (ACS) is a more detailed instrument given by the Census Bureau every year to a smaller sample of the population. In order to provide more accurate population data from a smaller sample, ACS data is averaged over a period of years. In this community health profile, we report data from the 2007-2011 ACS.

- To the greatest extent possible, all data for a given indicator are presented for the same time period. However, in some cases data at the local, county and national level are not reported for the same time period. In cases where the time periods on a graph do not exactly match up, a note clearly indicates the different years. These variations should be considered when making comparisons.

- The focus of the data indicators is on RML Chicago’s community, defined as: People in Chicago and Suburban Cook County who have suffered a severe, life-changing, debilitating illness requiring extensive psycho-social and health support services when they return home. As the elderly and low-income are most unlikely to have the resources to adapt well to these circumstances, we will focus on these populations.
Demographic Indicators

Total Population

Cook County is comprised of the city of Chicago as well as what is considered Suburban Cook County. Just over half of the population within Cook County resides within the city limits of Chicago (2,695,598) and the remaining population lives in the suburbs (2,499,077).

Sources: Decennial Census 2010, DP-1; *Cook County Department of Public Health, "Suburban Cook County Community Profile 2006-2008"

Cook County Total Population (2010)

[Diagram showing the population distribution between Chicago and Suburban Cook County]

Sources: Decennial Census 2010, DP-1; *Cook County Department of Public Health, "Suburban Cook County Community Profile 2006-2008"

Cook County Overall Population (2010)

[Bar chart showing the population distribution between Chicago and Suburban Cook County]

Sources: Decennial Census 2010, DP-1; *Cook County Department of Public Health, "Suburban Cook County Community Profile 2006-2008"
Age Distribution

Cook County’s residents are primarily between the ages of 25-69 years old. Individuals who are between 25 and 39 account for the largest amount of any given age population in Cook County at 23%. Adults aged 55-69 are 14.5% of the total population in Cook County.

Cook County Population

Source: Decennial Census 2010, DP-1

Suburban Cook County Population

Source: Decennial Census 2010, DP-1

Chicago, IL Population

Source: Decennial Census 2010, DP-1
Population Under 20 Years Old

Sources: Decennial Census 2000, SF-1; Decennial Census 2010, DP-1
Population 65 and Older

Suburban Cook County experienced a slight increase in the population of seniors 65 and older between the years of 2000-2010. The city of Chicago experienced a slight decrease in the elderly population within those same years, consistent with and overall population decrease in the city.

The proportion of seniors in Suburban Cook County (13.7%) is very similar to the national proportion. Chicago has a lower proportion of population 65 years or older (10.31%).

Sources: Decennial Census 2010, DP-1; *Cook County Department of Public Health, "Suburban Cook County Community Profile 2006-2008"
Cook County has a very large proportion of the region’s households with individuals 65 and older.

Households with Individuals 65+, 2009-2011

Source: 2009-2011 American Community Survey 3-year Estimate
Race/Ethnicity of the Population

**RML Chicago Service Area (2000)**
- Population, White: 50.85%
- Population, Black: 24.25%
- Population, Asian: 18.50%
- Population, 2 or more races: 1.90%
- Population, Hispanic: 4.50%

**RML Chicago Service Area (2010)**
- Population, White: 48.24%
- Population, Black: 22.53%
- Population, Asian: 21.78%
- Population, 2 or more races: 5.65%
- Population, Hispanic: 1.79%

Sources: Decennial Census 2000, SF-1; Decennial Census 2010, DP-1

**Cook County**

The largest change in Cook County took place in the Hispanic/Latino population.

**Ethnic Distribution of Cook County (2000)**
- Population, White: 51.3%
- Population, Black: 23.8%
- Population, Asian: 18.2%
- Population, 2 or more races: 4.4%
- Population, Hispanic: 2.3%

**Ethnic Distribution of Cook County (2010)**
- Population, White: 49.1%
- Population, Black: 22.0%
- Population, Asian: 21.2%
- Population, 2 or more races: 5.5%
- Population, Hispanic: 2.2%

Sources: Decennial Census 2000, SF-1; Decennial Census 2010, DP-1
Suburban Cook County experienced larger changes than did Cook County as a whole. The percent of individuals who identify as white decreased by nearly 10%. The Hispanic/Latino population increased by approximately 6% and the population who identified as black increased slightly as well. The Asian population experienced an increase of 2% between 2000 and 2010 in Suburban Cook County.

Chicago (city)

The race/ethnic make-up of the City of Chicago did not change substantially from 2000 to 2010. The proportion of white and Hispanic populations increased slightly while the population of people who identified as black decreased. The proportion of Asian population increased slightly.
Ability to Live Independently

Adults Living Alone

Adults 65-74 Living Alone

Source: 2009-2011 American Community Survey 3-year Estimate

Disabilities

Adults With Independent Living Difficulties

Source: 2007-2011 American Community Survey 5-year Estimate
Socioeconomic Indicators

In RML Chicago’s full CHNA service area of Cook County, the median household income is above the national average ($52,762). The city of Chicago has a lower median household income ($47,371).

Note: In 2010, the poverty line was set at $11,139 for a single person and $22,113 for a family of four with two children.

*Sources: 2007-2011 American Community Survey 5-year Estimate; *Cook County Department of Public Health, "Suburban Cook County Community Profile 2006-2008"
The poverty rates in the RML Chicago service shows disparity between individuals living inside the city of Chicago and living in Suburban Cook County. Nineteen percent of individuals living in Chicago are at or below 100% below the federal poverty line, contrary to Chicago; Suburban Cook County has only 6.4% of their residents below 100% of the poverty line. The overall 100% poverty rate in Cook County is 13.5% which is higher than both the state average (10.7%) as well as the national average (12.4%).

Sources: Decennial Census 2000, SF-1, Decennial Census 2010, DP-1; 2009-2011 American Community Survey 3-year Estimates; *Cook County Department of Public Health, "Suburban Cook County Community Profile 2006-2008"
Overall residents of the city of Chicago also have higher rates of 200% poverty. The 200% of federal poverty means that a single person who makes $22,278 is making 200% of the federal poverty line.

Throughout the RML Chicago CHNA service area the city of Chicago (16.7%) and Cook County (11.2%) have a higher percent of seniors who are at or below the 100% federal poverty line compared to Illinois (8.3%) overall and the nation (9.3%).

Health Indicators

Medicare Enrollment, 2011

<table>
<thead>
<tr>
<th></th>
<th>Cook County</th>
<th>DuPage County</th>
<th>Will County</th>
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<tbody>
<tr>
<td>Total 65+ Population</td>
<td>620,329</td>
<td>106,398</td>
<td>62,814</td>
</tr>
<tr>
<td>Part D Enrolled</td>
<td>235,630</td>
<td>38,063</td>
<td>20,368</td>
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<tr>
<td>Advantage Plan</td>
<td>76,166</td>
<td>7,361</td>
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<tr>
<td>Medicaid/Medicare</td>
<td>93,681</td>
<td>9,929</td>
<td>4,609</td>
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</tbody>
</table>

Leading Causes of Death, 65+, 2011

City of Chicago

Heart Disease
Cancer
Stroke
Chronic Lower Respiratory Disease
Flu/Pneumonia

Illinois

Heart Disease
Cancer
Stroke
Chronic Lower Respiratory Disease
Alzheimer’s
RML Patient Data

Age Distribution of RML Patients, FY2012

Race/Ethnic Make-up of RML Patients, FY2012

Length of Stay of RML Patients, FY2012

<table>
<thead>
<tr>
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<th>RML Chicago</th>
<th>RML Hinsdale</th>
<th>Total RML Patients</th>
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<tbody>
<tr>
<td>&lt; 3 weeks</td>
<td>29%</td>
<td>36%</td>
<td>33%</td>
</tr>
<tr>
<td>3-6 weeks</td>
<td>48%</td>
<td>43%</td>
<td>45%</td>
</tr>
<tr>
<td>6-9 weeks</td>
<td>17%</td>
<td>14%</td>
<td>15%</td>
</tr>
<tr>
<td>9-11 weeks</td>
<td>4%</td>
<td>4%</td>
<td>4%</td>
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<tr>
<td>12+ weeks</td>
<td>2%</td>
<td>3%</td>
<td>3%</td>
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</tbody>
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Discharge Data for RML Chicago Patients, FY2012

Patient Diagnoses, RML (both facilities)

Ventilator Weaning
(65% of patients)
- Neurological dysfunction
- Chronic and acute lung disease
- Post-operative complications
- Coronary artery disease
- West Nile Virus & other infectious

Wound Management
(10% of patients)
- Complex pressure ulcers
- Surgical wounds
- Vascular ulcer
- Burns
- Osteomyelitis
- Fistula Management

Medically Complex
(25% of patients)
- CVA
- Head injury
- Pre-rehabilitation
  - Orthopedics
  - Neurology
- Deconditioned
- Organ Transplant
- Ventricular Assist Devices
## Appendix C: Community Input Reports

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<td>RML Chicago</td>
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# Community Input Report - RML Hinsdale

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RML Hinsdale’s community: People in Chicago, Suburban Cook County, DuPage County and Will County who have suffered a severe, life-changing, debilitating illness requiring extensive psycho-social and health support services when they return home. As the elderly and low-income are most unlikely to have the resources to adapt well to these circumstances, we will focus on these populations.
Methods

Staff Focus Group

One focus group was conducted with eight staff members from different departments within RML Hinsdale. The focus group was conducted by Jessica Lynch and Kristin Monnard from IPHI and followed a semi-structured format. Topics ranged from the challenges and barriers patients face to the difficulties they experience when transitioning between care sites and managing their health long-term. The departments represented in the focus group were care coordination, nursing, patient ambassador, chaplain, intake, rehabilitation therapy, respiratory therapy as well as physicians.

Patient and Family Interviews

One-on-one interviews were conducted with previous patients and patient’s family members regarding their experiences with RML Hinsdale and their experience post-discharge. Five previous patients and patients’ family members from RML Hinsdale were contacted and were willing to participate in a short phone interview. The phone interviews were conducted by Jessica Lynch and Kristin Monnard of IPHI.

Staff Focus Group Results

The key informant interviews were conducted by telephone by Jessica Lynch and Kristin Monnard of IPHI. The interviews included representatives from different community organizations and facilities that are familiar with RML Hinsdale and/or the community it serves.
Results

The primary themes that were addressed in the RML Hinsdale focus group included:

- Inability of patients and families to manage the patient’s care needs.
- Gaps in Insurance coverage and high out-of-pocket costs.
- Need to assist families in accepting patient’s condition and developing realistic expectations.
- Need for additional education about home care and the disease process.
- Support for transitioning to next site of care and to home.

Barriers associated with transitioning and managing health include:

- Medical management is needed before and after hospitalization.
- Many patients and families do not have adequate conversations with their primary care physicians about how they can give the patient the highest quality of life by using hospice, palliative or end of life care.
- Lack of a protocol that “triggers” the request for a palliative care or hospice physician consultant to speak with the patient and family.
- Release of patients to home care staff or family members who have not received adequate training on caring for the patient.
- Patients and families do not feel comfortable with letting “strangers” or home health care workers in their homes.

Common barriers that are often associated with cost or insurance coverage include:

- High and unexpected out-of-pocket payments.
- Complicated Medicaid and Medicare requirements.
- Medications, medical supplies, home health care coverage, and many other essential services, such as chair-lifts, are not covered or provide limited coverage.
- PT/OT coverage is insufficient and not tailored to individual needs.
- County, State, and Federal income requirements for benefits all vary.

The focus group also identified that most of the patient’s family members have unrealistic beliefs and expectations about the patient’s outcome.

- The patient’s future quality of life and what families want for them or believe they deserve is not always covered by insurance.
- Family members who are going to be the 24-hour caregivers are often mentally unprepared for the stress and constant patient needs.
A lack of knowledge about the patient's disease process was a persistent theme that came up in almost all of the focus group responses as a barrier to:

- Understanding patient's health condition and the overall disease process ("should begin in the "acute" stage" – and should address how life will change and/or be in the next few months).
- Providing 24-hour care.
- Teaching how to use and implement therapeutic techniques regarding diets or changes in ability.
- Transitioning between RML to a Skilled Nursing Facility (SNF) or a Rehabilitation Facility.
- Understanding the difference and benefit of palliative and hospice care
  - Patient's families associate palliative and hospice with giving up on their family member.
  - Palliative care and hospice care can vary between providers.

The focus group also explained multiple concerns with the support available for their patients that are going to transition to either a new facility or home. Those concerns included:

- A lack of family and social support.
  - Transportation concerns.
- Emotional reactions.
  - Fear and anxiety of leaving.
  - Feeling of shock with diagnosis and prognosis.
  - Feelings of loneliness.
- Lack of follow up.
- Over-reliance on a resource list or brochure that highlights the services at other facilities. ("Seeing is different than reading.")
- Unfamiliarity with the availability of support from church groups, senior services and also park districts that can help with providing or obtaining home care and other services.
Staff Focus Group Questions

- What are some of the greatest challenges and barriers for patients and their caregivers in managing their health and recovery as they transition out of RML?
  - When they go home?
- What do you perceive as being the most challenging aspect of the transition after leaving RML?
  - Probe: any differences for RML Chicago patients?
- What seems to surprise patients and families most about the transition out of RML? What are they most unprepared for? (probe: eventual transition to home)
- What supportive services are most important for patients and their families after their hospital stay?
  - What supportive services are the most challenging to access?
  - What specific resources are most useful?
  - Which supportive services would you identify as priorities for improvement?
  - (probes can include: long term care residence, rehab care, home health, hospice, palliative care, advance care planning, respite care, caregivers)
  - If you could change something about these services, what changes would you make?
- What would be the most effective ways to improve quality of life for the types of patients that RML sees?
- How can RML best partner to support patient caregivers and family members to help them have the best quality of life possible back in the community?
- What do patients and their families need most from RML during their hospital stay to prepare them for life after RML?
- How can information be best communicated to patients, their family members, and key community stakeholders in caring for these patient populations? What types of information are most helpful?
Patient and Family Interview Results

The interviews with former patients and family members provided a firsthand account as to some common occurrences that patients faced during, as well as after their stay at RML Hinsdale. Overall, patients and families were quite happy and satisfied with the quality of care given by the staff at RML. Challenges included:

- Need for additional communication and education of patients and families.
- Difficulty transitioning to a new assisted-living facility or back to home.
- Gaps in Insurance coverage and high out-of-pocket costs.
- Overwhelming care needs after discharge and particularly upon return to home.
- Need for additional caregiver training.

In all of the interviews, communication was a major barrier. Overall, the interviewee’s concerns with communication regarding discharge were surrounding:

- Transitioning care between facilities often results in loss of information, misinterpretation and inconsistency due to mixed messages between the multiple facilities.
- Serving individuals from a multicultural background.
- Lack of follow-up after discharge.
- Not understanding the differences between “home health” and “home care.”

The interview participants also explained that transitioning between a new facility or home proved to be troublesome as well because:

- Even though the services were set up and ready, they were short lived.
- Unexpected mobility concerns like getting in and out of shower, using stairs, and obtaining medications.
- There were discrepancies between care given at RML and care given at new facility.
- Time and effort required to pick specialist or new facility to receive care.
- Lack of guidance or referrals to skilled nursing and rehabilitation facilities or medical specialists.

Insurance and cost were also brought up as an area of concern because:

- Information and eligibility information given to patient may be out of date.
- Lack of coverage between behavioral health, phone-based therapy, counseling and resources for in-home visits.
- Insurance won’t cover essential items that will help with mobility concerns such as a shower chair or high rising bed.
Due to the specific population RML works with, frequently additional health care is needed after they are discharged and the participants again addressed some situations that they encountered:

- Initially follow up care of a therapist was provided however that quickly stopped.
- A nurse was also made available however only for a short amount of time.
- Problems with finding quality in-home providers because of pay discrepancy and labor required.
- Lack of social and emotional support.
- Lack of caregiver training for specific populations who need more hands on health care assistance.
Patient and Family Member Interview Questions

- In thinking about when your loved one was at RML, what did you and your loved one need most from RML during the hospital stay? (probe: what path did your loved one take after RML)
- What supportive services are most important for patients and their families after their hospital stay?
  o What supportive services are the most challenging to access?
  o What specific resources are most useful?
  o Which supportive services would you identify as priorities for improvement?
  o (probes can include: long term care residence, rehab care, home health, hospice, palliative care, advance care planning, respite care, caregivers)
  o If you could change something about these services, what changes would you make?
- What are some of the greatest challenges and barriers for patients and their caregivers in managing their health and recovery after RML? What were some of the most challenging aspects of the transition after leaving RML for your loved one? What surprised you or were you unprepared for?
- What do patients and their families need most from RML during their hospital stays to prepare them for life after RML? How can RML best support patient caregivers and family members after they leave?
- How can information be best communicated to patients, their family members, and key community stakeholders in caring for these patient populations? What types of information are most helpful? (Probe: navigating insurance)
Key Informant Interviews

After speaking to key representatives from different agencies and facilities these concerns were raised the most:

- Lack of social support and education for family members.
- Caregiver stress.
- Gaps in Insurance coverage and high out-of-pocket costs.
- Need for effective communication and the importance of cultural competency.
- Support for transitioning to next site of care and to home.

Many of the key individuals that were interviewed explained and stressed the importance of social support and education of the client’s family members. The specific concerns brought up included:

- The family’s lack of coping strategies and expectations for unrealistic outcomes.
- Need for repeat and continued education for family members regarding their loved one’s condition and for services to process what is happening.
- Confusion regarding the differences between and the use of palliative care, hospice services, and end-of-life care.
- The lack of understanding and acceptance of the adjustment to the heightened and complex needs that these patients and families will need to go through.

Many key informants also addressed and noted concerns about the stresses that caregivers face. Those concerns included:

- Physical and mental strains of dealing with medically complex patients.
- Lack of understanding about the responsibility and expectations of being a 24 hour a day caregiver.
- Initial stress, shock, emotional strain, and anxiety for family members serving as the primary caregiver.

Costs and insurance related concerns included:

- Medicare and Medicaid landscapes are changing, frequently leading to higher out-of-pocket costs.
- Transitioning to hospice can be financially complicated.
- Case managers can assist in working through insurance coverage issues.
- Some seniors do not have good insurance coverage beyond basic Medicare Part A.
- Many home services and some home health care services and equipment are not covered by public or private insurance.
- Young patients with severe health problems have challenges with insurance coverage and referrals to community resources.
Key Informant Interview Questions

- What is the transition from RML to the rehab facility/SNF like?
- What needs to happen so that a patient can discharge to facility like yours?
- From your perspective, is there something more hospitals like RML could do to help caregivers and their families?
- What are the greatest challenges for patients and their caregivers during their time at your facility/receiving your services?
- What are the greatest challenges for patients and their caregivers after leaving your facility?
- At follow-up after discharge, what are the most commonly identified issues?
- How do you facilitate a patient’s transition back into the community? Do most patients continue rehabilitation at one of your outpatient sites? Does case management continue after discharge from inpatient care?
- Can you talk a little more about what resources/ suggestions you share in the caregiver support group? Do you address resources that caregivers can utilize after their loved one leaves the facility?
- What are the biggest challenges for older adults with severe conditions and their families when they are caregiving at home? What services/resources/systems are needed?
AgeOptions: Questions

- How does Age Options define the population that you serve?
- How does Age Options serve seniors who have suffered severe, life changing illness? (How often do you see seniors fitting this description?)
- What are some of the most common needs and struggles you see in this population?
- What are the most commonly needed services by these seniors?
- What are some of the most significant barriers seniors face in accessing the services they need? Caregivers?
- Do you feel that the community has adequate resources to meet the needs of this population?
- What services are missing and needed? What are the reasons those services don’t currently exist?

Questions that we may ask at this point if this information has not yet surfaced:

- What resources exist in Suburban Cook County specifically for individuals in need of extensive psycho-social and health support services?
- What is the greatest gap in the availability of these services for low-income elderly?
- Can you talk a little more about your Family Caregiver Support Program?
  - What are some of the most common service requests from caregivers?
  - Does Age Options connect caregivers to resources that can help finance the cost of services like respite or home care?
- Can you tell us a little more about your Caregiver Resource Centers?

- What are the most important changes that could be made in this community that would better serve the needs of older adults who have recently suffered a debilitating illness? How about caregivers?
- What is your perspective on how much service provision varies from county to county? Are there colleagues in Chicago or DuPage County that you would recommend we interview?
**AgeOptions: Information**

AgeOptions is a nonprofit community-based organization that partner’s with other area nonprofit organizations that serve older adults and their caregivers. AgeOptions can help connect you, or a senior you love and care about with programs and services in your community such as:

- In-home care
- Adult day services
- Telephone assistance to answer questions and link callers to the resources they need
- Problem solving with information specialists concerning care needs
- Nutritious meals
- Intervention against fraud, abuse and neglect
- Advocacy to protect the rights of older adults
- Employment and volunteer opportunities

In 2012, AgeOptions conducted the Needs Assessment Survey for Area Plan and Appreciative Inquiry Sessions and identified many needs that are unmet for older adults in suburban Cook County:

![Needs Assessment Survey Chart]
AgeOptions: Needs Assessment

Current Trends and Status:

- The total amount of individuals over the age of 60 is 481,119 which is an increase of 16.44% from the 1990 Census.
- Individuals who are over the age of 75 account for 6.76% of the total population, and that is an increase of 38% since the 1990 Census.
- Approximately 11% of the individuals 60 and over are 85 years or older.
- Surveys done by AARP show that 80% of baby boomers expect and intend to work past 65 years old in completely new second careers like social work and teaching.

Diversity in Suburban Cook’s Elderly Community:

- 15,236 Latino older adults, 65 and older, live in suburban Cook County. Research has found that these adults are:
  - Less likely to access services due to the lack of cultural training of staff members.
  - More likely to be foreign born and experience communication barriers
  - Less educated
  - Lower socioeconomic status
  - Receive large portion of income from Social Security, however have less access to benefits
  - Lower health insurance coverages
- According to the 2010 Census 93,138 individuals 65 and older currently live alone.

Education Level:

- White, non-hispanic, older adults have the highest percentage of high-school graduation compared to other groups. Asian and Pacific Islanders have the highest percentage college completion.
- These same patterns can be seen in sources of retirement income, finance savings and assets, as well as ownership of supplemental insurance.

Multiple Generations:

The number of households composed of multiple generations is higher than it has been in half a century due to job loss, foreclosures and the recession. One in ten children in the U.S. now lives with a grandparent.
Resources

- American Association of Retired Persons – website: www.aarp.org

  The AARP website contains articles about hiring a home care worker as well as other information about the different types of home-care providers available.

- AgeOptions – website: www.ageoptions.org

  AgeOptions core program focuses on Cook County and other collar counties and is funded by the Older Americans Act. There are 10 Caregiver Resource Centers located around suburban Cook County and includes opportunities for trainings, respite and adult daycare.

- Aging Care Connections – website: www.agingcareconnections.org

  Aging Care Connections meets with seniors at the hospital to assess needs and to inform them about services that are available in their community.

- Medicaid – website: www.medicaid.gov

  The official Medicaid website has details about what is covered by Medicaid and also the requirements needed to qualify.

- Medicare – website: www.medicare.gov

  The official Medicare website contains useful information, fact sheets and support for knowing about your own personal Medicare plan. There are also location services that can find the nearest doctors, health professionals, nursing homes, hospitals, home health services, medical equipment suppliers and also other specialty medical facilities. Information is also available to find out what is covered and how someone can qualify for Medicare.
The National Caregivers Library was developed by FamilyCare America, Inc. and contains a lot of useful information that caregivers can utilize in dealing with common occurrences as a caregiver. Examples of available tools include:

- Questionnaires
- Checklists
- FAQ Sheets
- Articles
- Important forms

Useful links available through National Caregivers Library:

- Caregiving and Housekeeping
- Medical Equipment And Medicare Coverage
- Adapting the Home
- Help With Home Modification
- How To Manage Your Pain
- Medication And Older Adults
- Good Nutrition: An Introduction
- Providing Day-To-Day Care
- Coping With Disabilities
- Helping With Disabilities
Community Input Report

RML Chicago

Prepared by the Illinois Public Health Institute and

RML Specialty Hospital
Community Input Report - RML Chicago

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RML Chicago CHNA Community

RML Chicago’s community: People in Chicago and Suburban Cook County who have suffered a severe, life-changing, debilitating illness requiring extensive psycho-social and health support services when they return home. As the elderly and low-income are most unlikely to have the resources to adapt well to these circumstances, we will focus on these populations.
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Patient and Family Interviews

One on one interviews were conducted with previous patients and patient's family members regarding their experiences with RML Chicago and their experience post-discharge. Two previous patients and patients’ family members from RML Chicago were contacted and were willing to participate in a short phone interview. The phone interviews were conducted by Jessica Lynch and Kristin Monnard of IPHI.

Staff Focus Group Results

The key informant interviews were conducted by telephone by Jessica Lynch and Kristin Monnard of IPHI. The interviews included representatives from different community organizations and facilities that are familiar with RML Chicago and/or the community it serves.
Results

Staff Focus Group

The RML Chicago focus group identified six themes that they felt were problem areas for their clients. Those areas of concern were:

- Inability of patients and families to manage the patient's care needs.
- Gaps in Insurance coverage and high out-of-pocket costs.
- Need to assist families in accepting patient's condition and developing realistic expectations.
- Need for additional education about home care and the disease process.
- Support for transitioning to next site of care and to home.
- Ensuring that cultural differences are taken into account when developing education and support services for patients and families.
- Lack of transportation for physician and therapy visits.

Many of the focus group members believed that the primary barrier for individuals at RML is transitioning because:

- Patients have limited options.
- Patients are used to a high quality of care and once they are moved that care either stops or is not the same as what they were used to.
- Other facilities have less staff members which results in poorer quality of care.
- The discharge planner attempts to make moves smooth however some individuals are much sicker than they appear once they arrive.
- Communication between doctor and care coordinators about needs and additional services.
- Lack of control over recommendations of care. Transferring a patient to a different location means a different doctor’s opinion and recommendations.
- Discharge orders are often written to make sure that client’s know their responsibilities.

Cost and insurance coverage’s were also brought up as barriers for the community because of a lack of access to care, lack of services available due to decreased funding and home care benefits are very limited.

The focus group also explained that families who decide to provide 24-hour care for the family members do not realize the requirements and devotion needed. The members explained that their patient’s family members were often surprised because:

- Of the lack of the availability of services according to insurance.
- Of the burden, and responsibility involved in being a caregiver.
- Of the amount of equipment needed to be a caregiver.
Education was also brought up throughout many areas by the focus group members. Educating the clients about topics such as:

- Lifestyle changes.
- Caregiver education and their role in the transition.
- Common challenges faced in transitioning and being a caregiver.
- Medication management.
- Involvement and commitment that care-giving requires.
- It takes the whole family!
- Make sure a clear understanding and agreement is in place, signed documentation of understanding and agreeing to responsibility as a caregiver.

A main topic of discussion throughout, as well as after, the meeting was having support for transitioning clients. The specific topics addressed:

- Mental health support for dealing with feelings like shock and anxiety about leaving the hospital.
- Mobility issues including living in a multi-level residences, or being required to walk a lot.
- Responsibility of making decisions by themselves.
- Follow up phone call correspondence is needed.

The focus group explained that they believed transportation to be a concern as well. The focus group explained that many people unable to go back and forth from their home to their appointments and rehab services because of being weak and unable to drive or take public transportation.
Patient and Family Interviews

Two family members of former RML Chicago patients were able to be interviewed and that person identified two main areas of concern. Those areas were:

- Caregiver training and support
- Additional care after discharge

The interviewees voiced concern over the preparation of being a caregiver for the first time. They explained that they felt they were not prepared or ready to be a caregiver. The family caregivers explained that they felt stressed and would have joined a support group if they had known one was available.

The caregivers explained that there quite a few of in-home services to help their family member transition however these services stopped very soon after the patient returned home. The caregivers also said that RML could give follow up phone calls after the patients leave the hospital. The caregivers also shared challenges with continuity of care, accessing physicians, and the cost of prescriptions and medical equipment.
**Key Informant Interviews**

After speaking to key representatives from different agencies and facilities these concerns were raised the most:

- Social support and education of family members
- Caregiver stress
- Insurances and costs of service
- Communication
- Transitioning
- Population specific concerns

Many of the key individuals that were interviewed explained and stressed the importance of social support and education of the client’s family members. The specific concerns brought up included:

- The client’s family’s coping strategies and expectations of both unrealistic and realistic outcomes.
- Education for family members of what is going on and offering services to process what is happening.
- Differences, uses and confusion between palliative services, hospice services and end-of-life care.

Many key informants also addressed and noted concerns about the stresses that caregivers face. Those concerns included:

- An emphasis needs to be focused on providing resources for caregivers.
- Physical and mental strains of dealing with medically complex cases.
- Lack of understanding about the responsibility and expectations of being a 24 hour a day caregiver.
- Initial stress, shock and emotional strain causes anxiety amongst family members serving as the primary caregiver.

Costs and insurance related concerns included:

- Medicare and Medicaid landscapes are changing.
- Transitioning to hospice can be financially complicated.
- Case managers can help learn what is an is not coverage.
- Some seniors are not on public aid and do not have good insurance coverage.
- Home services are private pay and some tools are not coverable.
Communication was also explained as being an area of concern because:

- Severity and expected outcomes may be difficult to convey to clients and their families.
- Case management and coordination would help with follow up and improving communication across facilities.
- Lack of knowledge of outcome for patients

Many areas of concern came when discussing transitioning for patients. Some of the specific concerns were:

- More utilization of communication between social workers at different facilities.
  - Emotional, psychological and physical state is important for other facilities to know where to pick up.
- Emotions like shock and loss from caregiver when patient goes back home.
- Stigma associated with accepting help, either physical or mental.
  - Sense of losing independence.

Due to RML having a specific population that they work with population specific concerns addressed are:

- The patients that go to RML are often very complex and sick individuals. The patients often have heightened needs and the family needs to be educated and informed on the adjustment and process they will be going through.
- Young patients have complications with coverage’s and referrals because of how the medical community is geared to assist elderly.
Specifically in Chicago, we spoke with the Chicago Area Agency on Aging. Some of the key findings from that interview were:

- The agency has 13 planning and service areas, 4 care coordination units and 21 senior satellite centers across the city.
- Currently engaged in initial stages of a city-wide age-friendliness assessment.
- Greatest needs/gaps in services for seniors include: age-friendly home retrofitting (installing grab bars in showers, etc.), transportation, and services for individuals in need of more than 20 hours a week of unskilled care.
- Joyce Gallagher, Exec Director of the Agency on Aging, convenes the "Well Being Task Force" to “provide services for and advocate on behalf of seniors living alone without internal or external support systems”, and they encourage RML to join.
- The agency is working to develop an Aging and Disability Resource Network (ADRN), which is intended to increase the agency’s ability to appropriately connect Chicago seniors with needed services. The ADRN is being created and expanded in partnership with the Mayor’s office, Access Living and others - this network will help individuals access programs and services “so that there is no wrong door.” In addition to connecting individuals to services, there will also be an education component.
Key Informant Questions

- What is the transition from RML to the rehab facility/SNF like?
- What needs to happen so that a patient can discharge to facility like yours?
- From your perspective, is there something more hospitals like RML could do to help caregivers and their families?
- What are the greatest challenges for patients and their caregivers during their time at your facility/receiving your services?
- What are the greatest challenges for patients and their caregivers after leaving your facility?
- At follow-up after discharge, what are the most commonly identified issues?
- How do you facilitate a patient’s transition back into the community? Do most patients continue rehabilitation at one of your outpatient sites? Does case management continue after discharge from inpatient care?
- Can you talk a little more about what resources/ suggestions you share in the caregiver support group? Do you address resources that caregivers can utilize after their loved one leaves the facility?
- What are the biggest challenges for older adults with severe conditions and their families when they are caregiving at home? What services/resources/systems are needed?
AgeOptions: Questions

- How does Age Options define the population that you serve?
- How does Age Options serve seniors who have suffered severe, life changing illness? (How often do you see seniors fitting this description?)
- What are some of the most common needs and struggles you see in this population?
- What are the most commonly needed services by these seniors?
- What are some of the most significant barriers seniors face in accessing the services they need? Caregivers?
- Do you feel that the community has adequate resources to meet the needs of this population?
- What services are missing and needed? What are the reasons those services don’t currently exist?

Questions that we may ask at this point if this information has not yet surfaced:

- What resources exist in Suburban Cook County specifically for individuals in need of extensive psycho-social and health support services?
- What is the greatest gap in the availability of these services for low-income elderly?
- Can you talk a little more about your Family Caregiver Support Program?
  - What are some of the most common service requests from caregivers?
  - Does Age Options connect caregivers to resources that can help finance the cost of services like respite or home care?
- Can you tell us a little more about your Caregiver Resource Centers?

- What are the most important changes that could be made in this community that would better serve the needs of older adults who have recently suffered a debilitating illness? How about caregivers?
- What is your perspective on how much service provision varies from county to county? Are there colleagues in Chicago or DuPage County that you would recommend we interview?
AgeOptions: Information

AgeOptions is a nonprofit community-based organization that partners with other area nonprofit organizations that serve older adults and their caregivers. AgeOptions can help connect you, or a senior you love and care about, with programs and services in your community such as:

- In-home care
- Adult day services
- Telephone assistance to answer questions and link callers to the resources they need
- Problem solving with information specialists concerning care needs
- Nutritious meals
- Intervention against fraud, abuse and neglect
- Advocacy to protect the rights of older adults
- Employment and volunteer opportunities

In 2012, AgeOptions conducted the Needs Assessment Survey for Area Plan and Appreciative Inquiry Sessions and identified many needs that are unmet for older adults in suburban Cook County:
AgeOptions: Needs Assessment

Current Trends and Status:

- The total amount of individuals over the age of 60 is 481,119 which is an increase of 16.44% from the 1990 Census.
- Individuals who are over the age of 75 account for 6.76% of the total population, and that is an increase of 38% since the 1990 Census.
- Approximately 11% of the individuals 60 and over are 85 years or older.
- Surveys done by AARP show that 80% of baby boomers expect and intend to work past 65 years old in completely new second careers like social work and teaching.

Diversity in Suburban Cook’s Elderly Community:

- 15,236 Latino older adults, 65 and older, live in suburban Cook County. Research has found that these adults are:
  - Less likely to access services due to the lack of cultural training of staff members.
  - More likely to be foreign born and experience communication barriers
  - Less educated
  - Lower socioeconomic status
  - Receive large portion of income from Social Security, however have less access to benefits
  - Lower health insurance coverages
- According to the 2010 Census 93,138 individuals 65 and older currently live alone.

Education Level:

- White, non-hispanic, older adults have the highest percentage of high-school graduation compared to other groups. Asian and Pacific Islanders have the highest percentage college completion.
- These same patterns can be seen in sources of retirement income, finance savings and assets, as well as ownership of supplemental insurance.

Multiple Generations:

The number of households composed of multiple generations is higher than it has been in half a century due to job loss, foreclosures and the recession. One in ten children in the U.S. now lives with a grandparent.
Resources

- American Association of Retired Persons – website: www.aarp.org
  The AARP website contains articles about hiring a home care worker as well as other information about the different types of home-care providers available.

- AgeOptions – website: www.ageoptions.org
  AgeOptions core program focuses on Cook County and other collar counties and is funded by the Older Americans Act. There are 10 Caregiver Resource Centers located around suburban Cook County and includes opportunities for trainings, respite and adult daycare.

- Aging Care Connections – website: www.agingcareconnections.org
  Aging Care Connections meets with seniors at the hospital to assess needs and to inform them about services that are available in their community.

- Medicaid – website: www.medicaid.gov
  The official Medicaid website has details about what is covered by Medicaid and also the requirements needed to qualify.

- Medicare – website: www.medicare.gov
  The official Medicare website contains useful information, fact sheets and support for knowing about your own personal Medicare plan. There are also location services that can find the nearest doctors, health professionals, nursing homes, hospitals, home health services, medical equipment suppliers and also other specialty medical facilities. Information is also available to find out what is covered and how someone can qualify for Medicare.
The National Caregivers Library was developed by FamilyCare America, Inc. and contains a lot of useful information that caregivers can utilize in dealing with common occurrences as a caregiver. Examples of available tools include:

- Questionnaires
- Checklists
- FAQ Sheets
- Articles
- Important forms

Useful links available through National Caregivers Library:

- Caregiving and Housekeeping
- Medical Equipment And Medicare Coverage
- Adapting the Home
- Help With Home Modification
- How To Manage Your Pain
- Medication And Older Adults
- Good Nutrition: An Introduction
- Providing Day-To-Day Care
- Coping With Disabilities
- Helping With Disabilities