LEHIGH VALLEY
RESEARCH CONSORTIUM

Good Shepherd Rehabilitation Network

The Lehigh Valley Disability Community: Re-Examining Community Needs & Opportunities

December 2015

Opportunity

Access

Affordability

Inclusion

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Project Overview

This report summarizes the best information that we have about individuals with disabilities living in the Lehigh Valley region, combining secondary data sources such as the US Census Bureau, with primary research conducted in Lehigh and Northampton counties, including a 2015 internet-based survey for people with disabilities. The analysis provides a demographic snapshot of the Lehigh Valley population of people with disabilities. It also provides a window into the lives of many people with disabilities who, through survey responses, share their perceptions of their health, wellbeing, and social inclusion, and provide a deeper understanding about the opportunities and challenges to living fully and independently in our community.

About Good Shepherd Rehabilitation Network

Good Shepherd Rehabilitation Network (GSRN), based in Allentown, Pennsylvania, is a nationally recognized rehabilitation leader, offering a continuum of care for adults and children with physical and cognitive disabilities. Good Shepherd is known for its inpatient and outpatient care for individuals with catastrophic injuries and conditions, such as spinal cord injury, brain injury, stroke, amputation and major multiple traumas. Good Shepherd also provides outpatient musculoskeletal and orthopedic rehabilitation services, inpatient long-term acute care and long-term care (skilled nursing). GSRN's most recent *2015 Report to the Community* is available here: http://issuu.com/gsrn/docs/web_gsr_financial_report_2015?e=8469064/30425403

About the LVRC

The Lehigh Valley Research Consortium (LVRC) operates within the Lehigh Valley Association of Independent Colleges (LVAIC), combining the expertise of researchers from institutions of higher education and community partners in the Lehigh Valley to examine issues and solutions in a regional context. **Dr. Lanethea Mathews-Schultz, Associate Professor of Political Science, with Dr. Robert T. Brill, Associate Professor of Industrial/Organizational Psychology at Moravian College, both in affiliation with the LVRC, conducted the research for this project and authored this report**. Questions and comments about this report are most welcome. Please contact, Dr. Lanethea Mathews-Schultz, Muhlenberg College, 2400 Chew St, Allentown, PA 18104; (p) 484-664-3737; email: mathews-schultz@muhlenberg.edu.

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The views expressed in this report are those of the research team and do not reflect the views of GSRN, the LVRC, LVAIC, Muhlenberg College, or Moravian College.

Executive Summary

When asked to identify their greatest unmet needs and the issues that are most important to them, respondents to the 2015 disability needs assessment survey emphasized four key themes: ***opportunity, access, affordability, and inclusion***. These themes cut across multiple areas of life including employment and education; transportation and housing; rehabilitative therapies and physical and mental health services; and community and neighborhood spaces.

Figure 1. Respondents' Most Significant Needs and Important Issues

Note: Word cloud is derived from the text of two open-ended survey questions asking respondents to identify their greatest unmet need and to identify important issues that the survey may have missed or failed to adequately capture in closed-ended questions. The size of each word represents the frequency of mentions. For example, the words, *people*, *care*, *needs*, *help*, *access*, *transportation*, and *job*, etc. appear larger in the word cloud because these were the most commonly mentioned words.

The pages that follow provide a detailed look at the population of people with disabilities in the Lehigh Valley, and summarize findings from a 2015 disability needs assessment survey, giving voice to more than 300 people with disabilities in our region.

Three primary research questions motivated this study:

1. *What are the greatest unmet needs of persons with disabilities in the Lehigh Valley?*
2. *Where are the most significant gaps in disability services in our community?*
3. *How have community-change practices made a difference for people with disabilities in our region?*

Key highlights of findings include:

- The ***population of people with disabilities in the Lehigh Valley is growing and diversifying***. The increasing number of Latinos with disabilities in the region gives strong cause for future research focused on this sub-population, not only to ensure that the voices of Latinos with disabilities are heard, but also to ensure that efforts to improve life for all individuals with disabilities are as inclusive as possible.

- The ***number of people with disabilities living in poverty, especially in Lehigh County, is a significant cause for concern***. Obstacles related to income and affordability—in areas including transportation, housing, medical and rehabilitative care, and social inclusion—are infused throughout respondents' perceptions. While very few people with disabilities lack health insurance (and the numbers are fewer than was the case in 2008-09, prior to the Affordable Care Act and the federal Medicaid expansion), this is no guarantee of adequate access to health outcomes and to the social determinants of wellbeing. Health insurance alone, moreover, cannot overcome barriers to equal opportunity in education, work, and community integration.

- Survey respondents provide generally positive views about how life in the Lehigh Valley has changed in the past five years for people with disabilities as a whole, but provide generally more mixed views about how their own individual lives have changed. When asked specifically about community perceptions of people with disabilities, survey respondents report more negative views than was the case in the 2008-09 needs assessment. Individuals with physical disabilities generally communicate more positive views about social inclusion than do individuals with other kinds of disabilities, particularly speech and cognitive disabilities. The relatively positive views of people with physical disabilities may reflect tangible ADA-related improvements toward making society more accessible. On the other hand, more negative perceptions among people with cognitive disabilities and speech disabilities may reveal the limits of the ADA in reshaping perceptions of what "disability" means, and what kinds of policy and social changes are needed to develop truly inclusive societies. Taken collectively, less than one half of the survey sample believes that our community treats individuals with disabilities the same way they treat "average" people, less than half believe that most people would "willingly accept a person with a disability as a close friend," and only 35% agree that "most people believe that a person who has a disability is just as intelligent as the average person." These findings suggest a ***clear need for additional research into community connectedness and inclusion for people with disabilities.***

- A majority of respondents rate their overall health in positive terms, but ***individuals with mobility, psychiatric and cognitive disabilities are more likely to report poorer health*** than respondents with other kinds of disabilities. Some of these differences may be due to age—the prevalence of mobility-related disabilities increases with age, for example. Additionally, these findings may suggest that individuals with cognitive and psychiatric disabilities are under-served and/or face unique barriers to health.

- When it comes to health care services—including things such as preventative health care, technology services, dental health services, long-term support services—respondents indicate relatively high satisfaction with access and quality, and less satisfaction with affordability. Respondents communicate ***the least satisfaction (on access, quality and affordability) in four key areas: technology services, care management, mental health***

care services, and long-term support services. Some technology related services are clearly out of reach for many survey respondents, whether due to cost barriers or access and transportation barriers.

- Respondents' ***expressed need for more and better mental health care services*** takes on added weight in light of a number of other community health studies, including the GSRN 2008-09 study, the St. Luke's Community Health Needs Assessment, and several studies of the regional senior population conducted by the United Way of the Greater Lehigh Valley's Alliance on Aging, each of which point to a general need for greater access to quality, affordable mental health care. To be sure, ***survey respondents convey startling information about the prevalence of feelings of depression and social isolation and loneliness***. More than one-half of survey respondents say that they have had two or more weeks of feeling sad, blue, or depressed in the past year—this is significantly higher than what we know about the overall Lehigh Valley population (including people without disabilities). Results from questions regarding mental health point to a clear need for developing social connections, as well as providing access to mental health services, for people with disabilities in our region. The need for social connectedness may be particularly pressing for younger people with disabilities, as one young respondent wrote:

  > *Friendships - this is almost impossible for young adult, unemployed, living at home, who has medical conditions that require planning activities and also has transportation only by being driven around by parents or limited availability of public transportation. Public transit doesn't go to the right places (i.e. Promenade Shops) so even going to a movie is essentially impossible. Individuals with disabilities that are cognitive in nature…are virtually invisible and generally looked down on. Add that to multiple physical conditions and the isolation is overwhelming.*

- Survey findings point to a need for ***more engaged, open, and honest communication with health care providers in the areas of reproductive health and sexuality for people with disabilities***. A significant majority of survey respondents say that their health care provider never discusses reproductive or sexuality concerns with them; close to 40% also say that their health care providers seem uncomfortable talking about these concerns when they do arise. Respondents communicate a clear sense of frustration as to how the medical community views people with disabilities when it comes to reproductive and sexual health—expressing a clear request for more inclusion and better access to this aspect of health and overall wellbeing.

- When it comes to rehabilitative therapies, ***respondents who have received therapy at Good Shepherd communicate high levels of satisfaction with access to and knowledge of rehabilitative therapies and its effectiveness in helping them reach their individual goals***. In general, respondents evaluate the quality of most types of rehabilitative therapies positively, no matter where they received that therapy. Respondents provided the most positive evaluations to inpatient rehabilitation and physical therapy.

- Perhaps the biggest barrier to access and affordability of all therapies, as respondents explained in open-ended survey questions, are mandated limits imposed by health insurance and Medicaid. For example, one respondent wrote:

  > *I need to do everything I can now, to keep myself at my current level of independence and prevent/slow further decline. To do this, I need to keep my appointments with my*

doctor and specialists, and follow their recommendations. I frequently have to cancel or postpone appointments due to not being able to afford the amounts Medicare doesn't pay. I have a broken tooth for over 3 years now, that I can't afford to get fixed - even though I have been using Lehigh Valley hospital dental clinic."

- When asked about ***additional rehabilitative therapies that respondents would benefit from, by far the most commonly mentioned was aquatic therapy***—many respondents indicated that there are very few affordable (i.e., covered by insurance or financially affordable for those with low income) and/or accessible locations for aquatic therapy (i.e., local, or easy to reach with existing transportation options).

- Among all types of rehabilitative therapies included in the survey, respondents gave the ***lowest evaluations to vocational therapy***. The need for assistance not simply with job training, but job placement and ongoing support, emerged in several places in the survey. Not only did respondents give low satisfaction ratings to vocational rehabilitation, they ***also expressed the greatest need for vocational rehabilitation among a list of different kinds of therapies***. To provide greater context for these findings, according to US Census Bureau data, while many people with disabilities are engaged in the labor force, the majority is unemployed. Additionally, at all educational levels, median earnings are lower for people with disabilities than for people without disabilities. Survey respondents clearly identified ***four key barriers to employment: job training, career placement, transportation, and employer discrimination.***

- Very few survey respondents report using public transportation or specialized transport for people with disabilities as their primary form of transportation. It is this subgroup of survey respondents that reports the greatest problems with transportation. These problems are well known: unreasonable wait times, missed pickups/drop offs, inconvenient schedules. Even among individuals who report few transportation problems, many survey respondents reported feelings of dependency on others (e.g., family, friends) for their transportation needs. ***Transportation access and affordability is clearly linked to opportunities in other areas, including employment, education, and access to rehabilitative and medical care***. Respondents' comments regarding transportation point to the interconnectedness of the economic and social limitations of disability.

- When it comes to housing related needs, survey ***respondents expressed concerns about the long-term affordability of being able to live alone and of maintaining independence in the activities associated with daily living***. Respondents with the most severe disabilities were also the least likely to agree that their current housing allows them to live independently now and/or that their current housing will allow them to live independently in the future. Particularly significant is the extent to which respondents drew connections between housing and transportation—as the two are intricately linked in fostering the ability to live independently. Looking toward the future, significant percentages of respondents worry about losing their independence, paying for their care as they age, and becoming a burden on family members. More than one half of the survey sample said that they are very or extremely worried about not having long term housing plans.

- The group of survey respondents who answered questions about education, about parenting and raising children, and about raising children with disabilities in particular, was much smaller than the overall survey sample. It is therefore difficult to draw conclusions

about the most significant needs that emerge from this sub-group. As is to be expected, parents of children with disabilities worry about providing for their child's care as they age. The greatest worry among parents of children with disabilities focuses in identifying, or knowing, who will care for their children as they age and are presumably less able to provide that care on their own. Several parents who completed the survey also expressed a desire for more and better support groups. One wrote:

> "*As a parent I would like to have more opportunities to meet with other parents with disabled children. I would love to be part of a social group that gets together out in the community. For example, meet with others on the weekends and go to the fish hatchery, go bowling, eat at restaurants, go to a pumpkin patch, attend a movie, etc."*

In sum, the survey identified several areas of unmet need and gaps in service—income and insurance related obstacles to health services and rehabilitative therapies; ongoing community exclusion driven, in part, by stereotypes and misunderstanding; unequal access to particular kinds of rehabilitative therapies, such as technology-related rehab services and aquatic therapy; neglect on the part of health care providers to the reproductive and sexual health of people with disabilities; insufficient access to affordable, systemic mental health care services; lackluster transportation options that limit opportunity in education, work, and recreation; unsatisfactory vocational training and job placement services (coupled with under-employment and low earnings); and deficient housing coupled with too few affordable housing options, especially long-term housing.

These are significant needs and it is difficult to overstate the interconnectedness of opportunity, access, affordability, and inclusion on individuals' ability to live independently and productively, to achieve better health, to fully realize social and political rights, and to be fully integrated into community. As one respondent explained:

> *I have been lucky to have worked for 30 years at a good paying job prior to a voluntary early retirement. But life for a person with a disability is expensive! Health Insurance doesn't always cover everything. I could really use a van with a ramp, a walk-in tub, a handicapped shower, a new pair of custom shoes, etc. I worry that if I get all of these items I may have difficulty with taking care of all of my other expenses.*

Often, it is the humanity of people with disabilities that is at stake, as one respondent wrote:

> *The medical doctors, nurses, staff, therapists are so busy and overwhelmed with looking for and treating the diagnoses that they often forget that there is a person inside the body they're treating. The person with the disability is most often dismissed. Whether it is because it is believed they won't comprehend what is needed to help the individual or because they won't take the time to explain things so that the individual can be a part of the process. (This does require a great deal of time and patience) Often the individual with the disability is left with an inner frustration that results in giving up, if only just to get some medical care rather than none. Diagnoses always [trump] the person.*

It is perhaps equally as important to recognize areas in which the Lehigh Valley region performs well and in which people with disabilities communicate positive views. For instance, survey respondents communicate clear and strongly positive views on the quality of health care

and (most) rehabilitative services that they receive in the region (including high marks specifically to GSRN rehab services). And while many survey respondents communicate concern about long term housing plans, a large majority says that their current housing meets their needs, is affordable, and allows them to live relatively independently now. Finally, the vast majority of people with disabilities who completed the survey report having health insurance and communicate positive views about its affordability.

It is more difficult to discern how specific community-change practices have made a difference for people with disabilities in our region. In part, this reflects the limitations of research design. The 2015 survey sample is relatively small and not representative of the diversity of the actual population of people with disabilities in Lehigh and Northampton counties. In order to have a better understanding of which kinds of community change practices have had the biggest effect for particular subgroups within the disability population, future longitudinal or cohort-based research studies may provide better information. Indeed, several respondents commented on the need for continuing high quality research that can capture the interconnectedness of social and health-related needs; one wrote, "*Before I began [the survey], I feared that it was going to be generic and not leave me the ability to convey my own personal experiences and the issues which I've dealt with for the past 45 years. I commend you on a thorough survey. Thank you!*"

It is also difficult to identify community-change practices because they may emerge quietly, often with little fanfare or publicity, and have non-measurable outcomes that nonetheless have community-wide benefit. It is important to celebrate these community-change practices, even if unaccompanied by quantitative data. The Partnership for a Disability Friendly Community (PfDFC), for example, recently launched several initiatives, including a voter mobilization campaign and a program designed to recognize accessible local businesses. Indeed, the PfDFC itself is a community-change practice that has undoubtedly led to greater coordination and cooperation among individuals and member organizations mutually committed to improving the quality of life for people with disabilities in the Lehigh Valley.

It is important to ***acknowledge both the value of this needs assessment and its limitations***. Due to small sample size and gaps between the survey sample and the actual population of people with disabilities in our region, we are unable to make statistical generalizations beyond the current sample. Nonetheless, given the similarity in survey responses to other surveys and previous studies (both national and local), we can have some confidence in the reliability and validity of the survey questions in evoking consistent and meaningful answers from respondents. Simply put, like all good research, this needs assessments raises more questions than it answers. It's greatest value, perhaps, is in pointing forward—toward future and more robust research studies, toward a clearer and more detailed understanding of the intertwined needs of people with disabilities in our community, toward better ways of communicating and responding to these needs.

Introduction

History of Research on Disabilities in the Region

According to the National Council on Disability, people with disabilities experience significant health disparities and barriers to wellbeing when compared to people who do not have disabilities. Individuals with disabilities often lack health insurance, prescription drug coverage, and access to specialty care, such as long-term care and rehabilitative services.[1] People with disabilities face additional obstacles in obtaining meaningful and gainful employment, significant obstacles to education and job training opportunities, and barriers in basic access to community space and social integration.

This past July 2015 marked the 25th anniversary of the passage of the Americans with Disabilities Act (ADA), making this an auspicious time to reexamine community needs and to reaffirm commitment to community change practices that will improve access and inclusion for people with disabilities in our community.

Good Shepherd Rehabilitation Network (GSRN) has long been at the forefront of underwriting research to assist the Lehigh Valley in improving the quality of life for people with disabilities. In 2001, GSRN assembled an internal needs assessment committee and commissioned a research firm (Felix, Burdine and Associates, Inc.) to help answer the question, "Are we doing all we can for persons with disabilities"? This study included a synthesis of secondary data (including the local 1992 Lehigh Valley Health Survey collaboratively sponsored by regional hospitals), a survey of 140 individuals with disabilities and their caregivers in April-June 2001, and a series of community discussion groups and service provider interviews. This research revealed several categories of concern, including poor access to medical and dental services, lack of affordable health insurance and prescriptions, limited knowledge about services and resources, perceived negative feelings toward people with disabilities, and overall lack of access to disability-friendly social and recreational opportunities. Additional concerns that emerged in community discussion groups included a need for greater and better employment opportunities, greater accessibility to public spaces in our communities, and better and more transportation options for people with disabilities.

The 2001 needs assessment was followed in 2008-2009 with a more significant research endeavor designed to measure the greatest unmet needs of individuals with disabilities living in the Lehigh Valley. Again underwritten by GSRN, this study was conducted by the Lehigh Valley Research Consortium (LVRC) from July 2008 through October 2009, and included a survey of individuals with disabilities and their caregivers, a survey of organizations and agencies serving individuals with disabilities, and several focus groups. This project was highly collaborative, seeking ongoing input from service providers and individuals active in disabilities communities. Key areas in this research included health care, employment, information and referral, transportation, housing, education, technology, political participation, community perceptions, and the associated needs of caregivers and parents of children with disabilities.

The 2008-2009 research provided for an in-depth examination of subgroups within the population of individuals with disabilities. Findings revealed that the Lehigh Valley is, in many ways, accessible and inclusive of many individuals with disabilities, but that there is significant room for improvement. Most notably, the research from 2008-2009 suggests that income, disability severity, and disability type are strongly related to individuals' perceptions of their own health and

[1] National Council on Disability, "The Current State of Health Care for People with Disabilities," September 2009. Available at, http://www.ncd.gov/publications/2009/Sept302009. Accessed November 5, 2015.

wellbeing. For example, while individuals with physical and mobility disabilities communicated significant challenges in access to transportation and public spaces, overall, these individuals reported more positive feelings about social integration and community connectedness than did individuals with cognitive and mental disabilities. Several questions emerged from the 2008-09 research. For example, in some instances, perceptions of individuals with disabilities seemed to conflict with the perceptions of key organizations and provider agencies. A majority of individuals with disabilities reported few problems with transportation or housing, for example, yet these were among the most significant obstacles for Lehigh Valley residents with disabilities identified by service providers. One possible explanation is that provider agencies may interact with individuals with the greatest transportation and housing-related needs. Or perhaps the intensity of some individuals' transportation and housing needs fuels perceptions about broader transportation problems.

Perhaps the most significant outcome of GSRN's leadership in research on disabilities in our region, and of the 2008-2009 study in particular, is that it served as a catalyst for the formation of the Partnership for a Disability Friendly Community (PfaDFC). The Partnership includes persons with disabilities, representatives from provider agencies, family members, and government and community leaders committed to making a measurable difference in the disability-friendliness of the Lehigh Valley. The Partnership seeks to achieve this goal through a number of grassroots-generated efforts intended to raise awareness, advocate for equal access, and influence public policy. More information is available at www.disabilityfriendlylv.com. The PfaDFC's efforts are bolstered (and at times given direction) by findings generated through more than a decade of GSRN's-sponsored research.[2]

Since the 2008-2009 GSRN study, passage of the Affordable Care Act (ACA)[3] has led to important changes in the landscape of community health, including extending health insurance and access to health care for millions of Americans and hundreds of thousands of Pennsylvanians including many with disabilities. In addition, requirements of the ACA have generated important opportunities for nonprofit hospitals and community organizations to identify roadmaps to improve health and wellbeing for people with disabilities.[4]

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[2] In addition to efforts to research the needs of Lehigh Valley residents with disabilities underwritten by GSRN, the Lehigh Valley Center for Independent Living, in conjunction with the Office of Vocational Rehabilitation (OVR), and the Pennsylvania Statewide Independent Living Council (PASILC), coordinated a statewide research project examining barriers to people with disabilities in emergency preparedness, assistive technology, employment, home and community based services, housing, medical and dental services, transportation, and voter access. These data provide a 'birds-eye' view of a twelve county region in the state of Pennsylvania but do not permit focused attention on the particular needs of individuals with disabilities in Lehigh and Northampton counties.

[3] The Patient Protection and Affordable Care Act mandates that every hospital facility conducts a community health needs assessment every three years. (Section 501(r)(3))

[4] Regionally, the Lehigh Valley is home to five nonprofit health care systems, including GSRN, St. Luke's University Health Network, Sacred Heart HealthCare System, the Lehigh Valley Health Network, and Kidspeace. Collectively, these four hospital systems, along with the Dorothy Rider Pool Health Care Trust comprise the Health Care Council of the Lehigh Valley (HCCLV), which released the Community Health Needs Assessment for the Lehigh Valley in 2012. Additional information and the full report can be found on GSRN's website, http://www.goodshepherdrehab.org/about/community-health-needs-assessment. This report is helpful in thinking broadly about community health needs, but does not offer a detailed focus on people with disabilities.

Against this backdrop, the current study, *The Lehigh Valley Disability Community: Re-Examining Community Needs & Opportunities* revisits key issues for people with disabilities in our communities in an effort to track our progress and to identify continued areas of concern. It is hoped that this information will assist the Good Shepherd Rehabilitation Network in setting goals and priorities in compliance with assessment and strategic planning requirements of the Affordable Care Act.[5] An additional goal is to measure the needs of current and potential future consumers of GSRN. Of particular importance, it is hoped that the findings of this research study will further validate and augment the ongoing work of organizations and individuals committed to creating a more inclusive and accessible Lehigh Valley for all people.

[5] Pursuant to the Patient Protection and Affordable Care Act (P.L. 111-148 123 Stat. 199, 2010), all nonprofit hospitals are required to conduct triennial Community Health Needs Assessments (CHNAs) in order to maintain their tax-exempt status. Community Health Needs Assessments, when done well, provide hospitals with opportunities to examine pressing health needs in their communities and adopt implementation strategies designed to address those needs. See Sara Rosenbuam, "Principles to Consider for the Implementation of a Community Health Needs Assessment Process," June 2013, George Washington University School of Public Health and Health Services, available at: http://nnphi.org/CMSuploads/PrinciplesToConsiderForTheImplementationOfACHNAProcess_GWU_20130604.pdf; and Mathews, Coyle and Deegan, "Building Community While Complying with the Affordable Care Act in the Lehigh Valley of Pennsylvania," *Progress in Community Health Partnerships: Research, Education, Action*, 2015.

Purpose of Current Needs Assessment

In brief, this report, *The Lehigh Valley Disability Community: Re-Examining Community Needs and Opportunities* examines three central research questions:

1. **What are the greatest unmet needs of persons with disabilities living in the Lehigh Valley?**
2. **Are there gaps in disability services in our community and, if so, what and where are those gaps?**
3. **How have community-change practices made a difference for persons with disabilities in the Lehigh Valley?**

More specifically, the objectives of the current project are to:

1) Identify the greatest unmet needs of individuals with disabilities living in the Lehigh Valley, across three major categories of disabilities (mobility, sensory, and intellectual/developmental) in six areas of concern:
    a. Medical rehabilitation needs, including physical therapy, occupational theory, and speech language pathology; complex medical care; neuro-rehabilitation; orthopedic rehabilitation; pediatric rehabilitation; and long term care;
    b. Transportation;
    c. Employment and education;
    d. Housing;
    e. Consumer perceptions (e.g., how persons with disabilities perceive their inclusion and acceptance by others);
    f. Parenting and family; and
    g. Children with disabilities

2) Estimate the reach of disabilities services; that is, instances in which individuals with disabilities are receiving adequate assistance, and areas in which there may be gaps in assistance and services; and

3) Evaluate community change practices intended to make the Lehigh Valley more accessible, more inclusive, and more welcoming to people with disabilities.

Research Methods

This study is designed to assist Good Shepherd Rehabilitation Network (GSRN) in meeting the requirements of the federal law, while giving voice to individuals with disabilities in specifying their particular health and social needs and concerns.

The findings reported in this analysis emerge from a two-pronged research strategy which rests on both secondary research derived from national surveys including the US Census Bureau and the Center for Disease Control's Behavioral Risk Factor Surveillance System (BRFSS), and perhaps more critically, primary data collected through an online survey. The survey was collaboratively developed by the GSRN and the LVRC with input from interested individuals and members of the Partnership for a Disability Friendly Community (survey questions and response frequencies are included in Appendix C).

According to the Centers for Disease Control, community health needs assessments are most effective when they involve multi-sector collaboration and diverse and broad community engagement, target health disparities, use evidence based interventions, and are characterized by "maximum transparency to improve community engagement and accountability."[6] Multiple methods, combining qualitative and quantitative data, provide the "truest" picture possible of the health-related needs of our regional population. This study follows the principles of community-based participatory research, which includes community benefits far beyond simply complying with the law. [7]

The survey was administered online in both English and Spanish using QuestionPro survey software between June 15 and September 30, 2015. Individuals who preferred not to, or were unable to, complete the survey online, were invited to take the survey via phone with the primary researcher (1 respondent), or via a hard survey copy through the postal mail (2 respondents). The survey was promoted through social media (Facebook), email, promotional flyers and postcards; and by word-of-mouth, using a snowball sampling technique. The survey was incentivized by giving respondents an option to enter a drawing for one of five $100 Amazon.com gift certificates at the conclusion of the survey.

Three hundred and twenty (320) individuals took the disability needs assessment survey and roughly 61% of these answered all questions in the survey.[8] Frequency data and survey questions are included in Appendix C, and contain information about the number of respondents (N) who answered each question.

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[6] See the CDC CHNA guidelines here: http://www.cdc.gov/policy/chna/

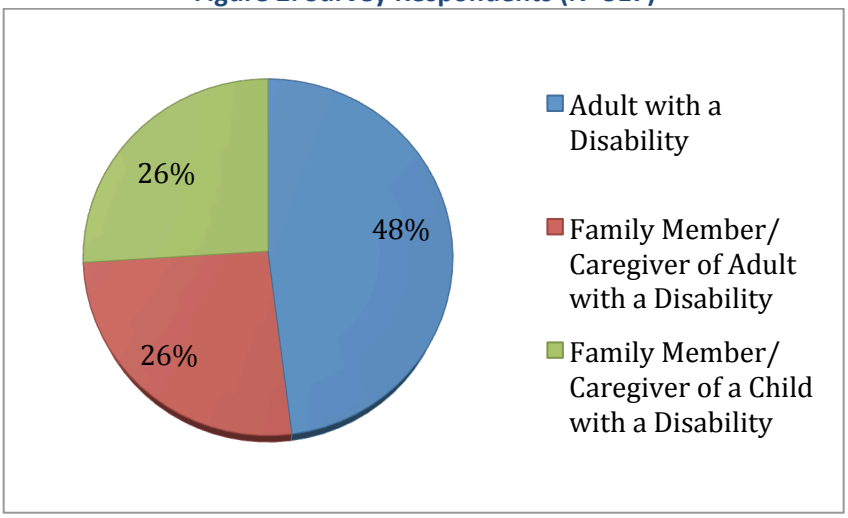
[7] Hicks, Wallersten, Avila, Belone, Lucero, et. al., "Evaluating Community-Based Participatory Research to Improve Community-Partnered Science and Community Health," *Progress in Community Health Partnerships* 2012: 289-299; Dguyen, Hus, Kue, Nguyen, Yuen, "Partnering to Collect Health Data in Hard-to-Reach Community: A Community-Based Participatory Research Approach for Collecting Community Health Data," *Progress in Community Health Partnerships* 2010: 115-119.

[8] At least 550 individuals viewed the survey and 375 began the survey by answering a few questions, however, these individuals did not complete enough questions to be counted in the data analysis presented here. The vast majority of respondents, 59%, completed the survey on a laptop or desktop computer, 25% completed the survey via a smartphone, and 16% used a tablet.

Survey Sample Summary

Three hundred and twenty (320) individuals responded to the disability needs assessment survey. The vast majority of respondents, 48%, are adults with disabilities responding to the survey on their own behalf; remaining respondents are divided evenly between family members completing the survey on behalf of adult family members with disabilities, and family members completing the survey on behalf of children (under the age of 18) with disabilities (Figure 2).

Figure 2. Survey Respondents (N=317)



Although 320 individuals took the disability needs assessment survey, only about 195 completed it in its entirety. Consequentially, information regarding the distribution of respondents across geography, race and ethnicity, sex, and income is somewhat limited. Equally as important is recognizing that the research method used to distribute and administer the survey did not produce a truly random sample of the population of individuals with disabilities in the Lehigh Valley.

Table 1 summarizes the demographic information that was provided by respondents answering all questions. As shown, a majority of respondents (56%) are female; 44% are male. The vast majority of respondents completing demographic information reside in Lehigh County (59%), followed by Northampton County (27%). These proportions are similar to those found in the sample for the 2008-2009 needs assessment.

The disability survey was intended primarily to reach Lehigh and Northampton counties, but some respondents are drawn from neighboring Monroe, Berks, Carbon and Bucks counties. Within the region, a majority of respondents who provided information about municipality reside in Allentown (18%), followed by Bethlehem (12%), and Easton (5%)—the urban cores of the Lehigh Valley. The survey reached suburban areas of the region as well, including South Whitehall (5%), Whitehall (5%), and Lower Macungie (3%).

Recognizing that the survey provides incomplete information about the sample, several significant limitations stand out and deserve elaboration. Most notably, the survey grossly under-represents the racial and ethnic mix of the Lehigh Valley. Only 3% of survey respondents who answered

demographic questions identify as Latino. As discussed further below, US Census Bureau data suggest that at least 18% of all people with disabilities in the region are Latino. Clearly, we cannot assume that the findings in this survey adequately represent the concerns of Latinos with disabilities.[9] Similar caution is warranted in drawing inferences about Black/African American individuals with disabilities in the Lehigh Valley.

Likewise, because we do not have full information about household income for people with disabilities (the US Census Bureau does not report family income for people with disabilities but it does report personal income, as discussed further below), we have limited information about how well the survey sample approximates the true population in the Lehigh Valley when it comes to income levels. Few respondents answered questions about family income and those that did may represent higher income households than the general population. For example, twenty-one percent of respondents who answered questions about household income report annual incomes between $60,000 and $99,999. Only 20% of respondents who provided income information report living in households with annual income below $25,000. As discussed further below, we know from US Census data that significant numbers of individuals with disabilities live below the federal poverty level (roughly equal to $15,930 for a family of 2 in 2013)—the survey sample likely underestimates the particular needs facing individuals with disabilities who are low-income as a result.

Although it is important to remain cautious when drawing inferences from the survey sample to the actual population of people with disabilities, it is reassuring that survey respondents broadly represent different kinds of disabilities. That is to say, ***the survey is well positioned to provide information about how disability type is related to overall wellbeing and needs***. As seen in Figure 2, a majority of survey respondents (56%) report a mobility or motor difficulty, such as a physical impairment. Forty-percent (40%) indicate an intellectual or developmental disability. Cognitive disability and speech or oral motor disabilities are the next most frequent responses (28%).

Data provided in Appendix C shows that approximately 57% of survey respondents said that they were born with their disability—in the 2008-2009 needs assessment sample, only 35% respondents said they were born with their disability, so this is a notable difference between the samples—and 46% characterize their disability as somewhat or very severe. As shown in Table 2 below, respondents are well distributed by disability type and severity. Among all disability types, respondents with psychiatric and mental health disabilities (anxiety, schizophrenia, mood disorder, etc.) most frequently characterized their disability as somewhat or very severe.

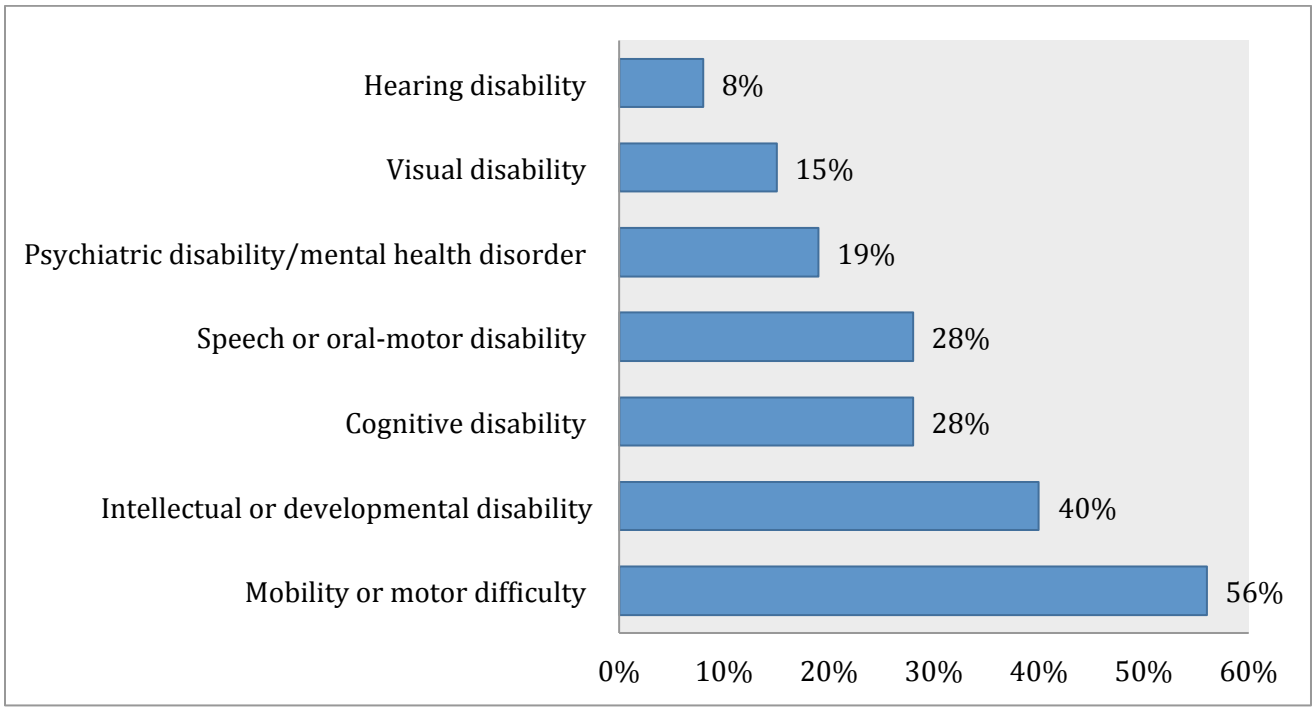
[9] The survey was available in both English and Spanish. Tellingly, no respondents completed the Spanish language version. Adequately capturing the voices of Latino individuals with disabilities has been a challenge for disability needs assessments since GSRN conducted its first in 2001 when only 6 of 140 respondents in that study were non-White. Similarly, in the 2008-2009 needs assessment, 4% of survey respondents were Latino and 3% were African American.

Table 1. Demographic Summary of Survey Sample

Sex	Female	**56% (105)**	**Veteran**	Yes	10% (18)
	Male	44% (82)		No	**91%(172)**
County	Lehigh	**59% (110)**	**Race/ Ethnicity**	White (non-Latino)	**95% (181)**
	Northampton	27% (50)		Black/African-American	1% (2)
	Monroe	2% (7)		Latino	3% (6)
	Berks	2% (7)		Other	1% (1)
	Carbon	1% (3)			
	Bucks	1% (3)	**Education**	Some High School	6% (11)
	Other	8% (7)		High school degree or equivalent	**29% (50)**
				Associate's degree or some college	26% (46)
Municipality	Allentown	**18% (31)**		College degree	21% (36)
	Bethlehem	12% (21)		Post-graduate degree	18% (32)
	Easton	5% (8)			
	South Whitehall	5% (8)	**Household Income**	Less than $14,999	8% (14)
	Whitehall	5% (9)		Between $15,000 and $24,999	12% (20)
	Lower Macungie	3% (5)		Between $25,000 and $39,999	12% (21)
	Northampton	2% (4)		Between $40,000 and $59,999	20% (35)
	Catasauqua	2% (4)		Between $60,000 and $99,999	**21% (37)**
	Salisbury	2% (4)		More than $100,000	13% (23)
	Coplay	2% (3)		Don't know	14% (24)
	Emmaus	2%(3)			
Age	18 and younger	15% (27)	**Employment**	Working Full Time	11% (25)
	19 to 64	70% (123)		Working Part Time	9% (22)
	65 and older	15% (25)		Retired	22% (51)
				Unemployed	18% (42)
Marital Status	Single/Never Married	38% (68)		Full time student	13% (30)
	Married	**46% (84)**		Stay at home partner	4% (9)
	Divorced/Separate	11% (20)		Other	**25% (58)**
	Widowed	4% (7)			
	Long term Partner	2% (4)			

Note: Frequencies are listed in parentheses following percentages.

Figure 3. Survey Respondents' Disability Types (N=319)



Note: Survey respondents could select more than one disability type.

Table 2. Respondents' Disability Type & Severity

Disability Type	Disability is Mild to Moderate	Disability is Somewhat to Very Severe
Mobility	52% (90)	49% (85)
Intellectual/Development	57% (72)	43% (54)
Cognitive	51% (44)	49% (42)
Psychiatric/Mental Health	41% (23)	59% (33)
Vision	43% (20)	58% (27)
Speech	46% (39)	54% (46)
Hearing	57% (13)	43% (10)

Note on Defining Disability

Measuring disability prevalence and identifying the needs of individuals with disabilities is made more difficult by the fact that no single consensus exists around the concept of "disability." In the context of the Americans with Disabilities Act (Pub. L. 101–336, § 3, July 26, 1990, 104 Stat. 329; Pub. L. 110–325, § 4(a), Sept. 25, 2008, 122 Stat. 3555) "disability" is a legal term (rather than a medical or social term) that refers to a "person with a disability," as "a person who has a physical or mental impairment that substantially limits one or more major life activity."[10] In general, common features of official definitions of disability, including those in the ADA, those employed by the US Census, and those used by international organizations such as the World Health Organization, contain an emphasis on physical or mental characteristics that are labeled or perceived as causing impairment or dysfunction, and some kind of personal or social limitation that is associated with that impairment.

The extent to which social attitudes and practices are mutually constitutive of limitations associated with physical or mental impairment is an area of contention in the scholarship on disability. Medical models of disability, for example, regard disability as a result of physical or mental impairment. In contrast, social models of disability understand disability relationally, resulting from the ways in which individuals interact with the social environment—seen in this way, individuals with particular mental and/or physical characteristics are excluded from major domains of social life though an environment that labels them as "having disabilities."[11] This is not merely an academic debate, since how we conceptualize disability is related to how we craft policy and health-related priorities that will assist community members in living as fully and healthfully as possible.

It is reasonable to suggest in this context that individual impairment and the social environment in which individuals live, work, and play are shared causes of limitations that people with disabilities must negotiate. In other words, the wellbeing and needs of individuals with disabilities is a product of concession between individual characteristics of physical and mental wellbeing and a variety of environmental and social factors. The survey included in this needs assessment, for example, seeks to better understand individuals' experiences with disabilities in the Lehigh Valley.

Making matters more complicated, there is no settled agreement on how best to identify different forms of disability. The language of disability remains in a state of flux; survey researchers, medical professionals and individuals use terms in different ways. The US Census, for example, includes just six categories of disability (impairments resulting from vision, hearing, ambulatory, cognitive, self-care, or independent living "difficulties"), and does not record these categories of difficulty across all ages in the population. The Center for Disease Control uses a more expansive notion of disability to include "any condition of the body or mind" that makes it difficult for an individual "to do certain activities and interact with the world around them." Relatedly, individuals participating in research studies, such as the survey that is included in this analysis, might not label themselves in the same ways that others perceive them. For example, a respondent might describe difficulties with muscle control as a neurological disability, whereas others might characterize these muscle control difficulties as a physical disability. The current study attempts to remain open to defining disability in a variety of ways, in order to think broadly and as inclusively as possible.

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[10] The legal protections of the ADA also extend to persons with a record of mental or physical impairment in the past, as well as individuals who are perceived as having such an impairment.

[11] Stanford Encyclopedia of Philosophy, "Disability: Definitions, Models, Experience," http://plato.stanford.edu/entries/disability/.

Disabilities in the Lehigh Valley: A Sketch of the Population

For the purpose of this needs assessment, "community" is defined regionally to include Lehigh and Northampton counties. This region is diverse, of course, and the experiences and needs of individuals with disabilities living in different locations within the Valley are variable. In addition, the boundaries of the Lehigh Valley community are porous and overlapping. As a result, the Lehigh Valley region is sometimes defined by the boundaries of the Allentown-Bethlehem-Easton, PA-NJ Metro metropolitan statistical area (ABE), encompassing Carbon, Lehigh and Northampton counties in PA and Warren County in NJ. This report primarily focuses on the counties of Lehigh and Northampton, but when relevant, makes references to the ABE metropolitan statistical area.

Population[12]

According to the US Census Bureau, in 2013, approximately 82,734 individuals, or 13%, of the population living in the Lehigh Valley have some kind of disability (Table 3).

The Census definition of disability includes six disability types, including hearing, vision, cognitive, and ambulatory difficulties, as well as self-care difficulty (trouble bathing or dressing for example), and independent living difficulty (defined as a difficulty doing errands or visiting a doctor alone due to a physical, mental or emotional problem).

Table 3. Individuals with Disabilities in the Lehigh Valley and Pennsylvania (2013)

	Lehigh County	Northampton County	Lehigh Valley Region	Pennsylvania
Total Population*	347,308	295,052	642,360	12,525,314
Individuals with a Disability	46,383 13.4%	36,651 12.4%	82,734 12.8%	1,651,733 13.2%

Source: US Census Bureau, American Community Survey, 2009-2013.
** Total population refers to the civilian, non-institutionalized population, which the Census Bureau defines to exclude individuals residing in institutions, including nursing homes, prisons, jails, psychiatric and mental institutions, and juvenile correctional facilities.*

The Center's for Disease Control's Behavioral Risk Factor Surveillance System (BRFSS) provides alternative estimates of disability prevalence in the region, including Lehigh, Northampton, and Carbon counties (Table 4). Respondents to the CDC's BRFSS are asked to indicate whether they are limited "in any activities because of physical, mental or emotional problems," and whether they have a health problem that requires the use of special equipment such as a cane, a wheelchair, a special bed, or a special telephone. As is to be expected, because the BRFSS questions are more fluid, and because the region is defined here to include Carbon County, the portion of respondents suggesting they have some kind of disability is higher. Approximately 21% of residents in the

[12] Additional and more detailed Census Bureau data on the Lehigh Valley population with disabilities are included in Appendix B.

Lehigh Valley say that they are limited in activities because of a physical, mental or emotional problem; 10% report needing to use special equipment as the result of a health problem.

Table 4. CDC BRFSS Estimates of Disability in Lehigh, Northampton, and Carbon Counties (2013)

Limited in Activity Due to Physical, Mental or Emotional Problems	21%
Health Problem Requires Use of Special Equipment	10%

Source: Centers for Disease Control, Behavioral Risk Factor Surveillance System (BRFSS), 2013.

Table 5 provides additional information about the prevalence of particular *types* of disability within the population of individuals in Lehigh and Northampton counties who have a disability. As shown, ambulatory difficulties are most commonly reported. Cognitive difficulties, independent living difficulties, and hearing difficulties are the next most commonly reported disability types.

Disability is related to a number of socioeconomic and demographic factors, including perhaps most obviously age, as seen in Table 6. As is to be expected, the prevalence of all forms of disability increases with age, such that more than 33% of residents of Lehigh County age 65 and older report at least one disability; this figure is 35% in Northampton County. Disabilities are also more common among women than men, and more common among Latinos and African-Americans when compared to individuals who are identified as white, non-Hispanic.

It is worth emphasizing that the Census data shows that there are more than 10,500 Latinos in Lehigh County and an additional 4,460 in Northampton County with disabilities. Similarly, there are 3,506 African Americans in Lehigh County and 1,487 in Northampton County with disabilities. These populations are significantly under-sampled in the current needs assessment (as well as previous needs assessment of the population with disabilities). As discussed above, this is an important limitation of the survey sample that makes it more difficult to draw inferences about the needs of the general regional population. Indeed, among all individuals with disabilities living in Lehigh County, a full 23% are Latino. In Northampton County, 12% of individuals with disabilities are Latino. Combined, 18% of individuals with disabilities living in the Lehigh Valley are Latino, a figure that is more than double the statewide rate of 6%. If Latinos generally face the same barriers as any individual with a disability from any racial or ethnic group (such as obstacles to full employment, problems with transportation, lack of accessible and affordable housing), this needs assessment may nonetheless under-estimate the unique needs of Latinos with disabilities. Language and cultural competency issues, for example, may be related to health outcomes as well as access to opportunities for social inclusion and community wellbeing.[13]

[13] Statewide, the prevalence of disability among Latinos is 14.5% in 2013, 15.5% among African Americans, and 10.7% among Whites according to Disabilitystastics.org.

Table 5. Disabilities in Lehigh and Northampton Counties, by Disability Type (2013)

	Lehigh Population with a Disability 46,383	Northampton Population with a Disability 36,651
Hearing difficulty	2.5%	2.9%
Vision difficulty	2.0%	1.5%
Cognitive difficulty	4.3%	3.9%
Ambulatory difficulty	4.8%	5.2%
Self-Care difficulty	1.7%	1.9%
Independent Living difficulty	3.1%	3.6%

Source: US Census Bureau, American Community Survey, 2009-2013.
Note: The Census only records cognitive, ambulatory, and self-care difficulties for persons ages 5 and older; independent living difficulties are recorded only for people ages 15 and older.

Table 6. Lehigh and Northampton Population with Disabilities by Age, Sex, Race, and Ethnicity (2013)

	Lehigh County			Northampton County		
	Total Population	Population with a Disability	Percent Population with a Disability	Total Population	Population with a Disability	Percent Population with a Disability
Total non-institutionalized population	347,308	46,383	13.4%	295,052	36,651	12.4%
Population under 5 years	21,275	228	1.1%	15,678	100	0.6%
With a hearing difficulty		152	0.7%		76	0.5%
With a vision difficulty		90	0.4%		60	0.4%
Population 5 to 17 years	60,520	4,973	8.2%	48,250	3,144	6.5%
With a hearing difficulty		344	0.6%		332	0.7%
With a vision difficulty		737	1.2%		334	0.7%
With a cognitive difficulty		4,036	6.7%		2,502	5.2%
With an ambulatory difficulty		282	0.5%		254	0.5%
With a self-care difficulty		473	0.8%		460	1.0%
Population 18 to 64 years	215,244	24,412	11.3%	185,035	17,309	9.4%
With a hearing difficulty		4,425	2.1%		3,471	1.9%
With a vision difficulty		5,012	2.3%		2,540	1.4%
With a cognitive difficulty		11,584	5.4%		7,695	4.2%
With an ambulatory difficulty		11,077	5.1%		8,472	4.6%
With a self-care difficulty		3,754	1.7%		2,999	1.6%
With an independent living difficulty		7,094	3.3%		5,677	3.1%

Table 6, *Continued*. Lehigh and Northampton Population with Disabilities by Age, Sex, Race, and Ethnicity (2013)

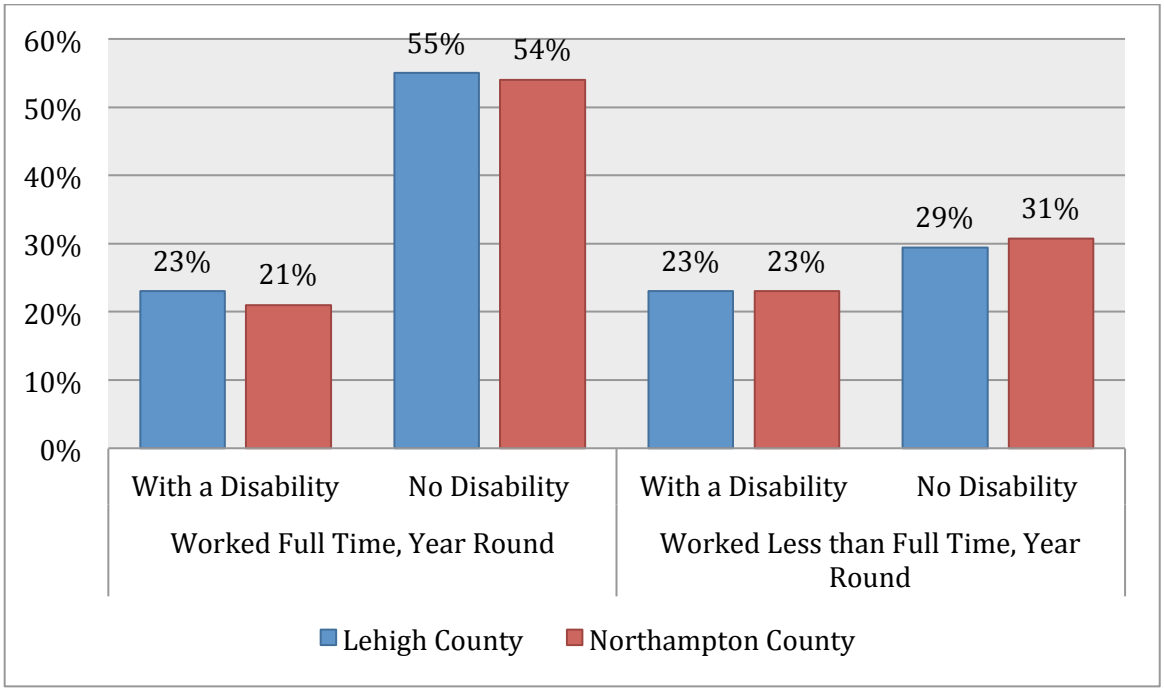
	Lehigh County			Northampton County		
	Total Population	Population with a Disability	Percent Population with a Disability	Total Population	Population with a Disability	Percent Population with a Disability
Population 65 years and older	50,269	16,770	33.4%	46,089	16,098	34.9%
With a hearing difficulty		6,504	12.9%		6,542	14.2%
With a vision difficulty		3,452	6.9%		2,741	5.9%
With a cognitive difficulty		4,213	8.4%		3,991	8.7%
With an ambulatory difficulty		10,838	21.6%		10,368	22.5%
With a self-care difficulty		3,604	7.2%		3,533	7.7%
With an independent living difficulty		7,508	14.9%		7,671	16.6%
Male	168,715	21,095	12.5%	144,251	16,778	11.6%
Female	178,593	25,288	14.2%	150,801	19,873	13.2%
Race and Hispanic or Latino Origin						
One Race	338,078	45,092	13.3%	287,721	35,881	12.5%
White alone	280,781	36,705	13.1%	256,209	32,694	12.8%
Black or African American alone	22,139	3,506	15.8%	14,694	1,487	10.1%
American Indian and Alaska Native	686	89	13.0%	764	141	18.5%
Asian alone	10,817	647	6.0%	7,779	486	6.2%
Some other race alone	23,655	4,145	17.5%	8,238	1,073	13.0%
Two or more races	9,230	1,291	14.0%	7,331	770	10.5%
White alone, not Hispanic or Latino	244,578	31,674	13.0%	236,818	29,922	12.6%
Hispanic or Latino (of any race)	68,228	10,540	15.4%	32,398	4,460	13.8%

Source: US Census Bureau, American Community Survey, 2009-2013.

Employment, Earnings, Education

Approximately 24% of the region's working age population with disabilities (ages 16 to 64) is employed in the paid work force, whether part or full time. While this suggests that many individuals with disabilities in the Lehigh Valley are benefitting from access to employment and contributing to the labor market, it pales in comparison to the 66% of working age individuals who do not have disabilities that are similarly working.

Figure 4. Full and Part Time Work in the Lehigh Valley (2013)



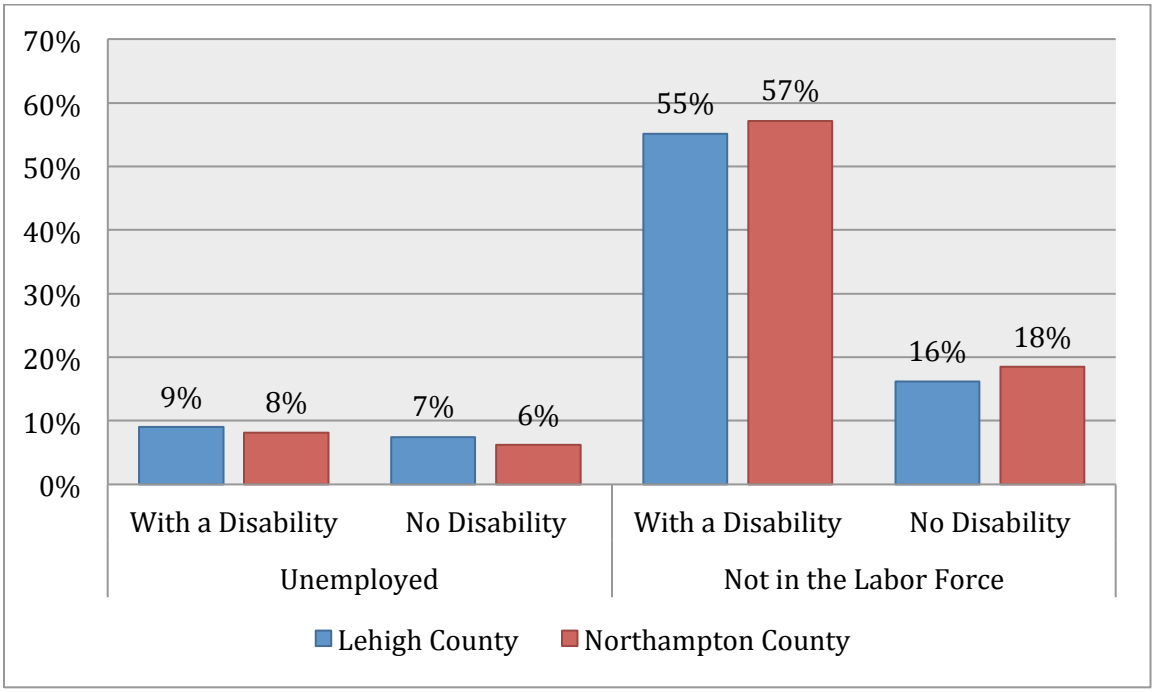
Source: US Census Bureau, American Community Survey, 2009-2013. Data refers to individuals between the ages of 16 and 64.

Regional estimates about the numbers of individuals with disabilities in the workforce are slightly better than national figures; nationwide, in 2015 only 20% of people with disabilities were participating in the labor force, compared to 69% of people without disabilities (National Council on Disability, 2015). Nonetheless, large disparities are present among both part and full time employees in the Lehigh Valley, as shown in Figure 4. More than one-half of individuals without disabilities in Lehigh and Northampton counties works full time and this is more than double the rate of full time employment among individuals with disabilities. Similar gaps exist among part time workers. Full and meaningful employment for people with disabilities is a critical priority and key component of the National Council on Disabilities vision for 2040, a list of policy recommendations designed to create a society in which all people with disabilities are fully engaged and have opportunities to choose their careers.[14]

[14] The National Council of Disabilities' Vision for 2040 is included in this 2015 national status report: https://www.ncd.gov/sites/default/files/Documents/2015NCD_Annual_Report_508.pdf

Data on unemployment is shown in Figure 5. suggest that individuals with disabilities are over-represented among the population that is not in the labor force at all (that is, not looking for work), and among the unemployed population (that is, currently looking for work).

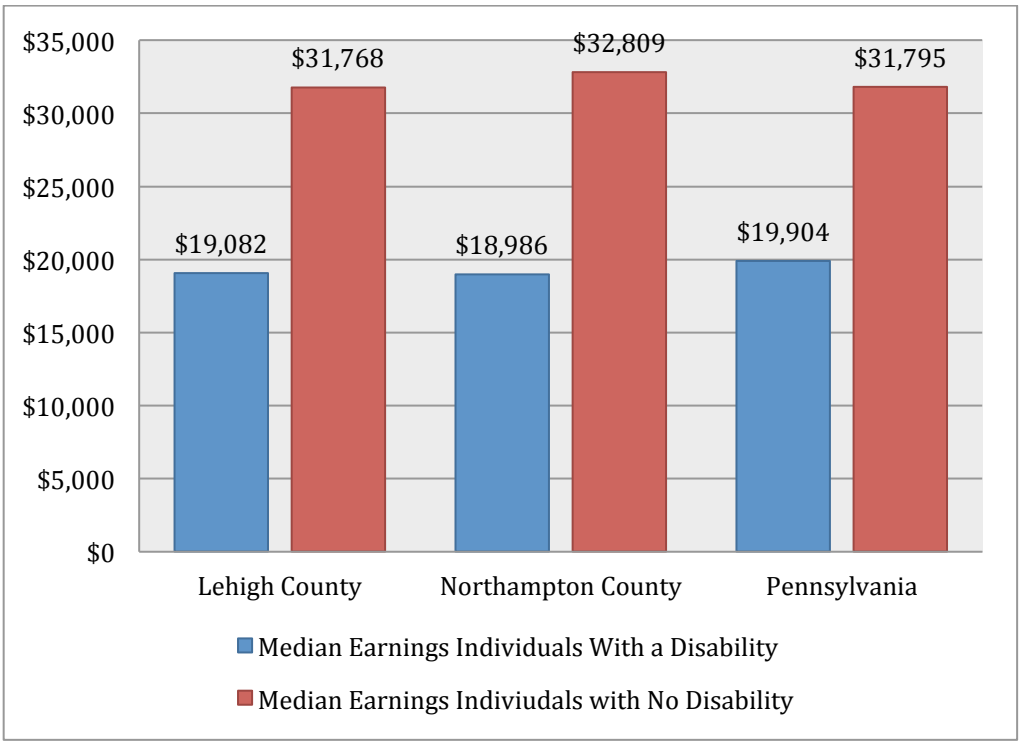
Figure 5. Unemployment and Percentage of Individuals Out of the Work Force (2013)



Source: US Census Bureau, American Community Survey, 2009-2013.

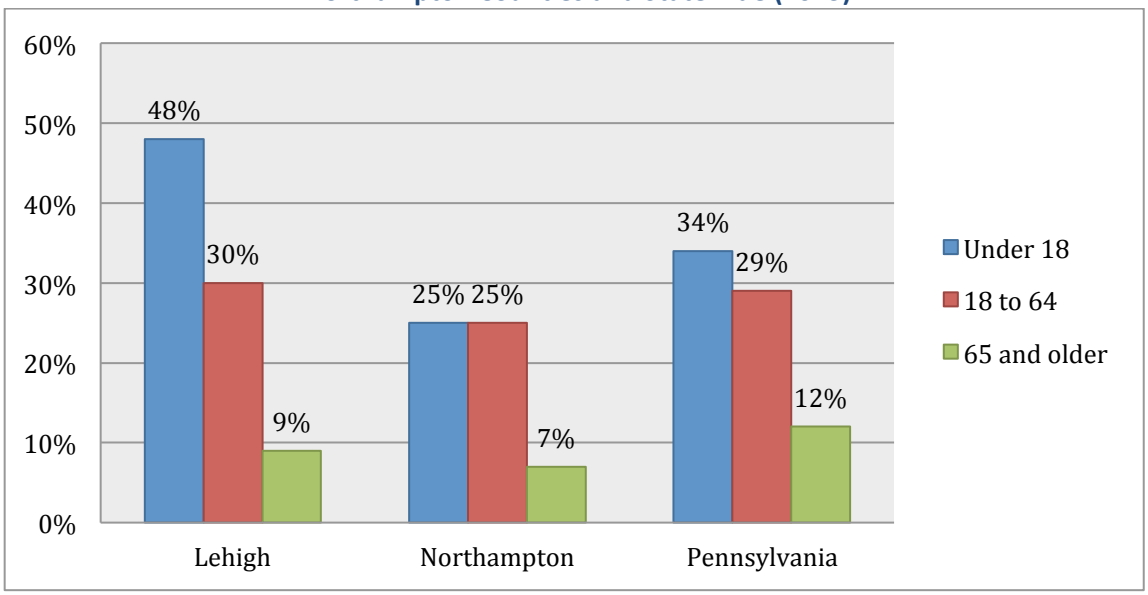
Income is a significant barrier to flourishing for people with disabilities, particularly in combination with barriers to employment and education. This is particularly the case because wages for people with disabilities are on average lower when compared to workers without disabilities. As seen in Figure 6, individuals with disabilities in the Lehigh Valley and statewide report significantly lower media earnings than do individuals without disabilities. Individuals with disabilities are also overrepresented within the lowest income categories. As seen in Figure 7, significant proportions of individuals with disabilities live below the federal poverty level. Rate of poverty among people with disabilities are significantly higher in Lehigh County when compared to Northampton County and are particularly troubling among individuals with disabilities under the age of 18.

Figure 6. Median Income in Lehigh and Northampton Counties and PA (2013)



Source: US Census Bureau, American Community Survey, 2009-2013.

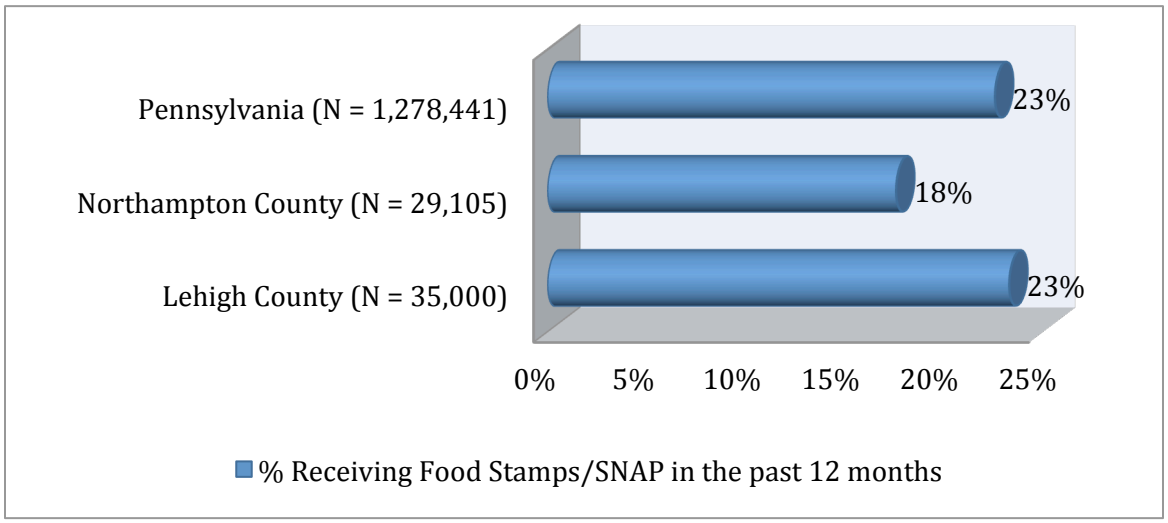
Figure 7. Percentage of Individuals with Disabilities Living in Poverty by Age in Lehigh and Northampton Counties and Statewide (2013)



Source: US Census Bureau, American Community Survey, 2009-2013.

Disabilities are linked to poverty at the level of families as well. Figure 8 shows that many individuals with disabilities live in households that, in 2013, received food stamps and/or SNAP (Supplemental Nutrition Assistance Program) during the previous 12 months.

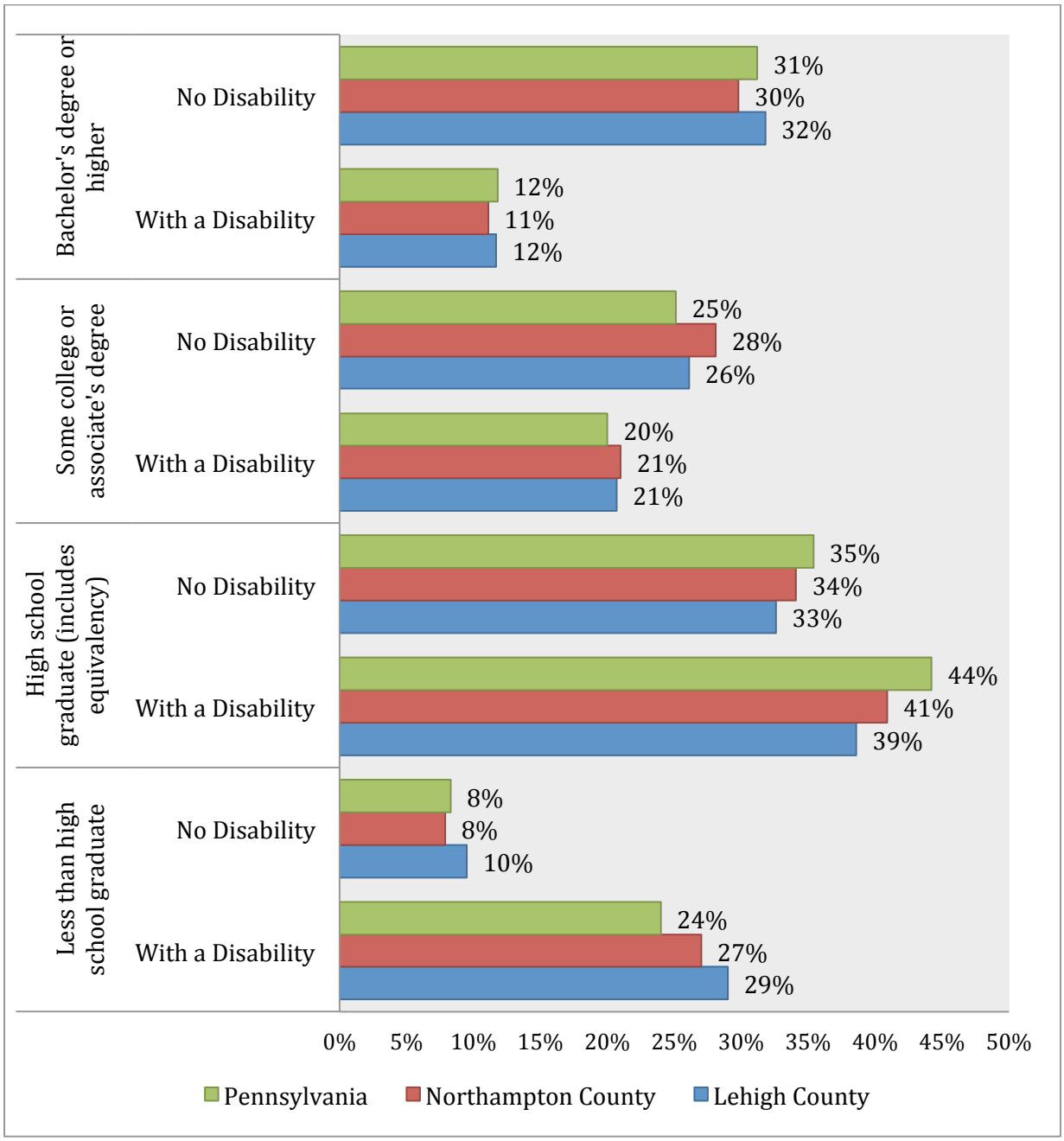
Figure 8. Percentage of Households Receiving Food Stamps (2013)



Source: US Census Bureau, American Community Survey, 2009-2013.
Note: Overall cases (N) represent the total number of households with one person with a disability.

Education, of course, is key to self-fulfillment, wellbeing, independence, career attainment and advancement, and financial stability. Education is closely correlated with employment rates, with earnings potential and, along with poverty status and unemployment, is an important social determinant of health. Individuals with disabilities continue to lag behind individuals without disabilities at all level of educational achievement. As shown in Figure 9, in Lehigh County, 29% of adults with disabilities do not have a high school diploma, compared to only 9.5% of adults without disabilities. Gaps in educational achievement are greatest among individuals with college degrees. In Lehigh County, only 11.7% of adults with disabilities have a college degree, compared to 31.8% of adults without disabilities. These figures are similar in Northampton County and statewide.

Figure 9. Educational Attainment (2013)

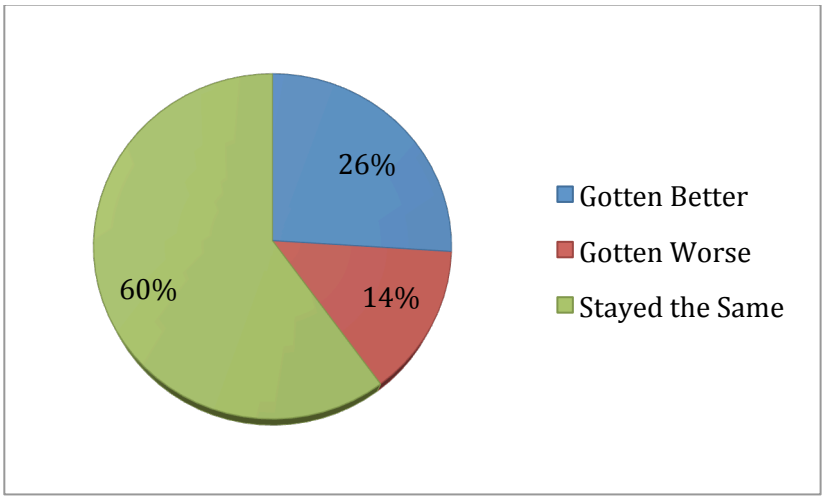


Community Needs Assessment Survey Findings

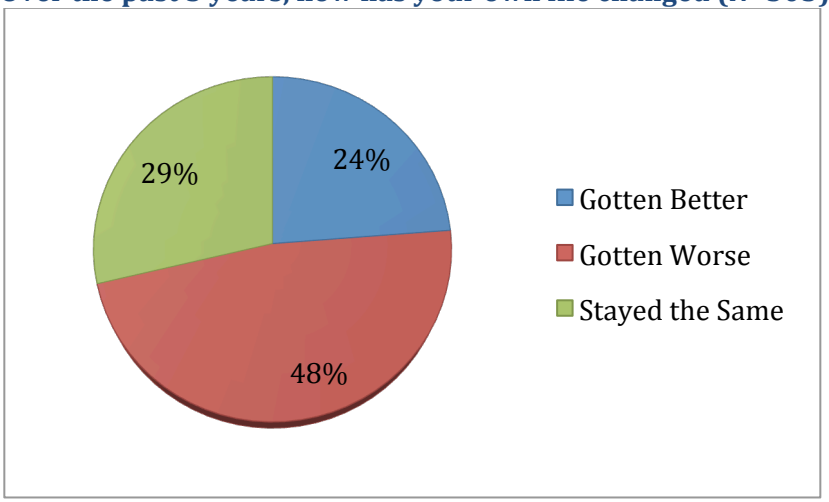
When asked broad questions about health and overall wellbeing, survey respondents paint a complicated picture, both of their own lives and their perceptions of the lives of others with disabilities living in the Lehigh Valley. For example, a majority of respondents (60%) believe that life in the Lehigh Valley for people with disabilities has stayed the same in the past five years; 26% believe it has improved and 14% believe that it has gotten worse (Figures 10). When asked about their own lives over the past five years, however, 48% report that things have gotten worse; only about one quarter say their lives have improved.

Figure 10. Respondents' Views on Life in the Lehigh Valley

Over the past 5 years, how has life in the Lehigh Valley changed for people with disabilities? (N=298)



Over the past 5 years, how has your own life changed (N=305)



The following sections summarize survey findings in several key areas, including health and rehabilitation, transportation, housing, consumer perceptions, parenting and families, and children with disabilities. These sections draw attention to the most significant needs raised by survey respondents, evidence of areas in which disability services might be improved, and respondents' views of the communities in which they live. Simply put, we hope to learn from survey findings what the Lehigh Valley is doing well, as well as what our communities could do better to make our region more welcoming, inclusive, and accessible for people with disabilities.

Health & Rehabilitation

A majority of survey respondents rate their overall health in positive terms. More than 60% of respondents say that their overall health is good or excellent. Similarly, more than 80% say that they are satisfied or very satisfied with the quality of health care they receive. The same is true of respondents' knowledge and awareness about health services and resources—66% say they are satisfied or very satisfied in this category. These findings are very consistent with previous regional studies (including the 2008-2009 GSRN needs assessment), which generally find residents of the Lehigh Valley rate their own health and the quality of their health care very favorably.[15]

Of course, while 60% of respondents say that their overall health is good or excellent, 40% report either fair or poor health. Moreover, respondents with mobility, psychiatric, and cognitive disabilities are more likely to report poorer health when compared to individuals with other types of disability as reported in Figure 11.

More than one-half of the survey sample reports requiring personal assistance or help with basic needs such as getting dressed, preparing meals or bathing. While it is not surprising that a majority of seniors (ages 65 and older) with disabilities indicate they need such assistance, roughly one-half of survey respondents under the age of 18, and one-half of respondent between the ages of 19 and 64, also report needing assistance with personal tasks. A large majority (71%) of these individuals receive help from family members (rather than, say, paid home health aides). About 23% of survey respondents say that they have needed personal assistance or support with basic tasks but have been unable to get it in the previous six months.

Most survey respondents report possessing health insurance, whether employment based health insurance (43%), Medicaid (41%), and/or Medicare (38%). Only 2 survey respondents reported being uninsured, which is a notable difference since 2008-2009, when 8% of survey respondents reported being uninsured.[16]

Of course, health insurance is not a guarantee of health care. While 67% of survey respondents report no major obstacles in obtaining required medical care or health services, 27% did say that this has been a problem for them in the past year. Among these individuals, most indicate that required medical services are not covered by health insurance and/or that needed health services cost too much.

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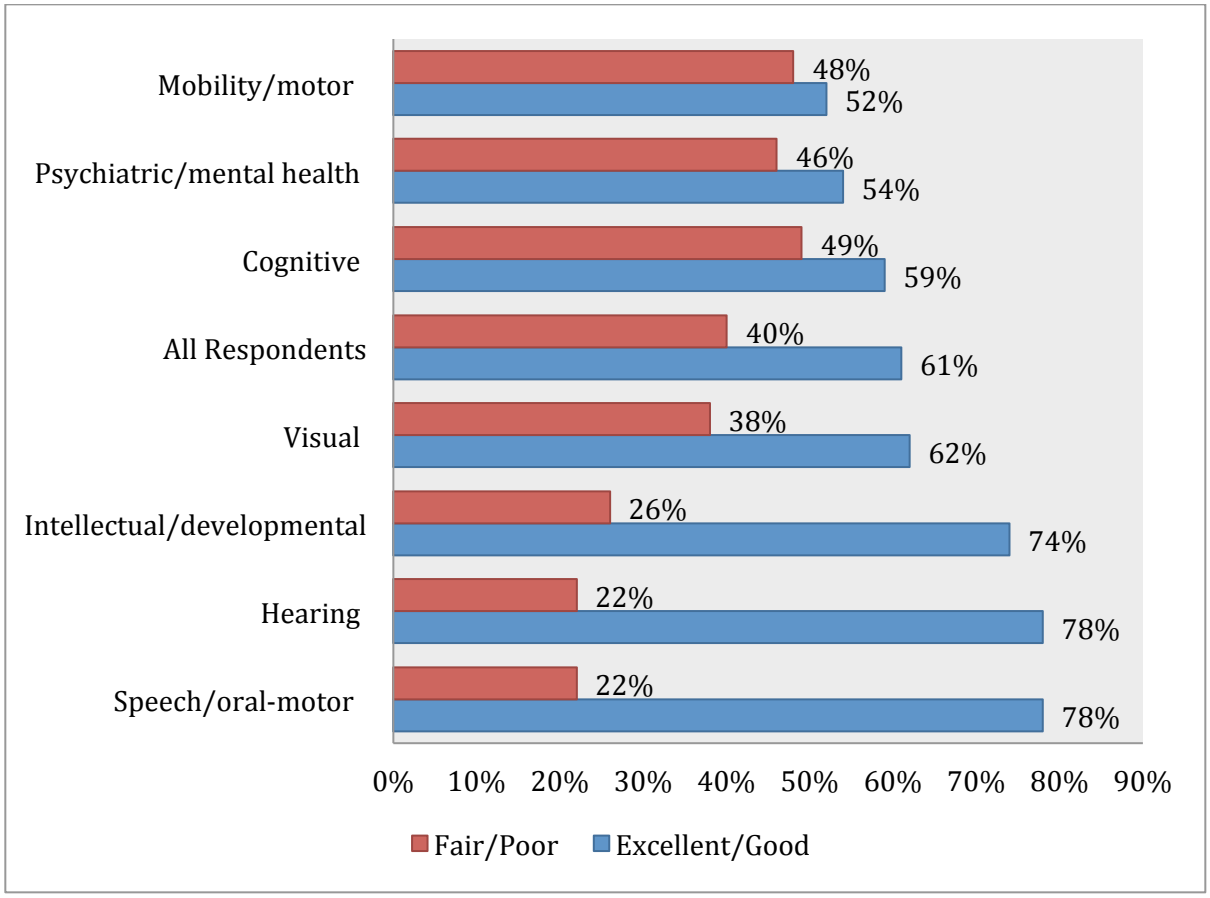
[15] Particularly interesting is the almost identical percentage of respondents—equal to roughly one-third of the survey sample—in both the 2008-2009 survey and the current 2015 survey who report dissatisfaction with their knowledge and awareness of health services and resources.

[16] Of course, lack of health insurance remains a problem for many people with disabilities, even after the Affordable Care Act. According to the US Census Bureau, in 2014, about 3800 adults (ages 18 to 64) with disabilities in Lehigh County, and 1147 adults (ages 18 to 64) with disabilities in Northampton County lacked health insurance.

Respondents' views on access to and the affordability and quality of a range of health services are also generally positive. Respondents were asked to rate their level of health services satisfaction on a scale of 1 (extremely satisfied) to 5 (extremely dissatisfied). Figure 11 lists the mean score for each health service. Numbers closer to 1 (i.e., short bars) indicate high average satisfaction; numbers closer to 5 (i.e., long bars), in contrast, indicate lower average satisfaction.

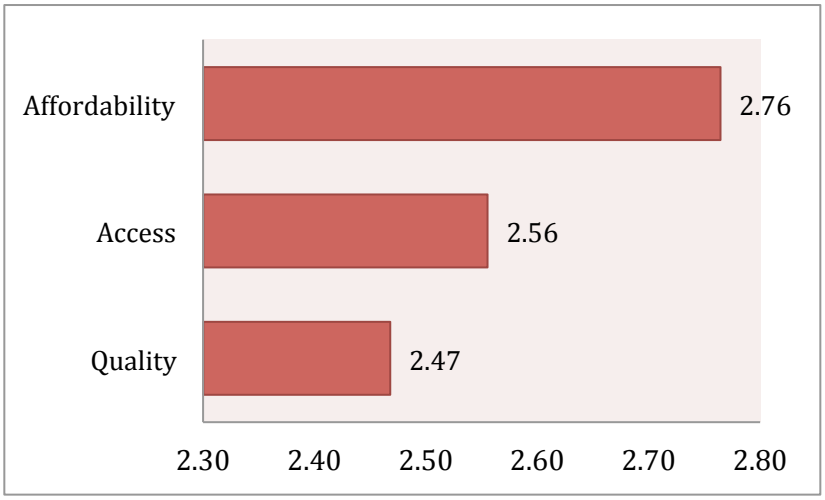
Figure 11. Respondents' Reported Overall Health by Disability Type



Note: Numbers closer to 1, or shorter bars, indicate higher satisfaction; numbers closer to 5, or longer bars, indicate lower satisfaction.

Figure 12 shows average mean satisfaction on the dimensions of access, affordability and quality across 11 different kinds of health-related services, including prescription drugs, preventative health services, medical care, health insurance, sexuality and reproductive health services, dental care, spiritual care, technology services, care management, mental health services, and long term support services. Perhaps not surprising, respondents indicate the highest level of satisfaction with the quality of services they receive and the lowest overall satisfaction with affordability.

Figure 12. Respondents' Satisfaction with Access, Affordability & Quality of Health Services Overall

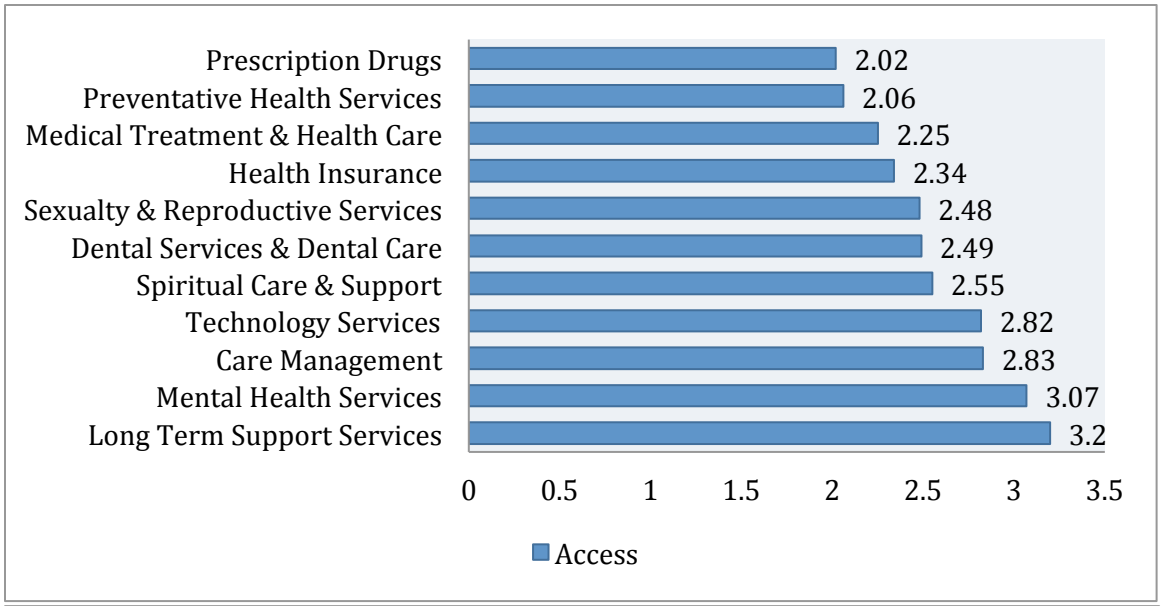


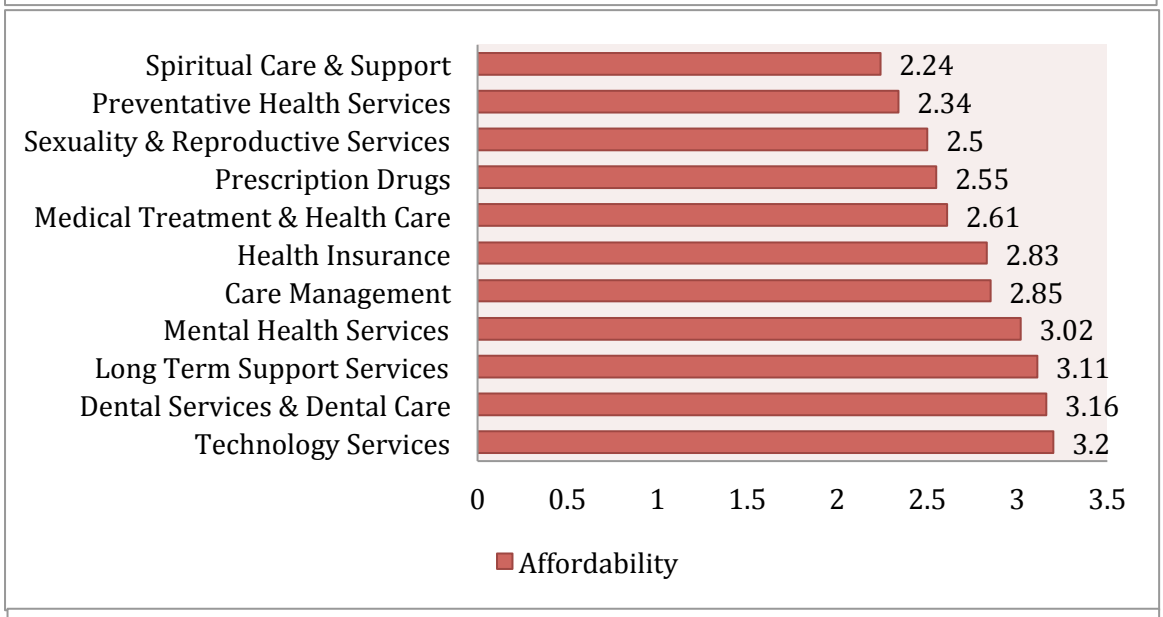
Note: Numbers closer to 1, or shorter bars, indicate higher satisfaction; numbers closer to 5, or longer bars, indicate lower satisfaction.

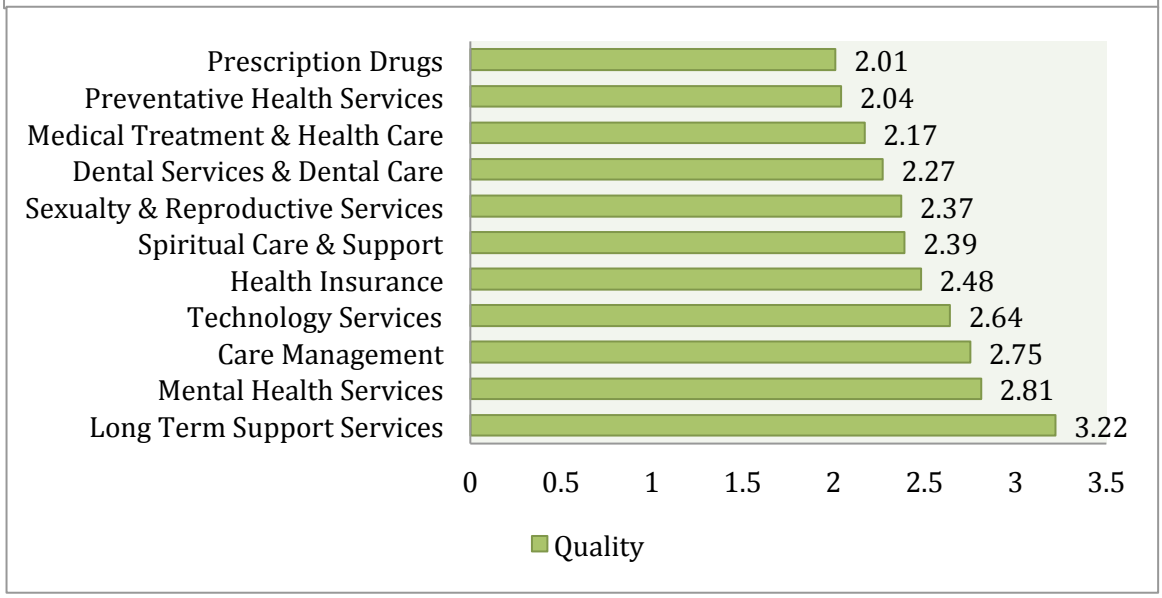
Figure 13 shows respondent scores for each of the 11 health-related services separately. Overall, respondents report the least satisfaction across all three dimensions (access, affordability, and quality) in 4 areas: technology services (e.g., assistive speech devices, voice activated technology, power wheelchair), care management, mental health services, and long-term support services.

On the flip side, higher average satisfaction in access, affordability and quality characterize respondent views of prescription drugs, preventative health services, medical treatment and health care, and dental care with a few modifications. Perhaps understandably, respondents provide less positive ratings about the affordability of prescription drugs, medical and health care, and dental care services when compared to how they assess quality and access to these services. It's worth emphasizing that survey respondents communicate generally more positive views about access and affordability of health insurance in the current study than was the case in either the 2008-2009 or 2001 needs assessment.

Figure 13. Respondents' Views on Access, Affordability & Quality of Health Services By Health Service Type



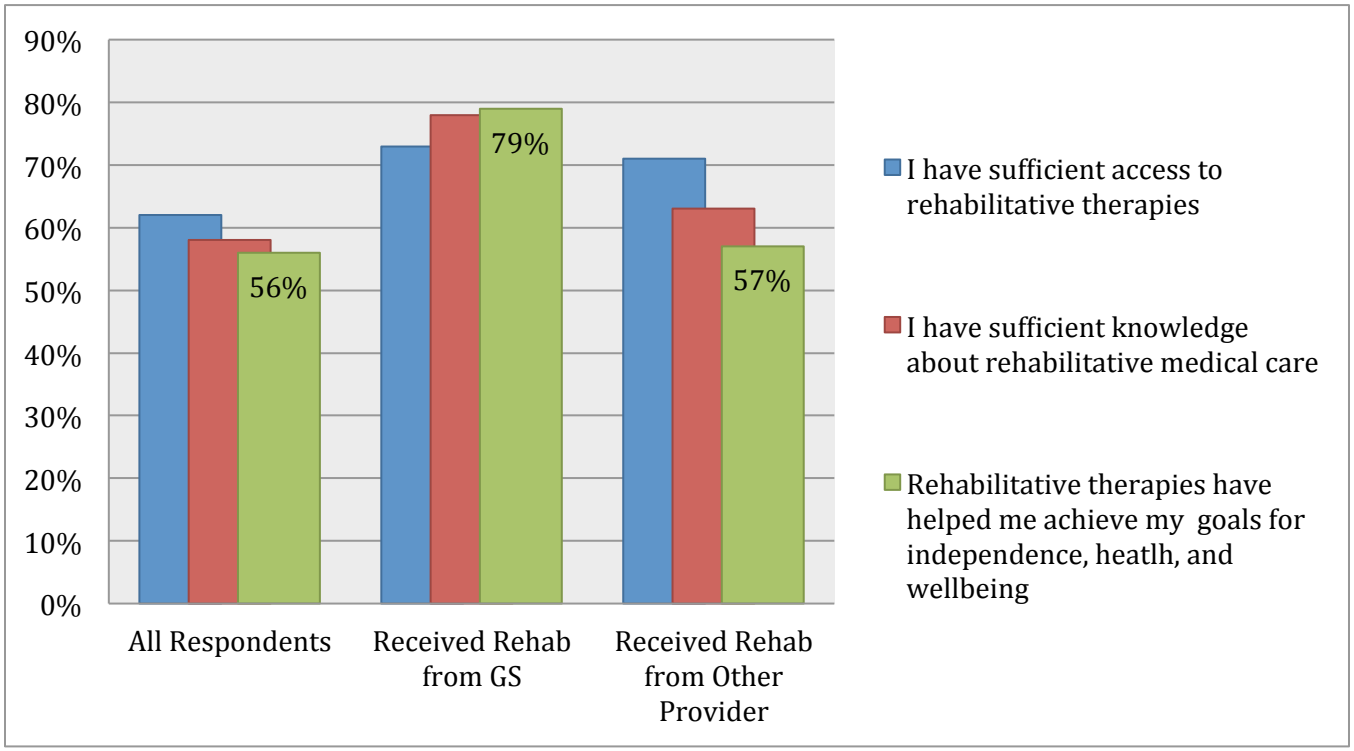




As a nationally recognized rehabilitative hospital network, the rehabilitative needs of individuals with disabilities in the Lehigh Valley are of obvious and primary interest to GSRN. Accordingly, the survey asked respondents to indicate whether or not they have a past or existing need for rehabilitative services and to indicate their level of satisfaction with access to and the affordability and quality of rehabilitative therapies available to them. The categories of rehabilitative care addressed in the survey include: inpatient rehabilitation, physical therapy, orthopedic rehabilitation, neuro-rehabilitation, occupational therapy, vision therapy, pediatric rehabilitation, cardiac or pulmonary rehabilitation, and vocational rehabilitation.

To put findings in local context, the survey asked respondents to indicate where they have received rehabilitative therapies. One hundred and fifty two (152) respondents answered this question and among them, 29% named Good Shepherd Rehabilitation Network (either alone or in combination with other providers in the region). Figure 14 provides a partial glimpse of respondents' perceptions about their access to and knowledge about rehabilitative therapies, as well as their evaluation of how well rehabilitative therapies have helped them to achieve their own goals. It is perhaps not a surprise that respondents who have received rehabilitative therapies—at Good Shepherd or elsewhere—are in stronger agreement that they have sufficient access and knowledge about rehabilitative services. What is most interesting are differences in respondent agreement about the extent to which rehabilitative therapy has helped them to achieve their goals for independence, health, and wellbeing; 79% of respondents who have received rehab from GSRN agree, compared to 57% of those who received rehab from another source.

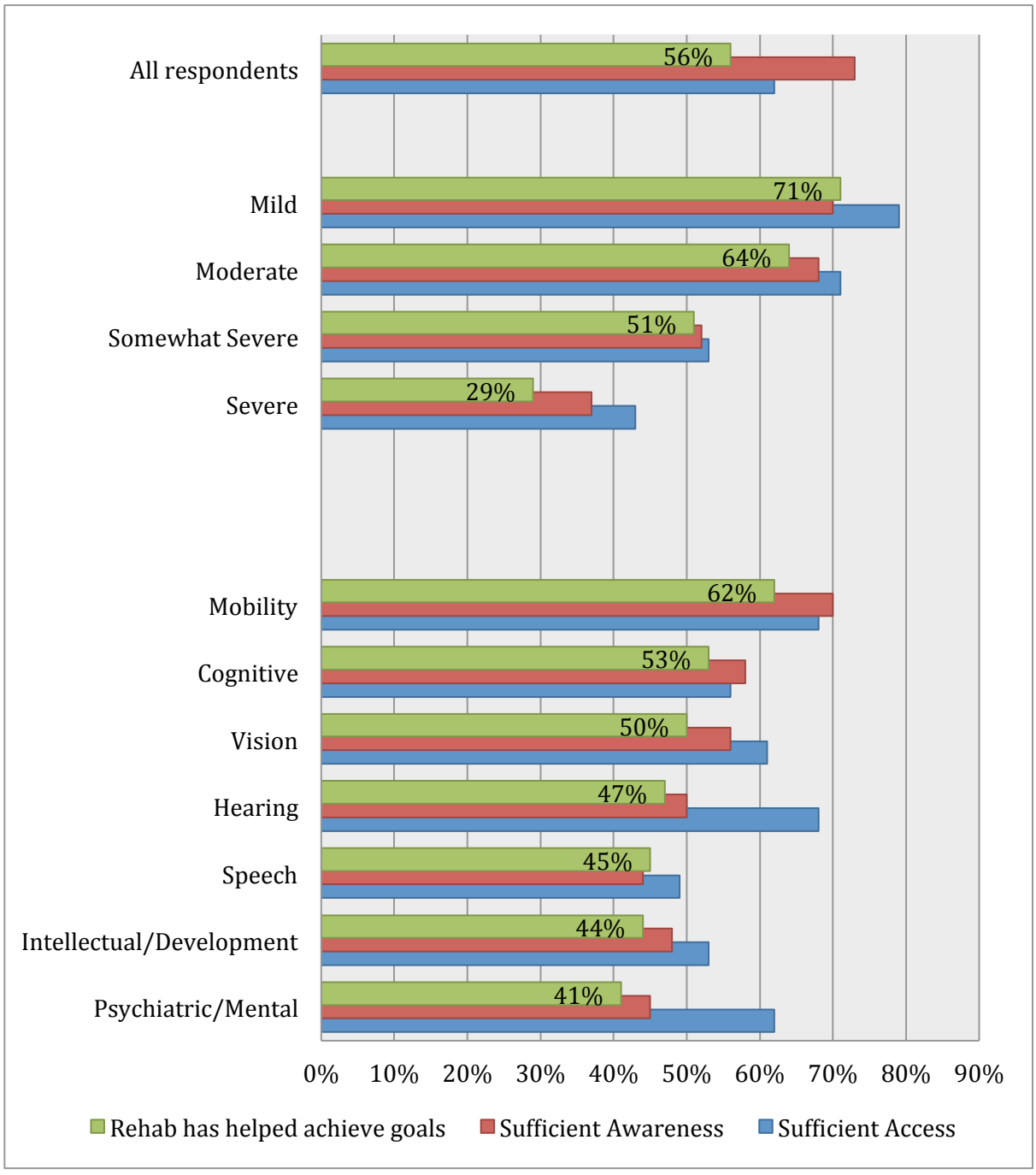
Figure 14. Respondents' Views on Access, Knowledge, and Success of Rehabilitative Therapy At GSRN



Note: Individuals who mentioned GSRN were coded as having received therapy at GSRN, even if they also received therapies in other locations.

Figure 15 considers how disability type and severity are related to views about rehabilitation. Disability severity clearly matters; the more severe a respondent's disability, the less likely she was to agree that she has sufficient access or awareness about rehabilitative therapies and the less likely she was to agree that rehabilitative therapy has helped her to achieve independence, health, and wellbeing.

Figure 15. Disability Type & Severity and Respondents' Views on Access, Awareness, and Success of Rehabilitative Therapies



Survey responses about particular types of rehabilitative services are summarized in Table 7. The most common rehabilitative therapy among respondents is physical therapy—48% say they have had physical therapy in the past and an additional 19% say they are currently receiving it. Occupational therapy was the second most frequently mentioned, with 35% of respondents indicating they've received it in the past and an additional 18% indicating that they are receiving it now. Turning next to satisfaction with access, affordability and quality issues, respondents generally offer more positive ratings for access and quality and less favorable ratings for affordability. Notable across ratings are vision therapy and vocational therapy. Respondents gave lower ratings in all three categories—access, affordability, quality—for vision therapy. Respondents' evaluations of vocational therapy suggest that quality and access is a greater issue than is affordability and this is a distinct pattern when compared to other therapies listed.

Respondents were invited to specify additional therapies that would be beneficial to them, and to explain barriers and obstacles preventing them from accessing those therapies. Respondents noted several kinds of therapies—ranging from aquatic therapy to support groups to locomotor training to RSD therapy to massage therapy to personal training for weight loss and exercise.[17] Among these, pool based aquatic problems were the most frequently identified need among survey respondents.

Beyond identifying these therapies, the overwhelming sense of respondents' comments hinged on cost related barriers to therapies that are available, particularly insufficient insurance coverage for rehabilitative services and, to a lesser degree, transportation costs associated with access.

For example, one respondent noted that income thresholds used to determine financial support and waiver services for physical rehabilitation were too low and, as a result, disqualify too many individuals who need rehab but are unable to afford it on their own.

Pointing to similar gaps in access another wrote, *"Medicare has a lifetime payment for 12 weeks of pulmonary rehab."* Another explained, *"my insurance visits ran out [and] I have no way of getting to [occupational therapy]."* One respondent described frustration with similar obstacles, *"I would love more PT [physical therapy] to help me walk even better with my prosthetic limb. However, insurance only covers 20 outpatient visits per year and I cannot afford these services without insurance."* A final comment summarizes the sentiment of many responses, *"Lack of quality therapists and locations are too far from us. Also, insurance only covers a certain amount of time and usually not enough to be of full benefit."*

[17] While the current survey did not ask respondents about physical fitness and exercise, it is worth recalling findings from the 2008-2009 needs assessment in which 40% of respondents indicated that they rarely or never exercise. Focus groups from the 2008-2009 echoed concerns about access to affordable fitness facilities and the specific lack of aquatic facilities that are both geographically and financially accessible for people with disabilities.

Table 7. Respondents' Experiences with, Need for, and Evaluation of Rehabilitative Therapies

	Received in Past	Currently Receiving	Need This Therapy	Access	Affordability	Quality
Inpatient Therapy	33% (79)	3% (8)	1% (3)	2.06	2.51	2.05
Physical Therapy	48% (119)	19% (47)	12% (31)	2.13	2.56	1.92
Orthopedic Rehabilitation	27% (63)	6% (14)	9% (20)	2.22	2.49	2.02
Neuro-Rehabilitation	24% (58)	8% (20)	20% (49)	2.64	2.80	2.38
Occupational Therapy	35% (85)	18% (43)	12% (29)	2.23	2.41	2.18
Speech Language or Communication Therapy	24% (57)	19% (47)	12% (30)	2.34	2.39	2.12
Vision Therapy	9% (20)	6% (14)	9% (20)	3.02	2.92	2.66
Pediatric Rehabilitation	9% (20)	6% (13)	3% (6)	2.25	2.54	2.07
Cardiac or Pulmonary Rehabilitation	6% (15)	3% (7)	5% (11)	2.55	2.74	2.55
Vocational Rehabilitation	13% (31)	7% (16)	16% (37)	3.25	2.79	3.33

Mental Health & Wellbeing

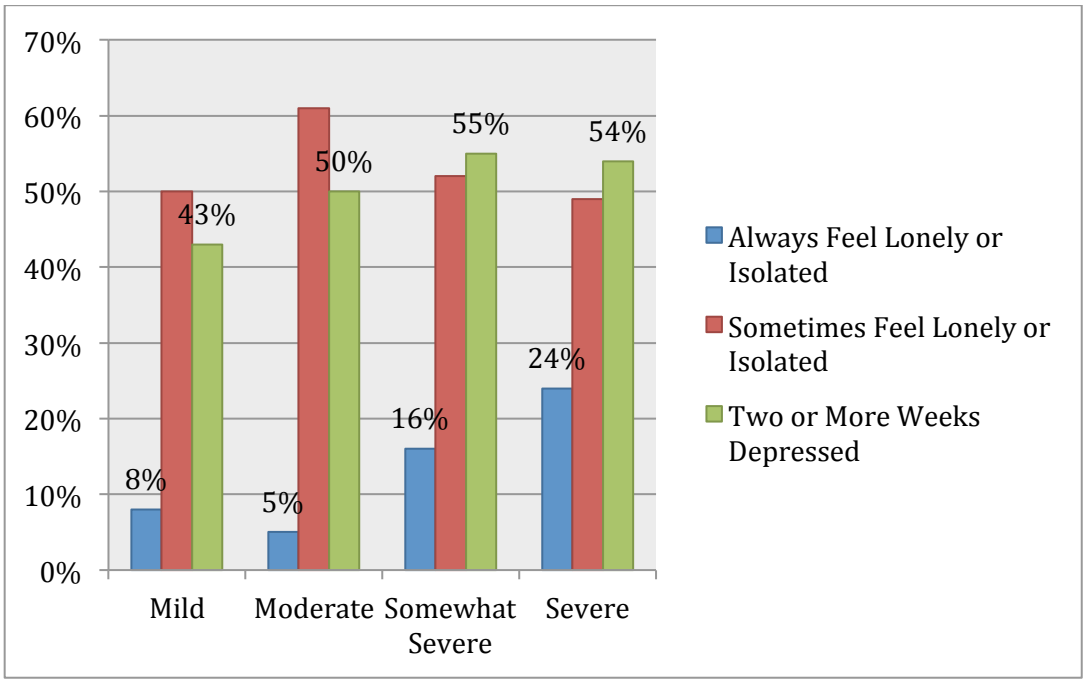
The survey included two questions related to mental health and wellbeing. More than one half of survey respondents say that they have had two or more weeks of feeling sad, blue, or depressed in the past year, while an alarming 66% of respondents report sometimes or always feeling lonely or isolated from others—11% of respondents say that they *always* feel lonely.

These figures are higher than what we know about the Lehigh Valley regional population as a whole. Similar questions asked in a community-wide health needs assessment for St. Luke's University Hospital in 2012 found that about 32% of individuals in the region report two or more weeks of feeling sad or depressed—this is less than ½ the rate among the current survey of people with disabilities. It is important to proceed cautiously when comparing findings from these two studies (the current disability needs assessment is not a random sample making it problematic to draw inferences), nonetheless, the disparity in findings regarding mental health and the seemingly high rate of feelings of depression among survey respondents point to a need for more careful research in this area.

The relationship between disability and depression is complex. According to the National Institute of Mental Health, major depressive disorder is the leading cause of disability among adults ages 18 to 64 in the United States.[18] The current study does not provide a measure of major depressive disorder among respondents, nor can we say much about the causal relationships between depression and disability among our respondents. Nonetheless, recalling from Figure 13 above that mental health services receive negative ratings on respondent satisfaction for access, affordability, and quality, several potential substantively significant relationships do emerge from survey findings. For example, whereas 43% of respondents who were born with a disability report two or more weeks of depression, this number is 58% among individuals who were not born with their disability. Individuals who were born with their disability are also less likely to report feeling lonely or isolated from others. In general, disability severity is linked to respondents' likelihood of reporting two or more weeks of depression and in reporting sometimes or always feeling isolated or lonely as seen in Figure 16. Whereas 43% of respondents who say their disability is mild report two or more weeks of depression, more than 50% of those with somewhat severe or serve disabilities say the same. There seems to be a positive relationship between disability severity and feelings of loneliness and isolation.

[18] http://www.nimh.nih.gov/health/statistics/index.shtml

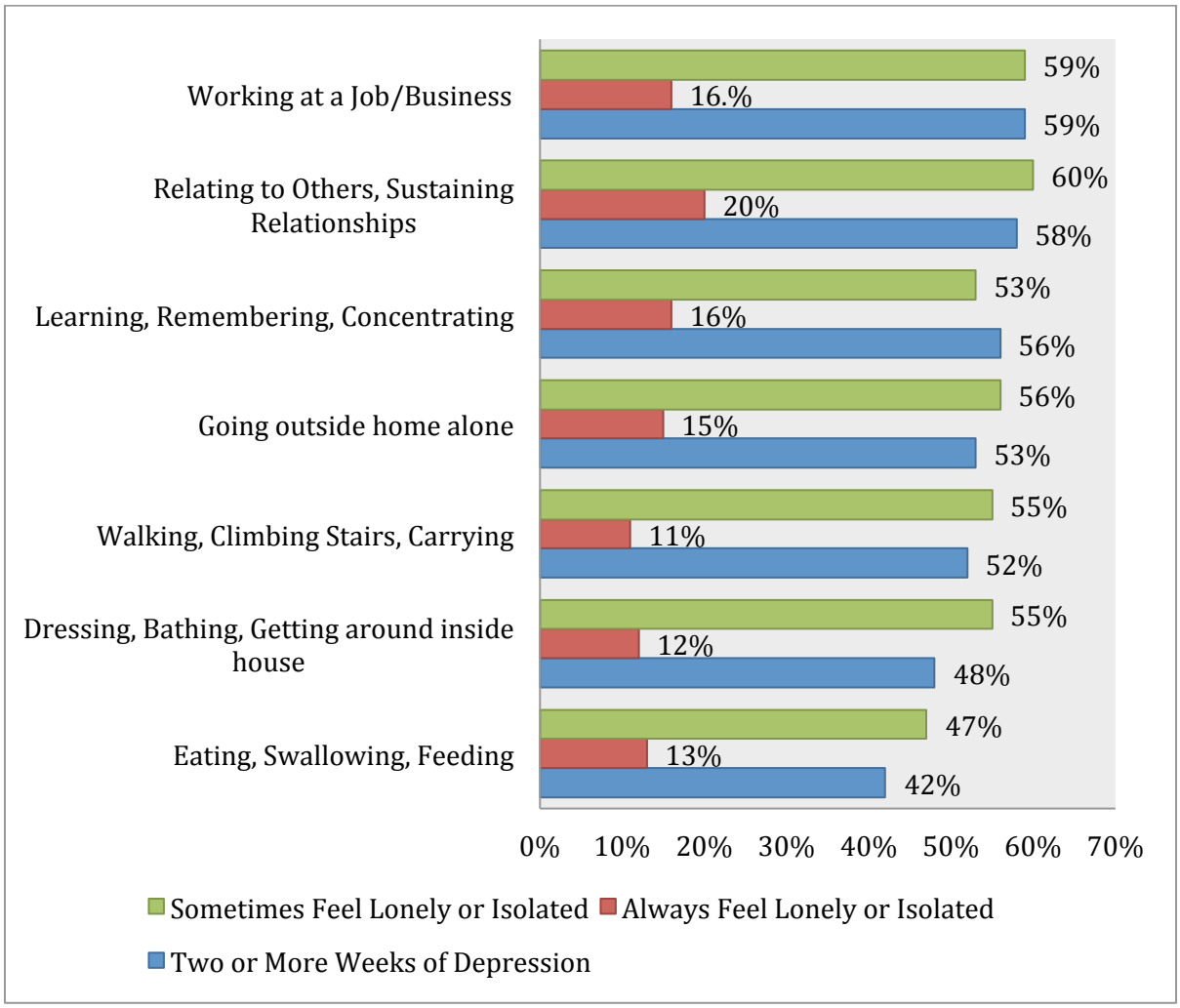
Figure 16. Disability Severity and Feelings of Depression and Loneliness



In addition to indicating disability type, the survey asked respondents to indicate how their disability "causes trouble" in a variety of activities related to daily and independent living, including getting around inside the house, going outside the home alone, working at a job or business, and being able to relate to others and to sustain relationships. Figure 17 illustrates the relationship between respondents' limitations in these activities and their reported experiences of feelings of depression. Close to 60% of respondents who say that their disability has led to trouble "working at a job or business" also report feeling sad, blue or depressed for two or more weeks in the past year. They are closely followed by 58% of respondents who say that their disability makes it difficult to relate to others or to sustain relationships. While these data are not surprising, they lend support to the value of social relationships in facilitating mental wellbeing and point to a potential need to find avenues for social connections among individuals with disabilities who are unable to work and who are limited in their abilities to form social ties for other reasons.[19]

[19] Similar findings have been found among the Lehigh Valley senior population (65 years old and older). A recent survey conducted by the Muhlenberg College Institute of Public Opinion for the United Way Alliance on Aging, A Collective Impact Movement of the United Way of the Greater Lehigh Valley, found that mental distress (feelings of depression, feelings of loneliness and alienation) is associated with seniors' limitations in their abilities to complete daily activities and with compromised independence. See *Lehigh Valley Seniors: Healthy at Home, 2015 Update,*: http://www.unitedwayglv.org/UnitedWay/media/PDFs/Alliance%20on%20Aging/LV-Seniors-Healthy-at-Home-2015-Update.pdf?ext=.pdf

Figure 17. Limitations Caused by Disability and Feelings of Depression and Loneliness



Note: Because responses are drawn from separate questions, percentages do not add up to 100%.

Reproductive Health & Sexuality

The survey contained a subset of questions designed to measure respondents' perceptions of their access to reproductive health care, including information about sexual relationships and intimacy. An additional set of questions asked respondents about their level of interest in sexuality, reproductive and intimacy concerns. Almost one half (47%) of survey respondents indicated that these are not issues of concern for them. It is not possible for us to determine the reasons why so many respondents say this is not a concern or whether a lack of concern reflects satisfaction or dissatisfaction. Survey findings do not suggest an obvious explanation. There are no significant differences, for example, in the ways in which male and female respondents answered these questions, nor are there patterns that overlap with respondents' age. Research conducted by the National Council on Disability suggests that individuals with disabilities, and especially women with disabilities face social misperceptions and stereotypes, and frequently untrained medical providers, that make it more difficult to obtain information about reproductive health and sexuality.[20]

Table 8 summarizes key findings and offers a complex picture of respondents' views on these issues. While a clear majority (67%) agree that their health care provider never discusses reproductive or intimacy concerns with them, respondents appear more evenly split on questions regarding the quantity and quality of information they receive from their health care providers on these matters. For example, 56% of respondents agree that their health care provider offers only minimal information about reproductive and intimacy concerns; 44% disagree. Similarly, while respondents' views are not overwhelmingly positive about the degree to which their health care provider offers them specific information (about one half of the sample agrees and the other half disagrees), they offer more positive feedback about the helpfulness of their health care provider in offering referrals

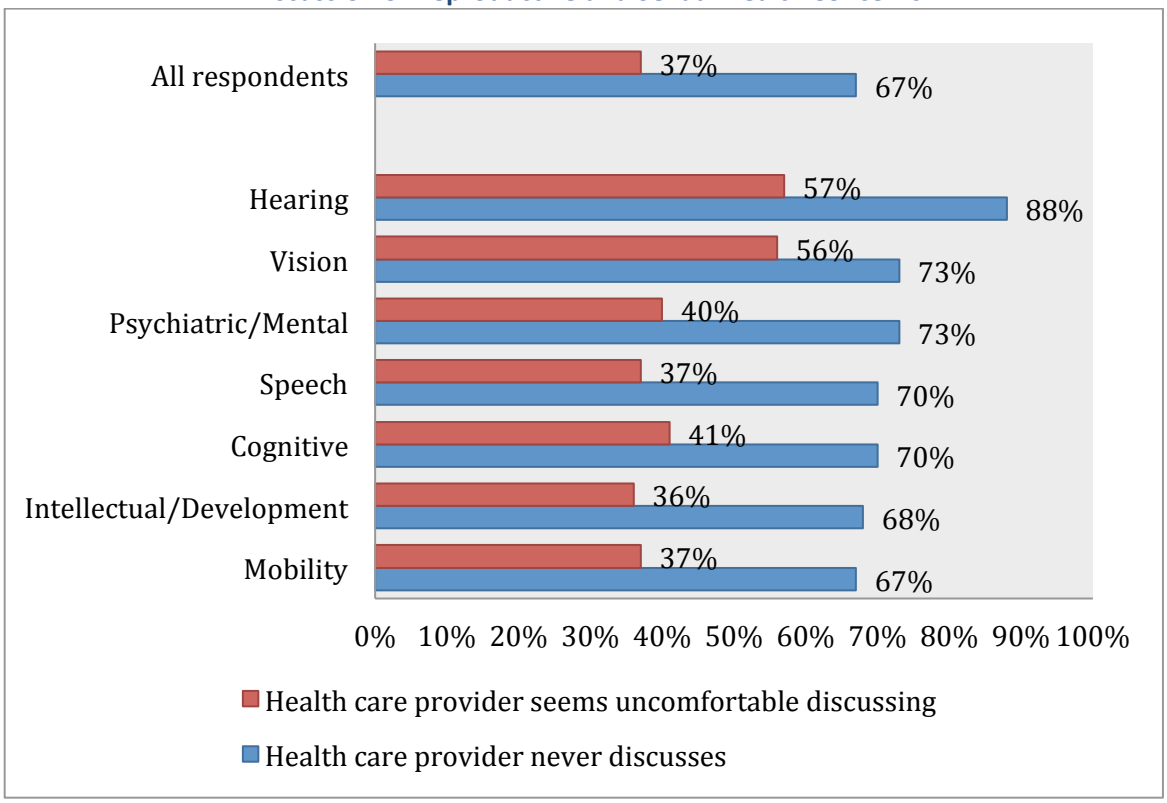
Figure 18 illustrates some interesting relationships between disability type and respondents' answers to questions about sexuality and reproductive concerns in the context of relationships with health care providers. While majorities of respondents in all disability type categories agree that their health care provider never discusses sexuality and reproductive concerns, and majorities in all disability types similarly agree that their health care providers seem uncomfortable discussing these concerns, agreement is even stronger among individuals with hearing, vision, and psychiatric/mental health disabilities. These data may point to variation in medical training and attention to reproductive, sexuality, and intimacy concerns among professionals working in different disability areas, and/or to implicit assumptions about individuals with particular kinds of disabilities.

[20] National Council on Disability, *The Current State of Health Care for People with Disabilities*, 2012.

Table 8. Respondents' Views on Health Care Providers and Reproductive and Intimacy Concerns

My health care provider never discusses reproductive or intimacy concerns with me. (N=222)		
	Strongly Agree	**36% (79)**
	Agree	31% (68)
	Disagree	22% (49)
	Strongly Disagree	12% (26)
My health care provider seems uncomfortable discussing reproductive or intimacy concerns with me. (N=203)		
	Strongly Agree	13% (27)
	Agree	24% (48)
	Disagree	**43% (87**)
	Strongly Disagree	20% (41)
My health care provider offers me only minimal information about reproductive and intimacy concerns. (N=201)		
	Strongly Agree	21% (42)
	Agree	**35% (71)**
	Disagree	29% (58)
	Strongly Disagree	15% (30)
My health care provider is very helpful in offering specific information about reproductive and intimacy concerns. (N=199)		
	Strongly Agree	14% (28)
	Agree	32% (63)
	Disagree	**33% (66)**
	Strongly Disagree	21% (42)
My health care provider is helpful in offering referrals for additional information about reproductive and intimacy concerns. (N=203)		
	Strongly Agree	12% (25)
	Agree	**36% (72)**
	Disagree	31% (63)
	Strongly Disagree	21% (43)

Figure 18. Respondents' Agreement with Statements About Health Care Providers' Discomfort and Discussion of Reproductive and Sexual Health Concerns



Respondents were invited to provide additional comment about reproductive and sexual health concerns. Their responses reveal important qualitative information about barriers to reproductive and sexual health and the social misunderstanding surrounding these issues for people with disabilities. Two respondents noted, for example, that they lack access to erectile dysfunction drugs due to cost and inadequate prescription drug coverage. Several others indicated that sexual difficulty was a problem for them in personal relationships, and pointed out that they lack access to counseling and/or therapies that might help them improve sexual relationships.

Others focused on stereotypes common among the medical profession, as one respondent wrote, *'the general public and medical community assume that all disabled [individuals] are asexual also."* Another commented, "*I feel like my doctor thinks I should be concerned about other issues. I feel like my doctor doesn't get it, doesn't understand."* One women respondent said that when she asked a medical doctor about sex, the doctor referred her to "magazines" rather than discuss how to engage in sexual activity given the limitations of her particular disability. A small group of respondents focused on assumptions about sexuality which may lead medical professionals to neglect the particular needs of gay, lesbian, or transgendered individuals with disabilities.

Lack of access to trained medical professionals also emerged, particularly among parents completing the survey on behalf of a minor child with a disability. One mother wrote in reference to a daughter with a disability, *"it has been difficult to locate a gynecologist who knows how to examine a person with an intellectual disability."* Another parent expressed concern about knowing how to negotiate sexual changes in a son with a disability: *"My son is 13 and we are just entering his*

hormonal stage. I am concerned how to address this with his limited understanding and don't know where to go for help."

While a few offered positive comments—one noted that her gynecologist was receptive to talking about birth control and supported her choice among options—the majority of comments provided by respondents in this area reflect frustration, lack of access and understanding, and in general a need for more frequently and helpful communication about sexuality and reproductive health.

Transportation

Mobility and transportation are twin concerns for access and inclusion for people with disabilities. Affordable and reliable transportation is crucial for opportunities in education, employment, heath care, housing, and community life. If a need for affordable and reliable transportation is clear, nonetheless, understanding the particular transportation-related challenges of people with disabilities in the Lehigh Valley is made more complicated by confusing quantitative data that often seems at odds with anecdotal experience.

In the 2008-09 GSRN disability needs assessment, for example, a survey of provider agencies suggested that transportation was a primary issue for individuals with disabilities in the region. Close to 70% of provider agencies agreed that transportation was a major problem for client populations. In contrast, people with disabilities participating as individual survey respondents in the 2008-09 needs assessment communicated a different view. Among survey respondents, only 14% said that transportation was a major problem for them while an additional 22% said it was sometimes a minor problem.

Subsequent surveys in the Lehigh Valley and beyond have similarly found that a majority a people with disabilities does not report a major problem with transportation. These include, for instance, The Lehigh Valley Center for Independent Living's Personal Experience Survey Report (2013), which suggested that close to 75% of individuals with disabilities living in the region report having no or only minor issues with transportation.[21] In the LVCIL study, the vast majority of survey respondents reporting no problems with transportation were individuals who either were able to drive independently, or relied on family members and friends to provide transportation assistance. Very few reported using public transportation. Among both the 2008-09 GSRN needs assessment and the LVCIL survey, individuals who rely on public transportation reported greater overall difficultly with transportation and obstacles related to unreliable and inconvenient schedules, as well as too few options for public transportation in the region.

The current needs assessment survey finds similarly that 58% of survey respondents report that transportation is not a problem for them, 24% say it is a minor problem, and 18% report it to be a major problem (Figure 19). Only a small minority of respondents, 9%, report using public transportation as their primary source of transportation (Figure 20). It is these latter two subgroups of the survey sample that report the most significant problems with transportation, as seen in Figure 21. Similar to the 2008-2009 study, the current survey found that individuals with more severe disabilities report greater challenges with transportation.

[21] The LVCIL survey encompassed a larger regional area beyond Lehigh and Northampton counties to include Bradford, Columbia, Lackawanna, Luzerne, Monroe, Pike, Sullivan, Susquehanna, Wayne and Wyoming counties as well.

Figure 19. Percentage of Respondents Reporting Major, Minor and No Problem with Transportation (N=226)

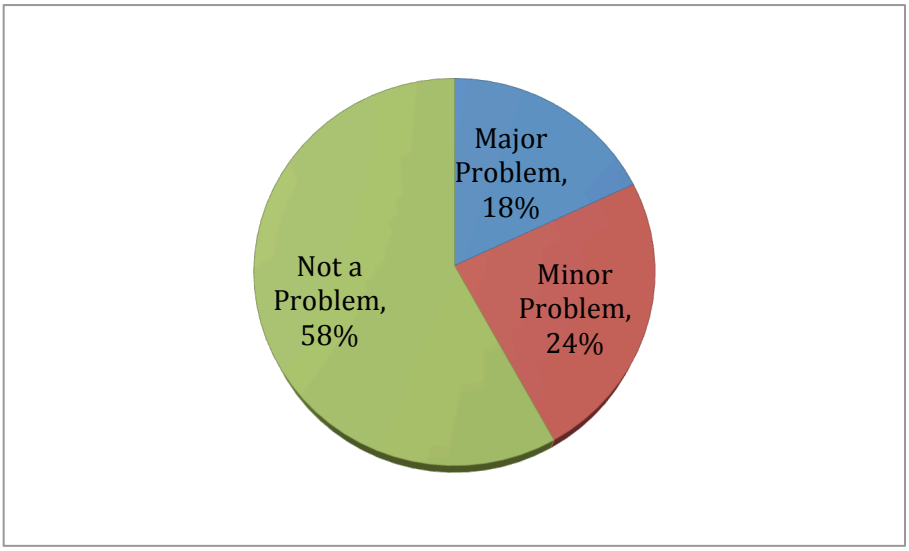


Figure 20. Percentage of Respondents Reporting Use of Different Types of Transportation (N=237)

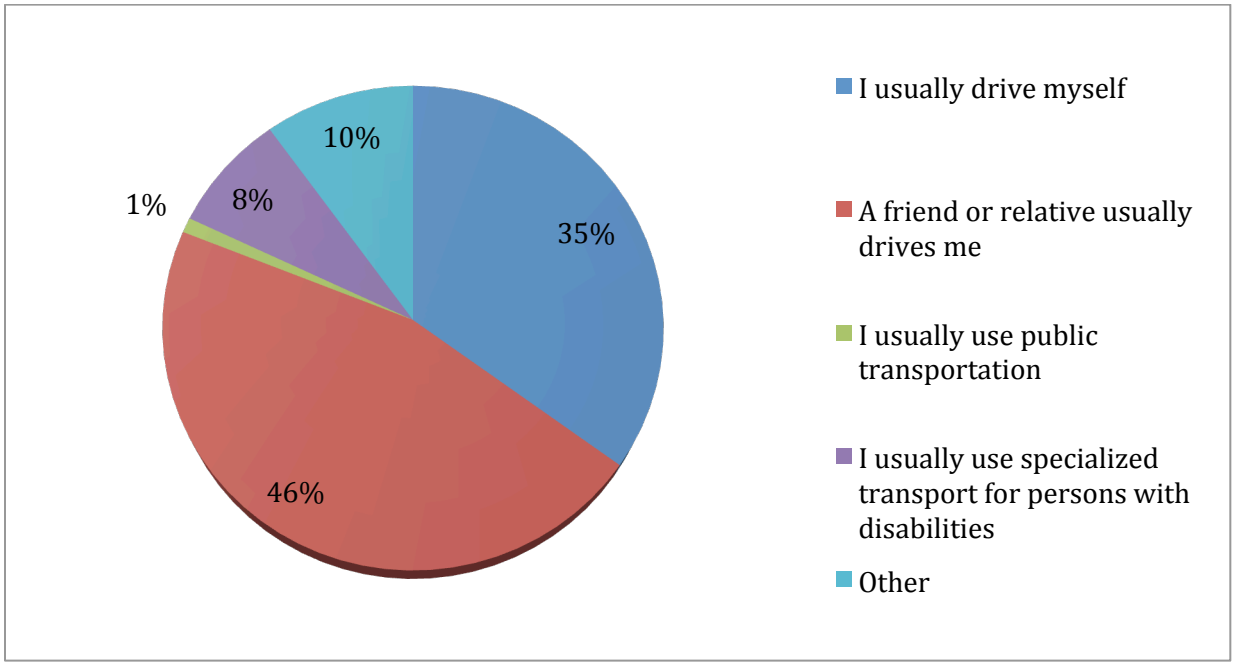
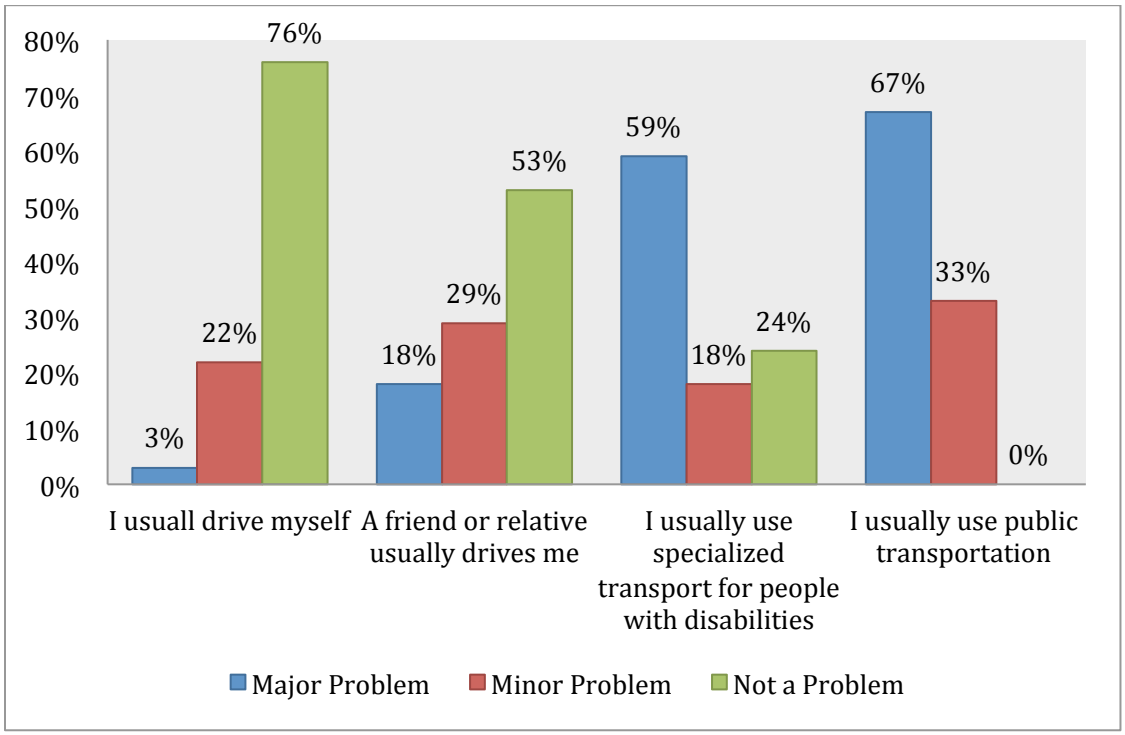


Figure 21. Most Frequent Mode of Transportation and Reported Transportation Problems



The survey included an open-ended question inviting respondents to describe the greatest challenges and obstacles they face when it comes to transportation. Respondents' comments echo similar concerns that were expressed in the 2008-2009 GSRN study, including problems with access, affordability, and reliability of public transportation and dissatisfaction with specialized transport, including Easton Coach, particularly concerning long wait times and unreliable drivers. Perhaps most importantly, respondents pointed to the health-related effects of transportation difficulties, including community and social isolation, and inability in some cases to access medical and rehabilitation services.

One respondent noted, for example, that using a cab service was not an option for her since, *"I cannot use a cab…with my electric wheelchair…it is difficult to put my wheelchair in and out of my van by myself, so I am limited in independent activities if I am [traveling] alone."*

Another wrote, *"…I am legally blind with correction. Therefore I do not qualify for a driver's license. There is no public transportation near me. Closest LANTTA bus stop is over 3 miles away. I rely on my parents to transport me everywhere I need to go. This is very inconvenient and a major obstacle in seeking employment."*

While a majority of survey respondents suggested that accessible parking was not a problem for them, 27% did say it was a minor problem, and 14% said it was a major problem. Respondents expressed frustration with too few handicap parking spaces. Several commented that even when

there are accessible parking spaces available "*they are still too far*" from many destinations to make them very useful.

Given the high numbers of people with disabilities that provide their own transportation by car, it is worth noting that costs associated with car maintenance and travel may be an obstacle for people with disabilities as well. One respondent noted, *"my car is paid off but I have no funding for any repairs. Gas and the distance that I have to go to my therapies, doctors, etc."* is a problem. A few others noted that given lack of access to meaningful well-paying jobs, affording a car was a major transportation challenge, particularly due to limited or non-existent public transportation options in many places throughout the region.

Car accommodations (e.g., electric lifts, hand controls) are expensive and generally inaccessible to many low-income respondents. Others noted that while some medical and health facilities provide valet service that will assist with loading and unloading scooters, wheelchairs, and walkers, others do not. One wrote, *"I must have a family member accompany me when I drive my vehicle to unload my power scooter. The exception is Lehigh Valley Hospital Cedar Crest where the valet service will unload my scooter for me. Not so good at Good Shepherd."*

Transportation is intricately related to independence and social integration. One respondent wrote, *"being disabled and a non-driver is hell, you can't go around. So you make each trip you can take count when you get to go out."* Another respondent pointed to a lack of special needs driving programs so that he would be able to learn how to drive. Another said similarly that, *"the greatest transportation challenge I face is learning how to drive with multiple sclerosis, and getting my driver's license."*

Employment & Education

As noted above, about 23% of the Lehigh Valley population of individuals with disabilities is employed in the paid labor force according to the US Census Bureau. Statewide, 33% of working age people with disabilities is employed. In the current survey sample, 11% of respondents report working full time and an additional 9% report working part time. Approximately 18% report that they are unemployed and an additional 22% say that they are retired and not working. Several respondents (58 individuals or 25% of respondents who answered this employment question) selected "other" as their employment status—many of these indicated that they are "on disability," or just "disabled." Taking these responses into account suggests that about 28% of survey respondents are unemployed.

Unfortunately, many survey respondents opted not to answer employment related questions and, as a result, survey results provide only limited information about potential employment-related needs of people with disabilities in the region. As shown in Appendix C, 46% of survey respondents (equal to 26 individuals) who answered questions about their own paid work believe that their work allows them to use their full talents and abilities; 16% say that their work allows them to use none or only a small amount of their talents and abilities.

As is to be expected perhaps, disability severity is related to employment. However, respondents volunteered additional insight about the challenges of employment for people with disabilities in our region that hinge on social context, rather than disability per se. For example, several noted that they have been discriminated against in seeking employment. One noted, *"prospective employers [are] very resistant to hiring those with disabilities."* Another simply wrote, *"disability discrimination DOES exist in the Lehigh Valley."* Other respondents focused on experiences trying to get

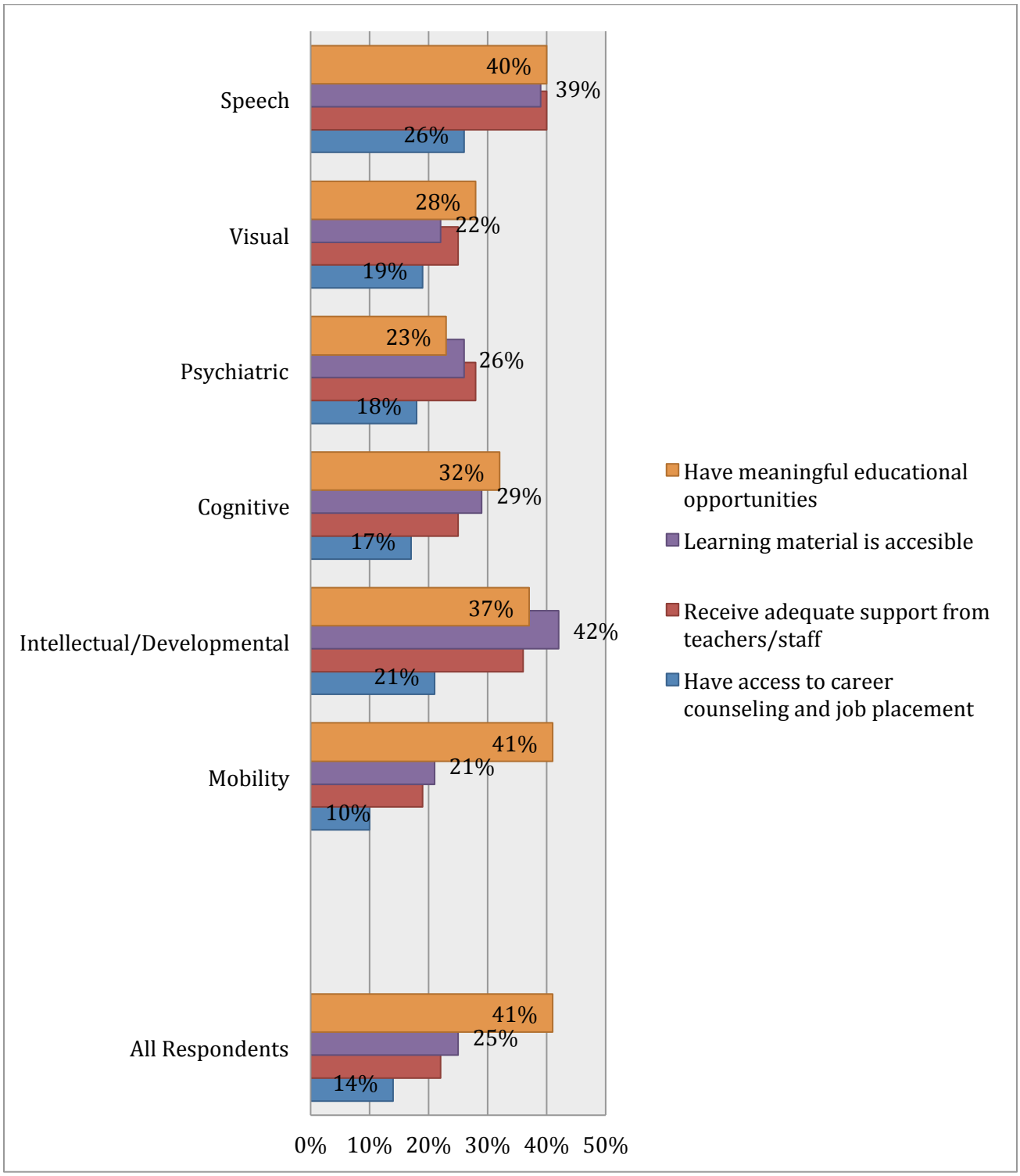
accommodations that could make work possible; "*the first time I asked for a reasonable accommodation...I was denied."*

Multiple respondents expressed a need for better training services and assistance locating work. One wrote, there is "*no support for advocacy and placement services…available job support and search services are useless."* This sentiment echoes findings reported above concerning respondents' generally unfavorable ratings of vocational services in the Lehigh Valley (see Figure X on page XX above). The survey asked additional questions about education and job training programs. To put these findings in context, about 24%, or 54 individuals, reported that they are currently in school or pursuing an education; 10% of respondents (21 individuals) said they are currently in a work training or job placement program. Figure 22 summarizes key findings about respondents' perceptions of educational opportunities and job training and placement.

When asked about specific barriers to education and career advancement, inadequate funding was the most frequent response—as one respondent put it, *"cost is a huge problem"*—followed next by problems receiving accommodations, and negative attitudes or stereotypes about people with disabilities.

Obstacles related to transportation were another common factor. Several respondents drew attention to the fact that education per se was less of a problem then transitioning from education to work, whether due to insufficient job placement, transportation issues, or problems with accommodations and employer attitudes. These comments confirm findings from national studies, which show that employment for people with disabilities is lower, compared to individuals without disabilities at all educational levels. One respondent said, *"Education has not been a major barrier. Lack of experience has limited my ability to get a job and I interview poorly due to autism."* In sum, survey respondents communicate the same barriers to employment that the National Organization on Disability has identified as the most significant—these include, low expectations and discrimination on the part of employers, lack of training and support locating work, and inadequate transportation.

Figure 22. Respondents' Perceptions of Educational Opportunities & Job Placement



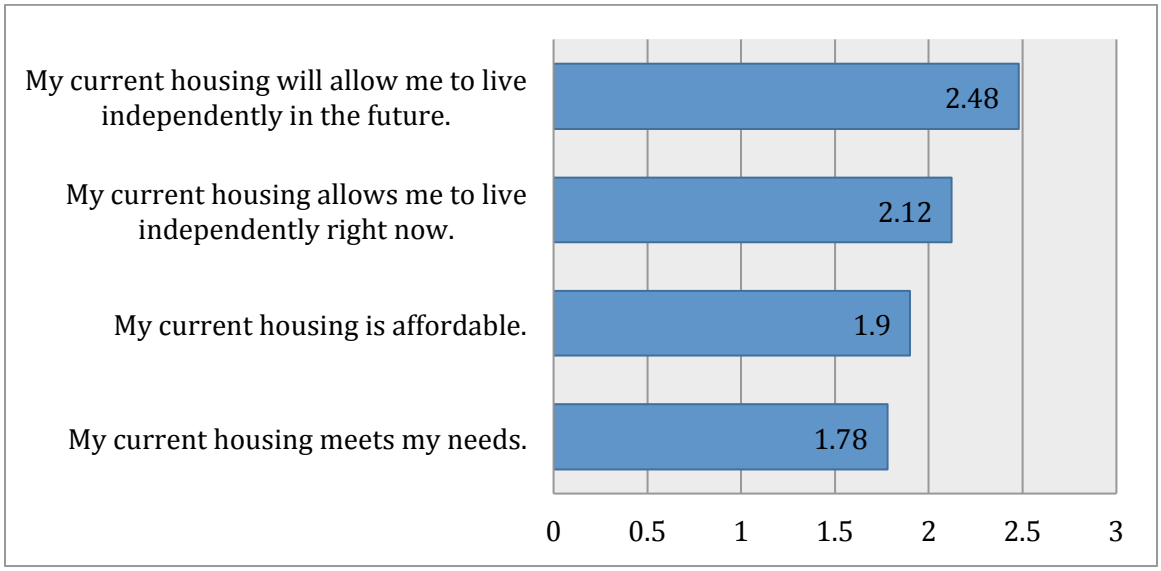
Housing & Housing Security

About one half of the survey sample lives in private housing that they own (or partially own); an additional 18% live in private rental housing, and 19% live with family rent free. The vast majority of survey respondents report living with others; only 28 individuals who completed the housing portion of the survey report living alone. Similarly, only 3% of survey respondents report residing in group living quarters or some kind of long-term housing. Given the low response rate, it is likely that respondents' perceptions underestimate the needs of people with disabilities living alone as well as those living in group-settings.

Majorities of respondents indicate that their current housing meets their needs (82%), is affordable (81%), allows them to live independently (71%), and will likely allow them to live independently in the future (51%) (See Appendix C for frequency data). These perceptions are summarized in Figure 23, which provide the mean score for all respondents on a scale of 1 (strongly agree to 4 strongly disagree). As seen, responses suggest that while respondents indicate strong agreement that their current housing meets their needs, they are less certain about whether their current housing will continue to allow them to live independently in the future.

Approximately 25% of survey respondents indicated that they currently have a need for home modifications in order to make their housing more accessible. The vast majority of these individuals mentioned physical accessibility accommodations such as ramps, countertops, bathroom modifications (such as modifications to showers, grab bars, etc.), and chair lifts to navigate stairs.

Figure 23. Respondents ' Perceptions of Housing Needs—Mean Scores



Note: Numbers close to 1 represent stronger agreement with the statement. Numbers closer to 4 represent stronger disagreement.

The survey included several questions designed to capture respondents' sense of personal security when it comes to housing related issues. In the 2008-2009 needs assessment significant percentages of respondents communicated concern about losing disability benefits, for example, losing health insurance, lacking long term housing plans, and worrying about having to move to a nursing home in the future. Findings from the current survey are summarized in Table 9.

In general, disability severity is linked to these concerns, such that the more severe a respondent's disability, the more likely he or she is to express worries about housing and housing security (Figure 24). Likewise, disability type is linked to housing issues; individuals with physical or mobility disabilities, for example, have different housing related needs than individuals with cognitive or sensory disabilities. Large majorities of respondents are very or extremely worried about loss of independence, being able to afford care or help as they age, and becoming a burden on families.

Figure 24. Respondents' Perceptions of Housing by Disability Severity

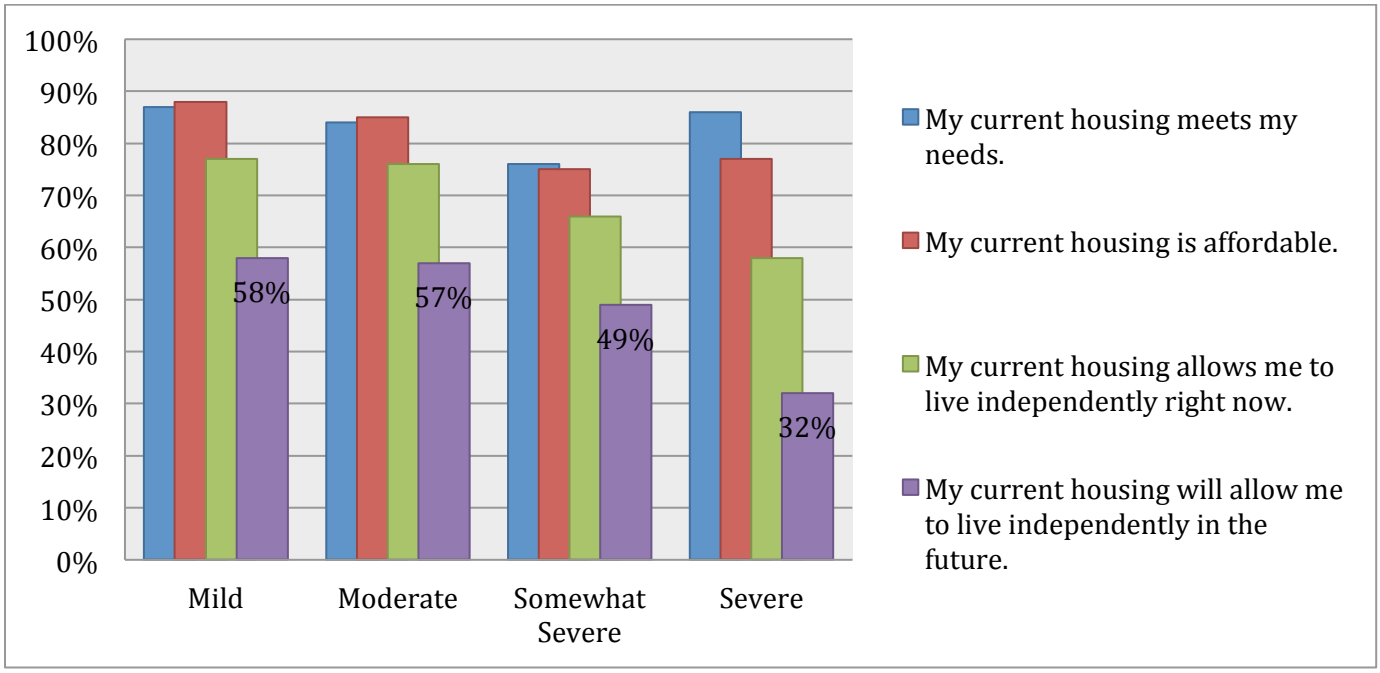


Table 9. Respondents' Concerns about Housing Security

Losing my independence and having to rely on others. (N= 201)		
	Extremely worried	**32% (64)**
	Very worried	23% (46)
	Somewhat worried	30% (61)
	Not at all worried	15% (30)
Losing my memory or other mental abilities. (N=201)		
	Extremely worried	18% (37)
	Very worried	18% (37)
	Somewhat worried	**34% (68)**
	Not at all worried	29% (59)
Being able to pay for care or help I might need as I grow older. (N=204)		
	Extremely worried	**37% (75)**
	Very worried	27% (55)
	Somewhat worried	25% (51)
	Not at all worried	11% (23)
Having to leave my home and move into a nursing home. (N=199)		
	Extremely worried	24% (47)
	Very worried	19% (38)
	Somewhat worried	27% (53)
	Not at all worried	**31% (61)**
Not having long-term housing plans. (N=196)		
	Extremely worried	**29% (56)**
	Very worried	14% (28)
	Somewhat worried	31% (61)
	Not at all worried	26% (51)
Being a burden on my family. (N=200)		
	Extremely worried	**37% (72)**
	Very worried	21% (41)
	Somewhat worried	28% (55)
	Not at all worried	16% (32)
Leaving debts to my family. (N=196)		
	Extremely worried	25% (49)
	Very worried	15% (30)
	Somewhat worried	23% (45)
	Not at all worried	**37% (72)**
Needing help with basic needs, like getting dressed, preparing meals, toileting, or bathing. (N=201)		
	Extremely worried	22% (45)
	Very worried	18% (37)
	Somewhat worried	**33% (67)**
	Not at all worried	26% (52)

As is the case in the area of transportation, quantitative survey findings in the area of housing are complex. While majorities of respondents communicate positive perceptions of their housing needs—this is the case in the current survey, the 2008-09 GSRN needs assessment and wider regional studies such as the LVCIL Personal Satisfaction Survey—there clearly are individuals within the disability population with significant housing needs related to affordability, safety, and accessibility. It seems that disability severity matters in this context and, clearly, income matters as well, although poor survey response on income questions makes it difficult to draw firm conclusions about the extent to which income is linked to long term housing security. National studies have shown that low-income people with disabilities, particularly those receiving SSI for example, pay upwards of 112% of their monthly income on housing costs, leaving few resources for additional living expenses, including food, clothing, transportation, and other costs associated with daily living.[22]

Survey respondents were asked to describe what they anticipate they will need in order to remain in their current home, living independently, in the future. Several noted income-related obstacles. One wrote, "*Social Security Disability is so minimal to continue to afford living alone—I am dreading group living—I was denied under 60 Waiver Services—I could use help.*" Many survey respondents similarly noted that the need for more affordable housing was critical and that the income requirements for HUD housing were so low as to make most ineligible for housing support. Barriers to meaningful employment only compound the problems of affordable housing for people with disabilities.

Others anticipate needing help with activities of daily living, as one respondent described, *"personal care for hygiene and showering, cooking, household chores, including laundry [and] cleaning, taking out garbage and recycling bins, shoveling snow."* Grocery shopping and managing instrumental activities of daily living were frequently mentioned. *"More supermarkets that deliver. Lower cost or subsidized home health aides to do light housework and chores [that] I cannot do."* Home maintenance and minor home repairs were frequently mentioned, home accommodations such as ramps, handrails and bathroom modifications loom large for many respondents, and some anticipate a need to move to single-floor or handicap accessible housing. A few respondents mentioned their dependence on family living situations, and expressed concern about their future circumstances; one respondent wrote, *"my current housing situation will change when my father passes away. [I] cannot afford the cost of the house."* Another noted that aging itself presents additional obstacles for people with disabilities, indicating *"I will require additional income or housing subsidies, or access to quality, affordable housing for elderly, disabled adults."*

Finally, it is worth nothing that several respondents drew connections to independent living and housing and transportation. That is to say, the extent to which one lives in their own home independently is often linked to transportation related obstacles that make it difficult or impossible to complete instrumental tasks of daily living, such as grocery shopping and making trips for medical appointments.

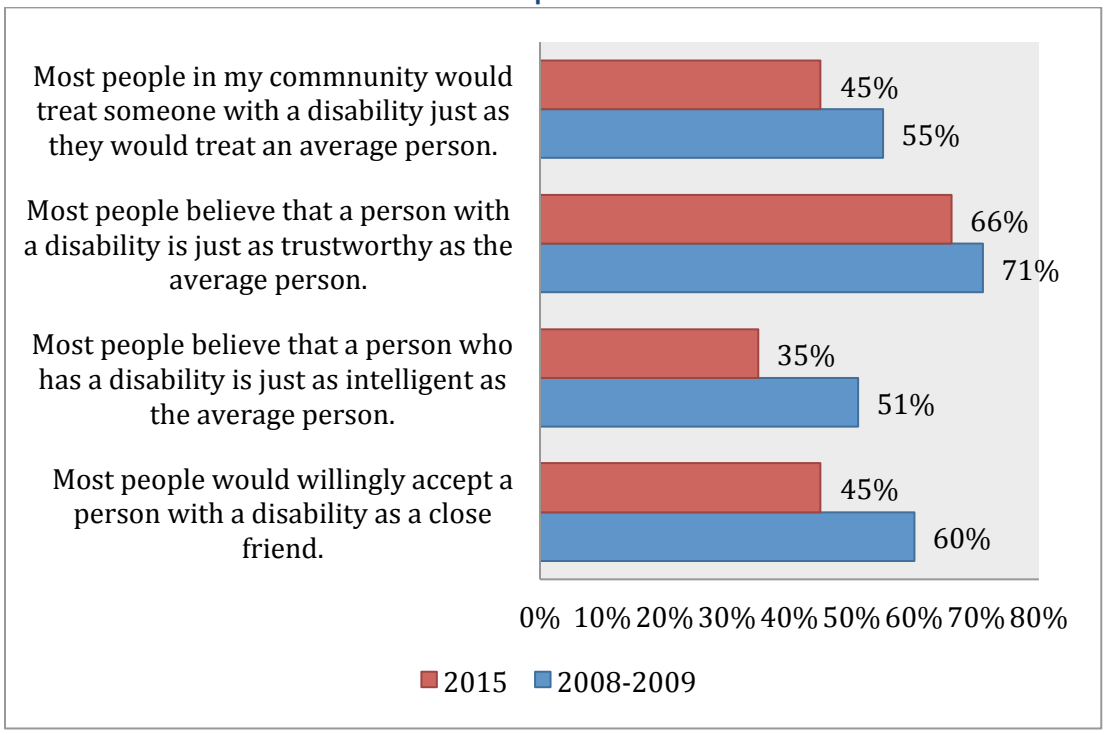
[22] See *Priced Out: The Housing Crisis for People with Disabilities*, Technical Assistance Collaborative, Inc., Consortium for Citizens with Disabilities, Housing Task Force. In the Allentown-Bethlehem-Easton region of PA, average SSI monthly payments in 2102 were $720; on average, payment for a single bedroom apartment equaled 101% of that payment.

Perceptions about Community & Inclusiveness

Negative attitudes toward people with disabilities are a major obstacle to physical health and emotional wellbeing for people with disabilities. In fact, the World Health Organization identifies stereotypes, stigma, prejudice and discrimination among the most significant barriers to inclusion and accessibility for people with disabilities worldwide. According to WHO, disability is too frequently viewed as a personal deficit or shortcoming, and as a result communities fail to recognize and share in the social responsibility that is necessary for people with disabilities to live full and independent lives. It is critical to understand what people with disabilities experience in this context.

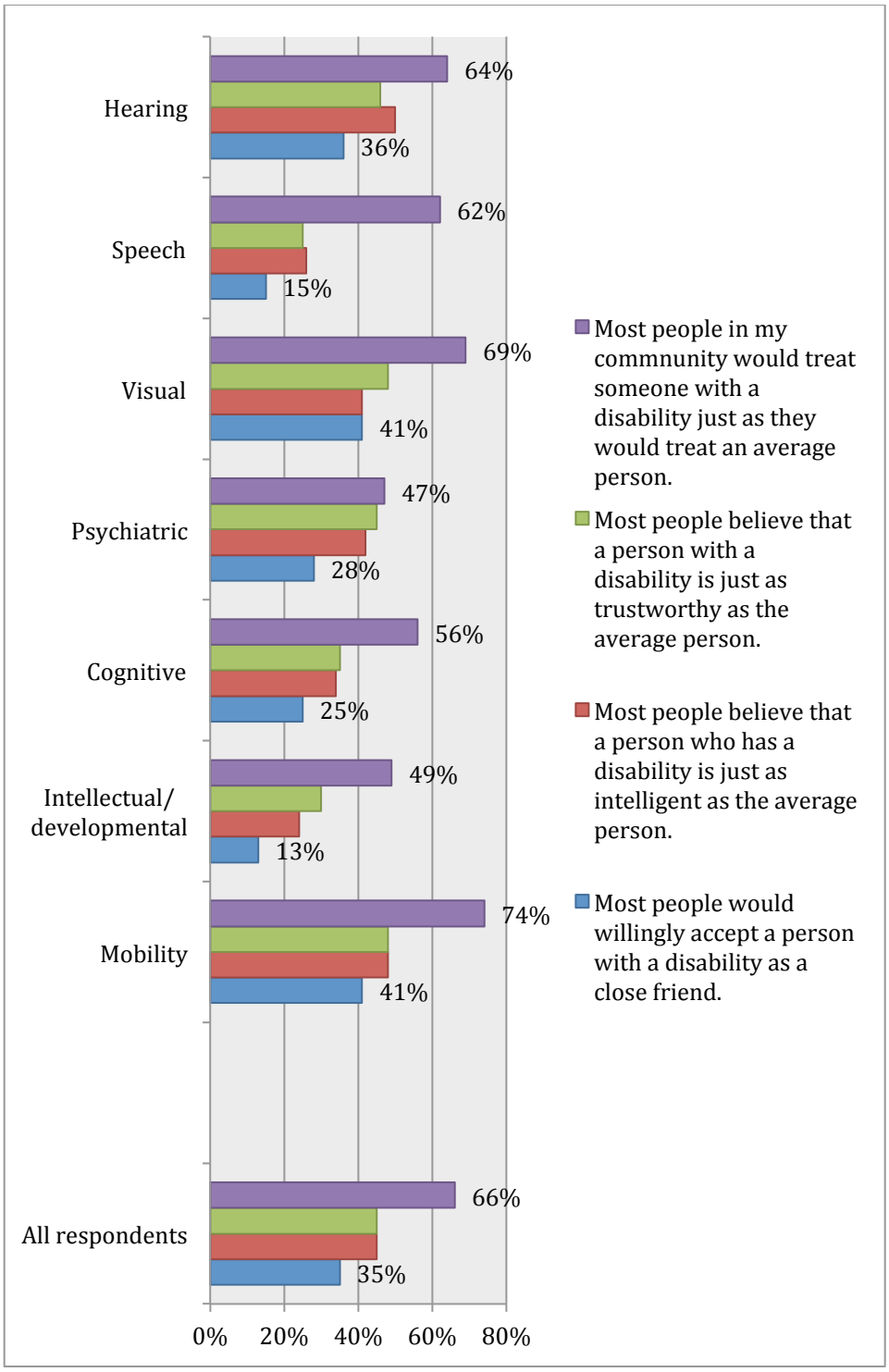
The survey asked a series of questions designed to gauge respondents' experiences in their communities and their perceptions of how welcoming their communities are to people with disabilities. These same questions were asked in the 2008-09 needs assessment survey and results are compared with the current survey in Figure 25. It is important to keep in mind that the 2008-09 survey and the 2015 survey have dramatically different respondent samples. It is difficult, therefore, to draw hard and fast conclusions about whether perceptions among people with disabilities are changing overtime. Nonetheless, Figure 25 raises questions about the extent to which the Lehigh Valley region has made progress in becoming more welcoming and accepting of people with disabilities. In each of the four categories about community inclusion and acceptance of people with disabilities, respondent attitudes were *more positive in 2008-2009 then they are reported in the 2015 survey*. At a minimum, the data summarized in Figure 25 point to a need for additional research and deeper community understanding about people with disabilities and the links between perceived acceptance of people with disabilities and actual health outcomes among the disability population.

Figure 25. Comparing 2008-09 and 2015 Respondents' Perceptions about Community Acceptance and Inclusion of People with Disabilities



Note: Percentages include respondents who strongly agree or agree with each statement.

Figure 26. Respondents' Perceptions of Community Acceptance of People with Disabilities by Disability Type



Note: Percentages include respondents who strong agree or agree with each statement.

Figure 26 provides further understanding about 2015 survey respondents' perceptions by considering the relationships between their perceptions and disability type. For example, people with physical disabilities indicate stronger agreement on all four measures of community inclusion than other disability types. Respondents with intellectual or developmental disabilities, in contrast, report lower levels of agreement. Respondents with cognitive disabilities and speech disabilities similarly report lower agreement, particularly when asked whether most people would accept a person with a disability as a close friend. While 41% of people with physical disabilities believe most people would accept a person with a disability as a close friend, only 14% of those with intellectual or developmental disabilities, and 15% of those with speech disabilities, say the same.

These findings are parallel to those reported in the 2008-09 study, which also found that individuals with speech disabilities and with particular kinds of intellectual disabilities had more negative views about community acceptance than individuals with other kinds of disabilities.

Parenting, Family & Children with Disabilities

Parenting intersects with opportunity, access, affordability, and inclusion for people with disabilities in myriad ways. The survey solicited perspectives from two sub-groups of parents: 1) individuals with disabilities who are parents raising children; and 2) parents of children with disabilities.

The National Council on Disability notes that supporting parents with disabilities and their families is essential to full implementation of the American with Disabilities Act and is a fundamental component of community integration. Personal assistant services that provide support for activities of daily living and instrumental activities of daily living, housing, transportation, public benefits and income assistance, adequate health care, and peer support—each of these is critical to helping parents with disabilities with parenting tasks. According to National Council on Disability, parents with disabilities often need special supports in pursuing and participating in recreational activities with their children, especially given transportation and mobility barriers that many face.

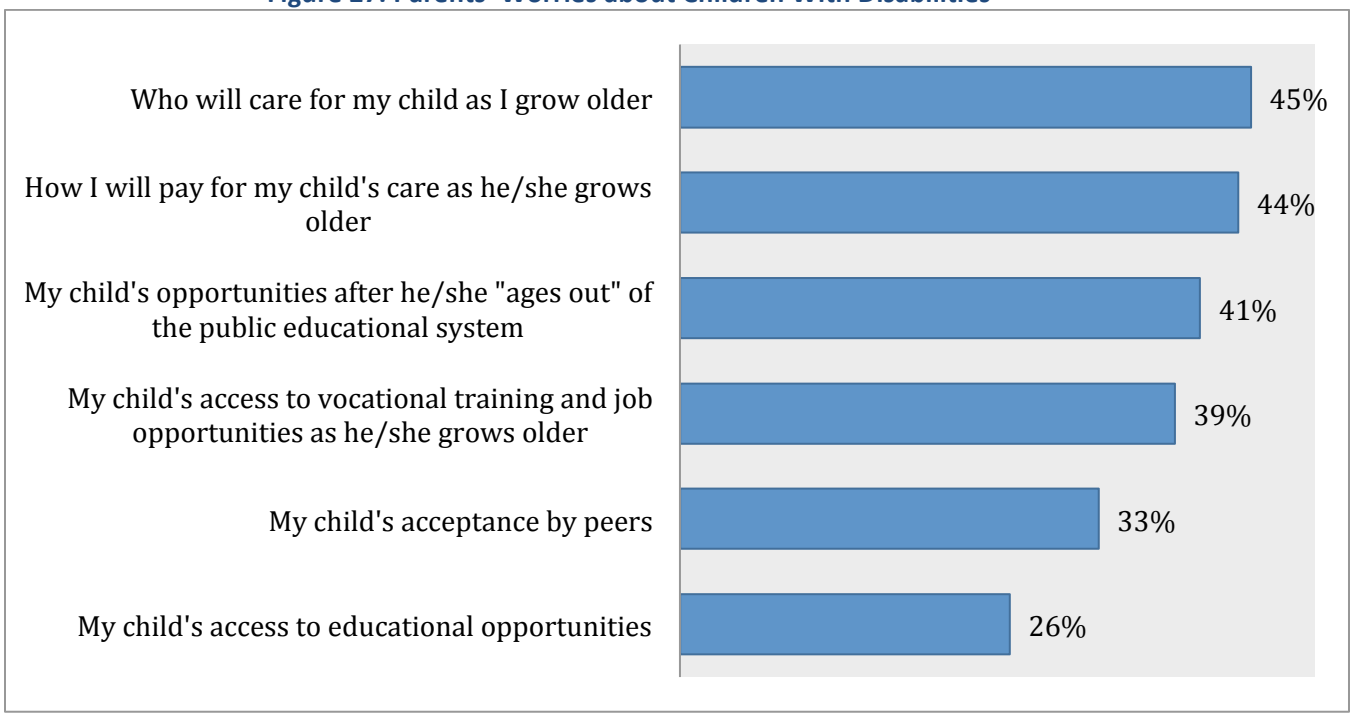
A few parents with disabilities who took the needs assessment survey shared their views on the particular kinds of support that would be of greatest benefit to them. Their comments echo key issues identified by the National Council on Disability. Several respondents, for instance, said they needed help completing activities of daily living such as cooking and cleaning. One simply wrote, *"household help."* Another noted that she needed *"transport and access to social interactions,"* with her children. Another parent expressed a need for peer support, writing, *"a parent support group or website of local information for parents."*

Several parents expressed concern that their own disabilities would increasingly become a burden on their children. One mother wrote, *"my concern is the responsibility [my daughter] feels for taking care of me and my husband, who is also disabled."*

The survey provides only limited information about the particular challenges parents with disabilities face raising children in our communities. It is clear that the demands of raising children and taking care of families are especially difficult for some parents with disabilities and that this is an area worth of future research. As one respondent wrote, *"being a single parent [it] is hard to function with physical disabilities and [to] try to keep up with raising your children."*

In addition to learning more about parents with disabilities, the survey included a subset of questions for parents of children with disabilities. About 116 individuals completed this portion of the survey, sharing concerns about their child's access to educational and work opportunities, acceptance by peers, and ongoing care. A summary of parents' greatest concerns is provided in Figure 27. As seen, parents' greatest worries concern continuing care for their children as they age, followed by concern about limited opportunities as their children transition to adulthood. Fewer parents of children with disabilities express concern about educational opportunities—this finding seems to confirm feedback gathered in the 2008-09 survey, which found generally (although not universally) high satisfaction with educational opportunities for children with disabilities in the Lehigh Valley region.

Figure 27. Parents' Worries about Children With Disabilities



Note: Percentages include respondents who are extremely worried or very worried about each statement.

Appendix A: US Census Bureau Questions Concerning Disability

The six questions used by the American Community Survey to identify individuals with disabilities are as follows:

1. *Hearing Difficulty/Disability:* Is this person deaf or does he/she have serious difficulty hearing?

2. *Vision Difficulty/Disability*: Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?

3. *Cognitive Disability*: Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions? *This question is only asked of persons ages 5 years and older.*

4. *Ambulatory Disability*: Does this person have seriously difficulty walking or climbing stairs? *This question is only asked of persons ages 5 years and older.*

5. *Self-Care Disability*: Does this person have difficulty dressing or bathing? *This question is only asked of persons ages 5 years and older.*

6. *Independent Living Difficulty/Disability:* Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping? *This question is only asked of persons ages 15 years and older.*

Appendix B. Detailed Census Data on Lehigh Valley Population with Disabilities

Table 10. Number of Persons with Disabilities by Age (2013)

	Lehigh County	Northampton County	Pennsylvania
Population with disabilities under 5 years of age			
With a Hearing Difficulty	152	76	3,551
With a Vision Difficulty	90	60	3,182
Population with disabilities between 5 and 17 years of age			
With a Hearing Difficulty	344	332	12,963
With a Vision Difficulty	737	334	16,160
With a Cognitive Difficulty	4,036	2,502	104,052
With an Ambulatory Difficulty	282	254	12,942
With a Self-Care Difficulty	473	460	20,674
Population with disabilities between 18 and 64 years of age			
With a Hearing Difficulty	4,425	3,471	159,543
With a Vision Difficulty	5,012	2,540	126,663
With a Cognitive Difficulty	11,584	7,695	372,185
With an Ambulatory Difficulty	11,077	8,472	412,308
With a Self-Care Difficulty	3,754	2,999	143,660
With an Independent Living Difficulty	7,094	5,677	302,847
Population with disabilities 65 years of age and over			
With a Hearing Difficulty	6,504	6,542	280,213
With a Vision Difficulty	3,452	2,741	116,690
With a Cognitive Difficulty	4,213	3,991	158,160
With an Ambulatory Difficulty	10,838	10,368	423,374
With a Self-Care Difficulty	3,604	3,533	145,372
With an Independent Living Difficulty	7,508	7,671	296,954

Source: US Census Bureau, American Community Survey, 2009-2013.

Table 11. Lehigh and Northampton County Residents with Multiple Disabilities, 2014

	Lehigh County, Pennsylvania		Northampton County, Pennsylvania	
	Estimate	Margin of Error	Estimate	Margin of Error
Total:	353,035	+/-1,360	297,398	+/-1,622
5 to 17 years:	60,088	+/-130	47,805	+/-413
With one type of disability	4,728	+/-1,358	1,409	+/-543
With two or more types of disability	1,164	+/-453	760	+/-440
No disability	54,196	+/-1,448	45,636	+/-854
18 to 34 years:	77,242	+/-812	63,820	+/-984
With one type of disability	5,640	+/-1,608	2,519	+/-947
With two or more types of disability	3,337	+/-948	1,330	+/-500
No disability	68,265	+/-1,899	59,971	+/-1,263
35 to 64 years:	139,902	+/-1,051	121,459	+/-951
With one type of disability	10,164	+/-1,447	7,969	+/-1,302
With two or more types of disability	8,240	+/-1,568	5,540	+/-1,090
No disability	121,498	+/-2,165	107,950	+/-2,119
65 to 74 years:	30,071	+/-762	27,058	+/-666
With one type of disability	4,159	+/-835	3,554	+/-721
With two or more types of disability	2,571	+/-618	2,718	+/-791
No disability	23,341	+/-1,116	20,786	+/-1,084
75 years and over:	24,529	+/-1,098	22,787	+/-747
With one type of disability	4,249	+/-785	5,060	+/-910
With two or more types of disability	6,691	+/-1,051	6,683	+/-1,177
No disability	13,589	+/-1,327	11,044	+/-1,136

Source: US Census Bureau, American Community Survey, 2014.

Table 12. Yearly Earnings for People With Disabilities & People Without Disabilities (2013)

EARNINGS IN PAST 12 MONTHS (IN 2013 INFLATION ADJUSTED DOLLARS)		**Lehigh County**	**Northampton County**	**Pennsylvania**
$1 to $4,999 or loss	With a Disability	20.60%	18.50%	19.50%
	No Disability	11.50%	13.10%	11.80%
$5,000 to $14,999	With a Disability	21.20%	23.00%	22.80%
	No Disability	15.50%	13.90%	15.00%
$15,000 to $24,999	With a Disability	17.80%	16.10%	15.50%
	No Disability	13.20%	12.50%	13.50%
$25,000 to $34,999	With a Disability	11.70%	13.30%	12.70%
	No Disability	14.00%	13.10%	13.80%
$35,000 to $49,999	With a Disability	11.60%	11.90%	12.20%
	No Disability	15.60%	16.40%	15.90%
$50,000 to $74,999	With a Disability	10.50%	10.80%	10.40%
	No Disability	15.80%	16.00%	15.80%
$75,000 or more	With a Disability	6.60%	6.50%	6.90%
	No Disability	14.40%	15.10%	14.10%

Source: US Census Bureau, American Community Survey, 2009-2013.

Table 13. Ratio of Income to Poverty Status (2013)

RATIO OF INCOME TO POVERTY LEVEL	DISABILITY STATUS	Lehigh County	Northampton County	Pennsylvania
Under .50	With Disability	11.43%	5.31%	7.52%
	No Disability	5.84%	4.07%	5.62%
.50 to .99	With Disability	12.65%	11.73%	14.49%
	No Disability	6.29%	4.57%	6.35%
1.00 to 1.49	With Disability	13.81%	11.06%	14.26%
	No Disability	8.36%	5.70%	7.50%
1.50 to 1.99	With Disability	11.64%	13.14%	12.17%
	No Disability	8.04%	8.20%	8.29%
2.00 & Over	With Disability	50.46%	58.76%	51.56%
	No Disability	71.47%	77.46%	72.24%

Source: US Census Bureau, American Community Survey, 2009-2013.

Table 14. Age By Health Insurance Coverage Status Within Lehigh & Northampton Counties And Pennsylvania (2013)

		Lehigh County	Northampton County	Pennsylvania
UNDER 18 YEARS OF AGE	WITH H. I.	98.08%	97.47%	97.07%
	PRIVATE H. I.	36.07%	53.95%	43.20%
	PUBLIC H. C.	76.93%	65.26%	72.05%
	NO H. I.	1.92%	2.53%	2.93%
18 to 64 YEARS OF AGE	WITH H. I.	85.45%	88.12%	88.53%
	PRIVATE H. I.	44.65%	53.92%	46.29%
	PUBLIC H. C.	52.77%	49.79%	55.85%
	NO H. I.	14.50%	11.88%	11.47%
65 YEARS & OVER	WITH H. I.	99.02%	99.85%	99.57%
	PRIVATE H. I.	66.30%	73.31%	68.34%
	PUBLIC H. C.	97.53%	99.29%	98.60%
	NO H. I.	0.98%	0.15%	0.43%

Source: US Census Bureau, American Community Survey, 2009-2013.

Appendix C. Survey Questions & Frequencies*

1. Which of the following best describes you? (N=317)	
I am an adult (18 years of age or older) with a disability	**48% (153)**
I am a family member or caregiver of an adult with a disability completing this survey on his/her behalf.	26% (82)
I am a parent, family member, or caregiver of a child (under the age of 18) with a disability completing this survey on his/her behalf.	26% (82)
2. Are you (or is the person you care for) limited in any activities because of physical, mental, or emotional problems? (N=317)	
Yes	**92% (291)**
No	8% (26)
3. Do you (or does the person you care for) have any health problem that requires the use of special equipment, such as a cane, wheelchair, braces, oxygen, communication device, special bed, or special telephone? (N=319)	
Yes	**62% (198)**
No	38% (121)
4. Which of the following best describes your disability (or the disability of the person you care for)? Check as many as apply.	
Mobility or motor difficulty (e.g., physical impairment that limits ability to carry out daily activities like walking, moving objects, dressing, feeding, toileting, etc.)	**56% (176)**
Intellectual or developmental disability (e.g., difficulty with reasoning, thinking, learning, problem solving or adaptive behaviors like communicating, socializing or self care, that began prior to age 18; examples include cerebral palsy, epilepsy, Down syndrome, autism, brain injury, spina bifida)	40% (127)
Cognitive disability (e.g., difficulty with mental tasks, memory, problem-solving, attention sometimes resulting from brain injury, stroke, dementia, injury or accident	28% (89)
Psychiatric disability or mental health disorder (anxiety disorder, schizophrenia disorder, mood disorder, substance abuse disorder that interferes with performance of majority life activities)	19% (60)
Visual disability (e.g., blindness, vision impairment that cannot be corrected with glasses, color blindness)	15% (49)
Speech or oral-motor disability (e.g., difficulty speaking so that others can understand you, stuttering or articulating difficulties)	28% (87)
Hearing disability (e.g., deafness or severe hearing impairment)	8% (25)

* Percentages may not equal 100% due to rounding. Open-ended questions are omitted from these survey frequencies, but results are summarized in this report.

Other[23]		9% (29)
5. Because of disability do you (or does the person you care for) have trouble with any of the following? Check as many as apply.		
Walking, climbing stairs, reaching, lifting or carrying?		**59% (188)**
Learning, remembering or concentrating?		52% (166)
Dressing, bathing, or getting around inside the home?		37% (117)
Going outside the home alone to shop or go to a doctor's office?		56% (180)
Working at a job or business?		56% (177)
Eating, swallowing, or feeding independently?		16% (51)
Being able to relate to other people or to sustain relationships?		40% (128)
6. How would you describe your disability? (N=312)		
	Mild	13% (41)
	Moderate	**40% (126)**
	Somewhat Severe	34% (108)
	Very Severe	12% (37)
7. Were you born with your disability? (N=315)		
	Yes	44% (137)
	No	**57% (178)**
8. In your opinion, over the past 5 years, how has life in the Lehigh Valley changed for people with disabilities? (N=29)		
	Gotten Better	26% (77)
	Gotten Worse	14% (42)
	Stayed the Same	**60% (180)**
9. Over the past 5 years, how has your own life changed? (N=305)		
	Gotten Better	24% (72)
	Gotten Worse	**48% (146)**

[23] Respondents who selected "other" were prompted to specify their disability type. Seven of these individuals indicated their disability type to be defined by breathing and/or respiratory problems (such as chronic COPD); two individuals specified they have Multiple Sclerosis; three mentioned sensory processing problems. Other individuals described symptoms, such as migraines, tiredness, and vertigo.

	Stayed the Same	29%% (87)
10. How would you rate your overall health (or the overall health of the person you care for)? (N=304)		
	Excellent	12% (35)
	Good	**49% (148)**
	Fair	33% (100)
	Poor	7% (21)
11. In general, how satisfied are you with the quality of health care you receive? (N=302)		
	Very Satisfied	26% (76)
	Satisfied	**56% (169)**
	Dissatisfied	15% (46)
	Very Dissatisfied	4% (11)
12. In general, how satisfied are you with your knowledge and awareness about the health services and resources that are available to you? (N=301)		
	Very Satisfied	19% (56)
	Satisfied	**47% (143)**
	Dissatisfied	31% (93)
	Very Dissatisfied	3% (9)
13. In the past year, have you had two or more weeks during which you felt sad, blue or depressed, or you lost interest or pleasure in the things you usually care about? (N=302)		
	Yes	**51% (155)**
	No	49% (147)
14. Overall, how often do you feel lonely or isolated from those around you? (N=303)		
	Always	11% (34)
	Sometimes	**55% (167)**
	Rarely	19% (58)
	Never	15% (44)
15.What kind of health insurance do you (or does the person you care for) have? Please check as many as apply.		
Employment based insurance that you get through work (or through a family		**43% (137)**

members' work)	
Direct pay insurance that you pay for as an individual (not through employment)	7% (23)
Veterans' Administration Insurance or Military Health Care (includes Tricare and Champva)	3% (8)
Medicare (a government plan for people age 65 and older and some young people with disabilities)	38% (120)
"Medi-Gap" Insurance, or another supplemental policy for Medicare	10% (31)
Medicaid, Medical Assistance, or another state plan for health care for low income people	41% (130)
Don't Know	1% (2)
No Insurance/Uninsured	1% (2)
Some Other Kind of Insurance	5% (15)
16. Was there a time in the past year when you (or the person you care for) needed medical care or health services but did not get it? (N=299)	
Yes	27% (87)
No	**67% (212)**
17. What was the primary reason that you did not get needed medical care or health services in the past year?	
I couldn't get an appointment.	6% (18)
I couldn't find a doctor or provider who speaks my language.	<1% (1)
I didn't know a good doctor or clinic to go to.	4% (13)
It costs too much.	9% (28)
The medical care or health services I need are not covered by my insurance.	**13% (40)**
It's too difficult to get transportation to the doctor's office.	3% (10)
I couldn't find a doctor's office that is accessible.	2% (5)
There's too much paperwork involved.	1% (3)
I was nervous or afraid.	2% (7)
I couldn't find a doctor who understands my condition and is willing to treat it.	6% (19)
Other	8% (24)
18.Do you (or does the person you care for) ever require personal assistance, or get help from someone for basic needs such as getting dressed, preparing meals, or bathing? (N=298)	
Yes	**55% (165)**
No	45% (133)

19. Who generally provides care and assistance with basic needs? (N=164)		
	Family members	71% (116)
	Friends	4% (6)
	Home health aid	7% (12)
	Another person paid to provide this help	6% (9)
	Other	13% (21)
20. Has there been a time in the past 6 months when you (or the person you care for) have needed help from someone for basic needs such as getting dressed, preparing meals, or bathing, but have not been able to get it? (N=162)		
	Yes	23% (37)
	No	**77% (125)**

21. For the following, please indicate your level of satisfaction with access to, the affordability of, and the quality of each item. 1 = Very Satisfied; 5 = Very Dissatisfied			
Care Management Services	Access (N=239) Mean 2.83	Affordability (N=230) Mean 2.85	Quality (N=229) Mean 2.75
1 Very Satisfied	13% (31)	14% (31)	14% (30)
2	16% (38)	11% (25)	16% (36)
3	**24% (57)**	**24% (54)**	**25% (58)**
4	16% (38)	10% (22)	12% (28)
5 Very Dissatisfied	7% (16)	9% (21)	6% (13)
NA	*25% (59)*	*33% (77)*	*28% (64)*
Medical Treatment & Health Care	Access (N=251) Mean 2.25	Affordability (N=243) Mean 2.61	Quality (N=243) Mean 2.17
1 Very Satisfied	**33% (82)**	23% (55)	**34% (83)**
2	31% (77)	23% (55)	30% (73)
3	20% (50)	**31% (74)**	22% (54)
4	10% (24)	9% (22)	9% (21)
5 Very Dissatisfied	6% (15)	11% (26)	4% (9)
NA	*1% (3)*	*5% (11)*	*1% (3)*

Dental Services or Dental Care		Access (N=250) Mean 2.49	Affordability (N=243) Mean 3.16	Quality (N=241) Mean 2.27
	1 Very Satisfied	**31% (77)**	17% (40)	**34% (82)**
	2	22% (54)	12% (28)	21% (50)
	3	18% (44)	**25% (61)**	17% (41)
	4	7% (17)	10% (24)	6% (14)
	5 Very Dissatisfied	15% (37)	24% (59)	10% (23)
	NA	*8% (21)*	*13% (31)*	*13% (31)*
Preventative Health Services (e.g., cancer screenings, pap smears, mammograms, blood pressure screening, nutrition counseling, immunizations)		Access (N=246) Mean 2.06	Affordability (N=241) Mean 2.34	Quality (N=236) Mean 2.04
	1 Very Satisfied	**34% (84)**	25% (60)	**33% (78)**
	2	29% (71)	**26% (62)**	28% (67)
	3	17% (41)	22% (53)	17% (39)
	4	5% (13)	7% (16)	6% (15)
	5 Very Dissatisfied	4% (10)	6% (15)	3% (6)
	NA	*12% (29)*	*14% (35)*	*14% (31)*
Mental Health Services		Access (N=241) Mean. 3.07	Affordability (N=227) Mean 3.02	Quality (N=228) Mean 2.81
	1 Very Satisfied	11% (27)	10% (23)	13% (29)
	2	9% (22)	10% (22)	11% (25)
	3	**15% (36)**	14% (32)	**15% (34)**
	4	8% (19)	8% (19)	8% (19)
	5 Very Dissatisfied	14% (33)	**12% (26)**	9% (20)
	NA	*43% (104)*	*46% (105)*	*44% (101)*
Sexuality and Reproductive Services		Access (N=232) Mean 2.48	Affordability (N=218) Mean 2.50	Quality (N=220) Mean 2.37
	1 Very Satisfied	**10% (24)**	9% (20)	9% (20)
	2	9% (20)	**10%(22)**	**11% (25)**
	3	7% (15)	7% (15)	9% (19)

4	6% (13)	4% (9)	2% (4)
5 Very Dissatisfied	3% (7)	4% (8)	3% (7)
NA	*66% (153)*	*66% (144)*	*66% (145)*
Technology Services (such as assistive speech devices, voice activated technology, power wheelchair)	Access (N=230) Mean 2.82	Affordability (N=218) Mean 3.20	Quality (N=219) Mean 2.64
1 Very Satisfied	11% (24)	8% (18)	11% (24)
2	13% (30)	8% (18)	**16% (35)**
3	**15% (34)**	14% (31)	15% (32)
4	5% (12)	8% (17)	5% (11)
5 Very Dissatisfied	10% (22)	**14% (30)**	7% (15)
NA	*47% (108)*	*48% (104)*	*47% (102)*
Spiritual Care and Support	Access (N=237) Mean 2.55	Affordability (N=222) Mean 2.24	Quality (N=222) Mean 2.39
1 Very Satisfied	**15% (36)**	**18% (39)**	**16% (36)**
2	11% (27)	9% (21)	10% (22)
3	14% (33)	11% (24)	14% (30)
4	3% (6)	3% (6)	3% (7)
5 Very Dissatisfied	8% (19)	4% (9)	5% (11)
NA	*49% (116)*	*55% (123)*	*53% (116)*
Health Insurance	Access (N= 241) Mean 2.34	Affordability (N=233) Mean 2.83	Quality (N=230) Mean 2.48
1 Very Satisfied	**32% (78)**	**25% (59)**	**29% (66)**
2	28% (68)	16% (37)	26% (60)
3	17% (40)	20% (47)	20% (46)
4	8% (18)	16% (36)	12% (28)
5 Very Dissatisfied	11% (27)	18% (41)	10% (24)
NA	*4% (10)*	*6% (13)*	*3% (6)*
Prescription Drugs	Access (N=242) Mean 2.02	Affordability (N=236) Mean 2.55	Quality (N=233) Mean 2.01
1 Very Satisfied	**41% (98)**	**29% (68)**	**41% (95)**

2	25% (61)	19% (44)	26% (61)
3	18% (44)	22% (52)	14% (33)
4	5% (11)	6% (13)	6% (13)
5 Very Dissatisfied	5% (12)	15% (36)	6% (13)
NA	*7% (16)*	*10% (23)*	*8% (18)*
Long Term Support Services (LTSS) (e.g., non-medical services that help you accomplish daily tasks, like managing a home, fixing meals, taking a bath, or supporting your employment)	Access (N= 239) Mean 3.20	Affordability (N=222) Mean 3.11	Quality (N=224) Mean 3.22
1 Very Satisfied	9% (22)	8% (18)	8% (18)
2	8% (19)	6% (14)	6% (14)
3	10% (24)	13% (28)	11% (24)
4	8% (18)	6% 913)	7% (16)
5 Very Dissatisfied	**14% (34)**	**11% (24)**	**13% (28)**
NA	*51% (122)*	*56% (125)*	*55% (124)*

Individuals with disabilities at times find that health professionals may not view them as sexually active or interested, or having reproductive or intimacy concerns or needs. Please indicate your level of agreement with each of the following statements.

22. My health care provider never discusses reproductive or intimacy concerns with me. (N=222)	
Strongly Agree	**36% (79)**
Agree	31% (68)
Disagree	22% (49)
Strongly Disagree	12% (26)
23. My health care provider seems uncomfortable discussing reproductive or intimacy concerns with me. (N=203)	
Strongly Agree	13% (27)
Agree	24% (48)
Disagree	**43% (87**)
Strongly Disagree	20% (41)
24. My health care provider offers me only minimal information about reproductive and intimacy concerns. (N=201)	
Strongly Agree	21% (42)

	Agree	**35% (71)**
	Disagree	29% (58)
	Strongly Disagree	15% (30)
25. My health care provider is very helpful in offering specific information about reproductive and intimacy concerns. (N=199)		
	Strongly Agree	14% (28)
	Agree	32% (63)
	Disagree	**33% (66)**
	Strongly Disagree	21% (42)
26. My health care provider is helpful in offering referrals for additional information about reproductive and intimacy concerns. (N=203)		
	Strongly Agree	12% (25)
	Agree	**36% (72)**
	Disagree	31% (63)
	Strongly Disagree	21% (43)
27. Please indicate your own level of interest in sexuality, reproductive, and intimacy concerns for people with disabilities. Select as many as apply.		
This is not an issue for me.		**47% (150)**
This is an area of interest for me, but I have a hard time bringing it up with my health care provider.		8% (26)
This is an area of interest for me, but I'm not sure who to talk to about it.		12% (39)
I have received some information about these issues, but it has not been adequate.		7% (21)
I have received information about these issues, and it has been helpful in addressing my needs and concerns.		6% (20)
28. Often, people with disabilities benefit from rehabilitative therapies to improve health, function, and independence. For each of the following, please indicate if you have received in the past, are current receiving, or have a need for these therapies now.[24]		
Inpatient rehabilitation (e.g., hospitalization focused on intensive rehabilitation or acute care) (N=243)		
	Received this therapy in the past	**33% (79)**
	Currently receiving this therapy	3% (8)
	Need this therapy now but not currently receiving it	1% (3)
	N/A	*63% (153)*

[24] Individuals were asked to name the service provider(s) for any rehabilitative services they have received in the past or are receiving now. Ninety-one respondents, or 60% of 152 respondents (N=152) who answered this question, indicated that they have received rehabilitation services from Good Shepherd Rehabilitation Network (in some cases, in combination with rehabilitative services from another provider). Forty percent, or 61 individuals among thee 152 who answered this question named rehabilitative service providers other than GSRN.

Physical therapy (aimed at improving mobility, strength, coordination) (N=249)	
Received this therapy in the past	**48% (119)**
Currently receiving this therapy	19% (47)
Need this therapy now but not currently receiving it	12% (31)
N/A	*21% (52)*
Orthopedic rehabilitation (for musculoskeletal injury) (N=232)	
Received this therapy in the past	**27% (63)**
Currently receiving this therapy	6% (14)
Need this therapy now but not currently receiving it	9% (20)
N/A	*58% (135)*
Neuro-rehabilitation (aimed at treating neurological diseases and conditions to improve movement patterns, strength, flexibility, functional ability, balance, and tone) (N=245)	
Received this therapy in the past	**24% (58)**
Currently receiving this therapy	8% (20)
Need this therapy now but not currently receiving it	20% (49)
N/A	*48% (118)*
Occupational therapy (focused on activities of daily living, including basic self care, fine motor skills (N=242)	
Received this therapy in the past	**35% (85)**
Currently receiving this therapy	18% (43)
Need this therapy now but not currently receiving it	12% (29)
N/A	*35% (85)*
Speech language or communication therapy (focused on swallowing, memory, problem solving, speech and language difficulties) (N=243)	
Received this therapy in the past	**24% (57)**
Currently receiving this therapy	19% (47)
Need this therapy now but not currently receiving it	12% (30)
N/A	*45% (109)*
Vision therapy (N=235)	
Received this therapy in the past	**9% (20)**
Currently receiving this therapy	6% (14)
Need this therapy now but not currently receiving it	**9% (20)**
N/A	*77% (181)*
Pediatric rehabilitation (N=230)	
Received this therapy in the past	**9% (20)**
Currently receiving this therapy	6% (13)

Need this therapy now but not currently receiving it	3% (6)
N/A	*83% (191)*
Cardiac or pulmonary rehabilitation (N=236)	
Received this therapy in the past	**6% (15)**
Currently receiving this therapy	3% (7)
Need this therapy now but not currently receiving it	5% (11)
N/A	*86% (203)*
Vocational rehabilitation (to overcome barriers to employment) (N=237)	
Received this therapy in the past	13% (31)
Currently receiving this therapy	7% (16)
Need this therapy now but not currently receiving it	**16% (37)**
N/A	*65% (153)*

29. For the following, please indicate your level of satisfaction with access to, the affordability of, and the quality of each item. 1 = Very Satisfied; 5 = Very Dissatisfied			
Inpatient rehabilitation	Access (N=219) Mean 2.06	Affordability (N=202) Mean 2.51	Quality (N=206) Mean 2.05
1 Very Satisfied	**19% (42)**	**15% (30)**	**20% (41)**
2	9% (20)	5% (11)	7% (14)
3	10% (22)	11% (22)	10% (21)
4	4% (7)	6% (13)	3% (7)
5 Very Dissatisfied	2% (4)	5% (9)	2% (4)
NA	*57% (124)*	*58% (118)*	*58% (119)*
Physical therapy	Access (N=227) Mean 2.13	Affordability (N=209) Mean 2.56	Quality (N=210) Mean 1.92
1 Very Satisfied	**35% (80)**	**23% (49)**	**42% (89)**
2	20% (45)	17% (35)	15% (32)
3	13% (30)	19% (40)	12% (25)
4	6% (14)	11% (22)	8% (16)
5 Very Dissatisfied	7% (15)	9% (19)	3% (6)
NA	*19% (43)*	*21% (44)*	*20% (42)*
Orthopedic rehabilitation	Access	Affordability	Quality

		(N=209) Mean 2.22	(N=192) Mean 2.49	(N=201) Mean 2.02
	1 Very Satisfied	**19% (39)**	**16% (30)**	**23% (47)**
	2	12% (24)	9% (17)	8% (15)
	3	8% (17)	12% (23)	10% (19)
	4	4% (8)	5% (9)	3% (6)
	5 Very Dissatisfied	4% (9)	6% (11)	3% (6)
	NA	*54% (112)*	*53% (102)*	*54% (108)*
Neuro- rehabilitation		Access (N= 210) Mean 2.64	Affordability (N=191) Mean 2.80	Quality (N=199) Mean 2.38
	1 Very Satisfied	**12% (26)**	**11% (20)**	**14% (28)**
	2	7% (14)	5% (10)	7% (13)
	3	9% (18)	**11% (20)**	6% (12)
	4	7% (14)	7% (13)	6% (11)
	5 Very Dissatisfied	5% (11)	6% (11)	4% (7)
	NA	*61% (127)*	*61% (117)*	*64% (128)*
Occupational therapy		Access (N=221) Mean 2.23	Affordability (N=204) Mean 2.41	Quality (N=211) Mean 2.18
	1 Very Satisfied	**26% (58)**	**23% (46)**	**25% (52)**
	2	15% (32)	11% (22)	16% (33)
	3	12% (26)	16% (31)	12% (25)
	4	9% (19)	8% (17)	9% (18)
	5 Very Dissatisfied	4% (9)	5% (11)	2% (5)
	NA	*35% (77)*	*38% (77)*	*37% (78)*
Speech language and communication therapy		Access (N=217) Mean 2.34	Affordability (N=202) Mean 2.39	Quality (N=208) Mean 2.12
	1 Very Satisfied	**22% (48)**	**19% (39)**	**23% (49)**
	2	11% (23)	7% (14)	12% (25)
	3	8% (18)	14% (27)	8% (16)
	4	7% (14)	7% (14)	5% (11)
	5 Very Dissatisfied	7% (14)	4% (8)	4% (8)
	NA	*46% (100)*	*50% (100)*	*48% (99)*

Vision Therapy		Access (N=206) Mean 3.02	Affordability (N=189) Mean 2.92	Quality (N=197) Mean 2.66
	1 Very Satisfied	4% (9)	5% (9)	**6% (11)**
	2	4% (9)	3% (5)	4% (8)
	3	5% (11)	**6% (12)**	4% (8)
	4	2% (4)	3% (6)	3% (3)
	5 Very Dissatisfied	**6% (12)**	4% (7)	3% (6)
	NA	*78% (161)*	*79% (150)*	*81% (159)*
Pediatric rehabilitation		Access (N=204) Mean 2.25	Affordability (N=188) Mean 2.54	Quality (N=200) Mean 2.07
	1 Very Satisfied	**6% (13)**	**6% (11)**	**8% (16)**
	2	3%(5)	2% (3)	2% (4)
	3	2% (4)	4% (7)	3% (6)
	4	1% (2)	1% (2)	0% (0)
	5 Very Dissatisfied	2 % (4)	3% (5)	2% (4)
	NA	*86% (176)*	*85% (160)*	*85% (170)*
Cardiac or pulmonary rehabilitation		Access (N=203) Mean 2.55	Affordability (N=188) Mean 2.74	Quality (N=197) Mean 2.55
	1 Very Satisfied	**4% (9)**	1% (2)	5% (9)
	2	4% (8)	5% (10)	2% (4)
	3	**3% (6)**	**6% (11)**	**5% (10)**
	4	2% (4)	1% (1)	2% (3)
	5 Very Dissatisfied	2% (4)	2% (3)	2% (3)
	NA	*85% (172)*	*86% (161)*	*85% (168)*
Vocational rehabilitation		Access (N=210) Mean 3.25	Affordability (N=197) Mean 2.79	Quality (N=207) Mean 3.33
	1 Very Satisfied	4% (9)	**12% (23)**	4% (8)
	2	**8% (17)**	3% (6)	6% (12)
	3	7% (14)	7% (13)	7% (15)
	4	5% (11)	5% (10)	7% (14)

	5 Very Dissatisfied	10% (21)	7% (14)	**9% (18)**
	NA	*66% (138)*	*67% (131)*	*68% (140)*

Please indicate your level of agreement with each of the following statements about rehabilitative therapies.		
30. I have sufficient access to rehabilitative therapies. (N=225)		
	Strongly Agree	26% (58)
	Agree	**36% (81)**
	Disagree	19% (42)
	Strongly Disagree	9% (21)
	NA	*10% (23)*
31. I have sufficient knowledge about rehabilitative medical care. (N=223)		
	Strongly Agree	25% (56)
	Agree	**33% (74)**
	Disagree	23% (51)
	Strongly Disagree	8% (17)
	NA	11% (25)
32. Rehabilitative therapies have helped me achieve my goals for independence, health, and wellbeing. (N=225)		
	Strongly Agree	27% (60)
	Agree	**29% (65)**
	Disagree	18% (41)
	Strongly Disagree	7% (16)
	NA	19% (43)
33. What kind of transportation do you use most frequently when getting around? (N=237)		
I usually drive myself		35% (83)
A friend or relative usually drives me		**46% (109)**
I usually use public transportation		1% (3)
I usually use specialized transport for persons with disabilities (such as Easton Coach)		8% (18)
Other		10% (24)
34. How often do you need transportation but are unable to get it? (N=230)		
Daily		8% (18)
About once a week		7 % (16)
Several times per month		18% (41)
Never		**67% (155)**

35. Is transportation a major problem, minor problem, or not a problem for you? (N=226)		
	Major problem	18% (41)
	Minor problem	24% (54)
	Not a problem	**58% (131)**
36. Is accessible parking a major problem, minor problem, or not a problem for you? (N=230)		
	Major problem	14% (32)
	Minor problem	27% (63)
	Not a problem	**59% (135)**
37. What is your current employment status? (N=237)		
	Working full time	11% (25)
	Working part time	9% (22)
	Retired and not working	22% (51)
	Unemployed	18% (42)
	Full time student	13% (30)
	Full time stay at home spouse or partner	4% (9)
	Other	**25% (58)**
*38. Do you feel that your work requires you to use… (*N=55; individuals who indicated in question 37 that they were working were prompted to answer this question)		
	My full talent and abilities	**49% (27)**
	Some of my talents and abilities	28% (15)
	Only a small amount of my talents and abilities	18% (10)
	Practically none of my talents and abilities	6% (3)
39. Are you… (N=53; individuals who indicated in question 37 that they were unemployed were prompted to answer this question)		
	Unemployed and looking for work	36% (19)
	Unemployed and not looking for work	**64% (34)**
40. Below is a list of possible reasons you may not be working right now. Please indicate whether or not these reasons explain why you are not currently working. Select as many as apply.		
	You are unable to work due to a disabling condition.	**36% (38)**
	There is no part or full time work available in your line of work.	7% (8)
	You don't believe that you can get the accommodations you need to effectively perform in the workplace.	11% (12)
	Additional income from work would make you ineligible for health benefits that are critical to your health and disability care.	12% (13)
	You need, but do not have access to, a personal assistant to help you get to work.	4% (4)

You need, but do not have access to, transportation to get to work.		7% (7)
You need, but are unable to obtain, work training or education for work.		7% (7)
Other reason		15% (16)
41. Are you currently in school or pursuing an education? (N=226)		
	Yes	24% (54)
	No	**76% (172)**
42. Please rate your level of agreement with each of the following.		
I have meaningful educational opportunities available to me. (N=214)		
	Strongly Agree	16% (34)
	Agree	**25% (54)**
	Disagree	13% (28)
	Strongly Disagree	8% (16)
	NA	*38% (82)*
I have affordable educational opportunities available to me. (N=212)		
	Strongly Agree	14% (29)
	Agree	**18% (39)**
	Disagree	17% (36)
	Strongly Disagree	10% (21)
	NA	*41% (87)*
I receive adequate support from teachers and staff in my educational program. (N=208)		
	Strongly Agree	8% (16)
	Agree	**14% (30)**
	Disagree	10% (20)
	Strongly Disagree	2% (4)
	NA	*66% (138)*
The learning material in my educational program is accessible to me. (N=205)		
	Strongly Agree	8% (17)
	Agree	**17% (34)**
	Disagree	6% (12)
	Strongly Disagree	3% (6)
	NA	*66% (136)*
My educational program is committed to supporting students with disabilities. (N=206)		
	Strongly Agree	9% (18)
	Agree	**15% (31)**
	Disagree	7% (15)
	Strongly Disagree	2% (5)
	NA	*67% (137)*

I have access to adequate career counseling and job placement services in my education program. (N=205)		
	Strongly Agree	3% (7)
	Agree	**11% (22)**
	Disagree	10% (20)
	Strongly Disagree	4% (8)
	NA	*72% (148)*
43. Barriers to education for all people take many forms. Please indicate which of the following, if any, have limited your ability to pursue or receive the education you want. Select as many as apply. (N=280)		
Inadequate funding		**22% (69)**
Physical inaccessibility (e.g., lack of ramps and elevators, inaccessible bathrooms, inaccessible transportation to and from school)		7% (23)
Problems receiving accommodations (e.g., due to time, cost, confidentiality concerns, or educating staff)		16% (44)
Problems obtaining assistive technology		9% (27)
Problems obtaining accessible learning material		9% (28)
Negative attitudes or stereotypes (on the part of teachers, staff, or other students)		12% (38)
Other		15% (48)
44. Are you currently working in a work training or job placement program? (N=224)		
	Yes	10% (21)
	No	**91% (203)**
45. Are you (or is the person you care for) a parent of a child under the age of 18? (N=222)		
	Yes	22% (49)
	No	**78% (173)**
46. How many people, including yourself, live in your household? (N=199)		
	1 (live alone)	14% (28)
	2	28% (56)
	3 or more	**58% (115)**
47. What kind of housing do you have? (N=217)		
Private housing that you own or partially own.		**50% (108)**
Private housing that you rent		18% (40)
Living with family rent free		19% (42)
Group living quarters		2% (5)
Long term care facility		1% (3)
Other		9% (19)

48. For each of the following, please indicate your level of agreement.		
My current housing meets my needs. (N=213)		
	Strongly agree	**42% (90)**
	Agree	40% (86)
	Disagree	15% (31)
	Strongly disagree	3% (6)
My current housing is affordable. (N=212)		
	Strongly agree	35% (74)
	Agree	**46% (97)**
	Disagree	13% (27)
	Strongly disagree	6% (13)
My current housing allows me to live independently right now. (N=204)		
	Strongly agree	27% (55)
	Agree	**44% (89)**
	Disagree	20% (41)
	Strongly disagree	9% (19)
My current housing will allow me to live independently in the future. (N=207)		
	Strongly agree	15% (32)
	Agree	**36% (74)**
	Disagree	34% (71)
	Strongly disagree	14% (30)
49. Please indicate how worried you are about each of the following.		
Losing my independence and having to rely on others. (N= 201)		
	Extremely worried	**32% (64)**
	Very worried	23% (46)
	Somewhat worried	30% (61)
	Not at all worried	15% (30)
Losing my memory or other mental abilities. (N=201)		
	Extremely worried	18% (37)
	Very worried	18% (37)
	Somewhat worried	**34% (68)**
	Not at all worried	29% (59)
Being able to pay for care or help might need as I grow older. (N=204)		
	Extremely worried	**37% (75)**
	Very worried	27% (55)
	Somewhat worried	25% (51)
	Not at all worried	11% (23)

Having to leave my home and move into a nursing home. (N=199)		
	Extremely worried	24% (47)
	Very worried	19% (38)
	Somewhat worried	27% (53)
	Not at all worried	**31% (61)**
Not having long-term housing plans. (N=196)		
	Extremely worried	**29% (56)**
	Very worried	14% (28)
	Somewhat worried	31% (61)
	Not at all worried	26% (51)
Being a burden on my family. (N=200)		
	Extremely worried	**37% (72)**
	Very worried	21% (41)
	Somewhat worried	28% (55)
	Not at all worried	16% (32)
Leaving debts to my family. (N=196)		
	Extremely worried	25% (49)
	Very worried	15% (30)
	Somewhat worried	23% (45)
	Not at all worried	**37% (72)**
Needing help with basic needs, like getting dressed, preparing meals, toileting, or bathing. (N=201)		
	Extremely worried	22% (45)
	Very worried	18% (37)
	Somewhat worried	**33% (67)**
	Not at all worried	26% (52)
50. Do you currently need home modifications to make your current home more accessible so that you can live independently? (N=213)		
	Yes	25% (55)
	No	**74% (158)**
51. Are you the parent of a child with a disability? (N=218)		
	Yes	32% (79)
	No	**64% (139)**
52. If you are a parent of a child with a disability, how worried are you about each of the following?		
My child's access to educational opportunities (N=118)		
	Extremely worried	13% (15)
	Very worried	13% (15)

	Somewhat worried	**22% (26)**
	Not at all worried	7% (8)
	NA	*46% (54)*
My child's access to vocational training and job opportunities as he/she grows older. (N=116)		
	Extremely worried	19% (22)
	Very worried	**20% (23)**
	Somewhat worried	15% (17)
	Not at all worried	3% (4)
	NA	*43% (50)*
My child's opportunities after he/she "ages out" of the public educational system. (N=117)		
	Extremely worried	**27% (31)**
	Very worried	14% (16)
	Somewhat worried	7% (8)
	Not at all worried	3% (4)
	NA	*50% (58)*
My child's acceptance by peers. (N=113)		
	Extremely worried	15% (17)
	Very worried	18% (20)
	Somewhat worried	**19% (21)**
	Not at all worried	7% (8)
	NA	*42% (47)*
Who will care for my child as I grow older. (N=116)		
	Extremely worried	**35% (41)**
	Very worried	10% (11)
	Somewhat worried	10% (12)
	Not at all worried	5% (6)
	NA	*40% (46)*
How I will pay for my child's care as he/she grows older. (N=117)		
	Extremely worried	**30% (35)**
	Very worried	14% (16)
	Somewhat worried	14% (16)
	Not at all worried	3% (3)
	NA	*40% (47)*
53. Please indicate how much you agree or disagree with the following statements.		
Most people would willing accept a person with a disability as a close friend. (N=183)		
	Strongly agree	9% (16)

	Agree	36% (66)
	Disagree	**47% (86)**
	Strongly disagree	8% (15)
Most people believe that a person who has a disability is just as intelligent as the average person. (N=182)		
	Strongly agree	8% (15)
	Agree	27% (48)
	Disagree	**53% (96)**
	Strongly disagree	13% (23)
Most people believe that a person with a disability is just as trustworthy as the average person. (N=181)		
	Strongly agree	13% (23)
	Agree	**53% (96)**
	Disagree	30% (54)
	Strongly disagree	4% (7)
Most people think less of a person with a disability. (N=181)		
	Strongly agree	15% (27)
	Agree	**50% (91)**
	Disagree	28% (51)
	Strongly disagree	7% (12)
Most people in my community would treat someone with a disability just as they would treat an average person. (N=180)		
	Strongly agree	12% (22)
	Agree	33% (59)
	Disagree	**44% (80)**
	Strongly disagree	11% (19)
54. Are you a veteran? (N=190)		
	Yes	10% (18)
	No	**91% (172)**
55. Is your disability the result of military service? (N=183)		
	Yes	4% (7)
	No	**96% (176)**
56. Are you (N=187)		
	Female	**56% (105)**
	Male	44% (82)
57. Year of birth (N=175): Calculated age in 2015		
	18 and younger	15% (27)

	19 to 64	**70% (123)**
	65 and older	15% (25)
58. Which county do you live in? (N=187)		
	Lehigh	**59% (110)**
	Northampton	27% (50)
	Monroe	2% (7)
	Berks	2% (7)
	Carbon	1% (3)
	Bucks	1% (3)
	Other	8% (7)
59. What city/town/municipality do you live in? (N= 176)		
	Allentown	18% (31)
	Bethlehem	12% (21)
	Easton	5% (8)
	South Whitehall	5% (8)
	Whitehall	5% (9)
	Lower Macungie	3% (5)
	Northampton	2% (4)
	Catasuaqua	2% (4)
	Salisbury	2% (4)
	Coplay	2% (3)
	Emmaus	2% (3)
	Hellertown	2% (3)
	Other	41% (73)
60. Which of the following best describes your race/ethnicity? (N=190)		
	White/Caucasian	**95% (181)**
	Black/African American	1% (2)
	Latino/Hispanic	3% (6)
	Other	1% (1)
61. What is the highest level of education that you have completed? (N=175)		
	Some high school	6% (11)
	High school degree or equivalent	**29% (50)**
	Associate's degree or some college	26% (46)
	College degree	21% (36)
	Post-graduate degree	18% (32)
62. Please indicate whether you are (N=183)		
	Married	**46% (84)**
	Single/never been married	38% (68)
	Divorced	9% (16)

	Separated	2% (4)
	Widowed	4% (7)
	Partnered/long-term relationship	2% (4)
63. Do you consider yourself to be one of the following? (N=180)		
	Heterosexual/straight	**92% (166)**
	Gay or lesbian	2% (4)
	Bisexual	1% (2)
	Prefer not to respond	3% (6)
	Something else	1% (2)
64. What was your family income (including everyone in your household) before taxes in 2014? (N=174)		
	Less than $14,999	8% (14)
	Between $15,000 and $24,999	12% (20)
	Between $25,000 and $39,999	12% (21)
	Between $40,000 and $59,999	20% (35)
	Between $60,000 and $99,999	**21% (37)**
	More than $100,000	13% (23)
	Don't know	14% (24)