Muhlenberg College
Institute of Public Opinion

Needs & Opportunities in the Lehigh Valley Disability Community: Engaging Diverse Stakeholders

A Community Health Needs Assessment
prepared for Good Shepherd Rehabilitation Network
in partnership with
the Disability Friendly Community of the Lehigh Valley

November 2018

Needs & Opportunities in the Lehigh Valley Disability Community: **Engaging Diverse Stakeholders**

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Good Shepherd Rehabilitation Network is the eighth largest rehabilitation provider in the country, according to *Modern Healthcare* magazine. Founded in 1908 in Allentown, Pennsylvania, Good Shepherd offers a post-acute continuum of care for adults and children with physical and cognitive challenges. Good Shepherd's 2,100 Associates treat 65,000 patients at more than 60 locations in Pennsylvania and New Jersey. Good Shepherd cares for adults and children with catastrophic injuries and conditions, such as spinal cord injury, brain injury, stroke, amputation and major multiple traumas and provides outpatient musculoskeletal and orthopedic rehabilitation services, long-term acute care and long-term care.

The Good Shepherd Physician Group is highly regarded for clinical excellence and its commitment to maximizing patients' functional outcomes, delivering compassionate care and being a national leader in the use of innovative rehabilitation technologies. Good Shepherd physicians are experts who specialize in various aspects of rehabilitation care. Good Shepherd is the world's leading clinical user of the Ekso Bionics® exoskeleton to treat patients with spinal cord injuries and was one of four facilities internationally designated by Ekso as a "Center for Robotic Excellence." Good Shepherd's long-term care facilities have consistently received 5-star ratings from *US News and World Report*.

Good Shepherd is a not-for-profit health-care network with a strong commitment to building better communities through partnerships with organizations whose vision and values reflect its own. Good Shepherd partners with the University of Pennsylvania Health System (UPHS) to provide comprehensive rehabilitation and specialty services in the Greater Philadelphia area through Good Shepherd Penn Partners, a joint venture.

The Muhlenberg College Institute of Public Opinion is a research center that conducts scientific based survey research projects on public policy and political issues of local, statewide, and national concern. In service to the College's pedagogical and community mission, the Institute also undertakes projects in conjunction with community partners to examine contemporary issues relevant to policy makers and to the public. It is directed by Dr. Christopher Borick, Professor of Political Science at Muhlenberg College (borick@muhleberg.edu).

The Disability Friendly Community of the Lehigh Valley includes people with disabilities, representatives of non-profits and for-profit service organizations, caregivers, family members, government and community leaders as well as people advocating for inclusion. More information is available at www.dfclv.org.

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A special thank you is extended to the community partners who graciously hosted focus groups for this project, including **the Lehigh Valley Center for Independent Living, the Center for Vision Loss, and the ARC of the Lehigh Valley**.

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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 MCIPO, Muhlenberg College, or the Disability Friendly Community of the Lehigh Valley.

Project Overview

The Patient Protection and Affordable Care Act of 2010 (Section 501 (r) (3)) requires charitable hospital organizations to conduct a Community Health Needs Assessment (CHNA) and to adopt an implementation strategy to meet the community health needs identified through the CHNA at least once every three years.[1] Community health needs assessments are processes of community engagement, involve the collection and analysis of data on health outcomes, help identify health disparities, and help hospitals determine and locate resources that can be used to address priority needs.

This report summarizes research findings from a 2018 study conducted by the Muhlenberg College Institute of Public Opinion (MCIPO) for Good Shepherd Rehabilitation Network (GSRN) in cooperation with the Disability Friendly Community of the Lehigh Valley. It serves as the major research component of GSRN's 2018-2019 CHNA cycle.

In the context of over a decade of research on disabilities in our region, this latest study combines secondary data from the U.S. Census Bureau and primary data derived from in-depth community focus groups conducted over several months in 2018. Taken together, these data give voice to people with disabilities and their families while assisting GSRN in identifying evidence-based ways to improve community health. This research is an integral piece of GSRN's ongoing efforts to comply with CHNA requirements of federal law while serving as a leader in making our region more accessible and inclusive and in fostering opportunities for people with disabilities to speak on their own behalf about their health and well-being and the challenges to living fully and independently in our community.

[1] The Patient Protection and Affordable Care Act of 2010 (PPACA), Pub. L. No. 111-148, 124 *Stat*. 119.

Executive Summary: Key Findings from Current CHNA

The research findings summarized in this analysis point to several key priorities critical to the health and wellbeing of people with disabilities in the Lehigh Valley. These have been identified through an analysis of secondary data drawn primarily from the US Census Bureau and primary data derived from a town hall and series of community focus groups conducted over several months in the summer of 2018.

People with disabilities in the Lehigh Valley face many barriers to good health. Some of these barriers are common to all individuals living the region. Infrequent exercise, for example, or poor access to mental health care may lead to poorer overall health for people without disabilities just as these may be a problem for people with disabilities. Aside from factors that shape health for everyone, ***this project highlights social conditions of health that have special significance for people with disabilities and that can lead both to lower overall health and health disparities*.**

Understanding Disability

A priority for building better health for people with disabilities begins with a more nuanced understanding of disability itself. Disability is a diverse part of the human experience. Most political, governmental, and medical organizations view disability through a medical, or functional, lens emphasizing the degree to which disability impairs the body, makes it difficult for individuals to execute tasks, and/or restricts participation in some way. Findings from primary research collected in this project point to ***the importance of viewing disability as a product of interaction between individuals' health and functional limitations and the social, economic, political, and cultural environment in which individuals live*.** Doing so turns the attention of health care communities to looking beyond simply treating disability alone to thinking more broadly about improving communities in ways that can facilitate healthier, happier living for all. Making sure that our communities provide adequately for all individuals is a priority in this respect. In fact, in the focus groups conducted for this study, when asked to talk about the greatest challenges to their own health, participants were far more likely to emphasize environmental and social issues (e.g., accessible parking, transportation, communication, education, job training) than the particular details of their disability or functional limitation.

Poverty, Education, Employment

People with disabilities in the Lehigh Valley are more likely to live in poverty, to be low-income, to have lower-levels of education, and to be unemployed compared to individuals without disabilities. Socioeconomic status is consistently correlated with poor health; inequities in the social determinants of health directly shape morbidity and mortality, limit rehabilitation processes, and make it difficult for individuals to forge social connections necessary for positive emotional health. The effects of being low-income may be compounded for people with disabilities who face steeper obstacles to education and employment and often face higher

health care costs. As one participant in a focus group put it: "*you have to be rich to be a person with a disability*." ***Working to eradicate inequalities in income, education, and employment would have positive health benefits across the region.*** At a minimum, it is important for community leaders and health care professionals to be aware of the connections between socioeconomic variables and health outcomes. Community focus group participants frequently mentioned interest in and need for change through legislative or policy change and more coordinated advocacy on the part of people with disabilities.

Transportation

Barriers to transportation are a key reason that people with disabilities lack adequate access to health care. Accessible, affordable, and reliable transportation facilitates opportunities in education, employment, housing, and full participation in community life. Despite limited gains in making public transportation more accessible for people with physical disabilities, similar to most transportation planning across the nation, development in the Lehigh Valley has prioritized private transportation in cars, an approach which only exacerbates inequalities connected to transportation. Public transportation is especially scarce in more rural parts of the region. Quite simply***, transportation equity is critical to ensuring equitable access to health and to full participation in public life.*** No issue was articulated more frequently and no issue was as salient as transportation to the community members who participated in this study. Key informants and consumers alike pressed the need for investment in more and better transportation options in our region.

Information & Communication

Information is power. Information is related to health care in several ways. For example, people with disabilities may lack adequate access to health care stemming from low levels of knowledge among health care providers (e.g., lack of knowledge about disabilities, how to communicate with patients who have disabilities, how to ensure that medical facilities are broadly accessible). Lack of education among health care providers about disabilities may result in implicit biases and result in a lack of access to mainstream health services, even in a region as rich in health care as the Lehigh Valley. Focus group participants expressed gratitude for the ways that social media communication technologies have made some kinds of information easier, at the same time that they expressed bewilderment about finding the information required to navigate complex health information (and health insurance) systems. Key informants themselves noted that it is difficult to help clients and patients absent meaningful centralized, information systems. In an information society, in which government, community, nonprofit, employment, and educational information is moving online, several priorities emerge, including ***ensuring that online technologies are accessible to individuals with different types of disability.*** Another priority is ***communicating and distributing information widely enough so that community members know where to seek information and how to access it***.

Community Attitudes & Inclusion for all Disability Types and for all Ages

Social connectedness is a key indicator of overall health. Previous research has shown that people with disabilities in our region suffer from higher rates of symptoms of depression and feelings of social isolation and loneliness when compared to people without disabilities. Moreover, the Lehigh Valley trails other counties in the state (and significantly lags behind the best counties in the country) when it comes to the ratio of mental health providers to the population (**see Appendix I**), potentially pointing to broader need for improved access to mental health services. Focus group participants noted that ***among the most valuable mechanisms for attending to their own health and well-being are support groups and they conveyed a keen interest in and clear need for more of them*.** Focus group participants noted a gradual shift in community norms toward greater acceptance of people with disabilities but pointed to ongoing challenges related to educating community about just what "disability" means and how to know if spaces are truly "accessible" for individuals with all kinds of disabilities. ***Compliance with the minimum requirements of the ADA is, quite simply, not enough to make community spaces accessible and inclusive***. Finally, the research suggests that community attitudes toward people with disabilities and inclusion of people with disabilities varies by disability type and age; of particular importance, ***post-school age young adults and middle-age adults with disabilities are a uniquely under-served population.***

Family Members and Caregivers

Family members and caregivers providing care to people with disabilities are themselves at risk. Caregivers often struggle with complex health related problems, including physical, emotional, and mental health issues, as well as strained personal relationships and feelings of helplessness. ***Findings ways to support and provide resources to caregivers is, therefore, integral to supporting and improving health for people with disabilities themselves***.

Much Remains to be Learned in the Future and Better Data would Help

A significant constraint in understanding the needs of people with disabilities in the context of community health is the lack of quality data and information, particularly at local geographies. A consequence of the absence of meaningful data is that it is difficult for regional policymakers and planners to have an accurate picture of the region and to appreciate the disparate impacts of development on people with disabilities. The same is true in health care. ***Better data about disabilities, about the links between disability and health, and about the compounding effects of income, age, education, and employment, is a prerequisite to imaging a future in which all can fully participate in our communities and achieve full health*.**

History of Research on Disabilities in the Region

Good Shepherd Rehabilitation Network (GSRN) has a long history of underwriting and facilitating research in the interest of improving life for people with disabilities and services to patients. Much of this history, summarized in **Figure 1**, predates the origins of the Affordable Care Act (ACA) which, since 2010, has required all charitable hospitals to undertake similar research for community benefit. Throughout each effort to assess community needs for people with disabilities, GSRN has engaged diverse community partners and stakeholders—patients, consumers, caregivers, parents, academic researchers, and private, public, and nonprofit organizations serving people with disabilities—and has been instrumental in shaping collective efforts to improve health in our region.

A few highlights from past research are worth noting since they inform current efforts to learn more. The first large scale study designed to measure unmet needs of people with disabilities living in the Lehigh Valley was conducted in 2008-09: *The Lehigh Valley Disability Community: Needs & Opportunities*. This research, based on a series of community forums and a mail-based survey in Lehigh and Northampton counties, was important in two primary ways. First, the 2008-09 study revealed important differences within subgroups of the population of people with disabilities, suggesting for example, that individuals with physical and mobility disabilities face different challenges than those with mental health, hearing, or vision disabilities. Put differently, disability type—along with a range of additional individual characteristics, including income, disability severity, and age—matters to the opportunities and needs of individuals in our region. If these conclusions are intuitive, the research provided evidence-based explanations to assist GSRN and other organizations in developing targeted strategies for change. The second way that the 2008-09 study was important is that it served as a catalyst for GSRN's leadership in forming the Disability Friendly Community (DFC; originally, the Partnership for a Disability Friendly Community), a coalition of 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 DFC continues to work on grassroots educational and advocacy campaigns, often taking direction from findings generated through GSRN's sponsored research (see www.disabilityfriendlylv.com). The DFC lent significant support to the current project.

Most recently, in 2015, GSRN completed a two-part CHNA comprised of first, an updated *Road to Health* needs assessment collaboratively produced by the Health Care Council of the Lehigh Valley (HCCLV) and, second, a study conducted by the Lehigh Valley Research Consortium, *The Lehigh Valley Disability Community: Re-Examining Community Needs & Opportunities*.[2] The

[2] Regionally, when the *Road to Health* was produced, the Lehigh Valley was home to five nonprofit health care systems, including GSRN, St. Luke's University Health Network, Sacred Heart Health Care System, the Lehigh Valley Health Network, and KidsPeace Psychiatric Hospital. These hospital systems, along with the Dorothy Rider Pool Health Care Trust, the Allentown Health Bureau, the Bethlehem Health Bureau, and Neighborhood Health Centers of the Lehigh Valley comprised the Health Care

HCCLV *Road to Health* is broadly focused on key health outcomes across the Lehigh Valley (for example, the report highlights data on morbidity and mortality, healthy behaviors, and social determinants of health for *all* individuals in the Valley without examining key subgroups of the population). The specialized research commissioned by GSRN through the LVRC emphasizes unique and specific needs and health challenges among people with disabilities—needs and challenges that would otherwise be rendered invisible in the HCCLA report. Efforts to recognize people with disabilities as a unique population are particularly salient in the context of the core mission of public health to address health inequities and disparities.

Generally, these recent past studies have revealed that there is much to be proud of in our region, but that there is room for improvement, particularly in adapting the social environment to make our community more accessible and inclusive. Key areas of concern noted in past research include: building more accessible and affordable housing; encouraging the development of better, more reliable transportation options; developing comprehensive, efficient information and referral services; fostering more explicit education, information, and access to mental, sexual and reproductive health services; supporting healthy interpersonal relationships and inclusiveness for people with disabilities; and recognizing the interconnectedness of physical, mental, and behavioral health through prevention, education, and collaboration.

This research also informed the 2017-2019 GSRN Community Health Needs Assessment Implementation Plan which prioritized strategies and identified actions in response to the community needs identified and prioritized through the CHNA process. In brief, the 2017-2019 Implementation Plan emphasized 1) providing more targeted information and referral resources, 2) promoting well-being, function, fitness and healthy behaviors; 3) increasing accessible housing; and 4) advocating for improved para-transit services.

Council of the Lehigh Valley which published two collaborative CHNA's, the *Road to Health* in 2012 and the *Road to Health Update* in 2015-6. The LVRC undertook significant primary research on people with disabilities in 2015 utilizing an online survey completed by 320 individuals. Additional information and copies of full reports are available on GSRN's website: https://www.goodshepherdrehab.org/about/community-health-needs-assessment.

Figure 1. GSRN Research on Disabilities in the Lehigh Valley, 2001-present

2001 Felix, Burdine and Associates, Inc.
Needs Assessment Survey of 140 individuals
"Are we doing all we can for persons with disabilities?"[3]

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2008-2009 LVRC Report: *Lehigh Valley Disability Community: Needs & Opportunities*[4]
+
2010 Creation of the Partnership for a Disability Friendly Community
(renamed Disability Friendly Community of the Lehigh Valley)

↓

Affordable Care Act (March 2010)

2012 *The Road to Health*
HCCLV joint CHNA

↓

HCCLV 2015-16 *The Road to Health Update*
+
2015-2016 LVRC Report
The Lehigh Valley Disability Community:
Re-Examining Community Needs & Opportunities

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2016-19 GSRN
Community Health Needs Assessment Implementation Plan

↓

2018 Community Health Needs Assessment
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[3] Findings from this early study were combined with a 1992 Lehigh Valley Health Survey collaboratively sponsored by regional hospitals. This research revealed several areas of concern including insufficient access to medical and dental services, lack of accessible social and recreational opportunities, employment barriers, and problems stemming from too few reliable transportation opportunities.
[4] The Lehigh Valley Research Consortium (LVRC) is an arm of the Lehigh Valley Association of Independent Colleges, the purposes of which include fostering collaborative relationships to examine social, political, health, and economic problems and solutions in a regional context.

Current Research Project: Needs & Opportunities in the Lehigh Valley Disability Community: Engaging Diverse Stakeholders

The current project is designed to assist Good Shepherd Rehabilitation Network (GSRN) in meeting the requirements of federal law, while giving voice to people with disabilities, a key public health population that is frequently underserved and often lacks equitable access to health and health care. This research uses evidence-based approaches to identify and prioritize community health needs, positioning GSRN to determine potential resources and strategies that may be best suited in addressing them.

With knowledge gleaned from past research on disabilities in our community, additional objectives of the current project are to:

1) Solicit feedback to evaluate community wide progress in improving the lives of people with disabilities.
2) Identify and prioritize new research questions and areas of concern that have not received adequate attention in previous studies or that have recently emerged as key issues for the health and wellbeing of people with disabilities.
3) Work with community members to identify potentially innovative practices for addressing community needs through informed research.
4) Collect meaningful, local primary data and publish findings that will be of benefit to organizations serving people with disabilities, to community planners, and to persons with disabilities themselves in collaborative efforts to build a more inclusive, affordable, accessible community.

Research Methods & Community Participation

This study uses a two-pronged research method to identify community health needs among people with disabilities.

1. First, this study updates and extends information derived from key secondary sources of data, including primarily the U.S. Census Bureau, the Centers' for Disease Control's Behavioral Risk Factor Surveillance System (BRFSS), the Robert Wood Johnson County Health Rankings, and the Pennsylvania Department of Health. Data provided by key federal and state agencies is critically important for tracking community health over time. It also helps identify social and environmental determinants of health and features of the social environment that interact with individual-level characteristics in shaping overall individual and community health. Finally, these data are also useful for identifying health disparities between people with disabilities and people without disabilities.

2. Second, this study also includes primary qualitative data derived from a community forum of key stakeholders (including people with disabilities, heads of public and private agencies serving the disability community, educators, elected representatives, county officials, advocacy organizations, representatives from the arts, religious, and

community organizations), and a series of focus groups in which key informants, people with disabilities and their families were invited to share insight about their own challenges to living fully, independently, and healthfully.

Both federal regulations and best practices for carrying out CHNAS emphasize the role of community input. A central goal of the current study was to engage diverse stakeholders as partners in research for people with disabilities, rather than simply as subjects or objects of the research.[5]

Figure 2 provides a quick illustration of the intersecting ways that public input has informed the research on disabilities in our region and the community-wide responses to that research. At each stage of the research process, community members were engaged in the research process, helping to identify research questions, reviewing and deriving meaning from secondary data from federal, state, and local sources, determining practices to solicit and engage additional community members, and providing feedback on past practice and current efforts.

Community & Patient Population

Good Shepherd Rehabilitation Network is based in the city of Allentown in Lehigh County, Pennsylvania, offering a continuum of care for people with injuries, complex medical needs and physical and/or cognitive disabilities. Its specialized programs include stroke, orthopedics, and sports injuries; brain injury; spinal cord injury; and amputee programs.

Approximately 57% of Good Shepherd's patients reside in Lehigh or Northampton counties. The remainder come from over 20 different counties in Pennsylvania, New Jersey and from as far away as New York and Florida.[6] Good Shepherd's mission is both forward-looking and outward-reaching; GSRN is committed to furthering positive change for people with disabilities across our region and to broadly changing understanding about disability. Therefore, this project defines the Lehigh Valley community of people with disabilities to include Lehigh and Northampton counties (see **Map 1** below), thereby embracing community members who are not necessarily receiving care at GSRN.

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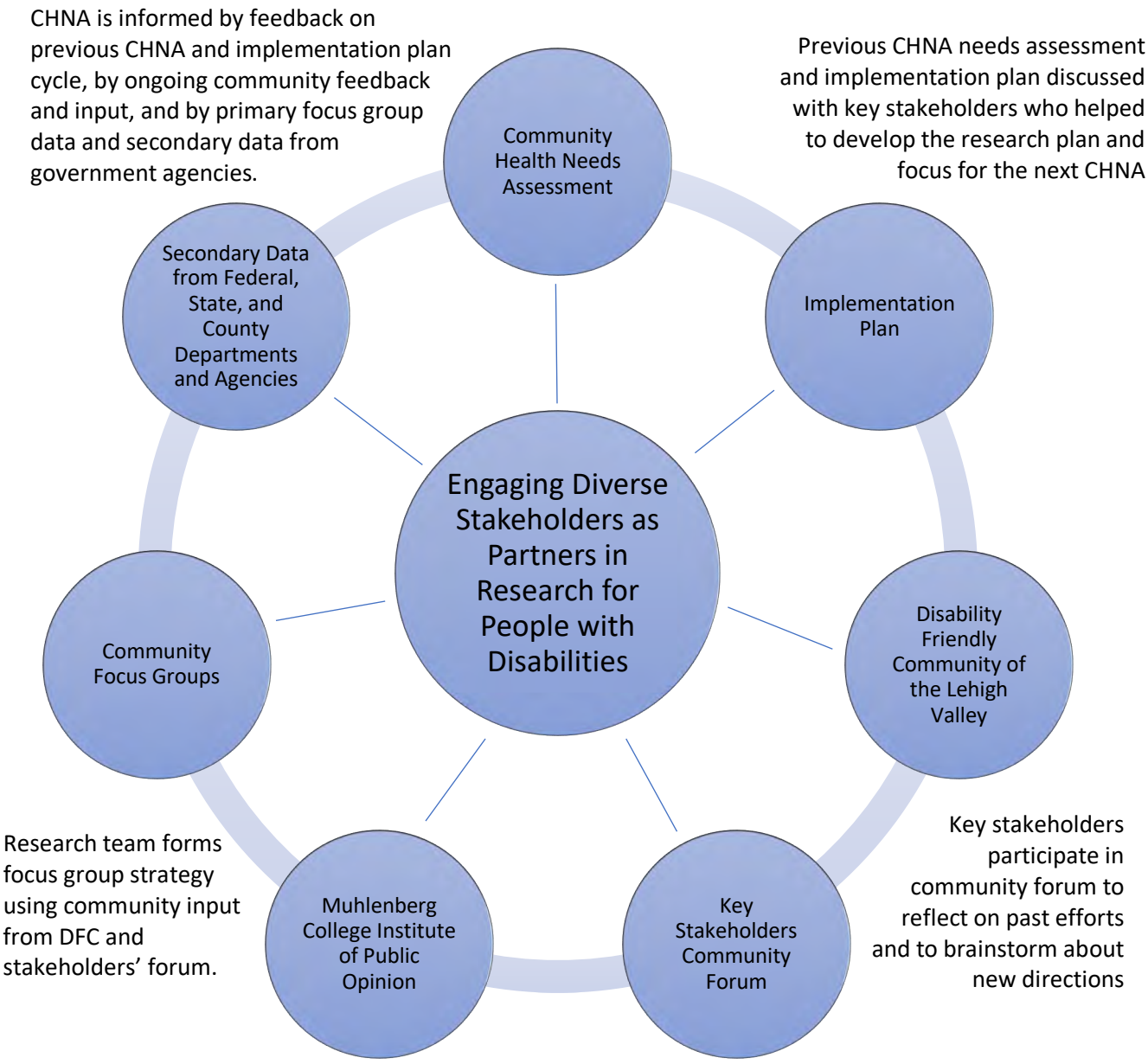
[5] See Additional Requirements for Charitable Hospitals; Community Health Needs Assessments for Charitable Hospitals; Requirement of a Section 4959 Excise Tax Return and Time for Filing the Return, Vol. 79 No. 250 Fed Reg., 78945 26 CFR Parts 1, 53, and 602 (December 31, 2014). In addition, although hospitals may revise previously conducted CHNAs in meeting these criteria, final regulations require input from persons representing the broad interests of the community anew in each three-year CHNA cycle, even if the new CHNA builds on a previously conducted CHNA.

[6] According to the PA State Data Center, both counties are projected to grow in overall population over the next 20 years, Lehigh at 9.9% and Northampton at 5.6%. This compares to the projected statewide growth of 6.8% during the same period. The 65 and over population, which comprise approximately 58% of inpatient cases, is projected to grow dramatically over 20 years. Lehigh County growth of the older population is projected to grow at +38.5% and Northampton County at +31.9%; both growth rates exceeding projections for the state overall (+28.8%).

Figure 2. Needs & Opportunities in the Lehigh Valley Disability Community:
A Sketch of the Research Process: A Continual Feedback Loop



The Lehigh Valley Disability Community: Summary of Secondary Research

It is common for Community Health Needs Assessments (CHNAs) to begin with an analytical summary of key health indicators that help to define the contours of a community—including, for example, morbidity and mortality data, quality of life rankings, the prevalence of disease and chronic health conditions, and other health related factors, such as behavioral health measures. Among other sources, these data are available for Lehigh and Northampton counties from the Robert Wood Johnson Foundation's County Health Rankings (http://www.countyhealthrankings.org/) (some of this data is summarized in **Appendix I**).

Of course, people with disabilities share many health-related challenges and opportunities with people who do not have disabilities. But, the disadvantage of this approach—summarizing statistics for an entire geographic population—for specialty hospitals such as Good Shepherd Rehabilitation Network, is that it obscures the unique needs of people with disabilities. Most if not all sources of data on disability and health in the United States—including the Census Bureau's American Community Survey, the CDC's Behavioral Risk Factor Surveillance System and Health Information National Trends Survey, approach disability status as a measure of health itself (similar to say, a measure of obesity in a population, or diabetes prevalence), rather than providing a window into the particular health needs of people with disabilities. In other words, these national studies define disability as a variable that helps to determine health, rather than providing a mechanism to understand the interactions between disability, social environment, and individual health.

The greatest challenging in conducting a CHNA to measure the needs of people with disabilities is a lack of existing data specific to that population, particularly at geographies smaller than the state level. This section summarizes what can be gleaned from the US Census Bureau at the county level, namely data on population, disability type and prevalence, demographic information, and information about employment, income, and education.

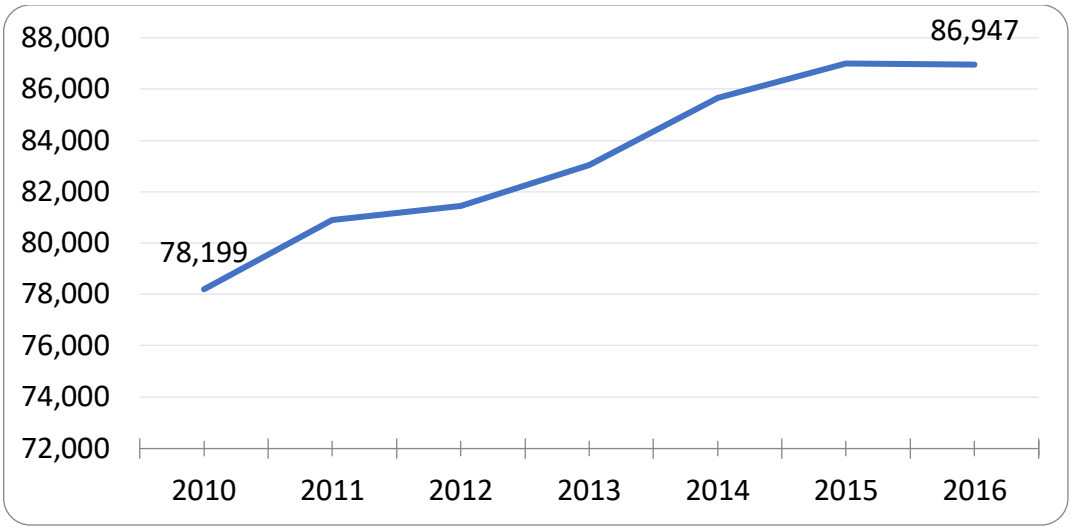
Population

While the state of Pennsylvania has generally experienced slowed population growth over the past ten-years, the Lehigh Valley region has seen impressive growth and increasing diversification of its population. According to the Pennsylvania State Data Center, growth in the state has been concentrated in the southeastern and southcentral regions, including the Lehigh Valley along with neighboring Berks and Montgomery counties. In Lehigh County alone, the population grew by 13,521 in just one year, between 2015 and 2016. Population growth in the region is largely driven by migration—Lehigh County has seen some of the highest numbers in net migration across the state since 2010.[7]

[7] Pennsylvania State Data Center, "2016 County Population Estimates," Research Brief, March 2017.

According to the U.S. Census Bureau's American Community Survey, in 2016, there were approximately 651,000 individuals residing in the area constituted by Lehigh and Northampton counties. Approximately, 13% of this population, or 86,947 individuals, have some kind of disability. As seen in **Figure 3**, the population of people with disabilities in the region has grown significantly since 2010, increasing from 78,199 in 2010 to 86,947 in 2016.

Figure 3. Lehigh Valley Population with a Disability, 2010-2016

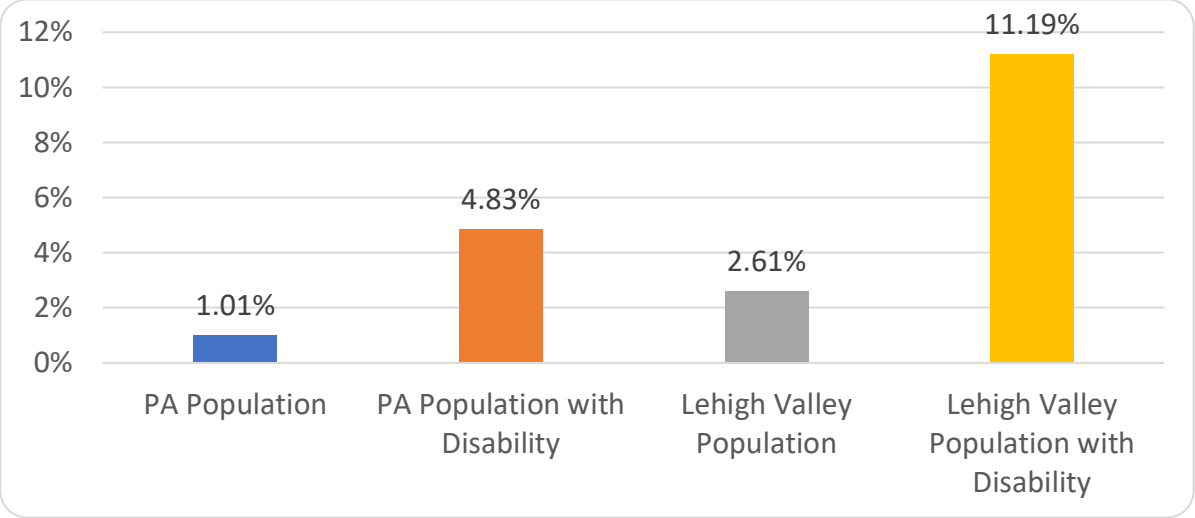


Source: U.S. Census Bureau, American Community Survey, Five Year Estimates 2011-2016. *Note*: Refers to the civilian, non-institutionalized population (i.e., excluding individuals who reside in institutions such as nursing homes, prisons, or psychiatric institutions).

As seen in **Figure 4,** total statewide population in Pennsylvania has grown by about 1% since 2010, but the statewide population of people with disabilities has increased by 4.83% over the same time. The differences are even more significant in the Lehigh Valley. The size of the overall population has grown by 2.61% while the population of people with disabilities has seen an increase of more than 11%.

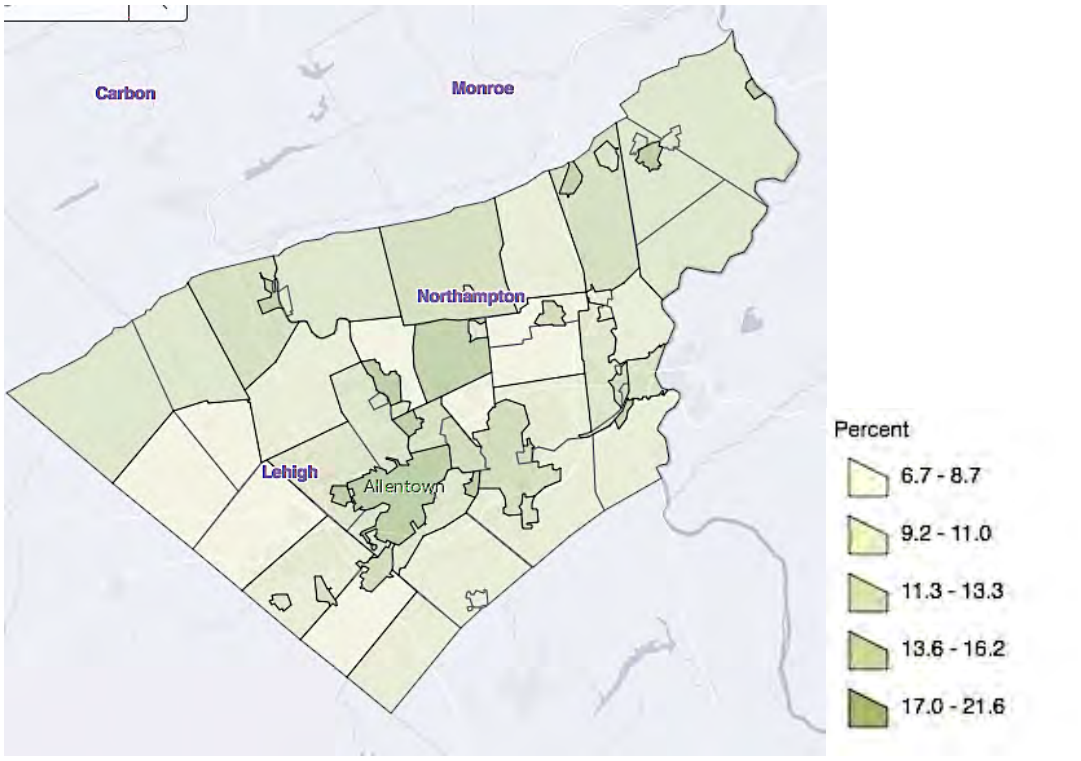
Map 1 (with additional detail provided in **Appendix II)** illustrates the distribution of the population of people with disabilities across the region. Individuals with disabilities live in all communities across our region. Recalling that across the Lehigh Valley region about 13% of individuals have a disability, several municipalities exceed this number, including the city of Allentown (18.4%), Catasauqua (18%), Fountain Hill (17.6%), Slatington (19.3%), Bangor (18.3%), Moore Township (15.6%), Northampton (18.4%), Plainfield (16.2%), and Portland (21.6%).

Figure 4. Population Change, Pennsylvania and Lehigh Valley, 2010-2016



Source: US Census Bureau, American Community Survey, Five Year Estimates, 2008-2010 and 2012-2016

Map 1. Percentage of People with Disabilities, Lehigh & Northampton Counties, 2011-2016



Source: U.S. Census Bureau, American Community Survey, Five Year Estimates 2011-2016

Disability Type

Table 1 provides insight into the most prevalent types of disability in the region.[8] Ambulatory difficulties are most common, followed by cognitive difficulties (defined as difficulty remembering, concentrating, or making decisions because of a physical, mental, or emotional problem), and independent living difficulties.

Table 1. Lehigh Valley Population by Disability Type, 2016

	Lehigh County		Northampton County		Lehigh Valley	
	Number	Percentage	Number	Percentage	Number	Percentage
Total population with a disability	49,613		37,334		86,947	
Hearing difficulty	12,364	3.49%	9480	3.19%	21,844	3.35%
Vision difficulty	9413	2.66%	6095	2.05%	15,508	2.38%
Cognitive difficulty	22,688	6.41%	14,485	4.87%	37,173	5.71%
Ambulatory difficulty	23,004	6.5%	19,389	6.51%	42,393	6.51%
Self-Care difficulty	8599	2.43%	6864	2.31%	15,463	2.37%
Independent Living difficulty	15,562	4.40%	13,776	4.63%	29,338	4.50%

Source: U.S. Census Bureau, American Community Survey, Five Year Estimates 2011-2016

To provide a comparative data estimate, the Centers for Disease Controls' Behavior's Risk Factor Surveillance System (BRFSS), a national telephone health survey in which Pennsylvania participates, offers similar measures of disability for a slightly different geography—considering the combined area of Carbon, Lehigh, and Northampton counties. Data from this survey are summarized in **Table 2**. According to these data, 22% of individuals living in the combined

[8] The US Census Bureau generally employs a "medical model of disability," measuring the incidence of six disability types: hearing, vision, cognitive, and ambulatory difficulties, as well as self-care difficulty (trouble bathing or dressing, for example) and independent living difficulty (difficulty doing errands or vising a doctor alone due to a physical, mental, or emotional problem). The Census only records cognitive, ambulatory, and self-care difficulties for persons ages 5 and older; independent living difficulties are recorded only for persons ages 15 and older.

region of Lehigh, Northampton and Carbon counties are limited in activity due to a physical, mental, or emotional problem—a broader measurer than what is available through the US Census.

Table 2. PA BRFSS Carbon, Lehigh & Northampton Counties, 2012-2017, Percentage of Population with a Disability

Have difficulty doing errands alone due to a physical, mental, or emotional problem	6%
Have difficulty bathing or dressing	4%
Have serious difficulty concentrating, remembering or making decisions due to a physical, mental, or emotional condition	9%
Have serious difficulty walking or climbing stairs	15%
Health problems require the use of special equipment	11%
Limited in activity due to physical, mental or emotional problem	22%

Source: CDC, Behavioral Risk Factor Surveillance System, 2012-2017

Disability & Age & Race

Some of the growth in the regional population of people with disabilities can be explained by age. Seniors, ages 65 and older, make up 16% of the total regional population of people with disabilities. However, disabilities span all age groups and, as shown in **Figure 5**, the age group 18-64 has actually experienced the steepest growth in the numbers of people with disabilities since 2010.

At the same time that the population of people with disabilities in our region is growing, it is also becoming more diverse. While whites still comprise a majority of the population in our region, Latinos (Hispanics) equal more than 20% of the population of Lehigh County and more than 12% of the population in Northampton County. Similarly, African Americans equal 6% of the overall population in Lehigh and 5% of the population in Northampton. This diversity is reflected in the proportion of the population with disabilities, as seen in **Figure 6**. Particularly noteworthy, although they continue to make up a minority of the overall population of people with disabilities, the population of Latino and African Americans with disabilities has seen more significant change in the past several years. Between 2010 and 2016, the population of Latino individuals with disabilities in the region grew by 21% while the population of African

Americans with disabilities increased by 25%. This compares to a corresponding increase of about 9.5% among whites with disabilities.

Figure 5. Lehigh Valley Population with Disabilities and Age Group, 2010-2016

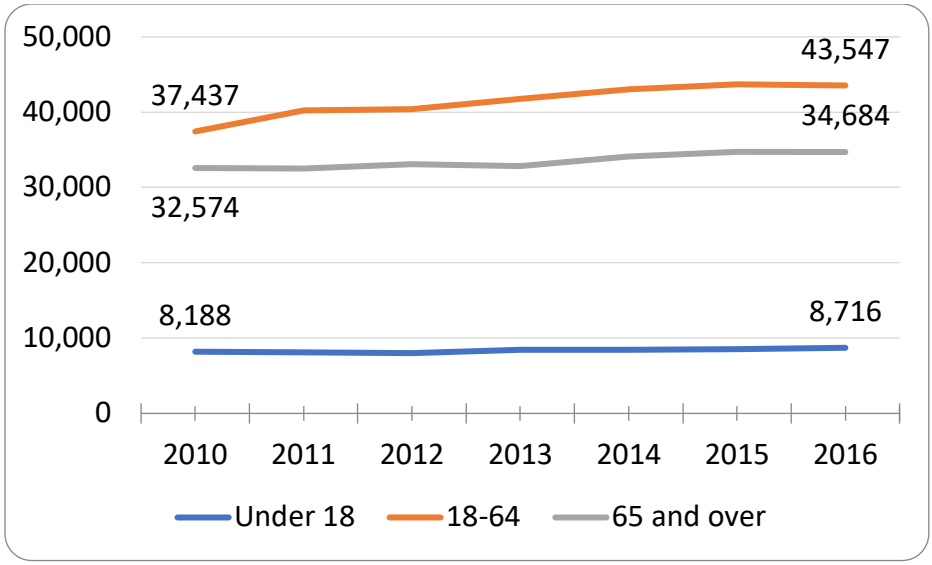
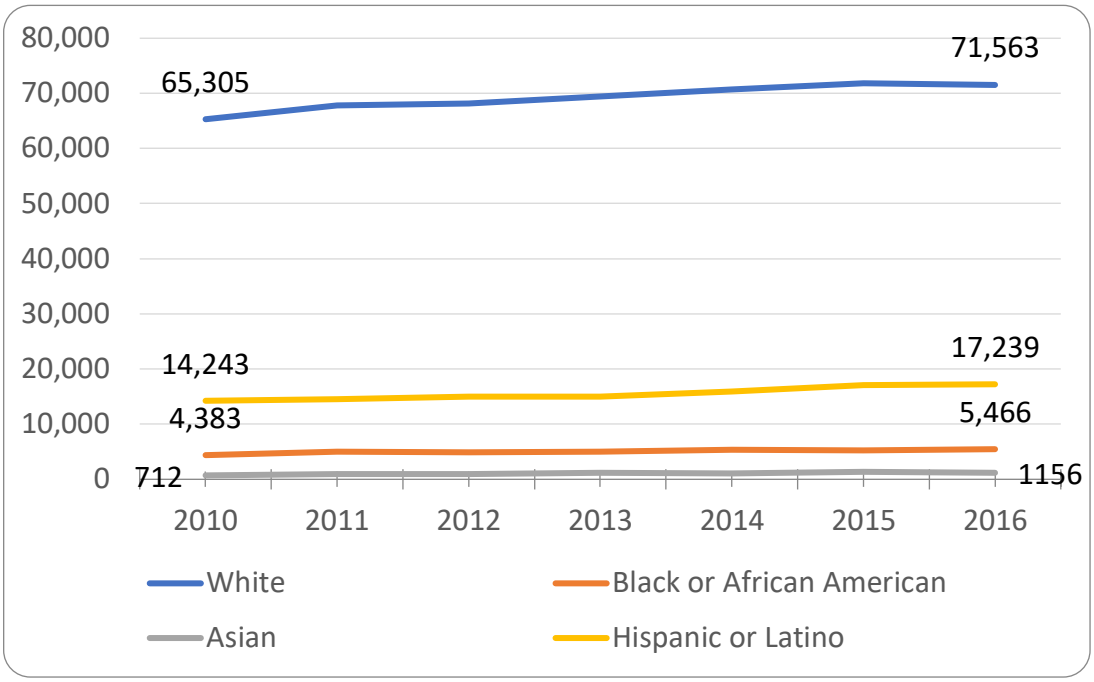


Figure 6. Lehigh Valley Population with Disabilities by Race/Ethnicity, 2010-2016



Source: U.S. Census Bureau, American Community Survey, Five Year Estimates 2010-2016

Disability & Income, Education & Employment

Measuring disability is difficult, in part, because the environments in which individuals live, work, and play are themselves determinants of disability. While government entities, including the US Census Bureau, generally use a "medical model" of disability—that is, defining a "person with a disability" as a person with a physical or mental impairment that limits major life activity—disability advocates and the public health community are increasingly attuned to thinking about disability relationally—that is, as a product of an individual in a larger social environment.[9] In this context, the social determinants of health—the opportunities and resources that allow us to live healthfully, independently, and safely in our neighborhoods and communities—take on even greater significance. Later sections of this report offer further insight into the kinds of opportunities, resources, and supports that people with disabilities themselves identify as critical determinants of their own well-being.

The US Census Bureau provides some data to begin thinking about factors related to the social and physical environment that promote, or limit, good health for people with disabilities. These data also highlight the extent to which people with disabilities as a group are more likely to experience social and economic inequalities that limit health.

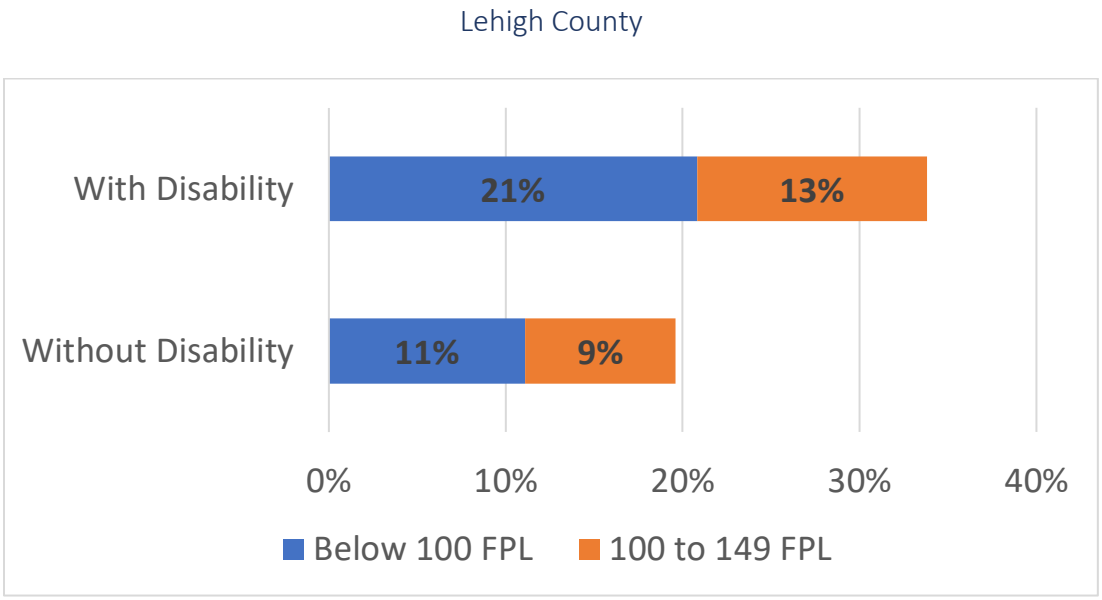
For example, **Figure 7** shows that significant numbers of people with disabilities in our region are living in poverty. Moreover, there are substantial inequalities in poverty status when comparing people with disabilities to people without disabilities. In 2016, 21% of people with disabilities in Lehigh County and 14% of individuals with disabilities in Northampton County reported annual household incomes at or below 100% of the federal poverty level. This compares 11% of people without disabilities in Lehigh County and 8% in Northampton county. Similarly, 13% of people with disabilities in each county were living between 100 and 149% of the federal poverty level in 2016.[10]

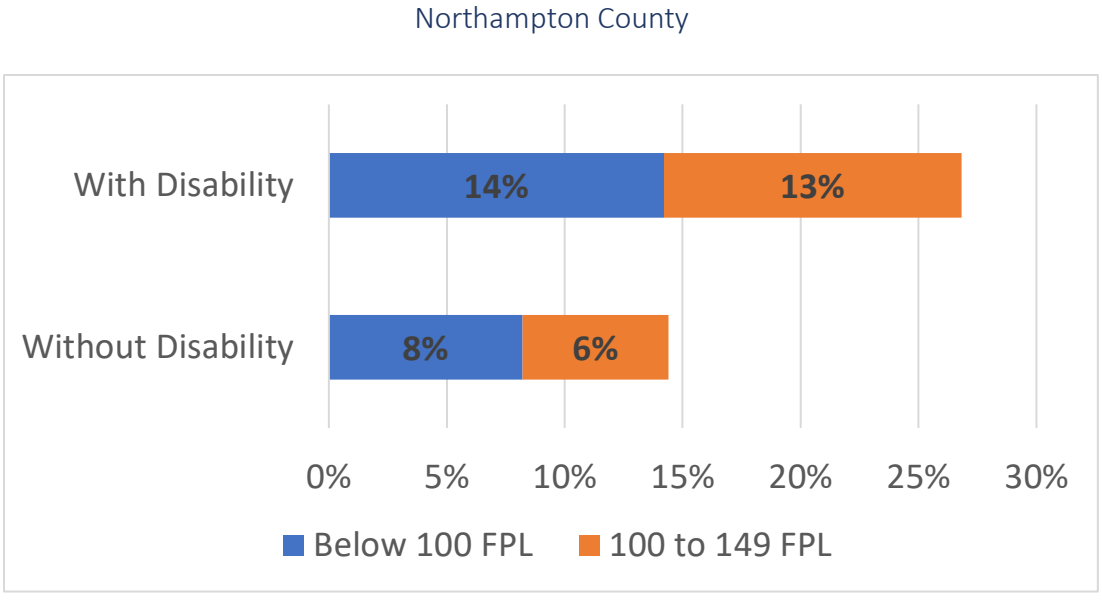
There are also gaps when it comes to median income, as shown in **Figure 8**. The gaps in median income are especially stark in Lehigh County (as well as greater than the statewide gap), where the median income for people with disabilities is more than $13,000 less than the median income for people without disabilities.

[9] Medical models of disability are used by the US Census Bureau, the World Health Organization, and inform the legal definition of disability for individuals in the context of the Americans with Disabilities Act. Defining different disability types is also inherently contested.

[10] In 2016, 100% of the federal poverty level (FPL) was approximately equal to $11,880 for a family of one or $16,020 for a family of two, annually. The 149% of the FPL equaled $17,820 for a family of one and $24,030 for a family of two in 2016. The preferred measure of income for many nonprofits, including the United Way for example, is 200% of the FPL as this is often seen as a truer measure of income required for meeting basic needs.

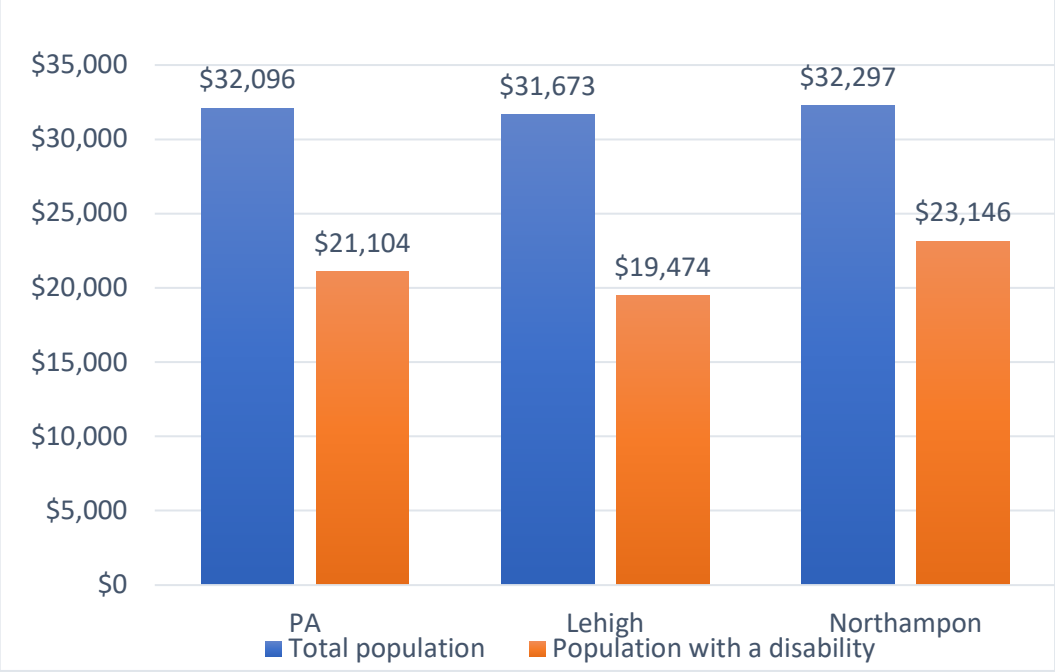
Figure 7. Poverty Status, With Disabilities and Without Disabilities, 2016





Source: US Census Bureau, American Community Survey, Five Year Estimate, 2016

Figure 8. Median Income and Population, 2016



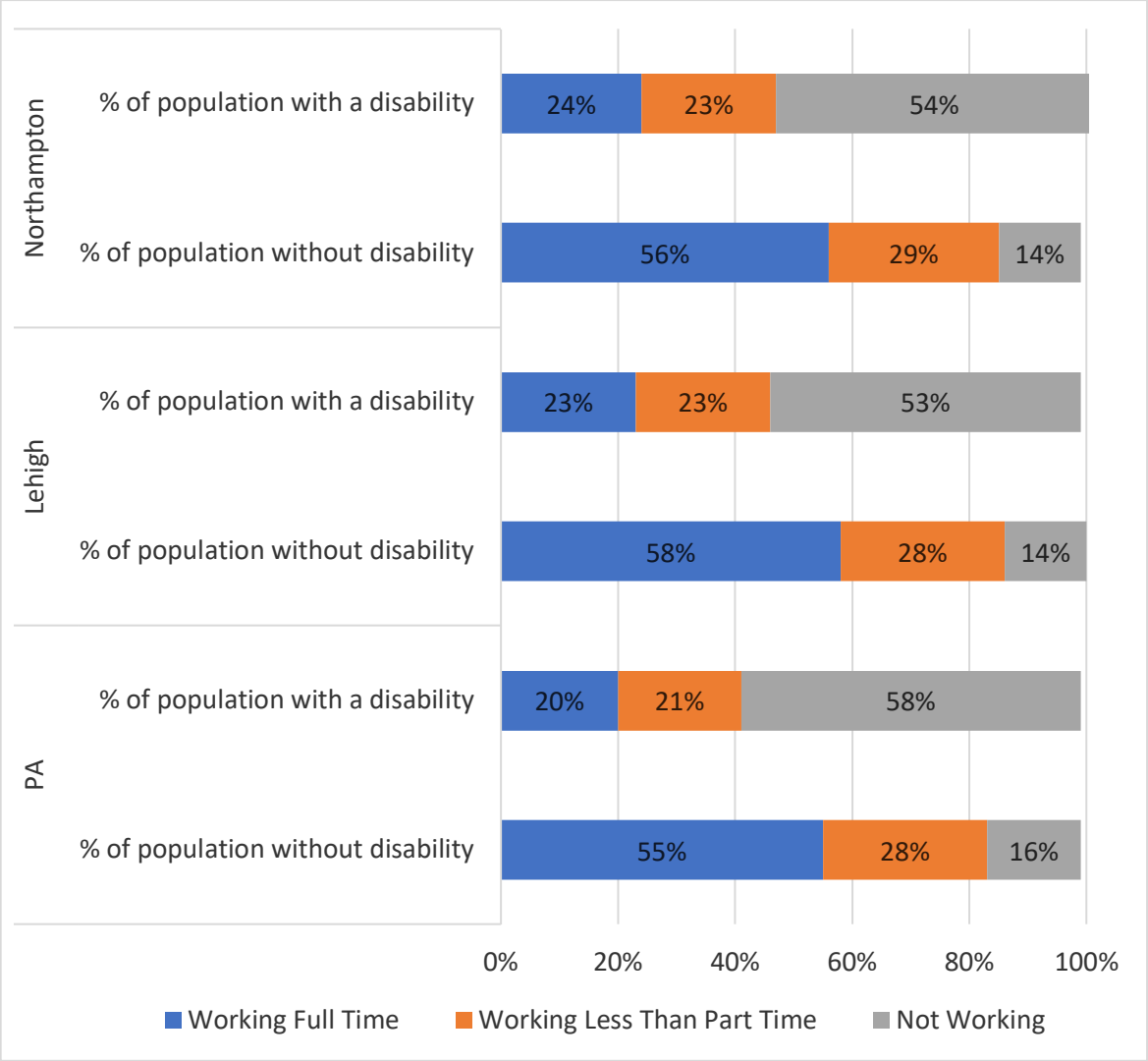
Source: US Census Bureau, American Community Survey, Five Year Estimate, 2016

Income is especially significant in combination with barriers to employment and education. The Census Bureau estimates that of the 403,523 individuals ages 18-64 (generally considered "working-age "adults) living in the Lehigh Valley region, 298,633 are employed. Only 16,886 of these individuals have a disability. Moreover, only 10,128 of working people with disabilities are working full time.

There are approximately 43,547 individuals with disabilities ages 18 to 64 in the Lehigh Valley region whose employment status has been determined by the US Census Bureau. As shown in **Figure 9**, people with disabilities in the state and in the Lehigh Valley region are more likely than people without disabilities to be working part time, or not to be working at all. Only 23% of people with disabilities, ages 18 to 64, in Lehigh County are working full time; in Northampton County the number is 24%. These numbers are slightly larger compared to the statewide average, which suggests that about 20% of people with disabilities work full time.

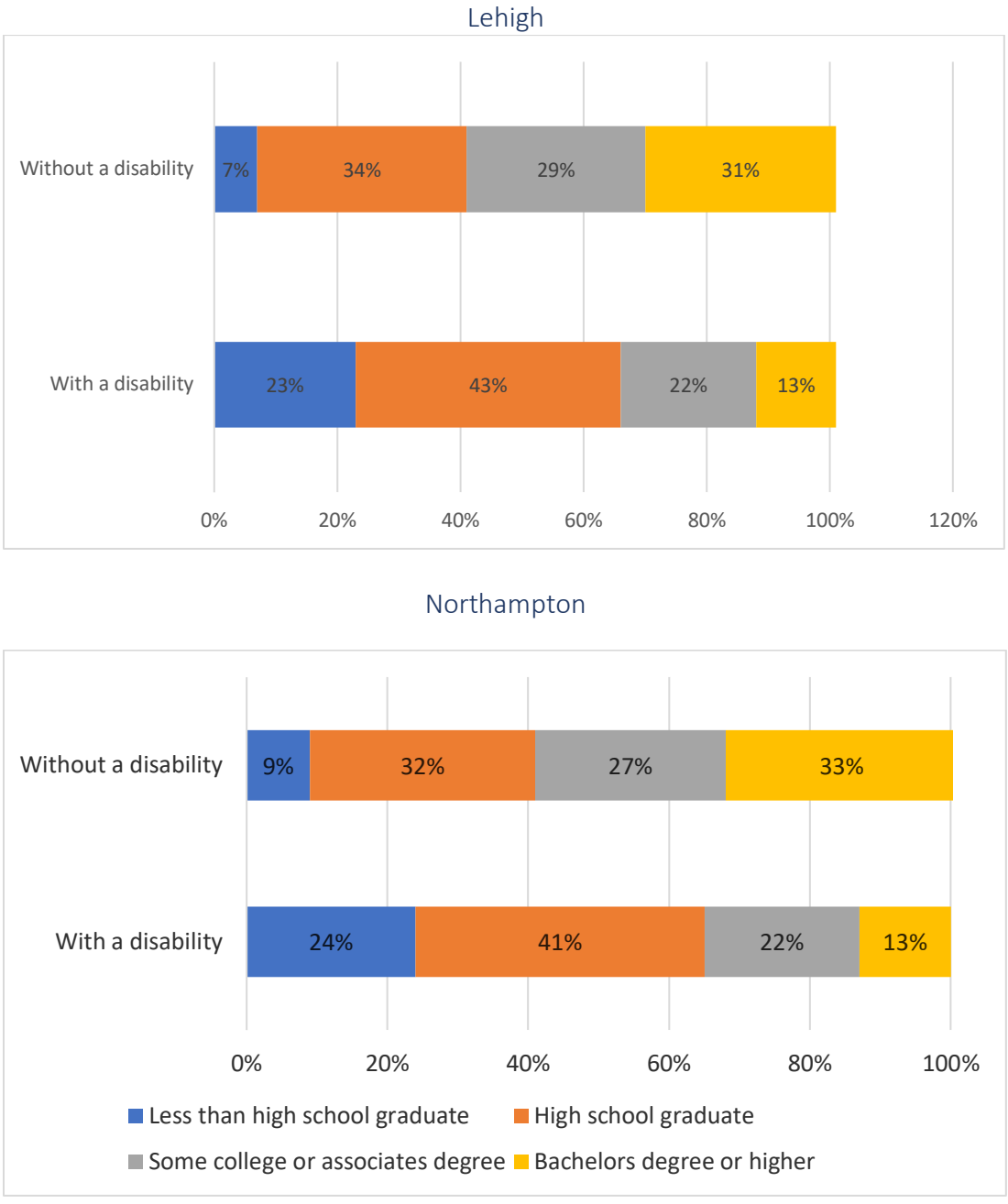
Finally, turning to consider education attainment, **Figure 10** summarizes educational attainment among adults over the age of 25 in Lehigh and Northampton counties. As shown, individuals with disabilities are more likely to have less than a high school or high school education only. Individuals without disabilities are more likely to have some college education or a bachelor's degree compared to people with disabilities.

Figure 9. Employment Status and Disabilities, 2016



Source: US Census Bureau, American Community Survey, Five Year Estimates, 2016

Figure 10. Educational Attainment Among People with and without Disabilities in Lehigh and Northampton Counties, 2016



Source: US Census Bureau, American Community Survey, Five Year Estimates, 2016

Partners in Research for People with Disabilities: Summary of Primary Research

In addition to what we know from US Census Bureau and other secondary data, GSRN has learned a great deal about the needs of people with disabilities, their contributions to our community, and gaps in services from past research that it has commissioned in our region. For example, we know that health insurance alone cannot overcome barriers to equal opportunity in education, work, and community and that these are key social determinants of wellbeing.[11] People with disabilities in the Lehigh Valley have communicated—through surveys and community discussion settings—a clear need for more inclusive neighborhoods, social gatherings, and community spaces. Many Lehigh Valley residents with disabilities convey feelings of depression, social isolation, and loneliness. Likewise, past primary research in the region has consistently shown that mental health care is a significant issue. Finally, previous research has clearly demonstrated that transportation, housing, education, and employment are interlinked, interdependent factors that can facilitate, or conversely limit, independent living, inclusion and, ultimately, health.

The current project started with knowledge gleaned from these past studies and with information derived from secondary data. The first stage of this project was convening a public forum of approximately 120 community members, including elected officials, hospital administrators, directors of community health departments, academics, public school officials, representatives from the arts community, private and nonprofit organizations, religious organizations, and advocacy groups. These "stakeholders" collectively reflected on past progress and helped to identify areas of regional improvement, lingering areas of concern, and new research questions.[12]

Community Forum

To set the context for establishing new directions, the community forum began with a presentation of the findings from the previous CHNA and an overview of GSRN's established priorities and previous implementation plan. Forum participants next met in small groups to discuss progress, to identify areas in which progress has been slow or stalled, and to work with the research team to establish next steps in the research process. **Table 3** provides a summary of discussion questions (both written and oral responses were collected).

[11] The Census Bureau provides limited data on health insurance status of people with disabilities. This information is included in the data tables in Appendix III.

[12] The community forum was held in March 2018 in a conference center in Bethlehem, PA, a central location in Lehigh Valley with ample accessible parking. The event was free and open to the public and, with the help of the Disability Friendly Community, was widely advertised through social and print media in both English and Spanish.

Table 3. Community Forum Discussion Questions

What kinds of **improvements, or progress**, have we made in our region that has made a positive difference to the lives of people with disabilities? What things have gotten better? Can you think of concrete examples?
As Good Shepherd sets out to update this research, we don't want to leave anyone out. What do you think might be **the best way to make sure that we are hearing all voices**? How can we reach out? Who should we reach out to?
You just heard a presentation on past research that has covered issues such as health care, housing, transportation, and community attitudes. **What steps might the community take to improve in these areas**? Can you think of concrete examples?
What are the elements, or ingredients, of independent living and well-being? Which of these elements or ingredients do you need more access to, or more of?
What areas of research have we missed? What kinds of new topics, topics that are critically important to people with disabilities, should we explore?
What does our community do really well? What are our greatest challenges?
How well have we been doing as a community to improve services, access, and inclusion for people with disabilities?

Following these discussion questions, several themes emerged from the community forum:

Imperfect Progress with Community Inclusion: The Lehigh Valley has made noteworthy, if imperfect, progress in improving accessibility and inclusion for people with disabilities.

> Educational and arts institutions, in particular, have made great strides in developing and promoting accessible performances and venues and in fostering opportunities for people with disabilities. Public primary and secondary schools continue to be leading examples of inclusion and access, helping to change norms by fostering awareness and acceptance of children with disabilities. Outdoor recreational spaces, churches and religious organizations, and public spaces including airports, libraries, malls, restaurants, and movie theatres have also become more accessible and more welcoming of people with disabilities.
>
> Major cities in the Lehigh Valley have made progress increasing the numbers of accessible curb cuts, making it easier for individuals who use wheelchairs to travel independently in the region's urban areas. While significant challenges in public

transportation remain (see more on this below), LANTA (the public bus transportation system in the region) has reached 100% wheelchair accessibility in all its busses; all busses now "kneel" and have roll-on ramps and off-aisle wheelchair spaces. Employers, too, have a better understanding about the talents people with disabilities bring to the workforce; several large employers in the region have developed good track records employing individuals with disabilities, including individuals with learning disabilities. Employers are more open to job coaches to help foster inclusive, diverse workplaces and internships and grant funding is increasingly available (through the Office of Vocational Rehabilitation) to help teenagers explore careers and employment. Finally, although housing remains a significant concern, there has been an increase in specialized housing for people with disabilities and in resources to assist with home modifications to allow individuals to age-in-place.

Of course, challenges remain. Parking is an especially salient issue, for example, and while some spaces like hospitals and schools have abundant handicapped parking, other popular community venues do not. Community attitudes may be improving, but people with disabilities still report higher than average symptoms of depression and feelings of loneliness and continue to experience negative perceptions from others.

Information Matters a Lot: With the ongoing development of social media and new communication technologies, information is both more readably available and seemingly harder to find.

Information is power. While many forum participants noted with appreciation improvements in community accessibility and changing attitudes, they also noted that it can be difficult to find information that would help people with disabilities participate in community more fully. There are many types of information, of course, and participants mentioned several ranging from information about long-term care options for aging adults with disabilities, to information about young and middle-aged adult programs, to waivers for Medicaid and Medicare (particularly for people with autism), to information about applying for subsidies for programs, to information about support groups and fostering networks and relationships.

Particular Needs of Young Adults, Ages 21 to 45: There are gaps in community services specifically designed to foster inclusion for post-school age young adults through early- to mid-adulthood.

Several small group discussions at the forum mentioned that while school-age children and young adults with disabilities have access to community events, support groups, and organizational programs—and similar opportunities often exist for seniors—these same resources and services do not exist for the post-21 age group. This age group, and the needs of adults age 21-45 (or even 21 to 64) may have been underrepresented in

previous research. As one participant shared, "***Young adults with disabilities need help with aging and future plans, there is a shortage of caregivers and funding and few drop off medical sources and resources for the post-21 age group (especially for those with very special needs).***" Another participant commented, "***Generational differences matter among people with disabilities.***"

The "Big Issues"—Housing & Transportation—are Still the Big Issues: Despite some important improvements in housing and transportation in the Lehigh Valley, these two issues remain the big issues, linked to almost all other factors shaping individual health, autonomy, independent living, emotional wellbeing, and community inclusion.

Community forum participants expressed extreme dissatisfaction with the limited availability of affordable public transportation options and, in particular, dissatisfaction with specialized transport options (Lanta's Easton Coach) which participants perceive as being unreliable and confined by unreasonable operational policies. One participant wrote, "***How do we solve the transportation puzzle? It is key to so much!***"

Many forum participants also pointed to difficulty finding affordable, accessible housing across the region (rather than simply in low-income neighborhoods) in close proximity to stores, parks, schools, etc. Growing interest and support for aging-in-place require resources for home modifications. Housing is key to social connectedness, financial independence, education, employment, independent living, and a sense of fulfillment.

Housing and transportation are also systemic—while individuals and organizations, including GSRN, can seek grant monies and help advocate for public policy change to improve housing and transportation in the region, making meaningful change in these areas requires sustained support and involvement from many constituencies, including government.

Medical Professionals Don't Always Show Sensitivity & Health Care Access Remains a Challenge for Some: While there have been notable improvements in the health care system, challenges remain. Health care professionals often demonstrate implicit bias toward people with disabilities. Access remains a challenge for key subgroups.

Similar to findings from previous studies, discussions at the forum revealed frustration with health care and medical professionals whom, some perceive, are not always knowledgeable about or sensitive to the needs of people with disabilities. In some ways, health care is improving—electronic medical records, for example, have made it easier for all people, including people with disabilities, to keep track of and share extensive medical records with many health care professionals. Nonetheless, constraints remain. For example, many individuals are limited in physical therapy and other rehabilitative services by health insurance caps; others living in rural areas of the region have difficulty

accessing special services and programs (and lack of access is only compounded by poor public transportation). Similarly, insurance reimbursement issues (e.g., due to physician coding requirements), were frequently mentioned by participants (for example, adults with Down Syndrome often end up continuing care with pediatricians rather than adult-patient physicians due to insurance coding issues).

The themes that emerged from the Community Forum, along with areas previously prioritized by GSRN in earlier CHNAs and implementation plans, helped to define a starting point for the development of a focus group strategy and protocol.

Focus Groups

The purposes of the focus groups were to:

1. Gather community members' perceptions, feelings, beliefs, and experiences as people with disabilities, and/or as family members of people with disabilities.
2. Understand the diversity of needs, opportunities, and interests of people with disabilities in our region.
3. Identify health concerns and needs of people with disabilities, especially as these intersect with the social, economic, and relational determinants of health, that have not been (or cannot be) adequately captured by available secondary data.

During the months of June and July, 2018, the research team conducted six focus groups. One of these was comprised of a group of 17 "key informants," that is, individuals who work for public, private or nonprofit organizations serving the disability community. The other five groups enrolled 61 people with disabilities and their family members. Focus groups were advertised and held in a variety of locations across the region in an effort to solicit participation from GRSN's client population as well as to broadly engage people with all kinds of disabilities. For example, the ARC of the Lehigh Valley serves individuals with intellectual and developmental disabilities and their families; the Center for Independent Living is a cross-disability organization and is also home to regular meetings of the Disability Friendly Community of the Lehigh Valley. See **Table 4** for a summary.[13]

A copy of the focus group protocol is included in **Appendix IV.** In brief, questions centered on accessibility of social and community spaces and activities, community inclusion, healthy relationships, information, changing needs and interests throughout the life-cycle, and opportunities to develop healthy behaviors. Participants were invited to bring up additional

[13] Focus groups were widely advertised through social media and email and in print at the locations at which they were held. Each participant was given a $75 Amazon.com as a token of thanks for their participation. Focus groups lasted approximately 90 to 120 minutes. Each participant signed informed consent documentation (see Appendix IV). Focus groups were audio recorded using a digital recorder and were later transcribed by student research assistants.

issues important to them. Researchers facilitating the focus groups took a relaxed approach, at times allowing the conversation to move in unanticipated directions.

Table 4. Focus Group Summary

Date	**Location**	**Target Population**	**No.**
June 18, 2018	Center for Vision Loss, Allentown, PA	Key Informants (e.g., agency heads and representatives, public officials)	17
June 21, 2018	GSRN Inpatient Pediatric Hospital, Bethlehem, PA	Parents of GSRN pediatric patient population	8
June 22, 2018	GSRN Health and Technology Center, Allentown, PA	GSRN patient population, members of support groups	16
June 25, 2018	Lehigh Valley Center for Independent Living, Allentown, PA	Cross-disability	16
July 10, 2018	ARC of the Lehigh Valley	Parents/families of individuals with developmental disabilities	14
July 23, 2018	Lehigh Valley Center for Independent Living, Allentown, PA	Cross-disability	7

Key Informant Focus Group

Key informants are individuals, who in their capacity as community leaders or employees of public, private, or nonprofit organizations have special insight into what is happening in the community and, in this case, what is happening in the lives of people with disabilities in our region. Participants in the key informant focus groups included representatives from the Lehigh Valley Center for Independent Living, the ARC of the Lehigh Valley, Easter Seals, Jewish Family Services, ARCH of the Lehigh Valley, the PA Office of Vocational Rehabilitation, the Center for Vision Loss, and other service providers and organizations whose work serves benefits with disabilities.

The key themes that emerged from this focus group were:

Accessibility

Many community venues—even if meeting minimum ADA compliance—are, in effect, inaccessible to people with disabilities who cannot walk significant distances and/or who use a wheelchair. Spaces such as movie theatres, music venues, including those recently developed in our region, such as SteelStacks and the Zoellner Arts Center, are

essentially inaccessible to people with physical disabilities due to parking limitations. Access is especially challenging for individuals who live in rural parts of our region. Public transportation constraints make it near impossible for individuals in rural areas to secure spontaneous transportation; many have to take several busses in a single trip to reach medical appointments in urban locations. There are options that might be available that cost more, or perhaps are unfamiliar to the disability community—for example, Cetronia ambulance provides on-demand transportation for individuals who use wheelchairs but at significantly higher costs than public transportation. The waiting time required for specialized transport is not feasible for older adults, or for parents with children with autism. Finally, the costs of public transportation have increased for many due to changes in Lanta's price structure.

Restrooms are another area of common concern. Key informants shared widespread agreement on the lack of accessible bathrooms, family bathrooms, and/or gender-neutral bathrooms that would permit individuals with disabilities and their caregivers to enter facilities together and/or that offer space for caregivers to assist adults with disabilities who need assistance using a bathroom and/or changing. These facilitates are lacking in most spaces, including medical buildings, malls and shopping centers, movie theatres, amusement parks, and spaces included GSRN's own outpatient facilities.

Community Perceptions & Attitudes

Key informants shared many experiences related to discrimination toward people with disabilities. Sometimes discriminatory treatment is overt; other times it stems from the invisibility of certain kinds of disability from the public eye, such as that experienced by individuals with chronic health conditions. Employers' discrimination, in particular, is a significant barrier to inclusion. This is not to suggest that there has been no positive change—one individual noted "***There are a lot of changes in the school system…so you have students [with disabilities] who are more visible out in the community and getting work experiences, doing things that 20/30 years ago they wouldn't have been doing.***"

Networks and Relationships

Key informants echoed the importance of networks, both among individuals working in agencies for people with disabilities and networks among people with disabilities themselves. One participant commented that agencies are "***gathering places for people with disabilities and also advocates.***" Public, private, non-profit organizations are often the sources of relationships for people with disabilities. Among key informants who themselves have family members with disabilities, respite care was another issue that arose during discussions about the kinds of resources that help foster healthy relationships.

Information and Communication

Key informants are, themselves, important sources of information. Some commented that when they need information not readily accessible or easily found, they use search engines, or call the Pennsylvania Disability Rights Council, admitting that this is not really an effective or efficient method.

The 211 system, designed to be a comprehensive information and referral service, is insufficient and not well-known throughout the region. Key informants are frequently solicited for information from the public and cobble together quick responses. One participant noted ***"I get phone calls from the community and I know I find myself doing referrals, I'm googling, I make referrals…I hate the 'Well, try this number, try that number.' I hate doing that to people."*** A key challenge is that "disability" is so broad and intersects with so many specific needs and community programs, that it is difficult to imagine one source covering everything. Many key informants are also, in effect, informal case managers for clients. One person noted, "***Of course, we refer to care management, and there are so many different services and depending on what the person is, there are waivers and who qualifies for a waiver, and those are systems I don't understand…There is nothing centralized."***

Of particular significance, the lack of coordinated information translates into great difficulty providing lifespan care for individuals with disabilities. This problem is especially acute as individuals transition from pediatric to adult medical care. Some of the difficulty, as noted, was not the availability of information, but rather effective communication about information that is available. One participant wondered what kinds of broad issues, such as financial planning, are included in care management services.

Life-Cycle and Aging Concerns

Key informants were asked to comment on specific questions about differences in the needs of individuals with disabilities depending on age, with a particular focus on the 21 to 45 age group. Some focus group participants suggested that the more appropriate age range would be 21 to 65, since this more accurately identifies individuals who are "too old" for school-age services and benefits and too young for services and benefits available to seniors. The age of the onset of disability makes a big difference to to the kinds of issues and obstacles (including mental health concerns) families confront when a family member has a disability, or becomes "disabled." The health care system, which bifurcates care between pediatrics and adults, thereby reinforces gaps in understanding and undermines medical knowledge about disability across an individual's lifespan. As one participant explained: "***There are people trained for pediatric diseased or disorders, and then [there are those who are trained to treat] adults." In*** the community, key informants noted, there are ample programs for young children, but there is a significant drop off for individuals after the age of 21.

Some of the key informants talked about their work with aging individuals with disabilities (say in their 40s), who often continue to live with their parents, who are also aging. Long-term care plans are often a challenge for families in these circumstances. Parents of young children with disabilities, similarly, must negotiate high degrees of uncertainty and anxiety about their children's social development.

What do people with disabilities need to live healthfully?

Key informants were quick to mention how integral transportation is to one's ability to live independently and healthfully—it is the key to accessing health care, dental care, and mental health services, as well as opportunities for exercise, support groups, and other social and community spaces. Accessible healthy living opportunities—adaptive yoga, for example, or affordable access to exercise physiologists—are few and far between in the Lehigh Valley. "***Generally, those kinds of things are inaccessible,***" one key informant commented. Others noted that fitness facilities in the region are not welcoming to people with disabilities, making exercise extremely "daunting" for people with disabilities to think about negotiating stereotypes and feelings of exclusion. The cost of gym and pool memberships and other recreational programs, even if the facilities are accessible, are insurmountable barriers to many people with disabilities especially those who are low-income.

Options for mental health services—meaning mental health professionals with particular expertise working with people with disabilities and disability affirmative therapy—are scarce in our region making it difficult for people with disabilities to attend to their own "whole health."

Others mentioned the energy and resources that are required for families to serve as advocates for people with disabilities, making the case for interpreters, resources, services—this takes a toll on entire families.

Other issues

When key informants were invited to offer other issues that were not included in the focus group protocol, they offered several. For example, some key informants suggested that there is a critical shortage of employees working in organizations serving people with disabilities, especially intellectually disabilities. One said, "***We're not creating…making it a career path, we're not paying people a living wage so that they do this as something they want to support and…it's a huge, huge problem."*** Other key informants focused on income and financial resources, noting, "***You have to be rich to be disabled."*** Living as a person with a disability requires extra resources, often for adaptive technology or specialized transportation, for example. The difficulties of finding meaningful employment as a person with a disability or the ramifications of receiving Medicaid become other forms of exclusion and inaccessibility. Relationships with law enforcement was another topic mentioned, "***You need a general understanding of how to approach someone and not taking disability into account or***

[if you] don't understand it, [it can] appear threatening." Building awareness among law enforcement and first responders regarding autism is especially important, suggested several participants.

Consumer Focus Groups

The remaining five focus groups included 58 individual "consumers," that is, people with disabilities and family members of people with disabilities. The same focus group protocol was used to facilitate conversation among the individuals who participated in these focus groups. The analysis that follows summarizes the most common issues and experiences that participants shared, noting any disagreement and paying special attention to unexpected findings.

Community: Access and Inclusion

The focus group facilitators asked participants to think about how the place where they live is connected to their experiences of access and inclusion. The Lehigh Valley is geographically diverse and, as a result, access to services and programs for people with disabilities is uneven throughout regional communities. For example, one focus group participant noted that smaller municipalities, such as those in the Slate Belt (Wind Gap, Pen Argyl, Bangor, Rosteo) lack the sources and activities that are accessible and feasible for people living in more urban communities. They noted, "***Everything is inaccessible, it is like living on an island."*** Transportation is inextricably linked to these issues. As one individual noted: ***"A great deal depends on whether you are able to drive…there may be places where you would like to go, that if you don't drive, you won't be able to go."***

As shown in **Table 5 A-B**, although focus group participants identified several community strengths when it comes to accessibility, nonetheless, they noted far more challenges. Among the meta-challenges, perhaps, is understanding what it means to "be accessible." One participant's story is an example:

> ***I think some people do not understand what accessible means…the new PPL center was supposed to be accessible. It was built so recently, and yet if you park in the parking deck and think how far that is to get anywhere, I don't consider that accessible. People who tell you, and [I] ran into this as Arts Quest, that they have accessible parking and they have a gravel parking lot. Have you tried taking a walker or wheelchair across gravel?***

Disability type clearly matters to individuals' ability to navigate spaces in our region and to feel included in community. One participant noted how, for example, "***large group things"*** are often not inclusive for individuals with sensory disabilities.

Table 5-A. Community Accessibility & Inclusion Strengths

Sources of support in the region are often found in **informal networks**. For example, networks facilitate through churches in the community frequently help with transportation challenges. **Facebook and social media** have provided space for informal, but powerful, **support groups** especially among parents of children with disabilities.
Youth programs are a source of inclusion for many children with disabilities, including programs run by local YMCA/YWCAs, the Special Olympics, the Eastern PA Down Syndrome Center, inclusive sports leagues, accessible arts programs (including sensory friendly performances, closed captioning), community libraries, etc.
There are many **community space**s that are increasingly working to become more accessible, including many major grocery chains, shopping centers, the Sands casino, area colleges and universities. Fitness centers such as Planet Fitness are making similar efforts.
There are resources and **programs designed to help business, organizations, and community** venues to become more accessible (e.g., the LVCIL can help business identify areas in which they could improve accessibility).
Across most participants there was a consensus that **post-21 young adults** lack access to programs and services available to those under 21, but there are noted **signs of progress** in this area, including programs designed to help individuals seek and transition to employment after school, to live independently, to learn about life skills like family finances, cooking, budgeting, etc.

Table 5-B. Community Accessibility & Inclusion Challenges

Transportation is the key to community inclusion. Individuals with disabilities who rely on specialized transport (e.g., Easton Coach or Lanta Van) routinely point to problems with this transportation service as being inadequate, unreliable, and somewhat unfriendly.
It is difficult to find programs in which kids with disabilities and kids without disabilities can play together. And, as kids continue to age and hit middle-school and high-school years, this kind of inclusion becomes more challenging (e.g., sports teams become more competitive and less welcoming to kids with disabilities, teenagers start driving and going to school events and it is difficult for those with disabilities to participate and to be included). **As kids age, it becomes less likely, as one mother put it, that other kids in the neighborhood will "*come to the door and say, "Hey, can he come out and play?*"**
There are too **few community programs centering around young adults**. Once individuals become 21, the prevalence of community programs and other group activities declines precipitously. In combination with transportation issues, this leads to a sense of isolation and greater family stress.

Table 5-B, continued. Community Accessibility & Inclusion Challenges

Bathrooms are a significant issue for people with disabilities and their families. Gender neutral and family bathrooms, along with accessible bathrooms, continue to be in short supply and this is directly related to individuals' abilities to be included in community programs and events.
Sidewalks and handicapped parking remain an issue in many locations and community venues throughout the region. This is the case even for venues that are designated as "accessible"; often times the distance between parking and entrances is too far or the parking conditions are not workable for people using walkers/wheelchairs, etc. These challenges are only exacerbated during the winter months when uncleared snow-covered sidewalks become another obstacle. Similarly, entrances themselves (heavy doors that do not automatically open) are significant obstacles. In many spaces, it is difficult for individuals who use walkers and/or wheelchairs to navigate inside spaces (e.g., shops with narrow aisles). Restaurants in the region are especially challenging.
Minimum requirements for meeting accessibility code regulations are not fully inclusive and leave room for thinking more holistically, particularly in **making spaces inclusive for the deaf and hard of hearing and individuals who are blind**. Not all public schools are equally accessible and this may require bussing kids with disabilities to a school other than their "home school," a move that creates complications for families with multiple children.
Medical and health care organizations are not always full accessible or inclusive. For example, many doctors are unable to speak to patients who are deaf or hard of hearing. Other medical facilities lack inclusive, accessible bathrooms.
Specialty care, especially in pediatrics, is in short supply in the region. Parents of children with disabilities frequently remarked frustration with waiting lists, the need to drive long distances to receive care for their children (e.g., Philadelphia's CHOP), and developing more effective communication between primary care pediatricians and specialty providers. For these parents, **geography is linked to access and quality of care for their children.**
Alternative transportation options—e.g., Uber and Lyft—are financially out of reach for many and are not reliably accessible for all.

Relationships & A Sense of Belonging

Talking with focus group participants about accessibility issues quickly led to a conversation about relationships, community perceptions, and a sense of belonging. Many focus group participants shared painful experiences with social isolation and feelings of rejection, reflecting their own personal experiences as well as experiences of their family members. For example, one parent commented that some of the regional school districts have programs designed to provide peer support for students with disabilities, another parent noted that her daughter was

not invited to join her class on field trips because her disability posed a "liability" to the school. Several parents conveyed distress that their children had few friends and no meaningful mechanisms for making friends.

Senior centers, communities centered around children with disabilities (e.g., Down Syndrome, autism), community venues like arts venues and fitness centers—these offer important sources of connections for people with disabilities and also help to foster personal relationships. A challenge to sustaining support networks for parents and family members is that most support groups do not provide child or elder care which would go a long way in making it more possible for parents and family members to attend and to have the support they need as caregivers.

"Support groups" another noted, ***"are wonderful."*** On this last point, participants spent some time talking about different kinds of support groups and the mechanisms that facilitate them. Organizations like the Center for Independent Living, for example, or the Eastern PA Down Syndrome Center, serve as institutional foundations for many support groups and also facilitate connections between individuals. Others noted that, increasingly, support groups are formed through happenstance or luck or though social media and online connections.

When asked what resources are most important to helping individuals to live healthfully, one caregiver emphasized support groups and explained:

> ***Definitely having a support system of people to talk to, people to listen, even if they don't fully understand what you're going through, they are willing to listen and have empathy…that's the biggest thing for me…having someone else that I can turn to, multiple someone "elses" (sic) so I don't feel like I'm burning out…anyone really, is important.***

Information

Knowledge is key; incomplete knowledge or missing information can lead to feelings of hopelessness and loneliness. This central point was reiterated several times among focus group participants. Focus group facilitators asked participants where they go to look for information, and also to comment on the kinds of information that seem most difficult to find.

- **Social and online media technologies**, including Facebook, are critical sources of information and provide up-to-date information about programs and events in the region.

- Several **organizations** in the region have established reputations for provided reliable, useful information, including the Center for Independent Living, GSRN, Magellan Behavioral Health, the Alliance on Aging. The 211 system was mentioned in one of the 5 groups, but the majority of individuals at that meeting were

unfamiliar with the system and it was not mentioned by any participants in the remaining 4 groups.

- **The health care system is complex and confusing**. There is perhaps so much information about health care providers and hospital systems that it can be difficult for individuals to make meaningful decisions. The simple logistics of navigating health care—including health insurance—can be overwhelming.

- For parents of young children with disabilities, a central challenge in locating information is **knowing what questions to ask**. One woman, the mother of a child with a brain injury, recounts her journey as one of ***"constant hide and seek"*** for information:

  I have had family members that are like, "Call your social worker, call your social worker," and I'm like, "Where do they give this social worker out? Does somebody issue social workers that I don't know about?" I don't have a case worker; I don't have a social worker. I go on Facebook support groups…I call the lady at the county assistance office and I say, "Are you my case manager, are you my social worker?" She's like, "Do you have a problem with the application, that's what I'm here to help you with" …There needs to be communication, there needs to be "Oh, if I can't give you that, I have a list of people who can help you."

  Another mother shared her experience:

  [We need a list] of resources. Everything that I found for my son, from therapy to adaptive winter sports to all those kind of things I found on my own with Google.

- The availability of information is a slightly different question than the ease with which information can be consumed. And, **for families new to disability, understanding complex medical information and communicating with doctor's can be a herculean task**. One participant suggested that people need information in ***"Plain simple language."*** Another commented, ***"You shouldn't need a dictionary to figure out,"*** the information you need. Another reason information may be available but nonetheless inaccessible is the nature of information and disability itself, particularly for individuals with sensory and/or vision disabilities.

At least one focus group participant pointed out the compartmentalized fashion in which information about disabilities is organized. They said:

Places where you find the information, that has been one of the most frustrating things for me because provider agencies' tendencies are to do programmatic things…why do we expect our children to fit into programs? So that goes back to the expansion of true person-centered thinking, person centered plans, not by the way the system has designed it, but how you incorporate natural support, community, circles of support…

Disability Across the Lifecyle

Individuals' needs change throughout the aging process. The focus group facilitators were interested in talking with participants about how they have seen, or understood, their needs as changing over the course of their lives, and how they anticipate needs changing in the future. Seniors, for example, often require home modifications in order to age in their homes; individuals with developmental disabilities may need to modify home arrangements with health care agencies as they continue to age. One focus group participant, an individual who works with people with developmental disabilities, commented:

I was just going to say, coming from the developmental disability side of things, this is actually a big discussion that we recently had with our individuals aging in place, because we find once they are getting older, they need home improvement, they do not want to move, they want to stay where they are. We don't want to rip somebody out of home that they have been in for 15 to 20 years, so we have been relying on home health agencies to come in a lot…

Finding ways to enable individuals with disabilities to live independently, particularly given the low prevalence of low-cost, accessible housing was a significant concern. In addition to housing, health insurance changes generate anxiety among families attempting to "navigate" complex health care and health insurance systems over time, systems themselves that change (e.g., transitioning to Medicare for example).

Several parents worried about how they would coordinate care for their children once they reached young adulthood. One parent worried: "***Once you reach a certain age with cerebral palsy, like 18 or 19 years, you fall off a cliff."*** Another parent in a different focus group used the same metaphor to describe her experience with her son:

I am hesitant to say this in a room with families with young children, but once you fall off the education cliff after 21 it is really, really, it's a whole new world and it's…I would say even more challenging now than it was when he was young. Even medically, not just educationally. It's medical, it's the independent living piece, it's everything.

Community education is critically important to fostering awareness of disabilities at all ages. Another participant commented that as children age, the extent to which they are accepted by the wider community may change.

> ***Kids are cute and we can forgive them a lot, but as they get bigger and older, their actions get more pronounced. [My son] is a large guy and people tend to react with fear. I see that now. He likes to go to playgrounds, we go for walks, and I see [parents] like moving their kids away or looking or whatever because a big, scary guy is coming.***

When they imagined the future, perhaps **no issue worried focus groups as much as the costs of care**. Financial planning services (e.g., educational seminars about special needs trusts) was a noted need among participants. One participant noted the help that she had experienced working with a disability life planner:

> ***It's a lot of planning. And as a parent you do want to start early because some...have overnight situations [sudden onset of disability] that changes your lives immediately. And then you have a loved one who has a disability and we sometimes presume that siblings will care for them…but that doesn't always happen…for whatever families are in my area, we could hold a training because there is a disability life planning who I work very closely with…because even if we financially—and I'm one of them, I'm just your average working family—it's hard to put away because we don't think we're going to die for a long time, we think we're going to live forever, but having someone help us plan, even if it's just minimal steps.***

Challenges to Living Healthful Lives

A key goal for GSRN, along with other regional hospitals—indeed, a key goal of ACA requirements that charitable hospitals conduct community health needs assessments—is finding ways to help individuals live healthier lives. Some of the most frequently articulated challenges came from parents and family members of people with disabilities, who commented on the stress that caregiving generates. When asked to comment on the challenges to living healthfully for people with disabilities and their caregivers, one participant remarked, "***Yeah, it's called managing stress."*** One mother of a young child with a disability put it this way: "***The stress is so high that sometimes you just lose it, right? ...You feel like you're navigating…you're the only person that's ever travelled this path and there is no guide."***

Table 6 summarizes additional points raised by this part of focus group discussions. In sum, participants noted that they take steps to live as healthfully as possible, but that there are significant stressors and obstacles that make it difficult.

What Focus Group Participants Said on Their Own

One of the more remarkable findings from focus groups was the spontaneous support participants offered each other. They exchanged information, shared phone numbers and email

addresses with each other, made plans to follow up and, most notably, offered words of encouragement and support to each other both during and after focus groups. On at least one occasion, focus group participants inquired about whether they could remain in the meeting room to keep their conversation going after the research team had departed. This is a notable, an unexpected finding, and one that very much points to the significance of support groups, friendships, and relationships as these intersect with health for people with disabilities.

Additionally, several focus group participants mentioned the need for policy and legislative change. One person noted ***"I think legislators. It's very important for them to understand because they make the laws."*** Although legislative change was not a central focus of the focus group protocol, it is clear that many of the issues participants raised—from health care to transportation to housing to information—reach the boundaries of policy change.

Table 6. Challenges to and Resources for Living Healthful Lives

Challenges to Living Healthful Lives	Resources for Living Healthful Lives
Managing **Stress**	Yoga, meditation, acupuncture and similar **wellness services**
Combatting feelings of **isolation** and **loneliness**	**Sharing information**, networking with others, development friendships
Finding a way to live "***as normally as possible,"*** what one participant called "***seeking typical"*** while also caring for a person with a disability; limited respite care	**Community** and Civic Engagement
Geographic distance and **transportation** challenges preventing social connections	**Support groups**
Lack of access to opportunities for physical exercise with specialized day care for children with disabilities	**Mental health care services**, such as counseling and therapy
Inability to afford paid caregivers	As one participant said: ***"A little bit of kindness goes a long way"***
Difficulty accessing and/or affording mental health care	

Limitations of Focus Groups

It is important to mention the limitations of focus groups and to be cautious about drawing inferences from these findings to the population of people with disabilities more generally. There are several reasons for this. First, focus group participants are not a representative sample of the population. The focus group facilitators did not collect systematic information about participants' age, education, employment status, marital status, disability type, or race/ethnicity, and as a result we are unable to draw conclusions about how adequately or inadequately focus group participants represent the diversity of the community.

Moreover, there are several ways in which the focus group participants are definitely not representative. When it comes to gender, for example, far more women participated than men. Almost all of the participants who identified themselves as a parent or caregiver of a person with a disability was female (perhaps reflecting gender imbalances in the distribution of care work in our communities). Similarly, most, although not all, focus group participants were white. Due to the high proportion of Lehigh Valley residents who are Latino (Hispanic) the research team made a concerted effort to recruit Latino individuals to participate in focus groups (printing all recruiting materials in Spanish, hiring a Spanish language interpreter), but were largely unsuccessful. Tapping into the experiences of Latino communities and individuals in research on disabilities has been a decade-long challenge.

Finally, although many individuals voluntarily disclosed information about their personal disability and shared information about disability onset and type, others did not. Therefore, while focus group participants included individuals with sensory disabilities (including individuals who are blind and deaf and hard of hearing), it is likely that this subgroup is under-represented. This imbalance may have been heightened by focus group participant recruitment which emphasized GSRN's client population.

Appendix I: Health in the Lehigh Valley: Key Indicators from the County Health Rankings

Although it is difficult to understand the particular needs of people with disabilities using available county level data on the general population, nonetheless, this data does provide some context for considering regional challenges with respect to health. Therefore, **Table 7** summarizes key indicators available through the Robert Wood Johnson County Health Rankings to provide a snapshot of how Lehigh and Northampton counties compare to each other, to other counties in the state of PA, and to top-ranked counties across the nation. Across many, but not all of these indicators, Lehigh and Northampton counties outperform the state of PA as a whole. Exceptions include several health measures in which Lehigh County fares worse, including premature death, the percentage of adults reporting poor or fair health, HIV prevalence, obesity, alcohol impaired driving deaths, sexually transmitted infections, teen births, and the ratio of mental health providers to population. On none of these health outcomes does the Lehigh Valley outperform the top performing counties in the nation.

Red = County performs worse compared to state as a whole
Green = County performs better compared to state as a whole

Table 7. Robert Wood Johnson 2018 County Health Rankings: Summary of Key Measures

County Health Measure	Lehigh	Northampton	PA	Top Counties in US (counties in the 90th percentile)
Premature Death (per 100,000)	**6100**	**5700**	6900	5300
Poor of Fair Health (% of adult reporting)	**16%**	**13%**	15%	12%
Poor physical health days (avg. no. of days in past 30 days)	**3.5**	**3.3**	3.9	3.0
Poor mental health days (avg. no. days in past 30 days)	**3.9**	**3.6**	4.3	3.1
Low birthweight (% of low weight births)	8%	8%	8%	6%
Frequent physical distress (% adults reporting 14 or more days per mo. of poor physical health)	**11%**	**10%**	12%	9%
Frequent mental distress (% adults reporting 14 or more days per mo. of poor mental health)	**12%**	**11%**	13%	10%

County Health Measure	Lehigh	Northampton	PA	Top Counties in US (counties in the 90th percentile)
Diabetes Prevalence (% adults ages 20+ diagnosed with diabetes)	11%	12%	11%	8%
HIV prevalence (No. persons age 13+ living with HIV per 100,000)	319	106	314	49
Adult smoking (% adults who are current smokers)	15%	15%	18%	14%
Adult obesity (% adults with BMI >30)	31%	29%	30%	26%
Food environment index (factors contributing to healthy food environment, 0 worse, 10 best)	8.6	8.6	8.2	8.6
Physical inactivity (5 adults age 20+ reporting no leisure-time activity)	25%	26%	24%	20%
Access to exercise opportunity (% population with access to locations for physical activity)	70%	74%	68%	91%
Excessive drinking (% adults reporting binge or heavy drinking)	20%	20%	21%	13%
Alcohol impaired driving deaths (% driving deaths involving alcohol)	32%	35%	30%	13%
Sexually-transmitted infections (no. diagnosed chlamydia cases per 100,000)	455.5	322.6	418.1	145.1
Teen births (no. births per 100,000 female population 15-19)	26	16	21	15
Food insecurity (% population lacking access to food)	10%	10%	13%	10%
Limited access to healthy foods (% population low income and live far from grocery store)	4%	4%	5%	2%
Drug overdose deaths (No. per 100,000)	21	23	28	10
Motor vehicle crash deaths (no. per 100,000)	9	8	10	9
Insufficient sleep (% adults reporting <7 hrs. per sleep on average)	34%	36%	38%	27%
Uninsured (% of population under age 65)	9%	7%	8%	6%

County Health Measure	Lehigh	Northampton	PA	Top Counties in US (counties in the 90th percentile)
Primary care physicians (ratio of population to pcp)	**1040:1**	**1170:1**	1230:1	1030:1
Dentists (ratio of population to dentists)	**1180:1**	**1850:1**	1480:1	1280:1
Mental health providers (ratio of population to mental health providers)	**600:1**	**530:1**	560:1	330:1
High school graduation (% of 9th grade cohort to graduate in 4 yrs.)	84%	**37%**	85%	95%
Some college (% adults ages 25-44 with some postsecondary education)	**63%**	**67%**	64%	72%
Unemployment (% pop. over age 16 unemployed and looking for work)	5.4%	5.2%	5.4%	3.2%
Children in poverty (% under 18 in poverty)	**20%**	**14%**	18%	12%
Social associations (no. membership groups per 10,000)	**10.5**	**10.7**	12.1	22.1
Violent crime (no. reported violent crime offenses per 100,000)	**242**	**173**	333	62
Severe housing problems (% households with overcrowding, high housing costs, or lack of kitchen or plumbing facilities)	**17%**	**16%**	15%	9%

Appendix II: Population with a Disability, Lehigh and Northampton Counties, by Municipality 2016

Lehigh County

Lehigh County Municipalities	Total Population	Population with a Disability	Percent of Population with a Disability
Alburtis borough	2,454	290	11.8
Allentown city	117,369	21,641	18.4
Bethlehem city	18,865	2,779	14.7
Catasauqua borough	6,509	1,220	18.7
Coopersburg borough	2,217	208	9.4
Coplay borough	3,232	376	11.6
Emmaus borough	11,363	1,550	13.6
Fountain Hill borough	4,414	775	17.6
Hanover township	1,716	233	13.6
Heidelberg township	3,480	400	11.5
Lower Macungie township	31,471	3,371	10.7
Lower Milford township	3,864	383	9.9
Lowhill township	2,112	176	8.3
Lynn township	4,314	558	12.9
Macungie borough	3,115	432	13.9
North Whitehall township	16,070	1,716	10.7
Salisbury township	13,307	1,637	12.3
Slatington borough	4,278	825	19.3
South Whitehall township	19,082	2,288	12
Upper Macungie township	22,414	1,788	8
Upper Milford township	7,516	603	8
Upper Saucon township	15,892	1,525	9.6
Washington township	6,733	943	14
Weisenberg township	5,070	339	6.7
Whitehall township	27,039	3,557	13.2

Northampton County Municipalities	Total Population	Population with a Disability	Percent of Population with a Disability
Allen township	4,630	360	7.8
Bangor borough	5,198	953	18.3
Bath borough	2,635	344	13.1
Bethlehem city	55,339	7,785	14.1
Bethlehem township	23,641	2,511	10.6
Bushkill township	8,341	903	10.8
Chapman borough	178	19	10.7
East Allen township	4,840	824	17
East Bangor borough	1,099	136	12.4
Easton city	26,087	3,357	12.9
Forks township	15,184	1,437	9.5
Freemansburg borough	2,633	368	14
Glendon borough	513	87	17
Hanover township	11,347	984	8.7
Hellertown borough	5,837	779	13.3
Lehigh township	10,414	1,179	11.3
Lower Mount Bethel township	3,088	364	11.8
Lower Nazareth township	5,905	395	6.7
Lower Saucon township	10,719	1,031	9.6
Moore township	9,239	1,440	15.6
Nazareth borough	5,581	784	14
Northampton borough	9,887	1,821	18.4
North Catasauqua borough	2,841	341	12
Palmer township	20,908	2,477	11.8
Pen Argyl borough	3,545	420	11.8
Plainfield township	6,138	995	16.2
Portland borough	482	104	21.6
Roseto borough	1,619	202	12.5
Stockertown borough	1,170	108	9.2
Tatamy borough	1,027	113	11
Upper Mount Bethel township	6,843	856	12.5
Upper Nazareth township	5,857	487	8.3

Walnutport borough	2,047	258	12.6
Washington township	5,069	645	12.7
West Easton borough	1,347	199	14.8
Williams township	5,985	644	10.8
Wilson borough	7,719	1,137	14.7
Wind Gap borough	2,709	487	18

Appendix III: Disabilities in the Lehigh Valley: Key Data Tables from the US Census

PA, Lehigh, and Northampton County Disability Population Data, 2012-2016										
Pennsylvania	2012-2016	Percent	2011-2015	Percent	2010-2014	Percent	2009-2013	Percent	2008-2012	Percent
Total Civilian Noninstitutionalized Population	12,579,598		12,575,088		12,553,967		12,525,314		12,492,799	
Population with a disability	1,719,069	13.67%	1,696,250	13.49%	1,671,703	13.32%	1,651,733	13.19%	1,646,256	13.18%
With a hearing difficulty	469,694	3.73%	467,083	3.71%	461,689	3.68%	456,270	3.64%	459,197	3.68%
With a vision difficulty	281,240	2.24%	274,957	2.19%	264,168	2.10%	262,695	2.10%	262,742	2.10%
With a cognitive difficulty	669,211	5.32%	657,701	5.23%	648,423	5.17%	634,397	5.06%	624,678	5.00%
With an ambulatory difficulty	875,379	6.96%	866,744	6.89%	855,087	6.81%	848,624	6.78%	846,624	6.78%
With a self-care difficulty	324,194	2.58%	321,588	2.56%	314,910	2.51%	309,706	2.47%	308,681	2.47%
With an independent living difficulty	617,272	4.91%	614,718	4.89%	607,516	4.84%	599,801	4.79%	596,972	4.78%
Northampton	2012-2016		2011-2015		2010-2014		2009-2013		2008-2012	
Total Civilian Noninstitutionalized Population	297,641		296,646		295,996		295,052		293,943	
Population with a disability	37,334	12.54%	37,487	12.64%	37,301	12.60%	36,651	12.42%	36,432	12.39%
With a hearing difficulty	9,480	3.19%	9,822	3.31%	10,344	3.49%	10,421	3.53%	10,627	3.62%
With a vision difficulty	6,095	2.05%	6,126	2.07%	5,720	1.93%	5,675	1.92%	5,512	1.88%
With a cognitive difficulty	14,485	4.87%	14,449	4.87%	14,861	5.02%	14,188	4.81%	13,468	4.58%
With an ambulatory difficulty	19,389	6.51%	19,744	6.66%	19,533	6.60%	19,094	6.47%	19,102	6.50%
With a self-care difficulty	6,864	2.31%	7,211	2.43%	7,170	2.42%	6,992	2.37%	6,816	2.32%
With an independent living difficulty	13,776	4.63%	14,000	4.72%	13,999	4.73%	13,348	4.52%	13,277	4.52%
Lehigh	2012-2016		2011-2015		2010-2014		2009-2013		2008-2012	
Total Civilian Noninstitutionalized Population	353,896		351,921		349,844		347,308		345,404	
Population with a disability	49,613	14.02%	49,510	14.07%	48,347	13.82%	46,383	13.36%	45,002	13.03%
With a hearing difficulty	12,364	3.49%	12,048	3.42%	11,972	3.42%	11,425	3.29%	11,051	3.20%
With a vision difficulty	9,413	2.66%	9,313	2.65%	9,429	2.70%	9,291	2.68%	8,539	2.47%
With a cognitive difficulty	22,688	6.41%	22,482	6.39%	21,458	6.13%	19,833	5.71%	18,948	5.49%

PA, Lehigh, and Northampton County Disability Population Data, 2012-2016, continued

Lehigh Continued	2012-2016		2011-2015		2010-2014		2009-2013		2008-2012	
With an ambulatory difficulty	23,004	6.50%	23,138	6.57%	22,802	6.52%	22,197	6.39%	21,887	6.34%
With a self-care difficulty	8,599	2.43%	8,445	2.40%	8,133	2.32%	7,831	2.25%	7,504	2.17%
With an independent living difficulty	15,562	4.40%	15,128	4.30%	15,213	4.35%	14,602	4.20%	14,552	4.21%

Lehigh Valley (Northampton & Lehigh Counties Combined)	2012-2016		2011-2015		2010-2014		2009-2013		2008-2012	
Total Civilian Noninstitutionalized Population	651,537		648,567		645,840		642,360		639,347	
Population with a disability	86,947	13.34%	86,997	13.41%	85,648	13.26%	83,034	12.93%	81,434	12.74%
With a hearing difficulty	21,844	3.35%	21,870	3.37%	22,316	3.46%	21,846	3.40%	21,678	3.39%
With a vision difficulty	15,508	2.38%	15,439	2.38%	15,149	2.35%	14,966	2.33%	14,051	2.20%
With a cognitive difficulty	37,173	5.71%	36,931	5.69%	36,319	5.62%	34,021	5.30%	32,416	5.07%
With an ambulatory difficulty	42,393	6.51%	42,882	6.61%	42,335	6.56%	41,291	6.43%	40,989	6.41%
With a self-care difficulty	15,463	2.37%	15,656	2.41%	15,303	2.37%	14,823	2.31%	14,320	2.24%
With an independent living difficulty	29,338	4.50%	29,128	4.49%	29,212	4.52%	27,950	4.35%	27,829	4.35%

Source: US Census Bureau, American Community Survey, Five Year Estimates

Disability and Age, 2013-2016												
		Percent total pop.	Percent pop. with disability		Percent of total pop.	Percent pop. with disability		Percent total pop.	Percent pop. with disability		Percent total pop.	Percent pop. with disability
Pennsylvania	2012-2016			2011-2015			2010-2014			2009-2013		
Total Civilian Noninstitutionalized Population	12,579,598			12,575,088			12,553,967			12,535,314		
Population with a disability	1,719,069	13.67%		1,696,250	13.49%		1,671,703			1,651,733	13.18%	
Under 18	140,174	1.11%	8.15%	138,758	1.10%	8.18%	137,259	1.09%	8.21%	136,833	1.09%	8.28%
18-64	871,015	6.92%	50.67%	862,720	6.86%	50.86%	850,248	6.77%	50.86%	839,281	6.70%	50.81%
65 and over	707,880	5.63%	41.18%	694,772	5.52%	40.96%	684,196	5.45%	40.93%	675,619	5.39%	40.90%
Northampton	2012-2016			2011-2015			2010-2014			2009-2013		
Total Civilian Noninstitutionalized Population	297,641			296,646			295,996			295,052		
Population with a disability	37,334	12.54%		37,487	12.64%		37,301	12.60%		36,351	12.32%	
Under 18	2,982	1.00%	7.99%	2,965	1.00%	7.91%	3,026	1.02%	8.11%	3,244	1.10%	8.92%
18-64	17,525	5.89%	46.94%	17,524	5.91%	46.75%	17,568	5.94%	47.10%	17,309	5.87%	47.62%
65 and over	16,827	5.65%	45.07%	16,998	5.73%	45.34%	16,707	5.64%	44.79%	16,098	5.46%	44.28%
Lehigh	2012-2016			2011-2015			2010-2014			2009-2013		
Total Civilian Noninstitutionalized Population	353,896			351,921			349,844			347,308		
Population with a disability	49,613	14.02%		49,510	14.07%		48,347	13.82%		46,383	13.36%	
Under 18	5,734	1.62%	11.56%	5,599	1.59%	11.31%	5,428	1.55%	11.23%	5,201	1.50%	11.21%
18-64	26,022	7.35%	52.45%	26,175	7.44%	52.87%	25,508	7.29%	52.76%	24,412	7.03%	52.63%
65 and over	17,857	5.05%	35.99%	17,736	5.04%	35.82%	17,411	4.98%	36.01%	16,770	4.83%	36.16%

Disability and Age, 2013-2016, continued

		Percent total pop.	Percent pop. with disability		Percent of total pop.	Percent pop. with disability		Percent total pop.	Percent pop. with disability		Percent total pop.	Percent pop. with disability
Northampton and Lehigh Combined	2012-2016			2011-2015			2014			2013		
Total Civilian Noninstitutionalized Population	651,537			648,567			645,840			642,360		
Population with a disability	86,947	13.34%		86,997	13.41%		85,648	13.26%		82,734	12.88%	
Under 18	8,716	1.34%	10.02%	8,564	1.32%	9.84%	8,454	1.31%	9.87%	8,445	1.31%	10.21%
18-64	43,547	6.68%	50.08%	43,699	6.74%	50.23%	43,076	6.67%	50.29%	41,721	6.49%	50.43%
65 and over	34,684	5.32%	39.89%	34,734	5.36%	39.93%	34,118	5.28%	39.84%	32,868	5.12%	39.73%
Source: US Census Bureau, American Community Survey, Five Year estimates, S1810												

Population of People with Disabilities By Disability Type, 2010-2016										
Pennsylvania	2012-2016	Percentage	2011-2015	Percentage	2010-2014	Percentage	2009-2013	Percentage	2008-2012	Percentage
Total Civilian Noninstitutionalized Population	12,579,598		12,575,088		12,553,967		12,525,314		12,492,799	
Population with a disability	1,719,069	13.67%	1,696,250	13.49%	1,671,703	13.32%	1,651,733	13.19%	1,646,256	13.18%
With a hearing difficulty	469,694	3.73%	467,083	3.71%	461,689	3.68%	456,270	3.64%	459,197	3.68%
With a vision difficulty	281,240	2.24%	274,957	2.19%	264,168	2.10%	262,695	2.10%	262,742	2.10%
With a cognitive difficulty	669,211	5.32%	657,701	5.23%	648,423	5.17%	634,397	5.06%	624,678	5.00%
With an ambulatory difficulty	875,379	6.96%	866,744	6.89%	855,087	6.81%	848,624	6.78%	846,624	6.78%
With a self-care difficulty	324,194	2.58%	321,588	2.56%	314,910	2.51%	309,706	2.47%	308,681	2.47%
With an independent living difficulty	617,272	4.91%	614,718	4.89%	607,516	4.84%	599,801	4.79%	596,972	4.78%
Lehigh	2016		2015		2014		2013		2012	
Total Civilian Noninstitutionalized Population	353,896		351,921		349,844		347,308		345,404	
Population with a disability	49,613	14.02%	49,510	14.07%	48,347	13.82%	46,383	13.36%	45,002	13.03%
With a hearing difficulty	12,364	3.49%	12,048	3.42%	11,972	3.42%	11,425	3.29%	11,051	3.20%
With a vision difficulty	9,413	2.66%	9,313	2.65%	9,429	2.70%	9,291	2.68%	8,539	2.47%
With a cognitive difficulty	22,688	6.41%	22,482	6.39%	21,458	6.13%	19,833	5.71%	18,948	5.49%
With an ambulatory difficulty	23,004	6.50%	23,138	6.57%	22,802	6.52%	22,197	6.39%	21,887	6.34%
With a self-care difficulty	8,599	2.43%	8,445	2.40%	8,133	2.32%	7,831	2.25%	7,504	2.17%
With an independent living difficulty	15,562	4.40%	15,128	4.30%	15,213	4.35%	14,602	4.20%	14,552	4.21%
Northampton	2016		2015		2014		2013		2012	
Total Civilian Noninstitutionalized Population	297,641		296,646		295,996		295,052		293,943	
Population with a disability	37,334	12.54%	37,487	12.64%	37,301	12.60%	36,651	12.42%	36,432	12.39%
	9,480	3.19%	9,822	3.31%	10,344	3.49%	10,421	3.53%	10,627	3.62%

With a hearing difficulty										
With a vision difficulty	6,095	2.05%	6,126	2.07%	5,720	1.93%	5,675	1.92%	5,512	1.88%
Northampton Continued	2016		2015		2014		2013		2012	
With a cognitive difficulty	14,485	4.87%	14,449	4.87%	14,861	5.02%	14,188	4.81%	13,468	4.58%
With an ambulatory difficulty	19,389	6.51%	19,744	6.66%	19,533	6.60%	19,094	6.47%	19,102	6.50%
With a self-care difficulty	6,864	2.31%	7,211	2.43%	7,170	2.42%	6,992	2.37%	6,816	2.32%
With an independent living difficulty	13,776	4.63%	14,000	4.72%	13,999	4.73%	13,348	4.52%	13,277	4.52%
Lehigh Valley (Northampton & Lehigh Counties Combined)	2016		2015		2014		2013		2012	
Total Civilian Noninstitutionalized Population	651,537		648,567		645,840		642,360		639,347	
Population with a disability	86,947	13.34%	86,997	13.41%	85,648	13.26%	83,034	12.93%	81,434	12.74%
With a hearing difficulty	21,844	3.35%	21,870	3.37%	22,316	3.46%	21,846	3.40%	21,678	3.39%
With a vision difficulty	15,508	2.38%	15,439	2.38%	15,149	2.35%	14,966	2.33%	14,051	2.20%
With a cognitive difficulty	37,173	5.71%	36,931	5.69%	36,319	5.62%	34,021	5.30%	32,416	5.07%
With an ambulatory difficulty	42,393	6.51%	42,882	6.61%	42,335	6.56%	41,291	6.43%	40,989	6.41%
With a self-care difficulty	15,463	2.37%	15,656	2.41%	15,303	2.37%	14,823	2.31%	14,320	2.24%
With an independent living difficulty	29,338	4.50%	29,128	4.49%	29,212	4.52%	27,950	4.35%	27,829	4.35%
Source: US Census Bureau, American Community Survey, five year estimates, S1810										

Key Demographic and Social Characteristics, 2016

	Lehigh County			Northampton County		
	Total Pop.	Pop. with a disability	Percent with a disability	Total Pop.	Pop. with a disability	Percent with a disability
Total civilian noninstitutionalized population	353,896	49,613	14.0%	297,641	37,334	12.5%
Male	172,271	23,077	13.4%	146,281	17,156	11.7%
Female	181,625	26,536	14.6%	151,360	20,178	13.3%
RACE AND HISPANIC OR LATINO ORIGIN						
White alone	278,611	38,495	13.8%	257,104	33,068	12.9%
Black or African American alone	23,580	3,830	16.2%	14,994	1,636	10.9%
American Indian and Alaska Native alone	684	82	12.0%	1,132	114	10.1%
Asian alone	11,653	672	5.8%	8,071	484	6.0%
Native Hawaiian and Other Pacific Islander alone	134	29	21.6%	53	14	26.4%
Some other race alone	28,890	5,077	17.6%	6,775	895	13.2%
Two or more races	10,344	1,428	13.8%	9,512	1,123	11.8%
White alone, not Hispanic or Latino	238,971	32,690	13.7%	233,340	29,809	12.8%
Hispanic or Latino (of any race)	77,484	12,260	15.8%	36,142	4,979	13.8%
AGE						
Under 5 years	21,339	185	0.9%	15,199	163	1.1%
5 to 17 years	60,662	5,549	9.1%	46,679	2,819	6.0%
18 to 34 years	77,480	7,050	9.1%	64,160	3,757	5.9%
35 to 64 years	140,381	18,972	13.5%	121,502	13,768	11.3%
65 to 74 years	29,899	6,428	21.5%	27,619	5,966	21.6%
75 years and over	24,135	11,429	47.4%	22,482	10,861	48.3%
With a hearing difficulty	(X)	12,364	3.5%	(X)	9,480	3.2%
Population under 18 years	82,001	493	0.6%	61,878	270	0.4%
Population under 5 years	21,339	119	0.6%	15,199	112	0.7%
Population 5 to 17 years	60,662	374	0.6%	46,679	158	0.3%
Population 18 to 64 years	217,861	4,324	2.0%	185,662	2,832	1.5%
Population 18 to 34 years	77,480	995	1.3%	64,160	256	0.4%
Population 35 to 64 years	140,381	3,329	2.4%	121,502	2,576	2.1%
Population 65 years and over	54,034	7,547	14.0%	50,101	6,378	12.7%
Population 65 to 74 years	29,899	2,343	7.8%	27,619	2,027	7.3%
Population 75 years and over	24,135	5,204	21.6%	22,482	4,351	19.4%
With a vision difficulty	(X)	9,413	2.7%	(X)	6,095	2.0%
Population under 18 years	82,001	730	0.9%	61,878	537	0.9%
Population under 5 years	21,339	87	0.4%	15,199	150	1.0%
Population 5 to 17 years	60,662	643	1.1%	46,679	387	0.8%
Population 18 to 64 years	217,861	5,238	2.4%	185,662	2,900	1.6%
Population 18 to 34 years	77,480	1,203	1.6%	64,160	497	0.8%
Population 35 to 64 years	140,381	4,035	2.9%	121,502	2,403	2.0%

Key Demographic and Social Characteristics, 2016, continued						
	Lehigh County			Northampton County		
	Total Pop.	Pop. with a disability	Percent with a disability	Total Pop.	Pop. with a disability	Percent with a disability
With a vision difficulty, continued						
Population 65 years and over	54,034	3,445	6.4%	50,101	2,658	5.3%
Population 65 to 74 years	29,899	1,002	3.4%	27,619	1,003	3.6%
Population 75 years and over	24,135	2,443	10.1%	22,482	1,655	7.4%
With a cognitive difficulty	(X)	22,688	6.8%	(X)	14,485	5.1%
Population under 18 years	60,662	4,583	7.6%	46,679	2,364	5.1%
Population 18 to 64 years	217,861	13,269	6.1%	185,662	7,902	4.3%
Population 18 to 34 years	77,480	4,874	6.3%	64,160	2,561	4.0%
Population 35 to 64 years	140,381	8,395	6.0%	121,502	5,341	4.4%
Population 65 years and over	54,034	4,836	8.9%	50,101	4,219	8.4%
Population 65 to 74 years	29,899	1,590	5.3%	27,619	1,205	4.4%
Population 75 years and over	24,135	3,246	13.4%	22,482	3,014	13.4%
With an ambulatory difficulty	(X)	23,004	6.9%	(X)	19,389	6.9%
Population under 18 years	60,662	698	1.2%	46,679	257	0.6%
Population 18 to 64 years	217,861	11,366	5.2%	185,662	8,619	4.6%
Population 18 to 34 years	77,480	1,667	2.2%	64,160	936	1.5%
Population 35 to 64 years	140,381	9,699	6.9%	121,502	7,683	6.3%
Population 65 years and over	54,034	10,940	20.2%	50,101	10,513	21.0%
Population 65 to 74 years	29,899	3,766	12.6%	27,619	3,489	12.6%
Population 75 years and over	24,135	7,174	29.7%	22,482	7,024	31.2%
With a self-care difficulty	(X)	8,599	2.6%	(X)	6,864	2.4%
Population under 18 years	60,662	756	1.2%	46,679	468	1.0%
Population 18 to 64 years	217,861	4,107	1.9%	185,662	2,726	1.5%
Population 18 to 34 years	77,480	928	1.2%	64,160	631	1.0%
Population 35 to 64 years	140,381	3,179	2.3%	121,502	2,095	1.7%
Population 65 years and over	54,034	3,736	6.9%	50,101	3,670	7.3%
Population 65 to 74 years	29,899	1,075	3.6%	27,619	980	3.5%
Population 75 years and over	24,135	2,661	11.0%	22,482	2,690	12.0%
With an independent living difficulty	(X)	15,562	5.7%	(X)	13,776	5.8%
Population 18 to 64 years	217,861	8,296	3.8%	185,662	5,827	3.1%
Population 18 to 34 years	77,480	2,204	2.8%	64,160	1,496	2.3%
Population 35 to 64 years	140,381	6,092	4.3%	121,502	4,331	3.6%
Population 65 years and over	54,034	7,266	13.4%	50,101	7,949	15.9%
Population 65 to 74 years	29,899	1,923	6.4%	27,619	2,017	7.3%
Population 75 years and over	24,135	5,343	22.1%	22,482	5,932	26.4%

Source: US Census Bureau, American Community Survey, Five Year estimates, 2016

EMPLOYMENT STATUS BY DISABILITY STATUS - Universe: Civilian noninstitutionalized population 18 to 64 years

	Pennsylvania		Lehigh County, Pennsylvania		Northampton County, Pennsylvania	
	Estimate	Margin of Error	Estimate	Margin of Error	Estimate	Margin of Error
Total:	7,829,145	+/-1,084	217,861	+/-236	185,662	+/-247
In the labor force:	6,052,002	+/-9,406	174,442	+/-1,353	145,766	+/-1,157
Employed:	5,624,851	+/-10,244	161,861	+/-1,335	136,802	+/-1,342
With a disability	302,417	+/-3,554	10,180	+/-725	6,706	+/-591
No disability	5,322,434	+/-11,054	151,681	+/-1,303	130,096	+/-1,330
Unemployed:	427,151	+/-4,833	12,581	+/-852	8,964	+/-628
With a disability	57,310	+/-1,795	1,892	+/-322	978	+/-200
No disability	369,841	+/-4,286	10,689	+/-733	7,986	+/-576
Not in labor force:	1,777,143	+/-9,077	43,419	+/-1,351	39,896	+/-1,124
With a disability	511,288	+/-5,714	13,950	+/-867	9,841	+/-691
No disability	1,265,855	+/-6,792	29,469	+/-1,187	30,055	+/-1,156

WORK EXPERIENCE BY DISABILITY STATUS - Universe: Civilian noninstitutionalized population 18 to 64 years

	Pennsylvania		Lehigh County, Pennsylvania		Northampton County, Pennsylvania	
	Estimate	Margin of Error	Estimate	Margin of Error	Estimate	Margin of Error
Total:	7,829,145	+/-1,084	217,861	+/-236	185,662	+/-247
Worked full-time, year round:	4,043,320	+/-9,564	116,511	+/-1,391	99,029	+/-1,360
With a disability	181,478	+/-2,772	5,993	+/-591	4,135	+/-404
No disability	3,861,842	+/-10,297	110,518	+/-1,429	94,894	+/-1,386
Worked less than full-time, year round:	2,145,475	+/-7,885	60,230	+/-1,320	53,451	+/-1,229
With a disability	184,017	+/-2,876	6,131	+/-493	4,002	+/-451
No disability	1,961,458	+/-7,626	54,099	+/-1,247	49,449	+/-1,162
Did not work:	1,640,350	+/-9,970	41,120	+/-1,287	33,182	+/-1,062
With a disability	505,520	+/-5,844	13,898	+/-878	9,388	+/-669
No disability	1,134,830	+/-7,172	27,222	+/-1,081	23,794	+/-1,003

Source: US Census Bureau, American Community Survey, Five Year Estimates, 2016 (C18121)

Health Insurance Status and Disability

	Lehigh County		Northampton County	
	Estimate	Margin of Error	Estimate	Margin of Error
Total:	353,896	+/-469	297,641	+/-380
Under 18 years:	82,001	+/-21	61,878	+/-75
With a disability:	5,734	+/-569	2,982	+/-354
With health insurance coverage:	5,615	+/-564	2,879	+/-359
With private health insurance coverage	2,210	+/-307	1,504	+/-247
With public health coverage	4,282	+/-543	1,895	+/-312
No health insurance coverage	119	+/-82	103	+/-55
No disability:	76,267	+/-567	58,896	+/-361
With health insurance coverage:	73,045	+/-761	57,215	+/-470
With private health insurance coverage	46,351	+/-1,504	41,508	+/-985
With public health coverage	29,237	+/-1,336	18,533	+/-1,126
No health insurance coverage	3,222	+/-494	1,681	+/-330
18 to 64 years:	217,861	+/-236	185,662	+/-247
With a disability:	26,022	+/-1,032	17,525	+/-942
With health insurance coverage:	23,003	+/-971	16,035	+/-913
With private health insurance coverage	11,304	+/-794	9,189	+/-641
With public health coverage	14,296	+/-927	9,060	+/-699
No health insurance coverage	3,019	+/-420	1,490	+/-319
No disability:	191,839	+/-1,068	168,137	+/-964
With health insurance coverage:	166,757	+/-1,648	150,721	+/-1,504
With private health insurance coverage	150,869	+/-1,772	139,518	+/-1,690
With public health coverage	19,556	+/-1,072	15,321	+/-944
No health insurance coverage	25,082	+/-1,303	17,416	+/-1,153
65 years and over:	54,034	+/-399	50,101	+/-297
With a disability:	17,857	+/-681	16,827	+/-775
With health insurance coverage:	17,721	+/-660	16,754	+/-766
With private health insurance coverage	11,718	+/-548	11,633	+/-709
With public health coverage	17,512	+/-658	16,673	+/-762
No health insurance coverage	136	+/-85	73	+/-58
No disability:	36,177	+/-679	33,274	+/-761
With health insurance coverage:	36,089	+/-687	33,113	+/-745
With private health insurance coverage	24,840	+/-682	24,571	+/-806
With public health coverage	35,045	+/-667	32,278	+/-729
No health insurance coverage	88	+/-65	161	+/-99

Source: U.S. Census Bureau, 2012-2016 American Community Survey 5-Year Estimates

Appendix IV. Focus Group Protocol

FOCUS GROUP SCRIPT

Moderator: Name of Researcher, Muhlenberg College
Assistant Moderator/Notetaker: Name of Research Assistant, Muhlenberg College

Thank you so much for taking the time to join in our discussion today. We have invited you here today because we are interested in learning more about your thoughts regarding steps that individuals, organizations, agencies, public officials, and community leaders can do to make the Lehigh Valley more accessible and inclusive for people with disabilities. We're interested in learning more about your thoughts and views about thinks like community engagement, information for people with disabilities, and healthy living.

Introduce and ask the participants to sign the consent form (if they have not already done so). Before we get started, I'd like to review the informed consent waiver that you received. *(Review and informed consent; verbally affirm consent and collect signed consent forms)*. We will record our discussion today with a digital tape recorder for post-analysis. After this tape is transcribed, it will be destroyed. Your name will not be revealed or linked to the transcript in anyway. All recorded information will remain confidential and will be used only for the purpose of this research project.

Please remember that you have the right to withdraw from the session at any time. Please help yourself to refreshments as you'd like throughout our time together today. We'll likely be here for about 90 minutes.

Facilitator Introduction
Assistant Facilitator/Note-taker Introduction

Participants Introduction

The facilitator will ask all participants to introduce themselves in a few sentences, using first names only.

Just a few requests as we begin:

1. *Only one person speaks at a time. We will be sure to hear from everyone.*
2. *Remember, you are not obligated to answer any questions, but we very much hope to be able to listen to your perspectives and viewpoints.*
3. *There are no "wrong answers," just different opinions.*
4. *Are there any questions before we get started?*

Consumer (e.g., people with disabilities) Focus Group Questions:

1. What kinds of locations, events, and activities are accessible, or inaccessible, to people with disabilities in your neighborhood or hometown? How does the place where you live matter to where you go and what kinds of things you do?

2. In what ways do you (or your family members with disabilities) participate in the community in which you live?
    - Is this your neighborhood, municipality, church, community organization, group?
    - What do you do for entertainment outside of your home (i.e., movies, shopping, eating out, spending time with friends)?
    - Are there other ways that you'd like to be involved in your community or neighborhood?
    - If you are not as involved as you'd like to be, why is that? What are the obstacles to being engaged and included in your community as fully as you'd like?

3. What has helped you to develop friendships and relationships with family members?
    - In what ways have you been able to develop relationships with family and with friends?
    - How do you feel others in your neighborhood or community view people with disabilities?

4. When you need information about something—whether it is information about services, resources, support, or things to do, recreation—where do you look for this information? Who do you ask? Where do you go?
    - What kinds of information are easy to find?
    - What kinds of information is difficult to find?
    - Do you know where and how to look for information about information especially relevant to people with disabilities? Where and how is that?
    - Do you need additional information that you're unable to find?
    - Are there organizations that you tend to rely on when your looking for specific kinds of information?

5. Have you noticed that your interests and your needs (or the interests and needs of your family member with a disability) have changed at different times throughout your life? As you're aging, are there different things that you need? Are there things that you needed when you were younger that you no longer need?
    - I'd like to think with you a bit about how individuals with disabilities who are ages 18 to 45 might have particular needs in our community? Past research has suggested that as individuals with disabilities reach adulthood, their needs and interests change. What's your thinking on this issue? What are the particular needs of individuals with disabilities who are ages 18 through 45 to 65?

6. What kinds of things do you do to take care of your health and wellbeing?

- Are there challenges to living healthfully?
- What kinds of opportunities, or resources, do you find helpful in living a healthy life?
- How do you take care of your physical and mental or emotional wellbeing?
- Do you need more help or assistance or information in order to live more healthfully? What might that look like.

7. Opportunity to raise issues that we haven't covered yet, that you'd like to offer up to the group for discussion.

Key Informant/Agency Representatives Focus Group Questions

1. What kinds of locations, events, and activities are accessible, or inaccessible, to people with disabilities in your neighborhood or hometown? In what ways does geography—that is, where people with disabilities live—matter to where they go and what they do?

2. In what ways do people with disabilities participate in the community in which you live?
    - Is this your neighborhood, municipality, church, community organization, group?
    - Are there other ways that people with disabilities could be, or ought to be, involved in your community or neighborhood?
    - What are the obstacles to being engaged and included in community for people with disabilities?

3. In what areas of life, neighborhood, and community, do you think people with disabilities are most accepted and included? Are there areas in which people with disabilities are not accepted and included?
    - What creates strong relationships for people with disabilities and family and friends?
    - How do you think others in the community view people with disabilities?

4. When you need information about something—whether it is information about services, resources, support, or things to do, recreation for people with disabilities—where do you look for this information? Who do you ask? Where do you go?
    - What kinds of information are easy to find?
    - What kinds of information is difficult to find?
    - Do you know where and how to look for information about information especially relevant to people with disabilities? Where and how is that?
    - Do you need additional information that you're unable to find?
    - Are there organizations that you tend to rely on when you're looking for specific kinds of information?

5. Have you noticed that interests and needs of people with disabilities change at different times throughout an individual's life? As people with disabilities age, are there different things that they need? Are there things people with disabilities need when they are younger, but that they don't need as much as they age?

- I'd like to think with you a bit about how individuals with disabilities who are ages 18 to 45 might have particular needs in our community? What might those needs look like?

6. What kinds of things can people with disabilities do, and what kinds of things might they already do, to attend to their own health and wellbeing?
    - Are there challenges to living healthfully for people with disabilities?
    - What kinds of opportunities, or resources, might help people with disabilities live healthy lives?
    - How do people with disabilities take care of their physical health and their mental health and emotional wellbeing?
    - Do you need more help or assistance or information in order to live more healthfully? What might that look like.

7. Opportunity to raise issues that we haven't covered yet, that you'd like to offer up to the group for discussion.