The Personal Experience Survey Report

Strategic Community Building Project

September 2, 2013

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Lehigh Valley Center for Independent Living (LVCIL)

The Lehigh Valley Center for Independent Living (LVCIL) is a registered 501(c)3 non-profit organization based in Allentown, PA that provides information, services and support to people with all types of disabilities.

LVCIL believes that every individual has the right to live a healthy, happy, and productive life in a community that is free from all barriers. Through supportive programs and services, LVCIL strives to empower people with disabilities to live independently and live life to the fullest. LVCIL provides four core services for consumers: Information and Referral, Peer Support, Advocacy, and Independent Living Skills. In addition, LVCIL also provides specialized services, such as Specialized Housing Search and Support services for low-income individuals, Veterans with disabilities, and landlords, a 24-hour Sign Language Interpreter Referral Service, youth transition services through the S2L Group, Road 2 Graduation, and Real World Lehigh Valley programs, job coaching for youth through the Career Path program, community accessibility services, and supports coordination under several waiver programs. The organization also provides community education, disability awareness training, and other community programs.

As one of eighteen Centers for Independent Living in the state of Pennsylvania, LVCIL is governed, managed, and staffed at all times by a majority of persons with disabilities.

Office of Vocational Rehabilitation (OVR)

The Office of Vocational Rehabilitation (OVR) provides vocational rehabilitation services to help persons with disabilities prepare for, obtain, and/or maintain employment. OVR provides services to eligible individuals with disabilities, both directly and through a network of approved vendors. Services are provided on an individualized basis.

In addition, OVR works through and with the Office of the Deaf and Hard of Hearing as well as the Bureau of Blindness and Visual Services. These units provide specialized services and support for persons who are deaf, hard of hearing, blind or visually impaired. OVR's services are designed to increase an individual's independence and employability.

Pennsylvania Statewide Independent Living Council (PASILC)

The Pennsylvania Statewide Independent Living Council (PASILC) is a nonprofit, cross-disability, consumer-controlled organization dedicated to securing public policies that ensure civil rights for people with disabilities by supporting the Independent Living (IL) philosophy.

The PASILC was established in 1992 to comply with the Federal Rehabilitation Act Amendments, which requires states to create a consumer-controlled advisory committee to the Office of Vocational - Rehabilitation's Independent Living Program. OVR and PASILC jointly develop the State Plan for Independent Living (SPIL). In 1992, the Rehabilitation Act Amendments gave PASILC co-signing authority on the federally-mandated SPIL. The statewide disability agenda is derived from the SPIL. The PASILC prepares the plan every three years based on the input from people with disabilities throughout

Pennsylvania. The plan identifies the issues people with disabilities want the PASILC to focus their efforts on during the next three years.

The SPIL provides guidelines to state departments as well as organizations involved in programs and/or services that impact the lives of people with disabilities on how to integrate the independent living philosophy in all relevant areas. Additionally, PASILC is able to provide limited funding to support these guidelines. PASILC's current SPIL focus includes:

- Education, with a focus on students making the transition from youth to adulthood, as well as current legislative initiatives focused on youth.
- Strengthening Pennsylvania's network of Centers for Independent Living (CILs).
- Grassroots Systems Advocacy in areas of concern for people with disabilities across Pennsylvania.

The key areas of grassroots advocacy are outlined more specifically in the PASILC's Disability Agenda.

PASILC Disability Agenda: Advocacy Focus Areas

Assistive Technology (AT) and Durable Medical Equipment (DME)

Assistive Technology (AT) and Durable Medical Equipment (DME) has empowered people with disabilities to live in the community through offering more ways to communicate, be employed, obtain education and provide enhanced transportation options. Having the equipment people need readily available ultimately gives people with disabilities the opportunity to be an integral part of their communities.

Emergency Preparedness

Being prepared for an emergency is crucial for everyone. Making sure that people with disabilities understand what it means to be prepared when faced with an emergency situation is critical to their well-being. In addition, it is just as critical for emergency personnel in our local communities to be aware of the needs of people with disabilities.

Employment

People with disabilities want to work and make excellent employees; research shows that people with disabilities have a wide range of education, skills and experiences, and are determined to use their talents to meet the needs of their employers. Advocacy efforts must be focused on providing people with disabilities with the proper training to obtain community based, competitive employment opportunities. In addition, employers must be educated on the benefits of hiring a person with a disability.

Home and Community Based Services

People with disabilities have a right to be able to live and work in the place of their own choosing. There needs to be a continued emphasis on providing the services and supports that people with disabilities use every day in a home and community based environment.

Housing

Issues with housing are one of the most critical issues the disability community is facing today. People with disabilities have been fighting for decades for the right to leave institutions and live in neighborhoods that are accessible to everyone.

Medical and Dental Coverage

In order to have a strong quality of life, people with disabilities must have the same access to care, services and medical products as the rest of the community. People with disabilities must have access to quality healthcare and be empowered to make informed decisions about the healthcare options presented to them by their various healthcare providers.

Transportation

Transportation is a vital aspect of living independently for everyone. For people with disabilities, accessible and dependable transportation is especially important for traveling to work, school, places of worship, stores and medical facilities. Improving transportation for people with disabilities has been a major focus for the disability community. Through partnership with the Transportation Alliance of PA and others, people with disabilities in Pennsylvania achieved a significant victory in 2007 with the creation of the Persons with Disabilities (PWD) Rural Shared-Ride Program. People with disabilities must continue to advocate for creation of accessible transportation options.

Voting

Throughout history, various groups have had their access to voting limited, including people with disabilities. It is everyone's right as a citizen of the United States to be able to vote. There must be continued efforts to educate people with disabilities about the importance of voting and helping them become a registered voter, so they can have their voice heard in the political process.

NOTE: The entire PASILC Disability Agenda document can be found on the internet at the following address: http://www.pasilc.org/CurrentSPILProjects/StatewideDisabilityAgenda.aspx

Project Description

What is the Strategic Community Building (SCB) Project?

The Office of Vocational Rehabilitation (OVR) and the Pennsylvania Statewide Independent Living Council (PASILC) partnered with the Lehigh Valley Center for Independent Living (LVCIL) to focus on strengthening community partnerships and coalitions. This is to assist people with disabilities with the goals of increasing independent living options, community access and expand the network of strategic community building groups to advocate for systems change.

LVCIL was asked to work in Region 5, which includes the following counties: Bradford County, Columbia County, Lackawanna County, Lehigh County, Luzerne County, Monroe County, Northampton County, Pike County, Sullivan County, Susquehanna County, Wayne County, and Wyoming County. The following are the expected outcomes of the project.

1. Gather consumer feedback through town hall meetings and a survey regarding barriers to people with disabilities according to the PASILC's Disability Agenda in the following areas:

   a. Assistive Technology/Durable Medical Equipment
   b. Emergency Preparedness
   c. Employment
   d. Home and Community Based Services
   e. Housing
   f. Medical/Dental Coverage
   g. Transportation
   h. Voter Access

2. Identify groups, partnerships, and coalitions that are interested in working together to improve systems and services in their respective communities

3. Provide education regarding issues and concerns affecting people with disabilities across Northeastern PA

Town Hall Meetings

As a component of the Strategic Community Building project, five town halls were held across Northeastern PA to gather information from the public on areas of concern for persons with disabilities. The town halls were held in the following locations:

- CareerLink in Monroe County
- Keystone College in Lackawanna County
- Lehigh Carbon Community College in Lehigh County
- Lehigh Valley Center for Independent Living in Lehigh County
- National Alliance on Mental Illness in Luzerne County

The format used for the town hall meetings was developed utilizing the questions from the survey the SCB team created. The town halls highlighted many issues and concerns in the disability community. In

addition, the town halls raised awareness in the community about the project. From the information gathered LVCIL was able to develop potential areas for advocacy for the project region.

Note: THM is used widely throughout this document to denote comments taken from "Town Hall Meetings."

Personal Experience Survey

The Personal Experience Survey was developed as a part of the Strategic Community Building project utilizing the Pennsylvania Statewide Independent Living Council (PASILC) Disability Agenda. The survey was developed to get a better understanding as to the issues affecting people with disabilities throughout the region.

The survey was available to the disability community for a three month period. Within the time, LVCIL received 913 responses. By doing this survey, people with disabilities were able to voice their opinions and their needs while not necessarily having to attend a town hall meeting. The success of the survey was due, in part, to having an electronic copy where people could fill out the survey online and it was also available in accessible formats.

Note: The data captures the initial findings and observations from the survey. The survey will be analyzed in more detail in the coming year. Sample size was collected via online and targeted outreach to private citizens, OVR customers, and consumers from Centers for Independent Living and other service providers and agencies in Region 5.

What We Found:

Biographic Information

56.7% of respondents were persons with disabilities that completed the survey on their own behalf. 19.8% respondents completed the survey with the assistance of someone else, such as a spouse, family member, trusted friend, or caregiver, and 23.4% of respondents filled out the survey as a parent of a child with a disability.

Which of the following best describes you?

	I am a person with a disability completing this survey on my own behalf.	I am a person with a disability completing this survey with the assistance of someone else.	I am a parent of child with a disability.
■ Percentage	56.7%	19.8%	23.4%
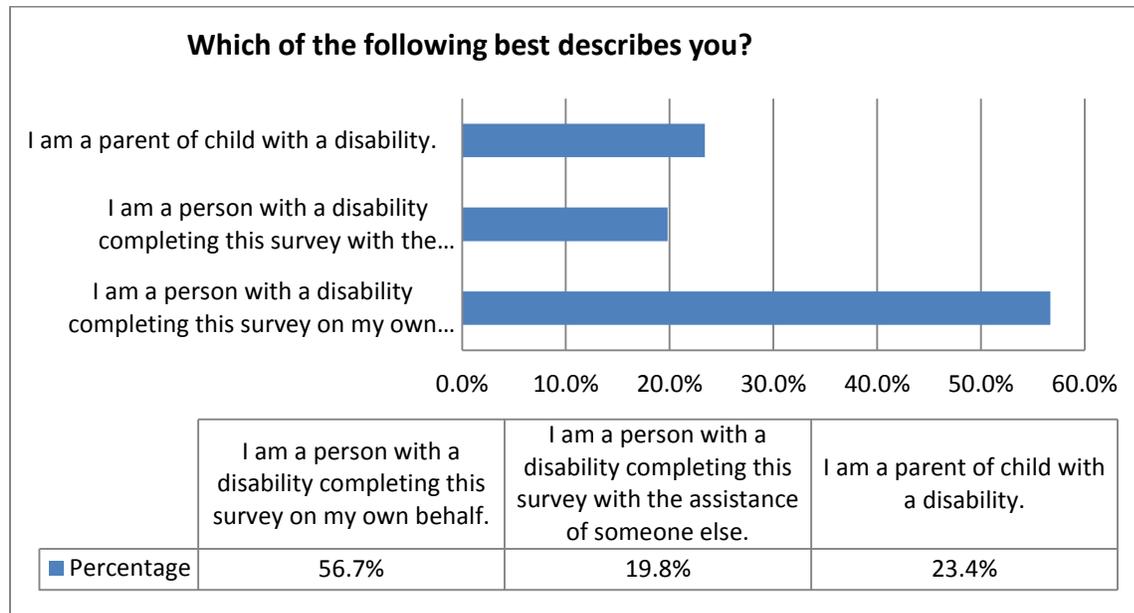
More than 84% of the people surveyed were adults with disabilities, with the greatest representation from people between the ages of 19-65. People with disabilities ages 10-18 made up 12.9% of survey respondents and 2.8% of respondents were younger than 10 years old.

Your age or your child's age (if you are a parent/guardian)?

	Younger than 10	10-18	19-35	36-65	66 or older
■ Percentage	2.8%	12.9%	37.5%	39.6%	7.1%
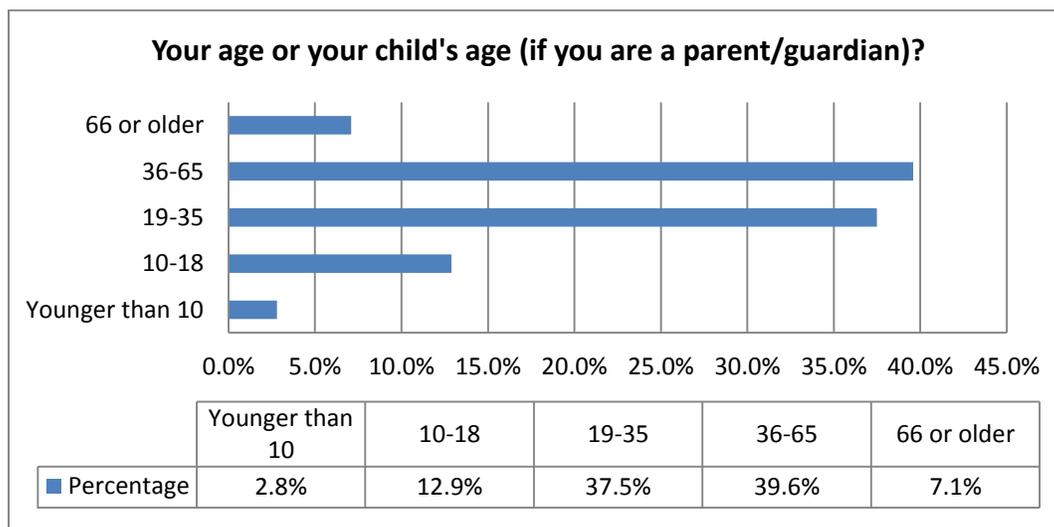
Even though many people may have more than one disability, the majority of respondents stated that they have a physical disability (30.7%). Learning disabilities were the second most common disability reported (19.5%). Of the 21.7% of responses under "Other," a large majority of the responses were choices already listed in the survey.

Which of the following best describes your disability?

	Physical disability	Psychiatric or emotional disability	Sensory disability	Learning or cognitive disability	Intellectual disability	Other
■ Percentage	30.7%	11.9%	7.8%	19.5%	8.4%	21.7%
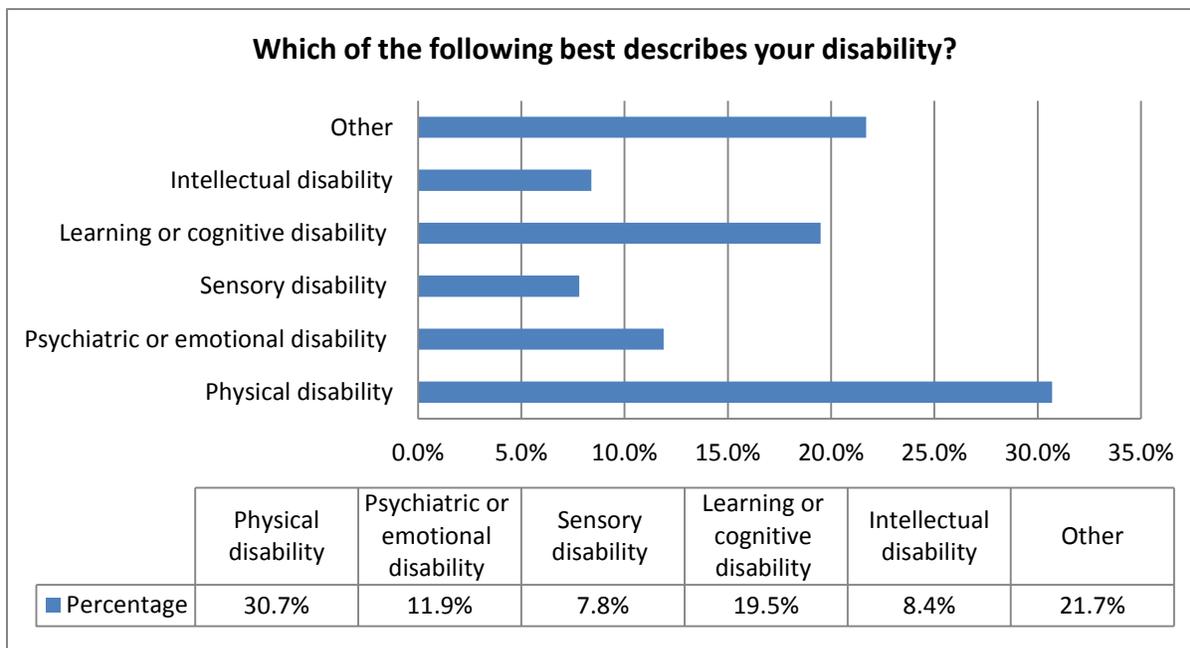
This chart shows all the counties included in the project. The Personal Experience Survey did reach all twelve counties; however, people with disabilities from Lehigh and Northampton Counties completed the most surveys. The survey was also taken by people from counties outside the project area, most notably Schuylkill and Carbon counties, with 49 and 39 responses from each county, respectively.

What county do you live in?

Answer Options	Response Percent	Response Count
Bradford	0.5%	5
Carbon	4.2%	39
Columbia	0.1%	1
Lackawanna	2.5%	23
Lehigh	39.1%	357
Luzerne	7.0%	64
Monroe	9.1%	83
Northampton	21.1%	193
Pike	3.2%	29
Schuylkill	5.3%	49
Sullivan	0.1%	1
Susquehanna	0.1%	1
Wayne	0.9%	8
Wyoming	0.2%	2
Other	6.3%	58

Assistive Technology/ Durable Medical Equipment

This section refers to people with disabilities use of assistive technology and durable medical equipment. Assistive technology is technology used by individuals with disabilities in order to perform functions that might otherwise be difficult or impossible, and can include: communication devices, applications on mobile devices, computer software that assists people with disabilities in having equal access to public life, etc. Durable medical equipment is described as any medical equipment used to aid in obtaining a better quality of life, such as wheelchairs, walkers, hospital beds, and crutches. It is a benefit included in most health care coverage and other insurance plans.

Under the questions concerning assistive technology, a majority (66.2%) of survey respondents stated that they were not using assistive technology. This result correlates directly to the question, "Are there types of assistive technology that you need but do not have?" where 36.4% of respondents answered "Not Applicable." However, under this question, many more individuals provided their own answer in the box marked "Other (please specify)" (48.8%) with answers ranging from the use of an iPad and other computer software.

Are you using assistive technology devices/equipment?

	Yes	No	I don't know
■ Percentage	28.2%	66.2%	5.6%

Are there types of or assistive technology that you need but do not have? (Check all that apply)

	Adaptive driving technology	Communication device/software	Hearing aid	Not applicable	Other (please specify):
■ Percentage	3.3%	8.2%	7.1%	36.4%	48.8%
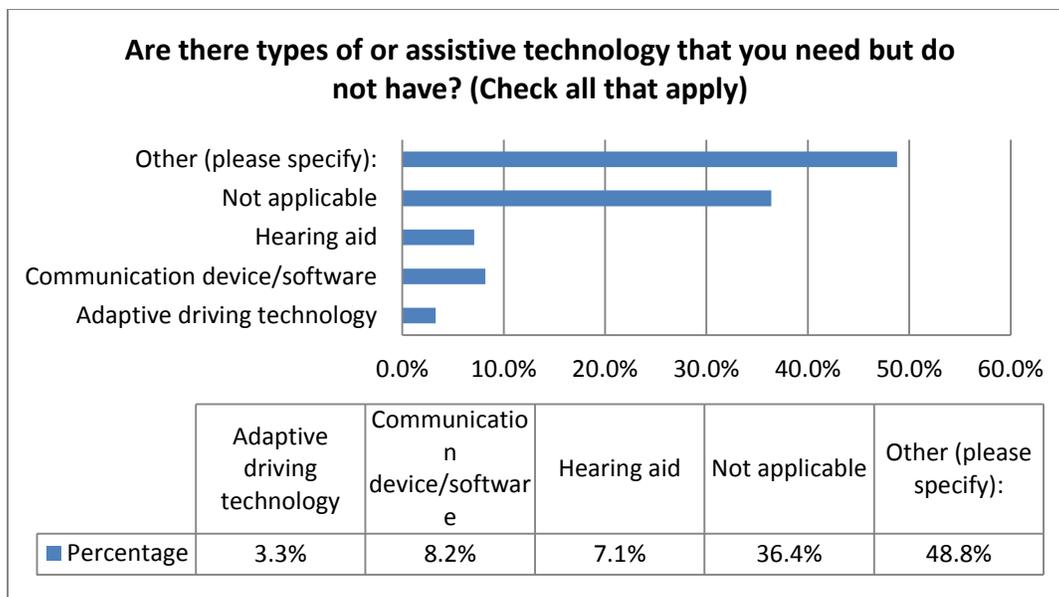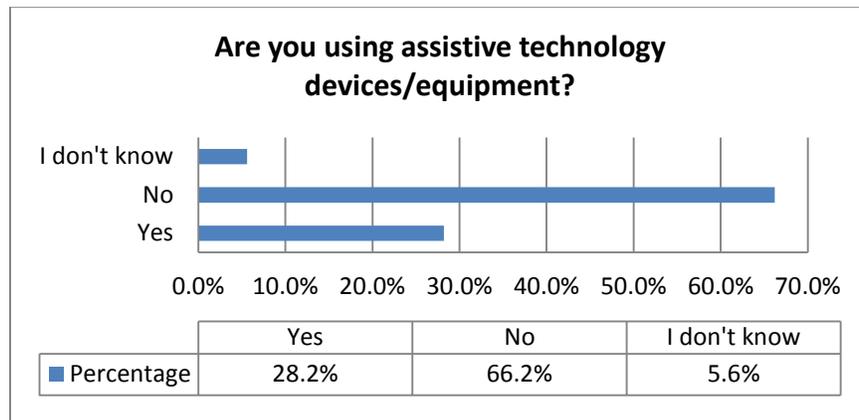
In terms of what is preventing people with disabilities from having the assistive technology they need, the majority of responses once again ranged from "Don't Know" (10.3%), "Not Applicable" (29.7%), and "Other (please specify)" (29.6%). In these areas, it was the public comment that was the most telling. For instance, one respondent stated:

> "What is assistive technology? We live in a senior citizen Hi Rise. My husband had stroke, his Right side was affected + uses a manual wheel chair. So we are both Disabled." (Submitted 2/5/2013)

Other responses gathered through the town hall meetings highlight the fact that a majority of people with disabilities are uncertain what constitutes assistive technology:

> "I, I see that people just don't know what is available and what is, people with disabilities don't know what's available or what's new." (Submitted 1/25/2013 THM)

What prevents you from having the assistive technology you need?

Answer Options	Response Percent	Response Count
I don't know where to get it	3.1%	26
I can't afford it	10.3%	87
I have it, but it's broken/doesn't work	0.7%	6
Insurance declined it	0.8%	7
I am on a waiting list for it	0.7%	6
I don't know how to use it	0.7%	6
I used it for a while, but it didn't really help me	0.9%	8
I never tried to get it	4.9%	41
Nothing, my assistive technology meets all of my needs	8.2%	69
Don't know	10.3%	87
Not applicable	29.7%	251
Other (please specify):	29.6%	250

Under the questions concerning durable medical equipment, a majority (64%) of survey respondents stated that they were not using durable medical equipment. This result again correlates directly to the question "Are there types of durable medical equipment that you need but do not have?" where 37% of respondents answered "Not Applicable." However, under this question, many more individuals provided their own answer in the box marked "Other (please specify)" (39%). Again, the majority of answers provided under this section were examples of durable medical equipment, such as braces for different areas of the body and wheelchairs.

Conclusion:

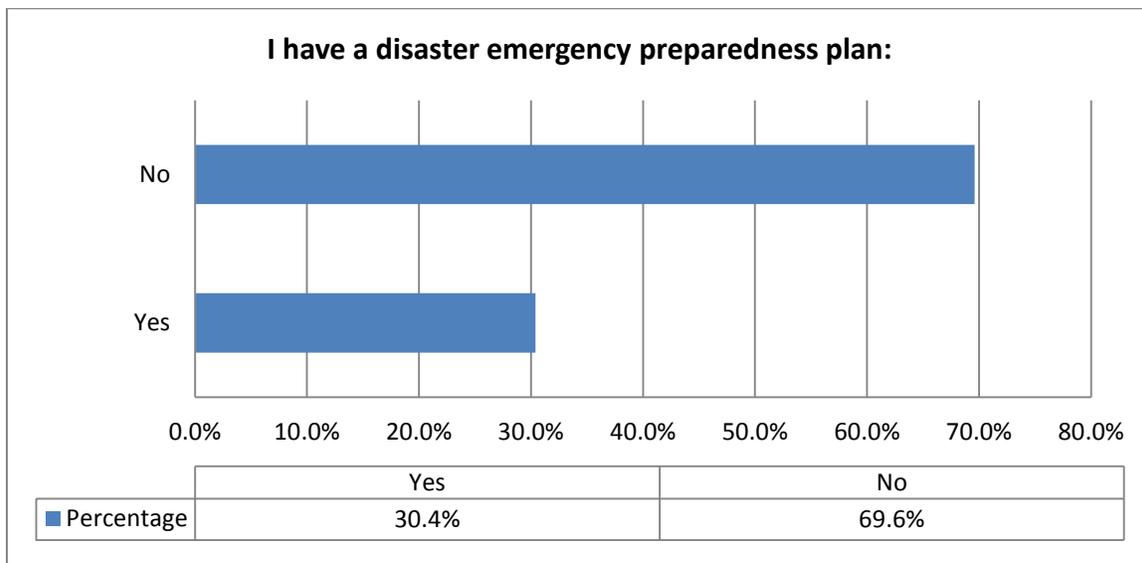When looking at how people obtain assistive technology and durable medical equipment, the results of the survey and town hall meeting are surprising. A majority of survey respondents receive necessary equipment and devices through their health care coverage and/or provider, however, the preceding findings would indicate that many people are simply unsure as to what constitutes assistive technology

and durable medical equipment. With the list of technology growing by the day, and the lack of clarification among people with disabilities, it would appear that more education is needed in this area to ensure that people have access to the vital devices and equipment needed to live independently.

Emergency Preparedness

Emergency preparedness constitutes all the necessary preparation needed in the event of a natural disaster, manmade disaster, or emergency. Eme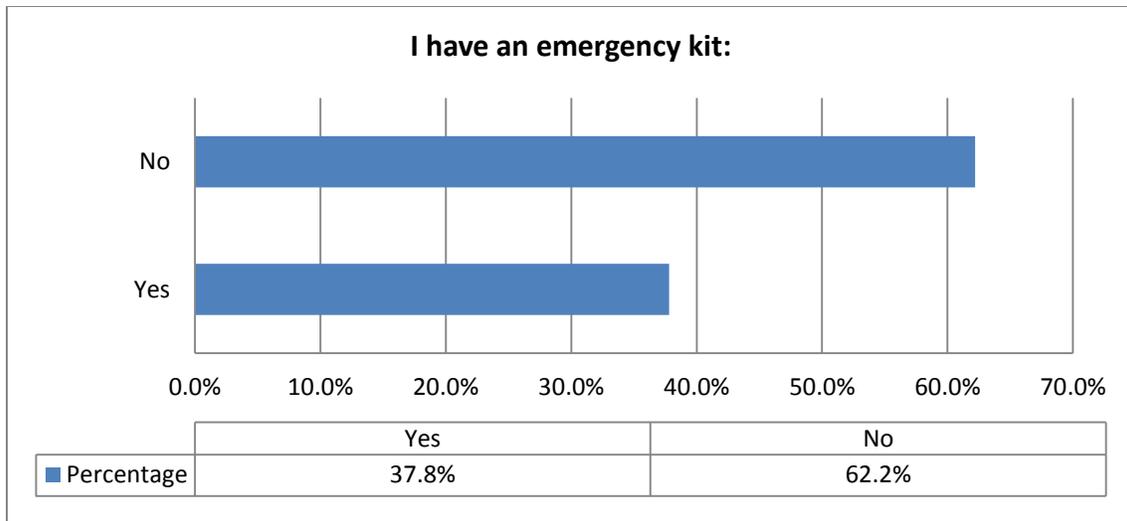rgency preparedness is made up of four important steps including making a plan that will allow you to anticipate your needs, putting together a survival kit of bare essentials and necessities, and, lastly, staying informed so that you may be better prepared in the event of an emergency.

Overall, survey respondents cited that they feel prepared for an emergency. When asked "I know what to do and where to go during a natural disaster or local emergency," a majority of respondents "Strongly Agreed" (22.5%) or "Agreed" (39.1%) with that statement. Although people may feel prepared in the event of a disaster or emergency, an overwhelming majority of people (69.9%) stated that they do not have an emergency plan and many people (62.2%) stated that they do not have an emergency kit.

I know what to do and where to go during a natural disaster or local emergency:

	Strongly Agree	Agree	Disagree	Strongly Disagree
■ Percentage	22.5%	39.1%	26.4%	12.0%

I have a disaster emergency preparedness plan:

	Yes	No
■ Percentage	30.4%	69.6%

13

I have an emergency kit:

	Yes	No
Percentage	37.8%	62.2%
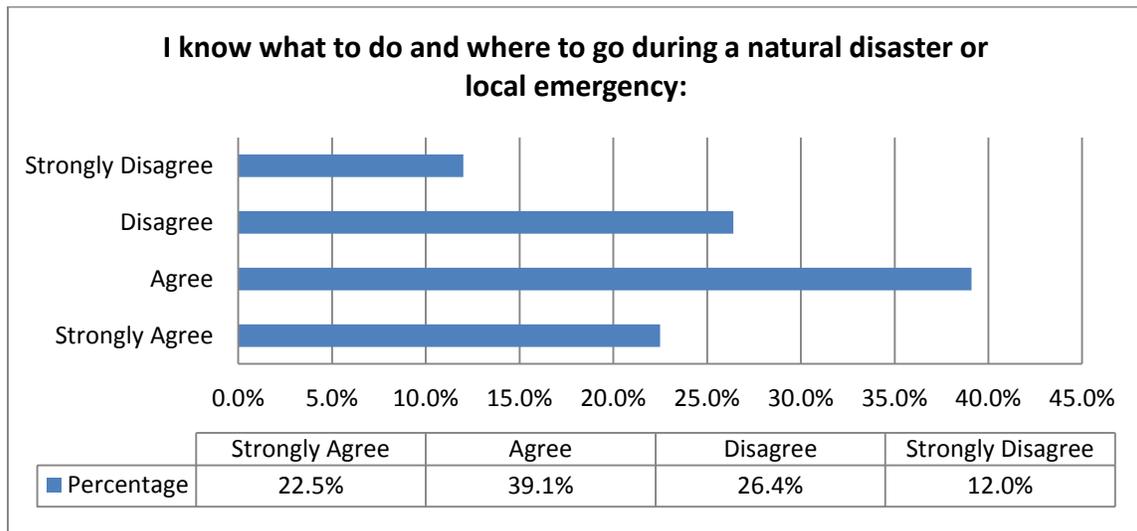
The public comments gathered through the survey and town hall meetings added to the idea that many individuals do not have an emergency management plan. While a majority of people (79.4%) stated that they have a cell phone to use in the event of an emergency, many more respondents and town hall participants spoke to the need to develop a plan to be better prepared in the event of a disaster or emergency.

Conclusion:

The data provides differing views of emergency preparedness. While a majority of individuals feel that they are prepared and have a cell phone to use in case of an emergency, many more people do not have any plans or preparation in place. This shows the need for additional education on emergency preparedness for people with disabilities. Additionally, making sure that first responders and other emergency personnel are educated on topics of disability awareness and disability sensitivity may be a crucial piece to ensuring the safety and wellness of people with disabilities in the event of a disaster or emergency as these individuals are the first in line to educate the public on emergency preparedness.

Employment

Employment is more than having a job; it is earning a competitive wage and, thus, contributing to the community. With the national unemployment rate sitting at 7.5%, many people throughout the nation are struggling to find work at a decent wage. However, for people with disabilities that have comparable skills to their counterparts without disabilities, and national unemployment rate is more than 13%. The "Allsup Disability Study: Income at Risk"[1] found that people with disabilities "experienced an unemployment rate approximately 65% higher than for those with no disabilities in the first quarter of 2013." Allsup, a national Social Security Disability claims services company, has conducted the quarterly study since 2009.

The first graphic illustrates that 33.2% of people with disabilities surveyed are currently "Unemployed." As referenced above, this statistic is well above the national average. As to why most people were unemployed, a majority of survey respondents stated that they were "Unable to work due to health problem or disability" (33.8%). Written responses under "Other (please specify)" totaled 28.2% of total responses and included such things as the lack of transportation (especially in rural areas) and the need for job training.

What is your employment status?

	Working full-time	Working part-time	Retired and not working right now	Unemployed	Full-time student	Other
■ Percentage	9.1%	12.2%	9.9%	33.2%	15.3%	20.2%
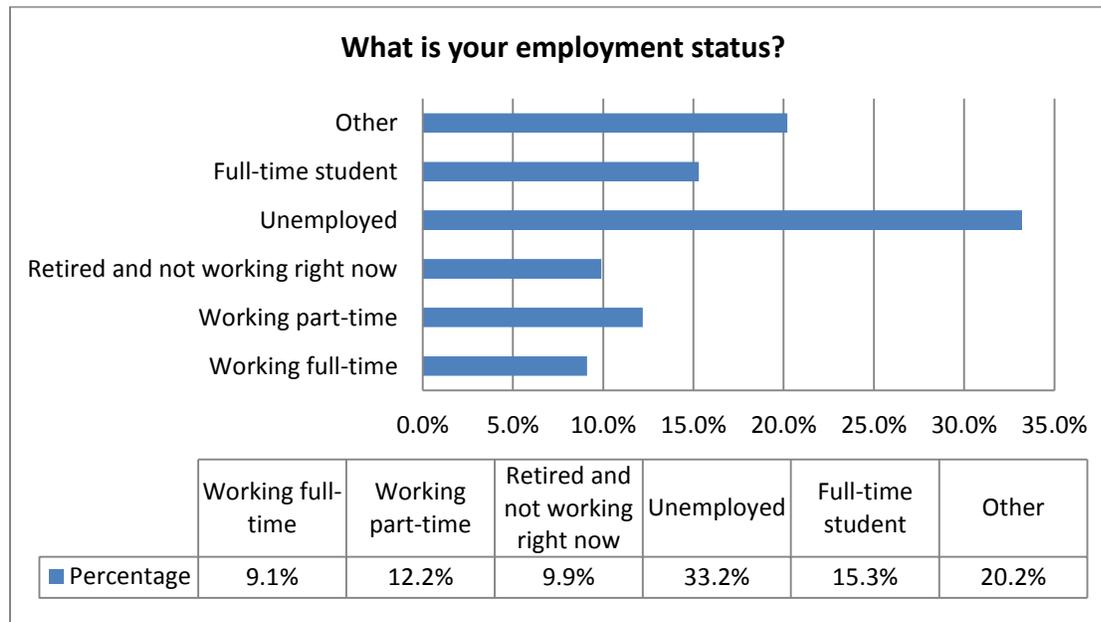
[1] "Allsup Disability Study: Income at Risk," Accessed online: http://www.allsup.com/Portals/4/allsup-study-income-at-risk-q1-13.pdf Courtesy of Allsup. Accessed: May 13, 2013

Answer Options	Response Percent	Response Count
Unable to work due to health problem or disability	33.8%	97
Unable to find a job that accommodates my disability	17.1%	49
I prefer not to work	2.8%	8
Might lose income assistance or health benefits if I work	4.2%	12
Unable to find a job based on my skills	13.9%	40
Other	28.2%	81

In addition to written responses, verbal comments made at the town hall meetings showed that employment is very important for people with disabilities. Most comments were around the idea of not being able to find a job due to disability, whether that is from discrimination on the part of employers, fear of losing benefits, or the lack of jobs for people with disabilities in rural areas. Comments include:

> "And some barriers that I have come across, age, it seems like they don't want to hire anybody over 50, my size, you know, forget it, they take one look at you, and these are for jobs that I know being disabled that I could probably do, like working in a hotel taking reservations, I could easily handle that, but they hire the 19-year-olds. So it's been very hard for me." (Submitted 1/23/2013 THM)

> "…I have looked for work for years. My husband, as he said, was unemployed. And I went through the right channels to try and get help to get work. I still do not have work. I know that some people I see working, I could work circles around them. But I'm not even given the chance to do that…" (Submitted 1/23/2013 THM)

Other comments on employment from the town hall meetings included the need for additional job training and more connections to job services agencies, such as the Office of Vocational Rehabilitation, in rural areas.

Note: 626 respondents skipped the question pertaining to the reason why he or she is not employed. This was because answers were only permissible if they stated "unemployment" was his or her employment status. For example, if a respondent entered "full-time student," the survey went to the next set of questions.

Conclusion:

Because unemployment is an issue of great importance among people with disabilities, the survey data demonstrates that many individuals have the drive to work. However, lack of skills, the inability to find work, transportation, and discrimination by employers continues to impact people with disabilities ability to find competitive employment. Disability awareness training for employers and better connections to work-readiness programs may help to bridge this gap.

Home and Community Based Services

Home and community-based services (HCBS) provide opportunities for people with disabilities to receive the services they need to live independently in their own home and access their community. These programs serve a variety of targeted populations, such as people with mental illnesses, intellectual disabilities, and/or physical disabilities.

A majority of survey respondents, 53.8%, stated that they have all the services they need to live independently. Respondents who answered "No" to the question of "Do you have all the services you need to live independently?" reported the need for additional "Independent living skills training" (46.5%) and "Housing services" (45%). In addition, "Peer support" (31.4%), "Self-advocacy training" (28.5%), and "Youth transition services" (23.9%) all reported high marks and, of the written responses, many individuals cited the need for vocational and transportation services.

If no, what other services would you like to receive? (Check all that apply)		
Answer Options	Response Percent	Response Count
Attendant care services	15.2%	59
Independent living skills training	46.5%	181
Nursing home transition services	0.5%	2
Youth transition services	23.9%	93
Healthcare transition services	14.9%	58
Self-advocacy training	28.5%	111
Housing services	45.0%	175
Peer support	31.4%	122
Other	36.8%	143

Comments received at the town hall meetings focused on attendant care services and supports for families, as well as a variety of topics, including housing, waiver services, Social Security, etc.

Conclusion:

While the majority of people with disabilities feel as if they have all the necessary services they need, those who do not have access to these services still desire to live independently. There is a direct correlation between the need for independent living skills training and the need for housing services, and, many times, these two needs converge to help an individual maintain his/her independence. The need for core services, including self-advocacy and peer support, shows that many people want to stay connected to the roots of the independent living philosophy, which is also apparent in the desire for more youth transition services, which often includes learning how to self-advocate, learning about independent living, and making the transition to housing.
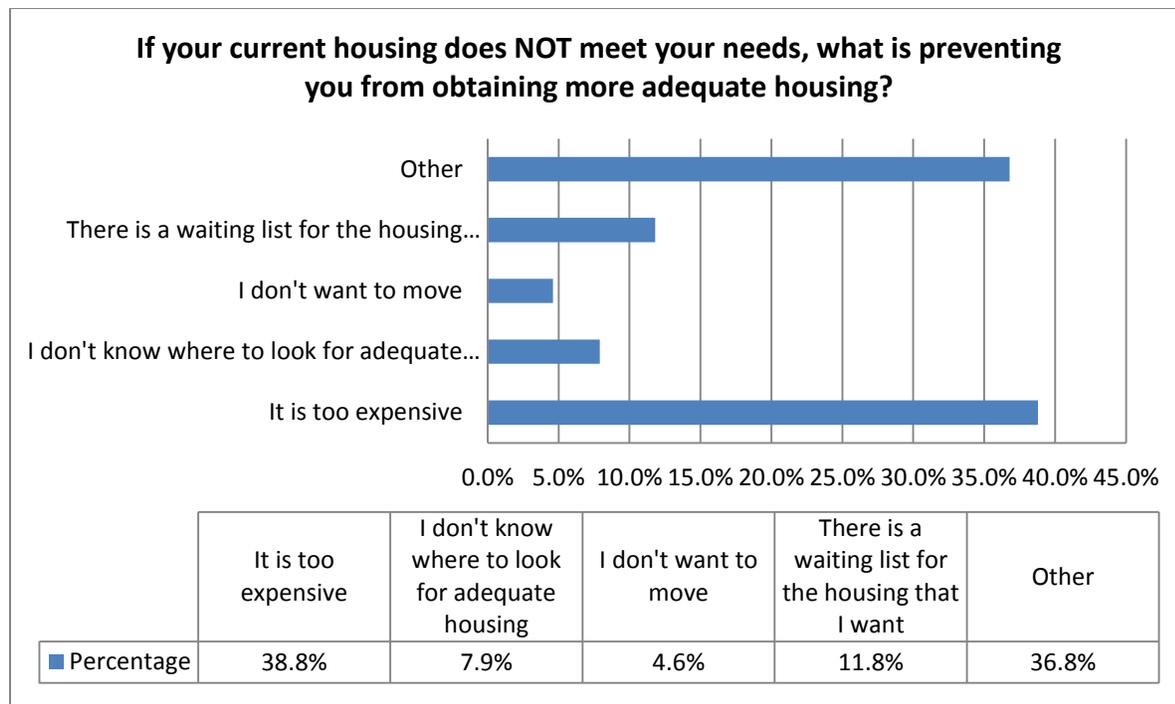
Housing

Housing is any shelter, lodging, or dwelling place where people can live. However, this is an issue that can be tied back to the roots of the independent living movement itself. The right to affordable, accessible housing has always been a hot button issue for people with disabilities, and, as the data will show, the survey and town hall responses once again highlight housing as a topic of concern.

The survey showed interesting results in the area of housing. Under the question "What type of housing do you have?" a majority of respondents stated "I live with one or more family member(s)" (54.3%). The second closest results were individuals that rent an apartment/home (17.6%) and individuals that own/partially own their home (15.2%). Of the individuals surveyed, 82.3% report that their housing currently meets their needs.

What type of housing do you have?

Answer Options	Response Percent	Response Count
I live with one or more family member(s)	54.3%	469
Private housing that I own/partially own	15.2%	131
Private apartment or home that I rent	17.6%	152
Community or shared living option	2.8%	24
Residential or long-term care	1.2%	10
I am staying with someone, near homelessness	1.9%	16
I am homeless or residing in a shelter	0.1%	1
Other	7.0%	60

However, 17.7% of survey respondents that stated their housing did not meet their needs when asked "If your current housing does NOT meet your needs, what is preventing you from obtaining more adequate housing?" A majority of respondents reported that "It is too expensive" (38.8%). Under this question, 36.8% of respondents chose the "Other" option and provided responses indicating the need for affordable housing and that there was little or no transportation near their home. In addition, 11.8% of respondents stated that "There is a waiting list for the housing I want" and 7.9% stated "I don't know where to look for adequate housing."

If your current housing does NOT meet your needs, what is preventing you from obtaining more adequate housing?

	It is too expensive	I don't know where to look for adequate housing	I don't want to move	There is a waiting list for the housing that I want	Other
■ Percentage	38.8%	7.9%	4.6%	11.8%	36.8%

In stark contrast to the preceding questions, a majority of respondents "Strongly Agreed" (33.9%) and "Agreed" (36.5%) with that statement "I am able to choose where I live." In addition, an overwhelming majority of survey respondents stated that they feel safe in their housing and find their housing affordable. This is again in contrast to those individuals that feel their housing does not meet their needs. During town halls, many responses showed that people are having a difficult time finding affordable housing:

> "It's tough. I have a whole list at home and I have tried and there is a lot of demand for it, and there is not supply. It's the biggest problem. The demand is too high and the supply is too low to put it simple." (Submitted 3/9/2013 THM)

> "There is not enough housing out there honestly or quality housing." (Submitted 3/9/2013 THM)

> "What kind of housing is there for someone that's disabled?" (Submitted 3/9/2013 THM)

Conclusion:

Both the survey and town hall responses painted a portrait of very different results. Without knowing the socioeconomic background of the groups, it is difficult to judge why many more individuals at the town halls felt that affordable, accessible housing is more difficult to find. While the survey data clearly shows that a majority of people with disabilities are comfortable with their current living situation, most respondents stated that they live with one or more family members, which begs the question: What would the individual's response be if his/her family member was no longer capable of providing housing? Furthermore, for those whose housing does not meet their current needs, affordability and locating quality housing is still of the utmost concern for many individuals. Although it is clear that public housing is still the surefire way to find affordable, accessible units, long waiting lists are a deterrent and more private housing options must be made available for people with disabilities.

Medical/Dental Coverage

Medical coverage encompasses a variety of topics of health care, including general medical care, medical insurance, doctor visits, treatments, procedures, and tests. Most often, medical coverage refers to the topic of health care insurance. Dental Coverage is often placed under the umbrella of medical care; however, it focuses solely on access to proper oral hygiene such as dentist visits, oral surgery and other procedures.

Under the questions regarding medical/dental coverage, a majority of survey respondents (56%) reported as having Medicare, Medicaid, Medical Assistance, MAWD, or the Access Card as their primary source of health insurance. 13.8% of respondents stated "Other" and reported they have private insurance, while 11.5% stated that they have insurance through someone else's employer—such as a family member or spouse.

What is your source of health insurance?

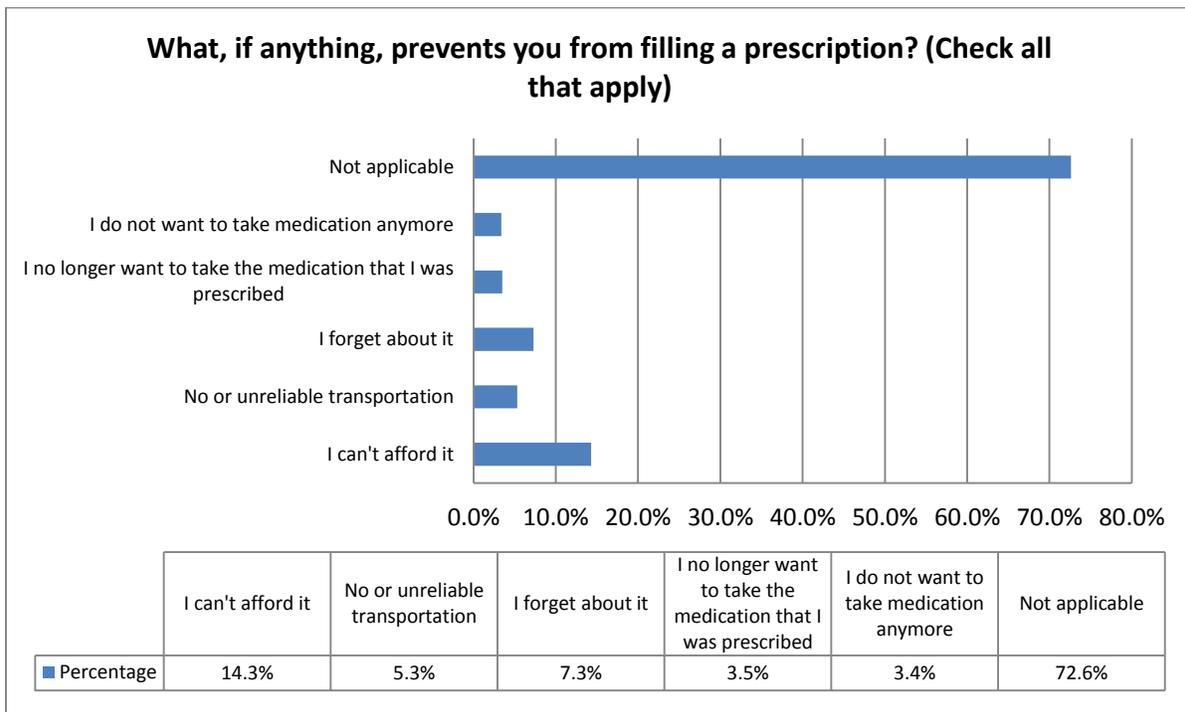| Answer Options	Response Percent	Response Count
Health insurance through my employer	9.7%	87
Health insurance through someone else's employer	11.5%	103
Medicare, Medicaid, Medical Assistance, MAWD, or the Access Card	56.0%	501
No health insurance	3.9%	35
Don't know	5.0%	45
Other	13.8%	123

When asked, "In the past year, was there a time when you needed medical care and DID NOT get it?" an overwhelming majority of respondents answered "No." However, of the individuals that did not receive care in the past year, many reported issues that can be tagged to insurance, such as not finding a doctor that would accept an insurance plan/card, not being able to afford a co-pay, or not having insurance at all.

Answer Options	Response Percent	Response Count
Couldn't find a doctor that would accept my insurance	19.0%	27
Couldn't afford my co-pay	19.0%	27
Not covered by insurance	36.6%	52
Couldn't get an appointment	12.7%	18
Unreliable transportation	15.5%	22
Transportation costs	9.9%	14
Doctor would not and/or could not accommodate my disability	9.9%	14
Other	26.1%	37

Of the survey respondents, 75.3% have stated that they do not use attendant care services. But, of the individuals that do utilize attendant care, a majority state that they are "Very Satisfied" (55.1%) and "Satisfied" (44.3%) with their attendant care.

Additionally, while 70.6% of respondents report filling their prescription drugs "All the time," nearly 20% of respondents stated they were not able to access their prescription medicine due to the high cost and lack of reliable transportation.

What, if anything, prevents you from filling a prescription? (Check all that apply)

	I can't afford it	No or unreliable transportation	I forget about it	I no longer want to take the medication that I was prescribed	I do not want to take medication anymore	Not applicable
■ Percentage	14.3%	5.3%	7.3%	3.5%	3.4%	72.6%

Comments on the survey and during the town hall meetings varied from individuals stating that they could not access proper medical care, to those who simply did not know where to find medical information. Additional survey comments include:

> "I don't have any medical coverage. So the thing is I cannot afford Medicare. I can't afford them to take out the money, the moneys out of my monthly check. So the thing is Pocono Medical don't offer charity services like St. Luke's. So it's like I understand that they take care of Monroe County and Pike County. But still, they are not really meeting the needs of the community."

> "Lack of information. Where do you go to -- like, for her, to receive information that you can or will not be accepted into the programs that we are talking about. She said something about Tricare. That's the first time I heard of it. I'm not a Vietnam vet, but what I'm saying is I don't have access to this information. Where do we go to get this kind of information?"

> "I would like to say that Medicaid is appropriate for people because people need to have coverage if they are sick, if they have an illness."
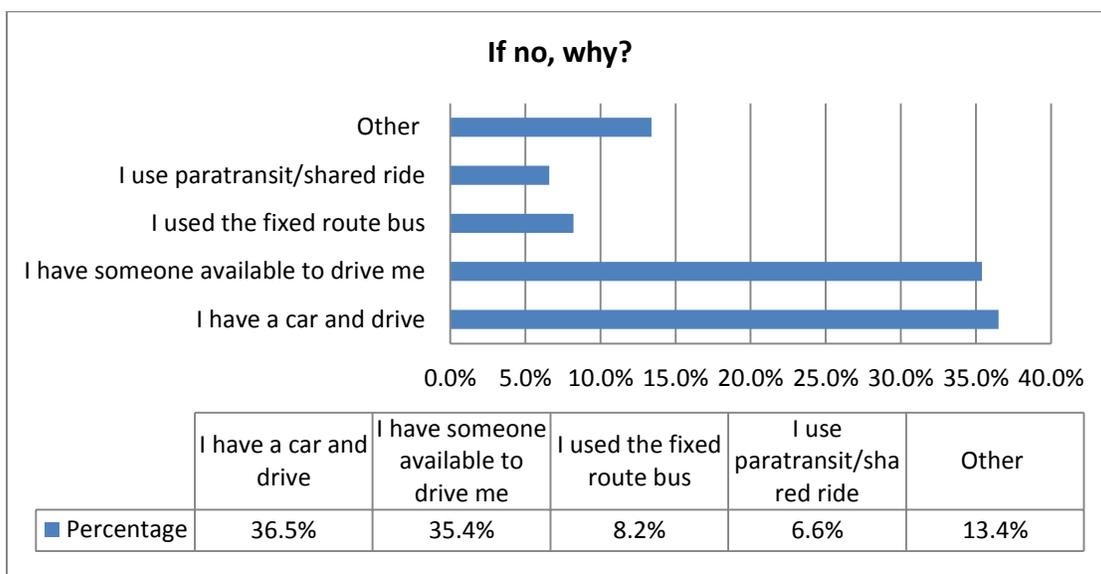
Conclusion:

Similar to housing, a majority of individuals who completed the survey stated that they have medical/dental coverage of some type. However, those individuals who do not have coverage report major issues, such as affordability, not being able to locate a qualifying doctor, and not having insurance in general. Additionally, comments received indicate that people with disabilities need more education on types of coverage options available, especially for individuals who are low-income as these individuals appear to lack the proper resources to access medical coverage.
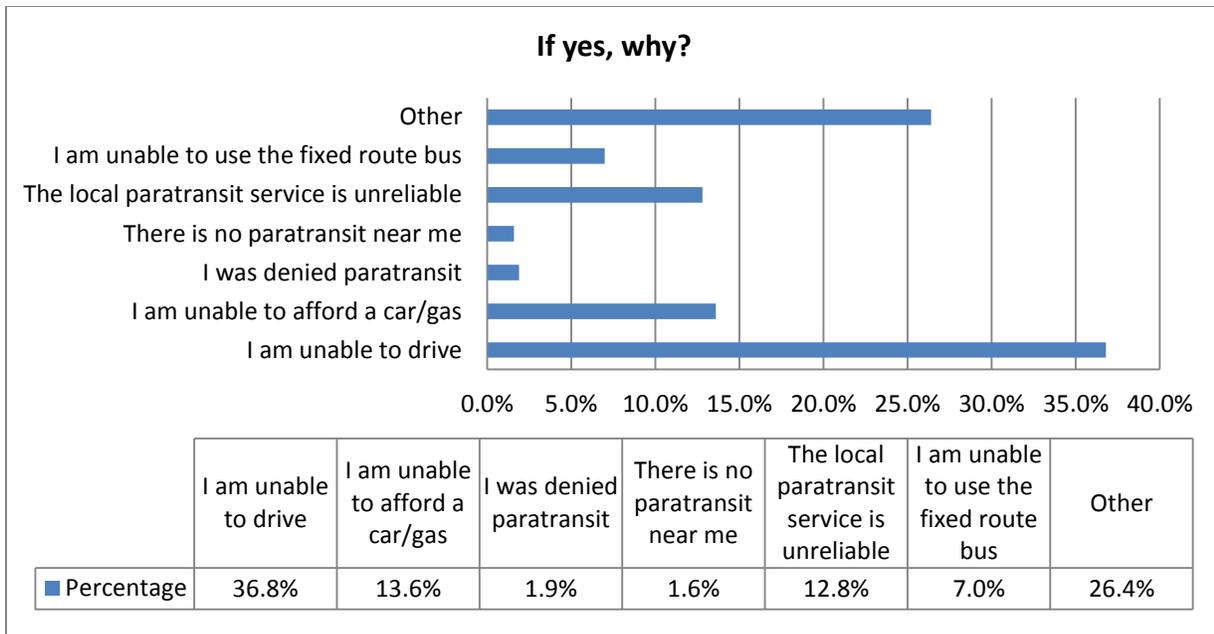
Transportation

Transportation is the ability to access the community and take advantage of its goods and services via public bus, paratransit system, car, or other mode. Being able to access reliable, accessible transportation is yet another issue that has truly impacted people with disabilities since the start of the independent living movement and implementation of the Americans with Disabilities Act. However, once again, the survey and responses from the town halls yielded different results.

On the survey, 73.5% of respondents stated that using/finding accessible transportation is not an issue. Individuals that answered "No" to this question cited the fact that they have their own personal car and can drive (36.5%) or that they have someone else available to drive them (35.4%). Of the respondents that answered "No," less than 20% utilize public transportation, via the fixed route and paratransit/shared ride systems.

If no, why?

	I have a car and drive	I have someone available to drive me	I used the fixed route bus	I use paratransit/shared ride	Other
■ Percentage	36.5%	35.4%	8.2%	6.6%	13.4%

However, of the 26.5% of individuals that stated using/finding accessible transportation was an issue for them, a majority of these individuals stated that they were unable to drive (36.8%) and nearly 14% of respondents state that they were unable to afford gas even if they did have their own form of transportation. Furthermore, 12.8% of respondents cited unreliability in the local paratransit system and 7% stated that they were unable to use the fixed route bus system. In addition, 1.9% of respondents stated that they were denied paratransit service and 1.6% stated that there was no paratransit service near them.

If yes, why?

	I am unable to drive	I am unable to afford a car/gas	I was denied paratransit	There is no paratransit near me	The local paratransit service is unreliable	I am unable to use the fixed route bus	Other
Percentage	36.8%	13.6%	1.9%	1.6%	12.8%	7.0%	26.4%

While the survey portrays a more positive view of public transportation among the majority of survey respondents, public comments taken during the town hall meetings differ quite drastically from the results of the survey. During the town hall meetings, public comments included:

"Transportation in this area is poor. The buses do not run often enough." (Submitted 1/23/2013 THM)

"It takes two or three mile walk to get to the bus." (Submitted 1/23/2013 THM)

"I'm a consumer at the CIL. I—there needs to be getting—I feel like there needs to be competition again because if you have just one company, they—like they don't care because they know that you are the only option that you have." (Submitted 1/25/2013 THM)
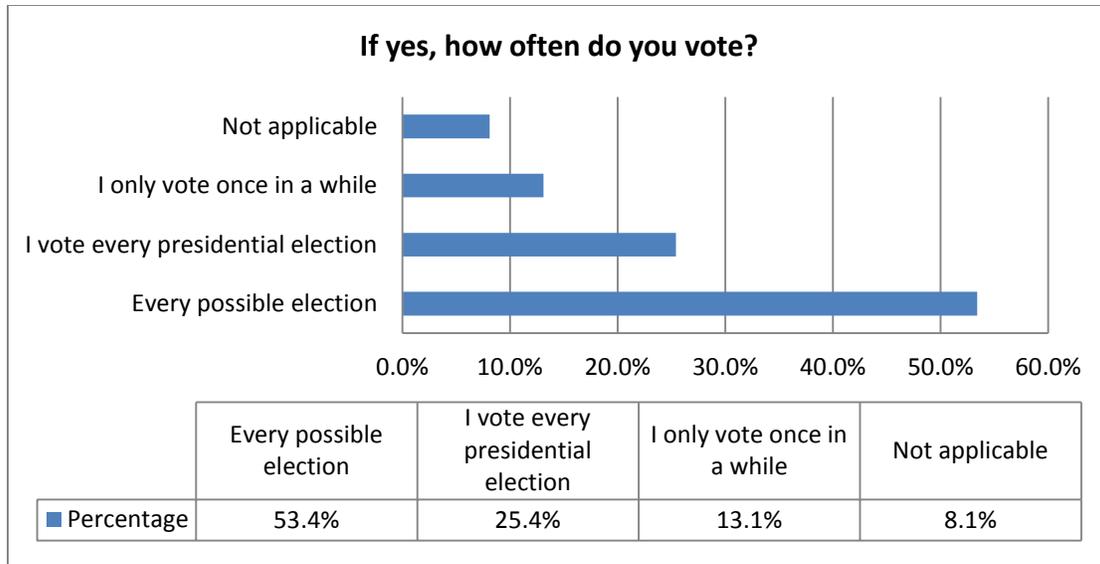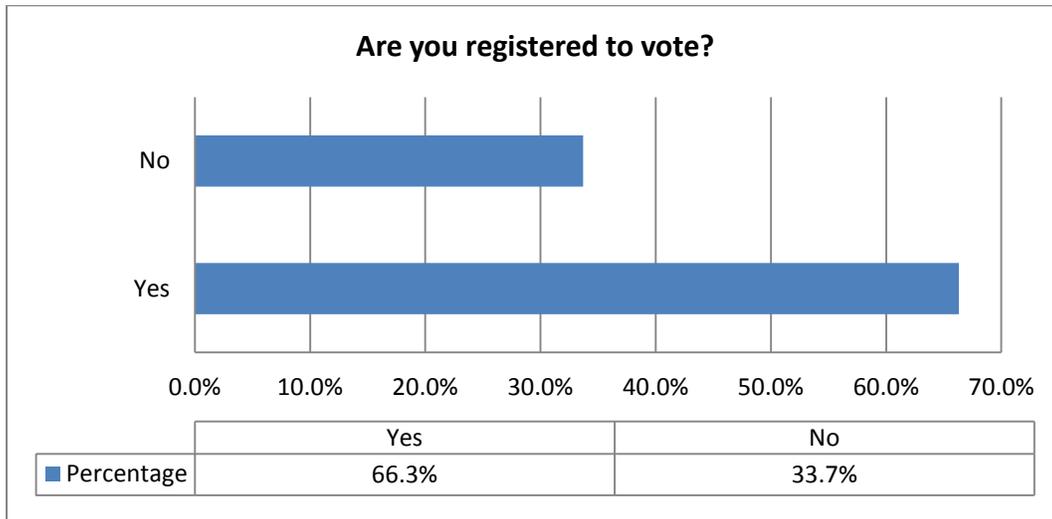
Conclusion:

At first glance, it does not appear as if public transportation is an issue for people with disabilities. However, as noted by the public comments (please see Appendix), the lack of public transportation in rural areas and unreliability of paratransit are two major areas of concern that impact people with disabilities and their ability to access the community, gain employment, and find affordable, accessible housing. More access is needed for people with disabilities in the public transportation system, which includes the need for more comparable service among paratransit systems. Having a car or having someone to drive you to important meetings, medical appointments, etc. was cited as the primary mode of transportation for most people with disabilities in the survey. However, taking those two factors out of the equation makes it difficult for many individuals to access the community and live whole, independent lives.

Voter Access

Voting is the cornerstone of democracy. As an American, every citizen over the age of 18 has the right to make their voice heard and to have equal access in which to do so.

In general, the questions under voter access received perhaps the most positive feedback. 66.3% of respondents stated that they were registered to vote, and 53.4% of individuals stated that they vote during "Every possible election."

Are you registered to vote?

	Yes	No
■ Percentage	66.3%	33.7%

If yes, how often do you vote?

	Every possible election	I vote every presidential election	I only vote once in a while	Not applicable
■ Percentage	53.4%	25.4%	13.1%	8.1%

For those individuals that are not registered to vote, the survey shows that 77.1% of individuals know how to register to vote. Additionally, across the board, greater than 80% of individuals feel that their polling place is accessible, that their voting machines are accessible, and that the workers at their polling place are willing to accommodate their disability. Furthermore, 86.6% of individuals stated that needing to show an ID to vote would not prohibit them from voting.

As seen throughout the project, the comments gathered at the town halls were mixed. Responses taken from the survey include:

> "I think ours is great. All of our precincts are accessible. They have the absentee. They actually go, I'm a political volunteer for two people. They actually will take no matter what party voters to the precinct that they need. They actually call the ones on that. So I would say in Hazleton, everything I take my scooter right in, I take my manual wheelchair right in. And it's not a problem. They have people to tell them how to do the new machines, like husband gets to help all the time, they have someone there, they have someone bilingual. I would say it's great."

> "It was easy for me to vote."

> "They don't care at all. I had to wait about 30 minutes, 30 to 45 minutes, and, because my last name starts with an S so I had to wait 30 to 45 minutes. And the whole system, I told them I cannot stand that long. And they said, well, take the chair, now, how stupid is this, take your chair and move it in the middle of the three aisles crowded, and just sit there. I mean there has to be a better way."

> "The past few times that I voted, I found that each time there was a different type of machine to vote on. And they don't tell you this ahead of time. So you go in and you say this isn't like the last one that I did. And it makes you spend more time in the booth doing it, and it makes backlog."

Conclusion:

Voter access is extremely important in the disability community, and the survey indicates better than average accessibility at polling places and poll workers that are generally accommodating of people with disabilities. In addition, the majority of survey respondents know the importance of voting and how to register if they have not already voted. The work of voter rights coalitions and disability awareness has proven successful in terms of voter access, however, in rural areas, it would appear that additional education for voters with disabilities and poll workers is needed to improve accessibility and understanding.

Recommendations

After examining the data from the Personal Experience Survey and the comments and written statements that were collected during the town hall meetings, it became apparent that the primary need for people with disabilities in Region 5 is education. The data and input gathered through the project highlighted the fact that many individuals are simply unaware of the disability agenda and do not understand many of the agenda topics. Furthermore, as the comments from the town halls illustrated, these individuals are oblivious to the types of services available in Region 5 that directly correlate to the disability agenda. An example of this is the topic of assistive technology/durable medical equipment. Many town hall respondents were unsure as to what constituted assistive technology or where to access this vital equipment. This can also be seen when discussing employment. Many individuals in the survey reported that they were unemployed, but during the town hall meetings many comments surrounding employment were about not understanding where to find jobs and how to receive job skills or work-readiness training. These examples relate to the fact that people with disabilities in Region 5 are unaware of the disability agenda and unaware of the services available that can support independence. With this in mind, it is obvious that more educational opportunities should be made available for people with disabilities in Region 5 to understand the disability agenda and gain information on the services in the region.

In addition to individuals with disabilities, there is also a need for education among service providers. Although the town halls were meant to gain input from people with disabilities in Region 5, many service providers attended the events and provided input as to their perspective on the disability agenda topics. However, the service providers, too, seemed unaware of the disability agenda and unsure of how to provide information and resources to their constituents on the agenda topics. Furthermore, some service providers lacked the knowledge on the assets, skills, and abilities of people with disabilities to succeed in the areas of independence and employment. This highlighted the need for more cross-disability resource sharing and disability sensitivity education that can help to showcase the potential of all people with disabilities to succeed, contribute to the community, and live independently. It is strongly encouraged that Center for Independent Living staff conduct these educational trainings from a person-centered approach.

In addition to the general need for education among people with disabilities and service providers in Region 5, the following are general recommendations drawn from the data under each specific disability agenda item:

Assistive Technology/Durable Medical Equipment:

As the data suggests, people with disabilities in Region 5 are unaware as to what constitutes Assistive Technology (AT) and Durable Medical Equipment (DME). To remedy this problem, more education is needed on the differences between AT and DME. Our recommendation is that all Centers for Independent Living should utilize one common online resource page on their respective websites that explain what AT and DME is, as well as the differences between the two. This online resource page should also be made available in print form for distribution to consumers. In addition, we recommend the implementation of educational seminars and demonstrations where people with disabilities in Region 5 can see AT and DME in action as well as ask experts questions about the equipment and devices available.

Emergency Preparedness:

As one of the largest areas of concern for people with disabilities in Region 5, emergency preparedness will require much attention. In the wake of Hurricane Sandy, many individuals with disabilities in Region 5 were left without power, transportation, and basic necessities for extended periods of time. Our recommendation is that Centers for Independent Living throughout the state should connect with their local Emergency Management Associations at the county level and American Red Cross branches to conduct outreach and trainings on emergency preparedness for consumers. These outreach events should include discussions on preparing emergency kits and emergency plans, as well as provide consumers with general starting supplies for kits, such as flashlights, first aid kits, etc. In addition, it is our recommendation that every Center for Independent Living offer consumers the opportunity to develop an emergency preparedness plan at intake. As person-centered, consumer-controlled agencies, case managers can help consumers develop a plan to fit their individual needs and location. Centers have had successful efforts in registering voters at intake, and this would be a similar process that can help prepare the consumer for any disaster or emergency.

Employment:

As the data showed, finding competitive, sustainable employment for people with disabilities can be very difficult. However, it is our recommendation that Centers for Independent Living should continue to promote the services that are already available for people with disabilities around employment, including services through OVR, CareerLink, Goodwill, and other vocational training organizations. More information regarding benefits counseling, resume development, and work-readiness needs to be provided, in addition to more job fair, job shadowing, job coaching, and mock interview opportunities. It is our recommendation that more outreach to employers is needed as well to educate them about the benefits of hiring people with disabilities and to create opportunities for more people with disabilities to be interviewed, hired, and included in the workplace.

Home and Community Based Services (HCBS):

Waiver programs offer people with disabilities the services and support they need to live independently. However, with a majority of survey respondents citing that they need more independent living skills services, and with many individuals at town hall meetings asking about waiver programs, there is an obvious need for increased education about the waiver programs in Pennsylvania. Our recommendation is that Centers for Independent Living need to conduct educational outreach to promote the variety of waiver services available throughout Region 5, and the state. Additionally, as consumer-controlled organizations, Centers must seek out opportunities to become service providers and help people with disabilities access the services they need to achieve independence.

Housing:

Housing continues to be of the utmost concern for people with disabilities. The lack of affordable housing, lack of accessible housing, and rising cost of rent and utilities are all major concerns that people with disabilities are faced with each day. Landlord education has proven successful in developing housing stock for people with disabilities, and it is our recommendation that landlord education efforts be adopted throughout Region 5. As an area that is sparsely populated, efforts to educate landlords would improve housing opportunities for people with disabilities throughout the region and educate landlords on the benefits of having tenants with disabilities. In addition, life sharing options have proven successful in offering people with disabilities the opportunity to live independently in a community

setting. Life sharing is when individuals live with others who have similar interests and life experiences. It is a proven best practice in providing housing opportunities for people with disabilities and it should be examined further as a housing solution.

Medical Coverage:

Understanding how medical benefits work, and how to obtain employment, housing, and other services without negatively impacting a person's benefits is difficult for people with disabilities to navigate. It is our recommendation that there should be more benefits counselors available to help people navigate the system. With more benefits counselors, more individuals will understand the system. This recommendation could include collaboration with Social Security, and would help Social Security better serve the people utilizing its benefit programs.

Transportation:

Transportation is another area of contention for people with disabilities, especially in the rural areas of Region 5. While it is important to have public transportation options for people with disabilities, it is crucial that people understand the system and their rights as riders of paratransit and other public transportation. Our recommendation is to provide more education to individuals with disabilities in Region 5 on their rights under the paratransit system, as well as educate them on alternative transportation options in the region, such as shared-ride programs. Additionally, Centers for Independent Living should provide educational outreach programs to inform consumers of their rights under current laws and regulations for public transportation. Centers should also work with local transportation authorities to improve transit service and customer service, which may include disability awareness education programs.

Voting:

It is clear from the survey that voter registration outreach is working. However, some comments from the town hall meetings have indicated that there is still some confusion about voter rights and laws. Continued outreach by voter rights coalitions and groups is needed throughout Region 5, with an emphasis on registering young adults with disabilities as voters. In addition, it is our recommendation that people must be made aware of their local legislators and be informed on initiatives on a local and state level that may impact their ability to live independently.