

**Adapting Existing Human Services to Meet the Needs of the Deaf Population: A Program
Evaluation on Administrative Case Management in American Sign Language**

by

Makenzie Kincaid White

BSW, Franciscan University of Steubenville, 2017

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This thesis was presented

by

Makenzie Kincaid White

It was defended on

April 15th, 2019

and approved by

Thesis Advisor:

Steven Albert, PhD, MSc, FGSA
Professor & Chair of Behavioral and Community Health Sciences
Behavioral and Community Health Sciences
Graduate School of Public Health
University of Pittsburgh

Committee Members:

Richard Garland, MSW
Assistant Professor of Behavioral and Community Health Sciences
Behavioral and Community Health Sciences
Graduate School of Public Health
University of Pittsburgh

Daniel Rosen, PhD, MSW
Professor of Social Work
Graduate School of Social Work
University of Pittsburgh

Donald Goughler, MSW
Professor of Social Work
Graduate School of Social Work
University of Pittsburgh

Kim Mathos, DO, MPM
Assistant Professor of Psychiatry, Adjunct Professor of Rehabilitation Science
School of Medicine, School of Health and Rehabilitation Sciences
University of Pittsburgh

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Abstract

The deaf population is a minority that has historically lacked access to a variety of services and today that is no different. Pennsylvania, and specifically the city of Pittsburgh, have always been at the front end of changes within the deaf community. In 1869 the Western Pennsylvania School for the Deaf was founded in Pittsburgh, and it was the first day school for the deaf in the country. This was a watershed event for deaf individuals and really established the city of Pittsburgh as the preeminent service provider for those who are deaf. While a lot has changed within the city, and the deaf community since the founding of this school, in many ways the city has expanded in the number of opportunities available for those that are deaf. However, the deaf population still has significant barriers in terms of accessing services—especially those that are adapted to their needs and in American Sign Language (ASL).

CLASS is a non-profit in Pittsburgh that has fifty plus years of experience working with the disability population. Over the years, CLASS has worked with deaf individuals but never offered a program specifically focused on this minority. CLASS has a comprehensive case management program for people with disabilities and the pilot program under review looks to adapt this program to fit the needs of the deaf population. The pilot program discussed in this paper provides free administrative case management in ASL in order to determine how existing human

services can be adapted to meet the needs of this population without creating a whole new program. The public health significance is that this program attempts to understand if providing services in American Sign Language (ASL) can in turn decrease health disparities the deaf population faces.

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Preface

I would like to thank my committee members for their support with this project and all the time they spent reading drafts. I would like to thank Community Living and Support Services, CLASS, for allowing me to run this pilot program under their guidance and use agency resources for this program. I would specifically like to thank Melva Gooden Ledbetter for her support and trust in me to create and run this program, and all the guidance she provided along the way.

1.0 Introduction

CLASS was founded in 1951 by a group of parents and community members and was originally affiliated with the United Cerebral Palsy (UCP) (CLASS, 2017). In 2013, CLASS became independent from the UCP and took on its new name. Originally, CLASS focused its services for school age and preschool children, however, as more programs developed similar services, they shifted to serve the adult disability population. In 1975, community skill building and supervised residential programs both began, later followed by specialized services for individuals with traumatic brain injury in 1984 (CLASS). The vocational and supported employment program was started in 1986. At the same time, a team of case managers was created (known as community partners) to provide support to people in the community who needed nontraditional case management to support them with independent living. In 1998, CLASS was given an Attendant Care contract which created a program focusing on supporting men and women with disabilities to enable them to live, work, and participate in the community through working with direct care workers (CLASS). In 2010, two important mergers occurred between the Multiple Sclerosis Service Society (MSSS) and the Alliance for Community Respite Care (ACRS). These additional programs allow CLASS to continue to support families and caregivers of those with disabilities and provide referrals to additional services. In 2015, a grant was received from the Institute on Disabilities at Temple University to offer services through Pennsylvania's Initiative on Assistive Technology (PIAT) which is now called Tech Owl (Technology for Our Whole Lives). CLASS is currently an 11-million-dollar non-profit with 330 staff employed (CLASS).

The mission of CLASS is to support people with disabilities as they explore options, participate in the community and strive toward equality (CLASS). The vision is working toward a community where each belongs. CLASS is *empowering people and creating communities*. Guiding principles that the agency adheres to are (1) supporting the uniqueness, wholeness and dignity of each person and responding to individual needs and preferences of each person. (2) Advocating for the rights of people with disabilities so they may fully participate in and contribute to community life. (3) Viewing all human life as having equal and unconditional value (CLASS). (4) Supporting the life-long process of personal growth and development of all people. (5) To take every opportunity to educate others and to advocate for the basic civil rights of people with disabilities. (6) Emphasize cooperation in getting things done through and with the people they serve.

Current programs at CLASS include: Multiple Sclerosis Service Society (MSSS), Residential In-Home Services, Technology for Our Whole Lives (Tech Owl), Community Partners, Centre Services, and Attendant Care and Options In-Home Services. MSSS is composed of an exercise and support program which provides in home exercises, emotional support, equipment and assistive living device evaluations (CLASS). MSSS also provides therapeutic social and recreational activities as well as providing community education. Residential In-Home Services provide personal care, in-home skills training, health and medication management, housekeeping and laundry, community involvement, meal planning and preparation, financial management, and transportation to individuals over the age of 18 (CLASS). CLASS supports around 22 homes or apartments throughout Allegheny County, with two to three individuals in each home. Tech Owl works to provide device demonstrations, short-term loan equipment through a lending library, reused and exchanged equipment partnership (REEP), telecommunication device

distribution program, public awareness, training and technical assistance. CLASS coordinates Tech Owl for all of Western Pennsylvania. Centre Services provides vocational services to adult's transitioning from high school to adulthood or adults rebuilding or developing new skills (CLASS). The Centre serves about 80 individuals on an average week through a variety of classes as well as community outings and volunteer opportunities. Attendant Care and Options provides personal care, care assessments, meal planning and preparation, mobility assistance, medication reminders, light housekeeping and assistance with errands or shopping (CLASS). Attendant care is for those aged 18-59 and then options serves individuals over 60. Both Attendant Care and Options are for individuals who live in their own home and are trying to remain as independent as possible.

While CLASS has a variety of different programs as mentioned above, Community Partners is the program that was utilized as a framework to create this pilot program. The Community Partner program provides case management to promote independence by assisting with things such as searching for housing, providing life skills education, assisting with finding employment etc. (CLASS). Community Partners employs a partnership model allowing the case manager and the consumer to develop individualized goals to meet their needs, strategies for getting the needs met and then working towards all this with the individual. These services can be short or long term depending upon the goals. The program brings individuals beyond traditional case management by aiding individuals in not just meeting their needs but connecting them to support and community resources, so they can build social capital and improve their independence and quality of life. The goal of the program is empowering consumers to reach complete community integration, therefore minimizing the need for services. Once participants start to reach their goals the community partner will start the fade out with the ability to return at any point if

needed. Community partners works with individuals to build resources in the community, assist with problem solving and decision-making skills, aid in like skills education, assistance with financial management, finding housing/employment/volunteer opportunities, coordinating transportation, providing in-home exercise programs and assisting with other major life issues as needed. Community partners provides traditional case management, community case management, community integration, and community habilitation.

CLASS's approach to case management is different because it is viewed as a partnership between two people to reach certain goals, as opposed to the medical model which looks at it more as a relationship between client/patient and worker. The other thing that makes CLASS'S case management unique is the experience and history of working with individuals with disabilities. Having case managers who understand common problems that individuals with disabilities face is essential to success of the program and is what makes it different and stand out from other case management programs.

This pilot program takes the framework outlined with Community Partners and adapts it to be used specifically with deaf/hard of hearing/deaf blind individuals. This pilot program aims to see if by providing these services in the individuals primary language, they will in turn gain more connections and increase their social capital which could help to decrease health disparities. By adapting existing services this information can be applied to a multitude of human service agencies, allowing for more comprehensive care without having to create separate entities to provide these services for the deaf population.

2.0 Background

2.1 The History of Case Management

Case management is not a new concept, yet it is being adopted in more diverse fields as a method to improve health outcomes (Harris & Popejoy, 2019). Case management can also be referred to as care coordination or care management. Case management has been proved to be useful in the management of complex physical, psychological, or social problems (Harris & Popejoy). Case management can be used in a variety of settings, in healthcare it is often used to help individuals with complex illnesses, multiple chronic illnesses, insufficient family or social support, or a combination of these factors. The point of a case manager is to serve as a communicator, they help to bridge the gaps between doctors/medical staff, patients/families, and other needed services (Harris & Popejoy). In many settings the case manager serves as a broker, connecting individuals to resources as well as helping to improve communication across multiple groups to support the patient. As of 2018 there were 42,000 board-certified case managers and this is an immense increase from the 27,000 that were reported in 2010 (Harris & Popejoy). This number does not necessarily include individuals who receive an education in a related field such as social work, public health, psychology, counseling etc. who then have the educational background to act as a case manager and do not require a certificate program.

While case management is now used in a variety of fields and specialties it originated in the 1920s out of the fields of psychiatry and social work (Cesta, 2017). It was originally created to help individuals with long term or chronic illnesses manage their health in outpatient and community-based settings. Some forms of case management can however be traced back as early

as the 1860s and the settlement houses where immigrants and poor people lived (Cesta). Workers used something called *patient care records* which was a card that indicated the individual and family needs and then what follow up was necessary. One of the first group of case managers was nurses, specifically public health nurses (Cesta). In the early 1900s case management was implemented by public health nurses at Yale University School of Nursing. These nurses were seen as responsible for cost containment, communication, collaborating with doctors, allocation of resources, responsibility of the overall care of the individual, providing emotional and psychosocial support, and coordination and management of care (Cesta). This is very similar to many case managers job descriptions today. Around the same time in history social workers were using similar techniques for connection patients and families to available resources that they were eligible for. Later in the 1950s case management was relied upon ever more with working with World War II veterans who had complex mental and emotional needs as well as physical disabilities (Cesta). This was when behavioral health case managers became prevalent as they were coordinating the service needs of veterans both on the physical and mental health side.

This continuum of care became more recognized in the 1970s and 1980s as it was supported by the federal government and reimbursement for services through Medicare and Medicaid became possible (Cesta, 2017). It was also during this time that case management was brought back to its origin of being in the community, and by the 1990s community-based case management was becoming very prevalent. At this time the Center for Medicare and Medicaid Services funded five projects where nurses filled the role of community case managers to help coordinate care (Cesta). The nurses in these programs aided with a variety of tasks including completing health risk assessments, authorization/coordination/evaluation/payment of services, transportation, respite care, home-delivered meals, health promotion activities such as exercise or nutrition,

durable medical equipment and minor surgical care. This movement to fully embrace case management came out of a need to lower healthcare costs, and the waste of health care costs that was occurring from lack of patient coordination (Cesta).

After case management started to be recognized as a successful way to lower health care costs while improving quality hospitals started to adopt this on their nursing floors. The first hospitals to adopt this were Carondelet St. Mary's Hospital in Tucson, AZ and New England Medical Center in Boston, MA (Cesta, 2017). Both of these hospitals adopted case management models to their nursing to help monitor individuals progress towards discharge. Carondelet collected data over the first four years and found that it not only improved quality and lowered healthcare costs, but that job satisfaction increased for nurses, their job stress decreased, patient satisfaction increased, patients with chronic illnesses were hospitalized less, those who were admitted had lower acuity levels, and length of patient stay was decreased (Cesta). These findings led to the first nursing health management organization (HMO) which was created in 1989, working specifically with the elderly. New England Medical Center Hospital in Boston approached it slightly differently, using senior staff nurses to fill the case manager role but both ways were deemed a success and hospitals around the country started to follow in suit. This also led to the buy in from other disciplines and eventually a movement away from incorporating it into nursing (Cesta).

Today case managers in hospitals usually report to a chief operations person or medical officers and it is separated from nursing (Cesta, 2017). This movement allowed for case management departments to become their own and gain more power in the organization. Now a lot of case managers have backgrounds in social work, psychology, counseling, mental health, sociology etc. While case management started in the community and moved to the hospital setting,

in many ways it is now back to its roots in the community (Cesta). This has allowed case management to broaden past hospital services and become in many ways its own discipline.

Case management has been used in a variety of settings over the years with a variety of different patients and settings. During the HIV epidemic, New York decided to implement case management services for the patients with HIV because of their complex care needs (Brennan-Ing, Seidel, Rodgers, Emst, Wirth, Tietz, Morretti, & Karpiak, 2016). “The goals of case management are to achieve care engagement and treatment adherence by helping the client function independently through access to housing and other supportive services (Brennan-Ing et. Al., page 12). This program in New York was known as Targeted Case Management (TCM) and it specifically targeted HIV-infected people who had comorbid conditions including behavioral health issues. The program was meant for individuals who required frequent contact with care providers and struggled to access medical and other supporting services (Brennan-Ing et. Al.) the specific goals of the program were to provide access services that would help foster independence, ensure adherence to treatment, prevent or delay institutionalization, increase access to HIV related services, and promote disease prevention. The findings of the study showed that TCM did improve the patient’s engagement with care and treatment adherence which in turn led to better health outcomes for the individuals as they saw a significant increase in the average CD4 T-cell counts (Brennan-Ing et. Al.)

Regardless of the group or the time that case management was utilized, it all shared one common goal—to improve communication and decrease barriers. Just like any other group, the deaf population has a unique set of needs that many service providers struggle to meet. Improving communication and decreasing barriers is something that is incredibly relevant to the deaf

population today. In order to understand the unique needs of the deaf population it is necessary to understand their robust history as a minority group in the United States.

2.2 The History of Disability Policies

In 1988, a joint hearing was held before the Senate Subcommittee on Disability Policy and the House subcommittee on Select Education (Mayerson, 1992). A room that held 700 people was overflowing with individuals with disabilities that came to support the passing of the Americans with Disabilities Act (ADA). The disability community, as well as the deaf community, was very active throughout this entire process of advocating for disability rights—specifically in regard to having access to a fair and equal education. Senator Harkin was the first to speak and he spoke about his brother who was deaf and started his speech in American Sign Language (Mayerson). Senator Kennedy talked about his son who had a leg amputation and Representative Coelho talked about his personal struggle with epilepsy and the discrimination he faced. When the senate voted it passed 76 to 8 and was sent to House in 1989. The ADA was officially enacted as a law in 1990 under the George H.W. Bush administration (Mayerson). This policy creation however was only the beginning of a movement across the country, and within the city of Pittsburgh, that put equality of individuals with disabilities at the forefront of every community.

The ADA is divided into five sections each referring to a different area of public life and each is overseen by a different government agency. The first section is employment and it is meant to help people with disabilities access the same employment opportunities and benefits as those who are not disabled. This requires that employers provide “reasonable accommodation” for employees that have a disability as long as it does not cause the employer “undue hardship.” This

part of the law is overseen by the U.S. Equal Employment Opportunity Commission (ADA National Network, 2014). This part of the law protects the disabled from discrimination in the form of employment, pay, job assignments, promotions, layoffs, trainings, benefits, and any other terms in the contract. Some of the reasonable accommodations that the EEOC suggests are making a workplace wheelchair accessible or providing a reader or interpreter for someone who is blind or hearing impaired. Businesses with 15 employees or more are expected to follow this policy. The EEOC has a three-prong approach for recognizing whether someone qualifies as having a disability. The first is that the person can be disabled if they have a physical or mental condition that affects major life activities such as walking, talking, hearing, seeing, or learning. The second is if the person has a history of disability such as cancer that is in remission. The last component is if someone experiences a disability that is expected to last six months or less such as a broken bone or a concussion. The EEOC oversees that anyone suffering from one of these three types of disabilities is not discriminated against in terms of employment (Equal Employment Opportunity Commission, 2014).

The second section of the act is nondiscrimination on the basis of a disability in state and local government services. This means that those with a disability cannot be discriminated against in terms of any government programs or services that are available to those who do not face a disability (ADA National Network, 2014). This part of the act calls for a degree of self-evaluation of the government agencies to see what could need to be changed. It calls for modifications to policies, practices, and procedures as well as identifying any barriers that could be in the way of those who are disabled. It also calls for effective communication and making any needed adjustments for those who suffer with hearing, vision, and speech disabilities. This part of the act is regulated by the Department of Justice (ADA National Network).

The third section of the act deals with public accommodations in commercial facilities. This prohibits the discrimination of those with a disability by public places and requires them to have accommodations for those with a disability. This applies to places such as hotels, restaurants, doctors' offices, private schools, day care centers, sports stadiums, movie theaters etc. This includes businesses taking necessary steps to be able to communicate with customers who are vision, hearing, or speech impaired. This part of the act is also regulated by the Department of Justice (ADA National Network, 2014). This is what required public transport entities to be wheelchair accessible. This is also where the edge of curbs being gradual declines came about so that those with wheelchairs would be able to easily access the sidewalk (101st Congress, 1990).

The fourth section is telecommunications. This mainly relates to the telephone and internet companies and requires them to have relay services that would allow those with hearing or speech disabilities to still use the phone as a way of communication. This is also what requires closed captioning on public service announcements. This part of the act is overseen by the Federal Communication Commission (ADA National Network, 2014). This section of the act requires that telecommunications relay services that operate every day for 24 hours as well as having minimum standards that must be met. It is also prohibited for operators to alter a relayed conversation and from disclosing anything that is discussed in the relayed conversation (101st Congress, 1990).

The last section of the act is the miscellaneous portion which includes the relationship between other laws, state immunity, the laws impact on insurance providers, prohibition against retaliation or coercion, use of illegal drugs, and attorney's fees (ADA National Network, 2014). It also talks about discrimination with attorney's fees and how this is prohibited (101st Congress, 1990).

The ADA was then updated in 2008 to broaden the definition of disability to consider limitations of a major life activity to be difficulty with seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentration, thinking, and communicating. Major bodily functions was also expanded to now include neurological disorders as well as the previous ones listed (DiNitto, 2011).

While the ADA is often the most well-known policy in regard to disability rights, there are many other policies that have impacted the lives of those with disabilities. In 1975 there was the Education for all Handicapped Children Act (EHA) which in 1990 was renamed to the Individuals with Disabilities Education Act (IDEA). EHA was created with three main provisions: to guarantee all children with disabilities a free appropriate education, to ensure rights of children with disabilities, and to aid states and local agencies in providing the education through grant-in-aid's (Lee Jones). This act specifically aimed to address children with disabilities and their families in relation to the education system. In 1994 the Goals 2000: Educate America Act was passed, and this is when the line between special education and regular education began to fade (Grigorenko, 2008). This was only shortly after the changing of the name of EHA to IDEA. IDEA was reauthorized in 1997 and there were some alterations made in things such as regulations. In 2001 the No Child Left Behind Act was created and this guided the further development of disability education regulations and allowed for the line between regular education and special education to continue to fade, further intermingling the two (Grigorenko). Ultimately this led to the Individuals with Disabilities Education Improvement Act of 2004, the most current act we as a country to guide special education practices. The short-term goal of these policies is to provide an education to all children despite their disability or rather their ability (Lee Jones, 2004). The long-term goal is to enhance the potential of each individual to live independently in society, which in turn

attempts to better the quality of life for these individuals (Individuals with Disabilities Education Improvement Act of 2004, 2004). See Table 1 for a timeline of disability policy.

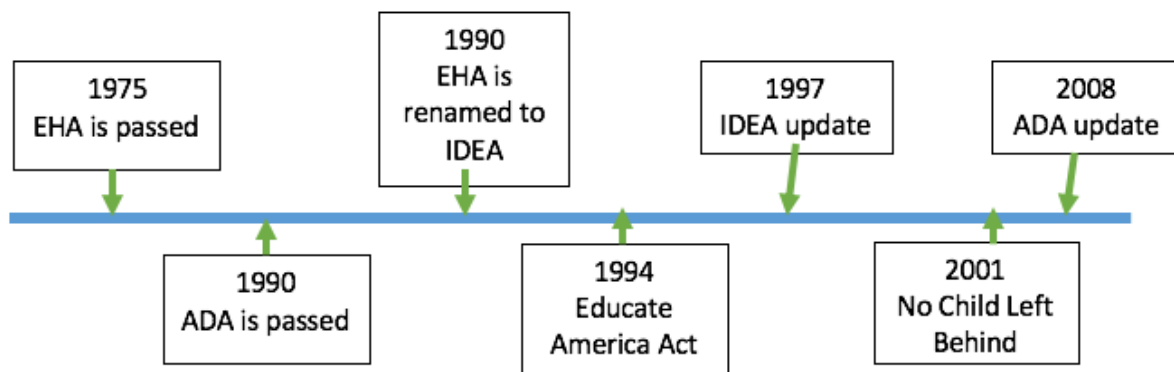


Figure 1 Timeline of Disability Policy

All of these various policies over the years shaped the disability community in general, but it also had specific effects on the deaf population. The ADA specifically had a large impact on the deaf community of Pittsburgh for a variety of reasons, but the change was not immediate, and it didn't happen overnight. Dr. Kimberly Mathos has been working with the deaf/deafblind/hard of hearing population, specifically in Pittsburgh, since 1985 and she describes significant changes that have occurred over the past thirty years. Mathos talks about how she finds younger deaf generations are far more educated on their rights and are aware of what services they should be offered (Mathos, 2017). Senior citizens with hearing loss are usually less informed of their rights. The ADA in many ways empowered the deaf community to get equal access to services.

Not only did the ADA empower deaf people but the laws mandated equal access to technology which continued to advance over the next century. The use of captions, and relay services on telecommunications broke down many barriers for the deaf and hard of hearing individuals. This made it possible for deaf and hard of hearing individuals to watch TV and movies, to use the telephone, to have alarm systems that were able to wake them in an emergency, and to have lights in the house that would flash when the doorbell was rung. All of these advancements drastically changed the day to day life of a deaf individual and made it easier for them to partake in the larger hearing community. Steve Farmer, the current CEO of the Western Pennsylvania School for the Deaf, stresses that social media in general has really fostered language and communication development for the members of the deaf community (Farmer, 2017). The ADA led to more technological and medical advancements. The ADA was just one of the many legislative acts that fostered change and helped the deaf community. It made equality a possibility, in both work and health care and led to advancements as well as more access to information. Amy Hart, President and CEO of Center for Hearing and Deaf Services of Pittsburgh, summarizes the impact of the ADA on Pittsburgh by stating, “The ADA and the Rehabilitation Act of 1973, as well as the internet has greatly expanded the Deaf Community’s right and ability to communicate under the first amendment (Hart, 2017).”

2.3 American Deaf Culture

For many members of the deaf community, “Deafness [is] not as a defect, but as a source of connection! Imagine yourself deaf, growing up with a beautiful language, visual literature, humor and theater. Imagine taking pride in your identity without any desire to become a member

of the majority culture (Halpern, 1996). Deafness is far more than a disability to individuals but rather it is an identity and a culture.

Hearing loss is the sixth most common medical condition in the United States with a prevalence of 9.4% (Mathos, & Pollard 2015). American Deaf Culture centers around the use of American Sign Language (ASL) and has a sense of unity with other deaf individuals (Gallaudet University, 2015). There are a variety of values and traditions that the deaf population values, similar to any group of shared history/ancestry etc. Deaf culture promotes an environment that relies heavily on vision as the main sense used for communication, it is through vision that deaf individuals interact with the world and are able to lead independent lives (Gallaudet University). The Deaf community value children and teaching ASL as a way to continue their traditions.

2.4 The History of the Deaf Population in Pittsburgh

Pittsburgh has always been a city that has welcomed the deaf population and has been on the forefront for innovation for this group. Calbraith Rodgers is famously known as the first pilot to make a transcontinental airplane flight across the United States between September and November of 1911. However, he is not only famous for making the trip, but also for being one of the first deaf pilots. Rodgers was born and raised in Pittsburgh, he became deaf later in childhood due to the scarlet fever (National Aviation Hall of Fame, 2017). Rodgers was one of the many deaf Americans during the beginning of this century that disproved the commonly held belief that deaf people were unintelligent and demonstrated that deaf people had abilities equivalent to that of those with hearing. Throughout Pennsylvania the deaf community only makes up at about 2.1% of the total population (Harrington, 2004). In Allegheny County there are an estimated 120,000

people who experience hearing loss and about 5000 individuals use American Sign Language (ASL) (Mathos et al). Pittsburgh is now considered to be one of the most deaf-friendly cities in the country (Deaf411, 2009).

Pennsylvania, and specifically the city of Pittsburgh, have always been at the front end of changes within the Deaf community. In 1869 the Western Pennsylvania School for the Deaf was founded in Pittsburgh, and it was the first day school for the deaf in the country (Western Pennsylvania School for the Deaf, 2010). This was a watershed event for deaf individuals and really established the city of Pittsburgh as the premiere service provider for those who are deaf. Throughout history there have been different beliefs on how to educate a deaf person. Ultimately there were, and still are today, two main perspectives on education of the deaf. The first—and older perspective—is referred to as oralism or currently is known as Listening and Spoken Language (LSL). The first oral school in the United States was established 1867 in New York and this school made oralism more popular because it proved the “impossible” of teaching deaf people to speak and lip-read (Gannon, 1981). The DePaul Institute of Pittsburgh was the first oralist school in the city and was created in 1908 with the Catholic Church to provide alternate means of educating the deaf. With the success of oralist schools such as these, deaf schools across the country began to embrace this oralist method (Gannon). This system contradicted the old beliefs that the deaf were incapable of being taught (M Nomeland & R Nomeland, 2012). The success of this oralist method led to the decline in the use of Sign Language as a teaching approach. In 1880, educators from around the world convened in Milan for the Second International Congress on Education of the Deaf (Nomeland & Nomeland). Out of 164 representatives, only one was deaf and the conversation amongst the delegates quickly led to them banning the use of Sign Language worldwide. This effect was seen in the US in the early 1900s with a decrease in deaf teachers and

an increase in oral programs (Nomeland & Nomeland). This was seen in the city of Pittsburgh in that it was right around the time the DePaul School was founded on the oralist method. However, it wasn't long before the National Association of the Deaf became worried that the beauty of sign language was going to be lost; as such, they established a motion picture committee which recorded some of the most talented signers for preservation (Nomeland & Nomeland). Over time people realized while the oral method was possible, there are some individuals it just does not work for and that Sign Language will still be the best solution for these individuals. As time passed after the ruling in Milan, Sign Language gradually become more accepted over time and a lot of schools began to slowly shift their focus back to Sign Language (Nomeland & Nomeland).

Alexander Graham Bell wrote about deaf education in 1905, saying that, "the best school for a deaf child, is a school with only one deaf child in it...one deaf child with an environment of hearing children (Van Cleve, 2007)." Bell was not the only one to share this belief, in fact, many believed that the deaf should be integrated with hearing students. And today that is truly possible. There are so many more options today in Pittsburgh for deaf education, ranging from the oralist method at the DePaul School, to the ASL approach at the School for the Deaf, to an integrated education where a child can be mainstreamed at most public or private schools. Remembering that at one point in relatively recent history, deaf individuals were not educated and were institutionalized, it is clear that education of the deaf has come a long way and that these changes in beliefs from oralism to American Sign Language to mainstreamed education have really impacted the Pittsburgh deaf community.

2.5 Barriers for the Deaf Population

While the ADA led to quality of life changes for many deaf individuals, inequalities and disparities in access to many services such as housing, employment, and health care is a persistent problem. It is also known that individuals who are deaf bear an increased burden of mental health problems (Mathos et al). While rates of mental health needs are higher in the deaf population, fewer individuals seek services (Fellinger, Holzinger, & Pollard, 2012). In 2005 only 200 deaf individuals in Allegheny County were enrolled in outpatient mental health care (Mathos et al). Deaf people who use ASL are medically underserved and excluded from a variety of health services such as research and public health surveillance (Barnett, Klein, Pollard, Samar, Schlehofer, Starr, & Sutter et al, 2011). A comparison of the 2008 NCDHR Deaf Health survey and 2006 Monroe County (Rochester, NY) Survey found that attempted suicide rate in the past 12 months was 1.8 times more likely for deaf individuals than hearing individuals (Barnett et al). Physical abuse was 7.1 times higher with deaf individuals, sexual abuse 15 times higher, and sexual abuse in the past 12 months was 3.1 times higher (Barnett et al).

This population throughout the country, but also in Allegheny County, lacks access to therapy services, mental illness recovery-oriented services, mobile therapy, case management, group therapies, drug and alcohol services, and general information related to mental health along with a variety of other things (Mathos et al). Often times this health disparity is a result of inability to communicate between provider and the individual. “Deaf patients with access to interpreters use more preventative services and receive more psychiatric and substance-misuse counseling than do patients who rely on note-writing with physicians (Fellinger et al). In Western Pennsylvania there has been an increased number of individuals being able to access counseling by an ASL fluent provider over the past 15 years (Mathos, 2015).

Communication between health care providers and deaf individuals is a big concern in today's society. Deaf individuals tend to have fewer doctor visits, participate in fewer preventative services such as mammograms and colonoscopies, and often experience misunderstanding between themselves and their doctor in regard to medication and follow up procedure (Hommes, Borash, Hartwig, & DeGracia, 2018). While now under the ADA health care facilities are required to provide interpreters, many clinicians continue to use note writing, lip reading, or use family members to act as translators. Recent studies have shown that only 22% of clinicians actually use ASL interpreters, even though they know they are required to provide that by law (Hommes et. Al.) Hommes and colleague's study surveyed thirty-seven interpreters and found that interpreters felt that providers rated lip-reading and written notes as adequate forms of communication and that because of that an interpreter wasn't always needed. The interpreters indicated that 59% of the time patients appeared unclear about medication risks, the need for follow up appointments, and any other important provider instructions was often unclear (Hommes et. Al.) Additional barriers that were noted in this study included provider time constraints causing appointments to be rushed and questions to not be answered. Another major barrier on the individual's side was the lack of empowerment to ask questions and to advocate for themselves. The interpreters interviewed also mentioned the need for enhanced health literacy and health education in the Deaf community so that they are able to advocate for themselves better (Hommes et. Al.)

Poor communication can put individuals at a high risk for health disparities as well as adverse health effects (McKee, Barnett, Block, & Pearson, 2011). McKee and colleagues conducted a survey of deaf individuals to look at concordant vs discordant communication with providers. The respondents who said communication was concordant were more likely to receive the flu vaccine than those who reported discordant communication (McKee et. Al.) Ultimately this

study was able to prove that deaf individuals who utilize ASL and receive concordant healthcare communication were more likely to engage in preventative healthcare than those who received discordant communication (Mckee et. Al.)

Another study showed that a health care workers decision to use professional language assistance, or interpreters, is often influenced by hectic working conditions (Kale & Syed, 2010). As a result, this causes health care workers to usually make a decision that is convenient for them but not necessarily optimal for the patient. Generally speaking the use of interpreters in health care is under-utilized, and lack of training of health care workers often feeds into the likelihood of a translator not being provided for a patient (Kale & Syed). Some of the other barriers to health care professionals utilizing interpreters is that often times in the ER setting they rely on untrained interpreters who usually do not have the skills or qualifications to be fully acting as an interpreter (Ramirez, Engel, & Tang, 2008). Health care professionals also tend to have a perception of additional time or labor that will occur when involving an interpreter, and similar to this most programs recognize the cost of providing an interpreter is often times not cheap (Ramirez, Engel, & Tang). On top of all of this the time when interpreters are being used there is really high use of non-professional interpreters being used a majority of the time. Nurses and physicians have been known to interpret 49% of the time, other medical staff 27% of the time, and family members or friends 12% of the time (Ramirez, Engel, & Tang).

Many of these issues of having an interpreter, and communication in a health care setting is not something that is only relevant to the deaf population. This is a common problem many groups face for speaking a different language, unfortunately American Sign Language is just as susceptible to this problem. One of the biggest problems the deaf population has that was previously mentioned is communication and struggling to communicate with others. One of the

case managers prime responsibilities is to improve communication between an individual's providers, therefore it only makes sense to attempt to use the framework of case management to help individuals who are deaf navigate a variety of services.

3.0 Methods

This program was created within CLASS's Community Partner program and framework. Prior to the start of this pilot program and advisory committee was formed with key stakeholders to advise on the development of the program. From within the agency the committee included Community Partners program Director, CLASS'S Chief Professional Officer, and the coordinator of assistive technologies (previous Sign Interpreter). Outside stakeholders that were included were an expert psychiatrist who works closely with the deaf community, a CLASS participant who is deaf, and two professors from the University of Pittsburgh's graduate school of social work. This committee was set to meet every other month, with e-mail updates on the off months. The committee was more heavily involved in the formation of the proposal and then as the program continued e-mail updates were able to become more commonly the method of contact.

After the creation of the advisory committee, the description of the program was created with a tentative start of service delivery of July of 2018. The program was established and accepting referrals in July and by August meetings with participants were being scheduled. The program aimed to engage with 5-10 deaf individuals who identify needs that fit within the goals of the program and meet the qualifications. Qualifications for participation in the program were:

- a. Individual must be between the age of 18-59.
- b. Individual must be deaf, hard of hearing, or deaf blind.
- c. Individual must use American Sign Language as a method of communication (it does not need to be the sole method of communication).
- d. Finally, the individual must live within Allegheny County, Pennsylvania.

The age range (18-59) was selected based upon corresponding age range in the Community Partner program. Requiring the diagnosis of deaf/hard of hearing/deaf blind and the use of American Sign Language was first to ensure the target population was reached and given priority. Second, the Community Partners program already currently supports individuals between the age range with all types of abilities, therefore this was intended to ensure the diversity within the program in terms of disability status. The program was restricted to only serving in Allegheny county in order to maximize quality of services since there was only one case manager. This decision was also made because the case manager is traveling to individuals' homes.

Individuals for the program were recruited throughout the community from a variety of sources such as the Western Pennsylvania School for the Deaf, Office of Vocational Rehabilitation (OVR), and Western Psychiatric Institute and Clinic. Individuals making referrals to the program were asked to complete a referral form allowing the case manager to then contact the individual (see Appendix). Once a referral form was completed the case manager would make initial contact with the potential participant to schedule a time to meet. Contacting the individuals was done mostly through a google voice texting number. This allowed for quick communication between the case manager and the client. TTY was also used if the individual had that available within their home. In one particular case the meetings were scheduled through the mother who was hearing so regular telephone calls were used as the contact method.

The community partner, or case manager, gave individuals the option to meet at CLASS's office or the community partner could come to the individuals home if that were more convenient. A variety of times for meetings were offered including evenings and weekends. At the initial meeting the individuals were given a packet of information (see Appendix) providing information on CLASS, Community Partners, and this specific pilot program. A short biography on the

community partner was also included as well as contact information for everyone involved in the program. A second packet of release forms was also reviewed and then signed by the participant (see Addendum). The first meeting held two purposes, first to ensure the participant understands the paperwork and are interested in the program, and second to conduct a needs assessment.

The needs assessment is a form to help organize the participant's strengths, needs, and interests. Information was gathered about medical history, hospitalizations, mental health diagnosis, any previous services, and important contacts such as service coordinators. The community partner aided participants in completing the intake form (can be seen in Addendum). After this meeting enough information should have been collected that the community partner is able to draft the outline goals form to follow in the program (can be seen in Addendum). This plan will then be reviewed and confirmed at the next meeting between the community partner and participant. This written service plan needs to be signed off on by both the consumer and the community partner. Ideally the community partner would then meet with the consumer one-two times a month depending on the level of assistance they need. Upon each visit case notes will be completed by the community partner (use the same visit notes form on page 23). The remainder of the individual's sessions after the first one focus on operationalizing the goals and objects and breaking them down into manageable steps and working on those steps with the consumer.

There are no expenses to the program, it was offered to individuals as free of charge. The community partner in this case donated their time to the program and only minor expenses were covered by the agency. These minor expenses would include printing packets and information, the time of senior management staff who advised on the project, and use of resources such as providing copies of agency brochures etc.

Evaluation was done through a post survey test. This post survey test includes questions regarding the individual's satisfaction with the program but also uses questions that can be found on the Harvard Social Capital Benchmark Survey. These questions will be utilized to understand the change prior to the programmatic intervention and to after. Chart 2 shows the process of the program from start to finish.

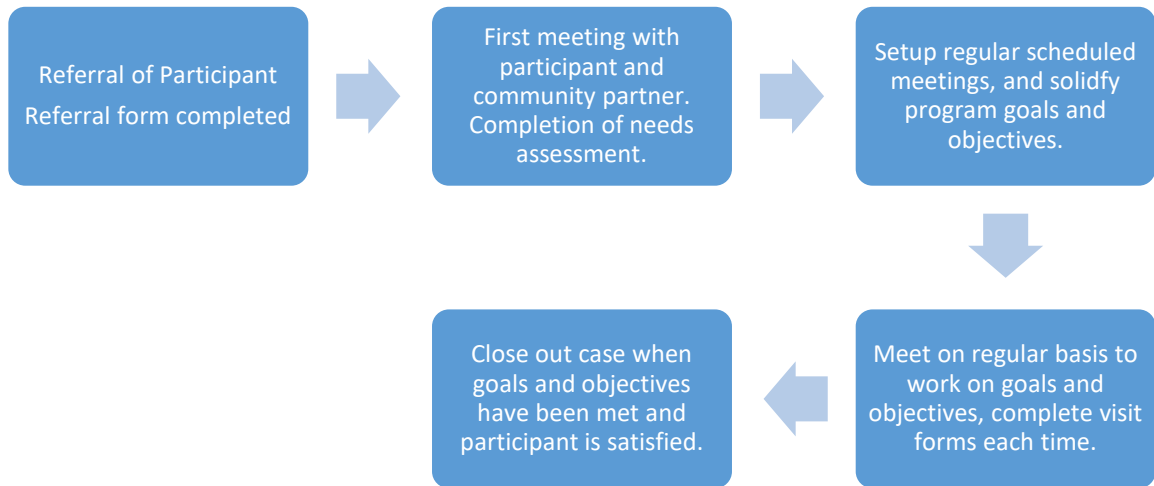


Figure 2 Program Flow Chart

4.0 Results

Table 3 shows a chart of the referred individuals and the specific goals they were looking to address with the program. Common themes in the needs of individuals were getting assistance to move into a residential home, and assistance with financial management. Both of the individuals that wanted to move into a residential facility were still living with their parent(s) who were now in their late eighty's. With both participants the families were concerned about their loved one being cared for when they were gone and were worried about what would happen if something happened to them. Participant 2 will be the main focus of this discussion as he has completed the program. There were ten individuals who were referred for the program, six of which started receiving services in some capacity, and four who did not follow through with services are did not express interest in moving forward with the program. All ten individuals referred were deemed eligible for the program.

Table 1 Identified Needs of Participants

Participant 1	Wanted assistance finding a residential program to move into
Participant 2	Wanted assistance finding a residential program to move into
Participant 3	Wanted assistance finding volunteer opportunities
Participant 4	Wanted assistance finding a job
Participant 5	Wanted assistance with financial management and understanding benefits from work
Participant 6	Wanted assistance with financial management and getting access to welfare services
Participant 7	Wanted assistance with community habilitation and finding a job
Participant 8	Wanted assistance finding a job
Participant 9	Wanted assistance getting ownership rights of individuals house
Participant 10	Wanted assistance with transition services out of high school and possible day program

Of the ten participants enrolled in the program 9 were deaf, and 1 was hard of hearing. All the participants had additional physical or mental diagnoses that were also impacting their life.

Participant two was enrolled in the program in August. The case manager went out and met with the participant and his mother. A majority of the first meeting was with the mother, explaining what this program was and what it could help their family with. The mother spent a lot of time explaining family history and some of the problems and struggles she has currently with still caring for her son. It was clear that the mother was experiencing caregiver burnout and needed help quickly. The case manager briefly spoke with the individual and he was happy to be able to sign with her. The mother knows a few signs but is not fluent and mostly relies off of him reading lips for their communication. At the first meeting the mother mentioned to not understanding how a lot of these programs or services worked and being pretty confused as to what her son was eligible for and not eligible for. The case manager agreed to review all the history and services as well as talk to the individuals service coordinator while also compiling a list of local residential facilities that at the next meeting they could start to review. After this meeting the case manager talked with the individual's service coordinator who was happy to hear someone would be working with the family. This is when the case manager realized that the individual was already enrolled in CHC or Community Health Choices and received services through UPMC. This meant the participant did not need to go through the process of being enrolled in services but rather just needed to find a residential program with an opening that had a contract with UPMC.

At the next meeting, the case manager provided the mother with a list of different residential housing programs in the area that could be considered. The mother was initially interested in CLASS's residential program because they already had some vacancies and had a contract with UPMC. The case manager at this point referred the participant to the residential

director who set up a meet and greet with them. There was a lot of education that took place with the mother, because she previously did not understand how services were offered and didn't even realize that her son didn't need to apply for services and that he had already gone through that entire process. She was also under the impression that her son needed to have an IQ below a certain number in order to qualify for services, and when she realized his IQ was higher, she was worried he wouldn't be able to qualify for services. The case manager worked with her to help her understand that because of the physical disability he had, cerebral palsy, there were other services he was eligible for that did not require a minimum IQ level.

The residential director met with both the mother and son and everyone agreed that it seemed like a good fit. The participant was very excited at the idea of moving out of his family's house and into a place more of his own. The residential director then accompanied the mother and son to visit the home that had a vacancy and the home supervisor also met them there. The individual was really excited and enjoyed seeing the house and meeting the two other individuals who live there. At this point the mother and son agreed that they would like to go forward with him moving into this house.

At this point the remainder of the work was coordinating with the service coordinator to get the participant assessed for how many hours of care he was eligible for. Then there was the logistics of getting the room ready for him to move in, getting all his prescriptions changed to the pharmacy the agency uses, and getting the equipment he needed into the house such as the TTY. He was officially able to move in by the end of December but choose to wait for the new year, so he could spend Christmas with his family.

The move in of the participant overall was seen as a pretty smooth process, he started to get along with roommates and staff very well and was enjoying the new independence of being

out of his mother's home. The agency is looking to hire a full-time staff member who signs to work they day shifts with him, so he can communicate more. The agency is also providing regular ASL trainings to the other staff working in the home, so they can begin to learn more sign language and communicate better with him. Recently the participant went with his two roommates to the casino one evening over the weekend and he really enjoyed being able to go out with his friends and do something that was in many ways considered normal. Most recently, he commented saying, "I feel like a real grownup now."

Participant 2 described above is the only participant of this program that has finished completely. The rest of the participants are still receiving services. Due to this the full results of this program are not complete at this time due to the fact that the program is not complete. The results are rather focused on participant 2 and adaptations that were made to the existing program to fit the needs of the deaf population.

The main adaptation to this program included change in communication methods, specifically how communication between the participant and case manager was handled. Because this program was targeted at the deaf population it was important to establish a main method of communication that would work for this population. CLASS's program Tech Owl does have a TTY phone set up in the coordinators office so this was used if individuals had access to TTY. The other solution to this was using texting as a main form of communication. The case manager used the google voice app in order to text with participants without using her personal cellphone. Google voice is a free app that attaches a phone number to it. This allows a person to text the case manager and it will go into the app. While the app is on the case mangers personal phone it allows for some separation and prevents the participant from having the case managers direct phone line. CLASS's Community Partner program normally uses phone calls as the main form of

communication outside of meetings so the use of google voice was an adaption to better the needs of the deaf population.

Another adaption that was made to the Community Partner's program for this specific pilot program was the use of American Sign Language in the sessions. This did not require the changing of any materials but rather just allows for communication between the case manager and the participant to take place in their primary language.

The last main adaptation that was made to this program was less of an adaptation and more just a shift in focus. Generally, CLASS's Community Partner program is focused on working with people of a variety of disabilities. Whether its housing, job opportunities, or applying for services this is all considered in the realm of the persons abilities and strengths. The deaf population has a unique set of needs which need to be considered in order to successfully make an impact. For an example participant 3 was interested in finding volunteer opportunities, while CLASS has relationships with many different organizations for volunteer work this was a unique situation because participant 3 had a different set of needs. One of the strengths of participant 3 that the case manager and participant found when working together is her ability to teach ASL and work with hearing individuals as well as deaf due to her being hard of hearing. Participant 3 is now running monthly trainings for staff at CLASS to learn ASL. This was a good fit for participant 3 because it allowed her to play on her strengths, but also become more independent in an environment that will encourage her own growth. Table 2 shows the current status of all participants in the program.

Table 2 Current Status of Participants

Participant 1	In the process of moving into a CLASS residential home
Participant 2	Moved into CLASS residential home
Participant 3	Is teaching monthly trainings of ASL to CLASS staff
Participant 4	Moved out of state so no longer receiving services
Participant 5	Never responded to case manager to set up meeting time
Participant 6	In process of needs assessment
Participant 7	Receiving community habilitation services from Mercy Behavioral, still looking for a job
Participant 8	Was hired by CLASS as a direct care worker to provide care to deaf individuals
Participant 9	Never responded to case manager to set up meeting time
Participant 10	Mother was not interested in assistance at this time

5.0 Discussion

One of the common themes that was noticed in this program is the difficulty individuals faced in navigating social services. This can really be seen with participant 2, because they were already enrolled in Community Health Choices (CHC) yet neither the participant or mother understood this. While this is not completely uncommon and a lot of people in the general population struggle to understand the welfare system, it is interesting that 100% of the program participants struggled with this. The deaf population is known for not having great access to interpreters and this can interfere with services because it often leaves them communicating through other means such as writing. While this may work in the moment, it is not ideal, and it is going to hinder communication and the participants understanding of the situation.

Another difficulty with serving this population is the lack of services they are eligible for. Participant 2 was able to be enrolled in CHC because of his diagnosis of Cerebral Palsy, it had nothing to do with him being deaf. A lot of the common waiver programs that are used by many agencies, including CLASS, are serving individuals with physical or mental disabilities. This pilot program was offered free of charge but in continuing this program funding could prove to be a huge barrier. This type of program is beneficial for deaf individuals who also have a physical or mental disability, but it fails to reach the population of deaf individuals who do not have a specific disability but may need assistance with financial management, finding a job or volunteer opportunities etc. Going forward there needs to be more advocacy efforts focused on finding a way to serve this population. Right now, in Western Pennsylvania there is this shift to managed care which is taking the place of all these waivers that used to exist such as OBRA, COMMcare etc. From the perspective of the client this managed care change truly is a good thing, it is allowing all

individuals to have access to a variety of services as opposed to separating them to smaller waivers that lock people into specific services. This change is allowing individuals to get access to a wider variety of services which for many people is a huge accomplishment. Western PA was the first part of PA to participate in the rollout of managed care and PA is the first state. This puts Pittsburgh in a unique spot to advocate for changes with managed care, specifically advocating for inclusion of the deaf population. Similar to how autism got a waiver to specifically cover services for those individuals, the deaf population is in need of their own waiver that can help to cover services like case management.

If this program were to be continued other than finding a consistent funding stream, CLASS would need to hire more than one case manager who is fluent in ASL. If the staff that are hired were fluent in ASL but also hearing this would allow them to work with deaf individuals as well as other individuals that may be referred to CLASS for case management. It would also be important going forward to build more relationships with stakeholders in the community who would be willing to take volunteers and would hire deaf individuals. Some already existing potential partnerships could be Eat N' Park, and Goodwill which are both stores/restaurants in Pittsburgh who are known for hiring deaf individuals. This however needs to be expanded because a huge need of the deaf population is finding work and more partnerships will be needed to fill this need.

One of the flaws with this pilot program was the size of the sample population. Due to their only being one case manager, and it being done on a volunteer basis, the number of participants in the program was rather limited. While this was a decent size to make some conclusions going forward it would be important to expand the program in the future.

Comparing this program to CLASS's standard Community Partner's program there are not many differences in terms of the rollout. The case manager was able to use the same forms the rest of the case managers used with other participants and the program was run with the same structure. The only difference in rollout was the modifications that were made to the program to meet the needs of the deaf population, mostly related to communication, and the process of getting referrals was slightly different since the target population was very specific. Prior to the program rollout there was concern as to whether the target population would be attracted to this type of service and whether it would really fill a gap in current services. Not only did the program rollout prove to be relatively simple, but the referrals came quickly and usually multiple came at once.

The feedback from other providers and professionals making referrals was overall very positive and there was a greater need than this pilot program was able to fill. If the case manager had been able to devote more time to this program, or there was more than one case manager the case load could definitely have been full. While it could have been difficult to reach the target population, having insiders who worked with deaf individuals was really quintessential in getting referrals for the program. Once a couple of professionals knew of the program word spread quickly and people from a variety of organizations were making referrals. One of the difficulties was that just because someone is referred, doesn't guarantee they will be open to receiving services. There were a couple of individuals referred who did not end up becoming participants in the program. While this could be for a variety of reasons it is hard to say without further research as to what would make people resistant to case management services when it would benefit them. If this program were to continue the recommendations would be to find diversified funding, recruit more participants and more workers and to increase project stakeholders.

6.0 Conclusion

The deaf population, like many minorities, has faced many difficulties over the years. Legislation and policy have come a long way over the years to provide the deaf population with access to more services and equality of access. They however, as a minority group, still face a multitude of health disparities and difficulties in their day to day lives. One of the greatest difficulties is receiving services in American Sign Language. This pilot program allowed for the opportunity to provide deaf individuals with free case management to see if it could have beneficial impact by offering the services in American Sign Language. CLASS has a long history of serving individuals with a variety of abilities, therefore offering this service also offered the chance to bridge a gap between a community needing more services, and an agency who could help to fill that gap for some individuals.

While this pilot program had a small number of participants it was successful in providing a needed service in an individual's first language while helping the individual to meet their goals. One of the big takeaways from this program was the ability to adapt an existing human service program to fit the needs of the deaf population without having to create a program from the beginning. This program is different than others because first it brings an agency with years of experience and connections in the Pittsburgh community to work with a population and their current needs. It specifically offered strong support to deaf individuals living with a physical disability, due to CLASS's experience as well as other programs the participants were able to benefit from. Overall this pilot program was successful, but for continued success moving forward there is a need for funding as well as additional case managers in order to meet the large need.

Further evaluation will also need to be reviewed to see the long-term effects on the individual's life and social capital.

Appendix A Referral Form & Intake Forms

Community Partners/
Community Health Worker



New Referral Form

Participant Information	First	Middle	Last
Name			
Address			
Zip Code			
Neighborhood			
County			
Home Phone Number			
Cell Phone Number			
Alternate Number			
Email Address			
Preferred Method of Contact			
Date of Birth			
Program Needs/Goals			
Diagnosis Information			
Diagnosis			
ICD-10 Diagnosis Code			
Onset Date			
Additional Information			
Diagnosis			
ICD-10 Diagnosis Code			
Onset Date			
Additional information			
Additional Information/Comments			



Participant Information	First	Middle	Last
Name			
Address			
Zip Code			
Neighborhood			
County			
Traveling directions			
<hr/>			
Home Phone Number			
Cell Phone Number		Is texting okay?	
Alternate Number			
Email Address			
Preferred Method of Contact			
<hr/>			
Date of Birth			
Social Security Number			
<hr/>			
Monthly Income			
Source			
<hr/>			
Program Needs/Goals			
Best days/times for Home Visits			
Interests			
Specific Likes			
Specific Dislikes			
Preference of staff (M/F)			
<hr/>			
Assistance Needed for Voters Registration			
Health Insurance			
Name			
Identification Number			
Group Number			
Plan Number			
Date Photo Taken of Card			
<hr/>			
Name			
Identification Number			
Group Number			
Plan Number			
Date Photo Taken of Card (front and back)			
Funding			
Type			
Name of Service			
Hours per week/month			
Start Date			
Service Coordinator			
Name			
Address			



Phone Number	
Email	
Service Coordination Agency	
Name	
Address	
Phone Number	
Diagnosis Information	
Diagnosis	
ICD-10 Diagnosis Code	
Onset Date	
Additional Information	
Diagnosis	
ICD-10 Diagnosis Code	
Onset Date	
Additional Information	
Doctor Information	
Name	
Address	
Phone Number	
Fax Number	
Type	
Date of last visit	
Name	
Address	
Phone Number	
Fax Number	
Type	
Date of last visit	
Name	
Address	
Phone Number	
Fax Number	
Type	
Date of last visit	
Name	
Address	
Phone Number	
Fax Number	
Type	
Date of last visit	
Name	
Address	
Phone Number	
Fax Number	
Type	



Date of last visit						
Screenings	Dates Completed					
Emergency Information						
Preferred Hospital						
Allergies to Medication						
Reaction						
Allergies to Medication						
Reaction						
Other Allergies						
Reaction						
Emergency Contact Name #1						
Address						
Phone						
Alternate Phone						
Email						
Relationship						
Reason to Contact						
Emergency Contact Name #2						
Address						
Phone						
Alternate Phone						
Email						
Relationship						
Reason to Contact						
POA Name						
Address						
Phone Number						
Alternate Number						
Email						
Relationship						
Additional Requests						
Medication List	Dosage	Time Taken	Reason			



Requires Assistance with Medications			
Type of Assistance			
Pharmacy Information			
Name			
Address			
Phone Number			
Fax Number			
Medical Information			
Seizure Disorder		Type of Seizures	
Dental Conditions or Needs			
Special Diet			
General Health	Normal	Limited	Absent
Ability to Sit			
Ability to Stand			
Ability to Walk			
Ability to Transfer			
Balance			
Ability to use Stairs			
Ability to Reach			
Ability to use Right Hand			
Ability to use Left hand			
Speech			
Hearing			
Vision			
Memory Function			
Memory Care needed			
Specific Tools/Strategies Used			
Cognitive Processing	Normal	Limited	Absent
Decision Making			
Attention to Task			
Organization			
Impulse Control			
Emotional Control			
Flexible Thinking			
Planning and Prioritizing			
Task Initiating			
Financial Assistance			
Requires Assistance Managing Money			
Type of Assistance			
Additional Information			
Representative Payee Information			
Name			
Address			



Phone Number				
Email				
	Yes	No	Would like to apply?	Additional Information
SSI/SSDI/SSA				
Medical Assistance				
SNAP				
Utility Assistance Programs				
Rent Rebate				
Section 8 voucher				
LIHEAP				
Safelink Phone				
My MedPak				
Home Information				
Accessibility				
Name/Relationship of others Residing in Home				
Name/Relationship of others Residing in Home				
Name/Relationship of others Residing in Home				
Name/Relationship of others Residing in Home				
Name/Relationship of others Residing in Home				
Pet Type/Name				
Pet Type/Name				
Pet Type/Name				
Service Provider Information				
Type of Service				
Name of Agency				
Address				
Phone Number				
Staff Name				
Phone Number				
Schedule				
Number of Hours				
Type of Service				
Name of Agency				
Address				
Phone Number				
Staff Name				
Phone Number				
Schedule				
Number of Hours				
Type of Service				
Name of Agency				
Address				
Phone Number				
Staff Name				
Phone Number				
Schedule				

Community Partners
Intake/Assessment



Number of Hours	
Type of Service	
Name of Agency	
Address	
Phone Number	
Staff Name	
Phone Number	
Schedule	
Number of Hours	
Adaptive Equipment	
Type	
Type	
Type	
Additional Information/Comments	

Preparer's Signature

Date

Community Partners
Daily Log

Community Partner/Community Integration Specialist/ Habilitation Aid		Date		
Participant's Name				
PARTICIPANT'S GOALS				
1				
Outcome Statement				
2				
Outcome Statement				
VISIT INFORMATION				
Starting Time	Ending Time	Reason if late to scheduled appointment	Reason not at scheduled appointment	Reason left earlier than scheduled time
Participant's Signature				
PROGRESS NOTES				
Goal 1				
Activities/Progress				

Community Partners
Daily Log

Goal 2	
Activities/Progress	
Outcomes	
Additional Supports Provided	

Appendix B Participant Packet

About the Agency

CLASS was founded in 1951 by a group of parents, medical personnel, educators, and other stakeholders. It was originally chartered as an affiliate of United Cerebral Palsy to serve Allegheny County and the City of Pittsburgh. In 2013, CLASS became independent of the National UCP Organization. Growing from a small diagnostic clinic linked to Children’s Hospital, CLASS now reaches thousands of people directly and indirectly in multiple counties across southwestern Pennsylvania.

Initially, CLASS focused efforts on [programs for school age and preschool children](#). As similar services developed in the Pittsburgh area, the focus shifted to much needed [adult programs](#). CLASS currently offers residential services, community skills training, vocational programs, attendant care services, outreach, and advocacy.

Since 1965 programs like information and referral and community follow along services through the Elks Home Service Nurse Program have been offered. [Community Skill Building](#) and supervised [Residential Programs](#) both began in 1975. Specialized services for persons with traumatic brain injuries began in 1984. The [Vocational and Supported Employment Program](#) was initiated in 1986. In that same year, a team of case managers/community partners was developed to provide support to people in the community who needed nontraditional case management to assist them with living more independently in their homes and communities. This was named the [Community Partners Program](#).

In 1998, CLASS was awarded the [Attendant Care](#) contract. This program focuses on providing quality care, employs hundreds of direct care workers and supports over 200 men and women with disabilities; enabling people to live, work, and participate in the community. In the year 2000, [UCP Kids Program](#) was created to provide recreational opportunities to children with disabilities in the same venues as their non-disabled peers. This program later saw success with their T.E.A.C.H.E.R. program and Vocational Ventures endeavor.

In 2007, CLASS initiated a number of new, community based programs and expanded into the Erie service Area. In 2010 two mergers with similar missioned organizations, the [Multiple Sclerosis Service Society \(MSSS\)](#) and the [Alliance for Community Respite Care](#) occurred. Through these programs CLASS was able to provide additional support to families and caregivers of people with disabilities, and to provide peer counseling and information and referral services to people with multiple sclerosis (MS) and related conditions. In 2012, CLASS realized another unmet need of the disability community and instituted its Assistive Technology and Home Modification services; a program that provides consultation, technical assistance, and training for individuals with disabilities and professionals with concerns related to increasing the accessibility of living environments. The program also assists businesses and individuals with understanding and accessing resources to provide accessible options that allow people to remain safely in their own homes.

The [Board of Directors](#) represents all aspects of the Pittsburgh community. With a staff compliment of several hundred employees and additional staff for which CLASS serves as a payroll agent, the agency budget is \$13.5 million dollars with funding coming from the [United Way, Office of Vocational Rehabilitation](#), Allegheny County Department of Federal Programs,

Mental Health/Mental Retardation Office, Office of Long Term Living, various contracts with private organizations and private insurance.

With a dedicated [board of directors](#), enthusiastic consumer/family base, and a [committed staff](#), CLASS is an incredible asset to the health, welfare, and well-being of the local Pittsburgh community and to southwestern Pennsylvania in general.

The mission of CLASS is to support people with disabilities as they explore options, participate in the community, and strive toward equality. We are *"WORKING TOWARD A COMMUNITY WHERE EACH BELONGS."*

The vision of CLASS is to be the provider of choice for people with disabilities and their families; to be the employer of choice for new and existing staff; and to be the investment of choice for individual, corporate, and foundation donors.

GUIDING PRINCIPLES

- We support the uniqueness, wholeness and dignity of each person. We shall strive to respond to the individual needs and preferences of each person we support and serve.
- We enthusiastically advocate for the rights of people with disabilities so they may fully participate in and contribute to community life. This includes enjoying a secure home, family, friends, education, services, and work they find meaningful.
- We view all human life as having equal and unconditional value. Each life should be nurtured, respected, celebrated, and fulfilled.
- We support the life-long process of personal growth and development of all people.
- We will take every opportunity to educate others and to advocate for the basic civil rights of people with disabilities:
 - "The Right to prevention, early diagnosis and proper care.

- The right to a barrier-free environment and accessible transportation.
- The right to necessary assistance given in a way that promotes independence.
- The right to a choice of lifestyle and residential alternatives.
- The right to an income for a lifestyle comparable to the able-bodied.
- The right to training and employment as qualified.
- The right to petition social institutions for just and humane treatment.
- The right to self-esteem."

~Bill of Rights for the Disabled

- We emphasize cooperation in getting things done through and with the people we serve.
- We vigilantly adhere to these values.

To learn more about CLASS and our programs please visit www.classcommunity.org

Community Partners

The Community Partners Program supports adults with disabilities in their homes and communities of their choice. Working in a partnership model, individuals collaborate with Community Partners to design individualized programs, setting specific goals to meet their needs, developing strategies to meet these goals, and working toward them.

This partnership provides one-on-one, short- or long-term support based on the individual's goals. The program moves beyond traditional case management, giving the individual the opportunity to not only manage their personal needs, but develop valuable connections to natural support and resources to be successful in the community and enhance their quality of life. The Community Partners Program does not offer personal care.

The Community Partners Program guides individuals toward complete community integration and aims to minimize the need for formal human services. Once the individual is comfortable with the support and strategies put in place, Community Partners may begin to fade out, with the option to return if needed.

Community Partners can collaborate with individuals to:

- Promote relationships and build connections to community resources
- Develop compensatory strategies
- Assist with problem-solving and decision-making
- Provide life skills education including, but not limited to, financial and household management
- Search for housing
- Explore employment and volunteer resources
- Promote advocacy in transportation
- Provide an in-home range of motion exercise and wellness program
- Assist with other life-affecting issues as needed

Specific services offered include, but are not limited to:

- Traditional Case Management
- Community Case Management
- Community Integration
- Community Habilitation

About this Pilot Program

This program will run from July of 2018 to July of 2019. Participants will meet with case manager 1-2 times a month. These meetings can take place at CLASS's main office or at the consumer's home. During the first visit an assessment form will be completed to determine client needs and goals for the program. This information will be used to create a plan of goals and objectives between the case manager and the client. This program has a capacity for ten individuals at a time, but will hold a waiting list to add others when individuals have completed the program and terminate. This program will exist as part of Community Partners program at CLASS.

Eligibility for the program:

1. Individual must be 18 years of age or older
2. Individual must be deaf, hard of hearing, or deaf blind
3. Individual must use American Sign Language as a method of communication
4. Individual must live within Allegheny County or very close to the county line

Needs the program can help address:

1. Problem-solving and decision-making
2. Finding housing
3. Finding employment or volunteer opportunities
4. Aid in obtaining access to assistive technology
5. Other life-affecting issues as needed

This program is a pilot study meaning that depending on the results will depend on whether the program continues in the future. The case manager responsible for carrying out this program is using this work for a master's thesis. The topic of the thesis is *Adapting Existing Social Services*

to Fit the Need of the Deaf Population. This thesis will not use information from individuals but rather will look at the adaptations the case manager made to the community partners program to make it applicable for this population. All client information is kept confidential and can only be seen by program director if needed. If information on the success of the program is published it will be focused on the outcomes of the program and participants will be given the chance to review the paper prior to publishing.

The case manager facilitating this program is not a certified Sign Language interpreter, but has several years of experience learning ASL in the classroom as well as working with deaf individuals who sign. The program will still be done through ASL to the fullest extent possible.

Everything between the case manager and the client is confidential except for any information that could harm the client themselves or another individual. CLASS is a mandated reporter so information shared regarding abuse or harm of an individual must be reported.

About the Case Manager: Makenzie White

Makenzie is a graduate student at the University of Pittsburgh studying for a Master in Social Work and Master in Public Health. She will graduate in spring of 2019. Her concentrations are in Behavioral Community Health Sciences and Social Administration. She is in certificate programs for Global Health and Human Services Management. She is a Juanita C. Evans Fellow for leadership in social work and public health education. The past year she was an Intern at CLASS working with senior leadership to learn more about non-profit management. In April she got hired as a Recruitment and Development Assistant.

Before coming to the University of Pittsburgh, Makenzie attended Franciscan University of Steubenville in Ohio and received a Bachelor in Social Work with a minor in biology and concentration in Spanish. While there she did a 400 hour internship with a state run group home for adults with disabilities, and then another 400 hour one with a hospice agency.

While working for CLASS she also works for the Charte Center through Mercy Behavioral as a Habilitation Aid for a deaf individual. Prior to moving to Pittsburgh Makenzie worked at Camp Horizons in Connecticut, a year round camp for children and adults with disabilities, for two summers as a counselor and two summers as an Administrator. Makenzie is originally from Connecticut where her family still lives.

Makenzie's interests include disability advocacy, program management, global health, human services management, working with the deaf population, linguistics, research, evaluation, and leadership.

Resources

CLASS

Main Number: 412-683-7100

Makenzie White's Number: 412-683-7100 x. 2197 (desk phone for calls)

724-307-5424 (work phone for text)

mwhite@classcommunity.org

Melva Gooden-Ledbetter's Number: 412-683-7100 x. 2126 (for problems with program or case manager)

mledbetter@classcommunity.org

Emergencies

For medical emergencies please call **911** first, if you need to reach the case manager after work hours text **724-307-5424**, it could take up to 12 hours for a response please do not rely on a response to assist in an emergency. This program does not provide on call services.

1-888-796-8226 Resolve Crisis Network (24 hour hotline for mental health emergencies or crises)

211 for community information and referral services (not necessarily an emergency but need answers quickly)

Appendix C Required Program Paperwork

Consent to Participate in a Pilot Program

CLASS • Pittsburgh, PA

Title of Study: Administrative Case Management in American Sign Language

Investigators: _____

Community

Name: Makenzie White

Dept: Partners

Phone: 412-246-2197

Introduction

- You are being asked to be in a pilot program which provides administrative case management to deaf individuals in American Sign Language.
- You were selected as a possible participant because you are deaf/hard of hearing/deaf blind, use American Sign Language as a method of communication, are 18 or older and live in the greater Pittsburgh area.
- We ask that you read this form and ask any questions that you may have before agreeing to be in the program.

Purpose of Study

- The purpose of the program is to learn how to take existing social services and adapt them to successfully fit the needs of the deaf population.
- Ultimately, this program and outcomes will be published in work towards a master's thesis at the University of Pittsburgh as well other further possible publications.

Description of the Study Procedures

- If you agree to be in this study, you will be asked to do the following things:

1. Sign and agree to this form.
2. Meet with the case manager 1-2 times a month until goals are accomplished.
3. Work with case manager to establish goals and objectives for the program and then continue to work on goals together at each visit.
4. Take a pre-test and post-test survey.
5. Complete a satisfaction survey after termination of services.

Risks/Discomforts of Being in this Study

- There are no reasonable foreseeable (or expected) risks. There may be unknown risks but the case manager and participant will work to ensure all risks are limited if not eliminated.

Benefits of Being in the Study

- The benefits of participation are working towards individual goals and objectives as well as creating new relationships through interactions with case manager as well as the entire CLASS agency.

Confidentiality

- The records of this study will be kept strictly confidential. Research records will be kept in a locked file, and all electronic information will be coded and secured using a password protected file. We will not include any information in any report we may publish that would make it possible to identify you. Information published will specifically be related to outcomes of the goals and whether they were accomplished.
- Your identity will be disclosed in the material that is published. However, you will be given the opportunity to review and approve any material that is published about you.

Payments

- There is no charge for this program and you will not at any time be asked to make a payment or receive a payment.

Right to Refuse or Withdraw

- The decision to participate in this study is entirely up to you. You may refuse to take part in the program *at any time* without affecting your relationship with the investigators of this study or Community Living and Support Services. Your decision will not result in any loss of benefits to which you are otherwise entitled. You also have the right to withdraw from the

program at any time if you so choose. To withdraw contact the case manager and let them know you are interested in terminating services.

Right to Ask Questions and Report Concerns

- You have the right to ask questions about this program and to have those questions answered by me before, during or after the program. If you have any further questions about the study, at any time feel free to contact me, Makenzie White at mwhite@classcommunity.org or by phone at 412-683-7100 x. 2197 or text at 724-307-5424. If you would like, a summary of the results of the program will be sent to you. If you have any other concerns about your rights as a participant that have not been answered by the case manager, you may contact Melva Gooden-Ledbetter, Chief Professional Officer of CLASS at 412-683-7100 x..
- If you have any problems or concerns that occur as a result of your participation, you can report them to the Melva Gooden-Ledbetter at the number above.

Consent

- Your signature below indicates that you have decided to volunteer as a program participant for this project, and that you have read and understood the information provided above. You will be given a signed and dated copy of this form to keep, along with any other printed materials deemed necessary by the case manager.

I would like to receive a summary copy of the final results of the program. (Check for yes or leave blank)

Subject's Name (print):

Subject's Signature:

Date:

Case Manager's

Date:

Signature:

Appendix D Community Partners

Consent to Receive Services

Name: _____

I understand that the purpose of the Community Partners Program is to assist individuals to attain personal goals that will enable them to remain in their home in the community, be as independent as possible, and to participate in the community to the greatest extent possible.

- It is my choice to participate in the Community Partners Program.
- I understand that the Community Partners Program is a goal-oriented service designed to support my success in the community.
- I agree to commit to a 50/50 partnership and put forth my best effort in order to participate in community activities and meet the goals I have identified with my Community Partner.
- I agree to interact with my Community Partner and the Coordinator of Community Partners with the same respect that I expect for myself.
- I understand that the results of The Community Partners programs will be shared with policy makers in order to promote funding for programs.
- I understand that due to an agency policy, my Community Partner is not authorized to transport me in his/her vehicle at any time.

- I understand that if I fail to communicate with my Community Partner, after 60 days I will receive written notification requesting to contact my Community Partner. If I make no effort to do so within 2 weeks from the date on the letter, it may result in dismissal of the program.
- I understand that if the abuse or neglect of taking prescription medications interferes with my Community Partnership it may be necessary to reevaluate the partnership.
- I understand that if the abuse of illegal drugs and/or alcohol interferes with my Community Partnership it may be necessary for to reevaluate the partnership.

I have read, understand, and accept all responsibilities listed above.

Signature: _____ Date: _____

Witness Signature: _____ Date: _____

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