

Spring 2014

Personal Reflections from ePortfolio: AHRC New York City

Daria Afanaseva
Pace University

Recommended Citation

Afanaseva, Daria, "Personal Reflections from ePortfolio: AHRC New York City" (2014). *Community Action Forum: Seidenberg School*. Paper 25.
http://digitalcommons.pace.edu/forum_seidenberg/25

This Report is brought to you for free and open access by the Ivan G. Seidenberg School of Computer Science and Information Systems at DigitalCommons@Pace. It has been accepted for inclusion in Community Action Forum: Seidenberg School by an authorized administrator of DigitalCommons@Pace. For more information, please contact rracelis@pace.edu.



My Semester of Service at AHRC New York City

by Daria Afanaseva

Me



My Biography - What I Am Bringing to AHRC New York City

Hi, I'm Daria Afanaseva, an upper sophomore here at Pace University. My major is Finance. I'm almost 20 years old.

I'm Russian. I came to New York about 2 years ago. I'm interested in learning different languages, so, besides English and Russian, I have been learning French and Japanese since 18 years old.

Currently, I'm working as a finance intern for Price.ME LLC, which is a comparison shopping agent, that helps online shoppers find lower prices and good deals.

Also, I have a fashion blog www.darialoves.it - which I created myself using the Wordpress Platform.

I used to work at Kindergarten when I was in Russia. So, I was spending about 25 hours a week interacting with children from 2 to 8 years old. I'm very grateful for this experience, because it has changed my point of view on life a lot, and I realized that helping people can definitely be helpful for you in some way.

Wordle About Me



My Partner

My partner Marisela is 24 years old. She is Mexican, but she was born in New York. She went to Sign Language High School and she is using communication device to express herself. She loves art, especially, she likes to draw. Her favorite picture is Frida.

Marisela attends AHRC New York League, and also she volunteering in many other projects, like Soup Kitchen, Recreation Center and Gallop New York.

Marisela wants to become more independent and learn how to use a communication device so she can communicate her ideas easier and more effectively. Her dream is to find a real job.

Fortunately, me and my partner Marisela never had any communication problems or difficulties. She is a really nice girl and she is always eager to help people around her if possible. Everybody likes her. When I came to AHRC to see how her life there looks like I was happy to see that she has so many friends there and everyone likes her.

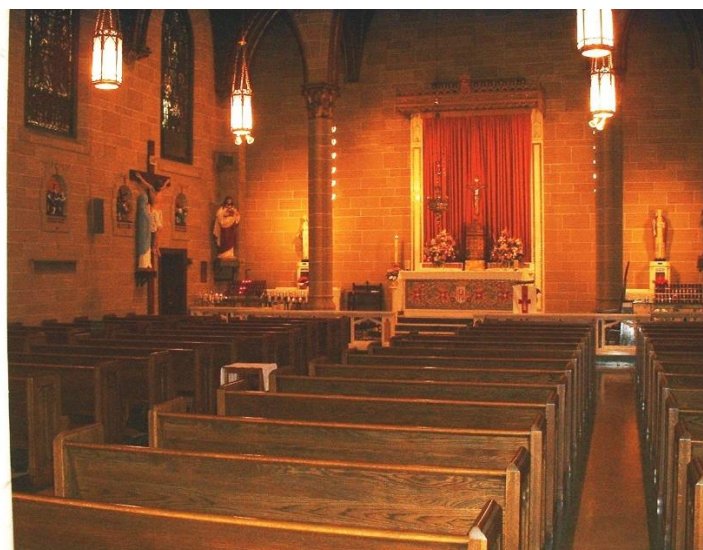
It was not easy for me at the very beginning to use Marisela's Communication Device. I used to forget about the "clear" button and her device kept repeating previous sentences. Also, I did not know how to customize this device creating new phrases and pages. But now I do know how to do basic things and it does not seem that difficult anymore.

My Project at AHRC New York City

St. Elizabeth Church. provides religious and social services for Deaf and Hard of Hearing, using sign language as the principle means of communication. They have many religious education programs, such as Classes in the Catholic faith and Preparation for Baptism. Also they have Masses for deaf every first Sunday of the month.

211 East 83 Street

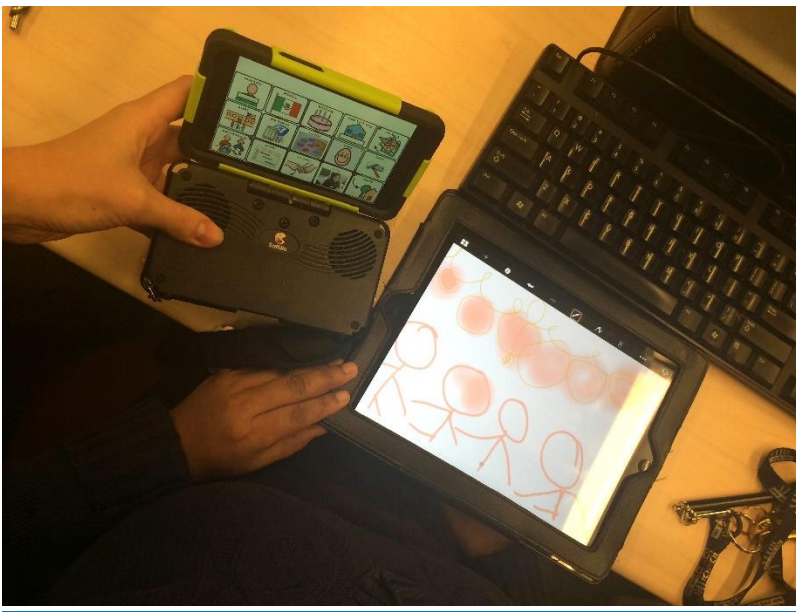
New York, New York 10028-2854



My Technology

Assistive Communication Device "NOVA chat 5"

It has a 5" color touchscreen, integrated sound amplifier, weighs only 0.95 lbs., and measures only 5.8"x3.5"x1.5".



Vendor's Website:

<http://saltillo.com/products/nova-chat-5>

Daria Afanaseva's Journal

Critique (on Professor Questions) of 1/28/14

Posted by Daria Afanaseva on 04 February 2014, 6:03 PM

Critique 1A:

The two websites I chose are <http://cerebralpalsy.org/> and <http://www.disabilitybenefitscenter.org/social-security-disabling-conditions/motor-neuron-disease>. The first website was created to help people who suffer from Cerebral Palsy and their families. I found this website very helpful and easy to use. Starting from their domain "cerebralpalsy.org", they made it easy for people to access their website. You can find there all the information about the disease: what cerebral palsy is, types of it, what causes it, and what life is like for people with this condition. This website is well-developed into sections, which makes it easy to find what you are looking for. Also there is a community blog, where everybody can share different information. But what's more important, there is a call center, so, if you couldn't find the information you need, you can always call them. The second website I chose is Social Security Disability Help Center with its link made especially for those who has motor-neuron disability. This website is very helpful as well, because it's not only tells you what's motor-neuron disability and its types, but also provides a free case evaluation, which can easily acknowledge you for your qualification for disability benefits provided by Social Security Administration. To conclude, I think both websites are helpful in learning about resource services for those with these disabilities and have simple features to explore these websites.

Critique 1B:

One of the most useful apps for your Iphone/Ipad is "My Emergency Info". It's absolutely affordable, its price is only 99 cents. This app has all the important information that is necessary in case of emergency for not only disabled people, but also for those around them. It allows you to create profiles with all the information about your insurance, prescriptions, allergies, medical conditions, and contacts of hospitals, doctors and your relatives. The second app attracted my attention is "ISpectrum Color Blind Assistant". It helps colorblind people to identify any color by using their phone's cameras. It differentiates more than 500 colors. Its price is not expensive as well, which is \$2.99. The third app is "My Choice Board", which was created for people with limited communication skills, especially for those who suffer from Autism, communication delays and learning differences. This app allows them to express what they want. All you have to do is download different pictures, videos or sounds, and then a person with disability can easily show you what he or she wants. And even if the person couldn't find needed information, this app helps to eliminate a guessing process. Its price is \$9.99, which is not that cheap as the first two apps, but still more than affordable.

Critique 1C:

I found two websites illustrate and expound Stephan Hawking's theories of the universe, and many others. The first one is <http://www.hawking.org.uk/the-origin-of-the-universe.html>, and the second - <http://www.pbs.org/wnet/hawking/html/home.html>. The communication device that unabled Stephan Hawking to express himself is essentially a computer, capable of running Windows. The new system uses facial recognition technology to recognise cheek movements, twitches from his mouth and eyebrows to send words to a new speech machine. They created a better word predictor, which is not only speaks, but also varies the intonation.

[Critique \(on Professor Questions\) of 2/4/14](#)

The blog post, "My child with a disability is not my hero", by Ernie Bufflo (Sarah) made me realize that people with developmental and intellectual disabilities are just human beings like us. You don't have to feel sorry for them and do anything that can make them feel like they are different. I remembered an amazing movie called "The Intouchables" where the main hero, Philippe, had a tetraplegia, paralysis caused by illness or injury that results in the partial or total loss of use of all their limbs and torso. He was interviewing candidates to be his live-in caregiver, and he chose a black ex-con from the projects, because "That's what I want. No pity." This black guy treated Philippe like one of his closest friends, and that's what really important for people with disabilities, they do not need a pity, nor do they want to feel that they are vulnerable. Everybody must be treated as equals, because disability doesn't mean inability.

I do agree with Sarah, and I think that her blog post should be appreciated by other parents of teenagers with developmental and intellectual disabilities. She thinks that the term "heroes" dehumanizing kids with disabilities, and she views her child like any other person, because she believes that is how they want to be treated. She wants to raise him like she raises her other child without a disability, because there is actually no difference between both of them.

[Blog \(on Partner and Project\) of 2/11/14](#)

I was really impressed by the assistive communication devices, because I've never seen them before. And during the class I had a chance not only to see one of them, but also to use it. This device looks just like a regular cell phone we all have, but it has a special case that protects it from damage and allows it to sound loudly enough to be used in crowded places. The assistive communication devices help people to express themselves, it gives them a voice that they would otherwise not have. Also, we had a chance to meet Adil who was able to talk to us through a device. He told us that he is able to customize his device very quickly and say whatever he wants to say, that's why he is working and studying like all of us with the help of this magic technology. The speech pathologist said that it's not about the assistive communication device, it's about possibilities it opens for people. Unfortunately, it costs about \$2500, which is waaaaaay too much expensive. As an alternative, people use Ipads, which is not that expensive and easy to get.

[Critique \(on Professor News Story\) of 2/11/14](#)

<http://www.disabilityscoop.com/2014/02/11/olympic-gold-brother/19099/>

Skier Alex Bilodeau won a gold medal at the Olympic Games, and he is very grateful for the inspiration his brother Frederic with a cerebral palsy always gives him. "With the motivation that he has, if he would be a normal person like I have the chance to be, he would be three times Olympic champion. There's no doubt." What is admirable is that they are always acting like a team, helping each other. I think it is a huge moment of self advocacy for Frederic, because he is not only learning how to speak up for himself, and make his own decisions, but also inspire people around him to advocate for themselves. I'm really happy to hear such stories when people with disabilities inspire, encourage and give strength to people without disabilities. Everybody is equal. And we are all here to help each other no matter what.

[Blog of 2/18/14](#)

Today I finally met my AHRC New York City partner Marisela and her mentor Elena for the first time. During the class we had a chance to know a little bit about each other. My partner is using communication device for about a year. She's from Mexico, but now she lives in New York City and works with AHRC NYC. We filled out the Positive Person Profile, and I learned more about Marisela's strengths and talents, interests and preferences, community life experiences, work and volunteer experiences, dreams, and challenges. She likes art, that's why she enjoy drawing something or taking pictures and videos by her Ipad. Today we spend some time drawing using an App called Sketch Book. She is very nice and friendly. Marisela is taking care of her sister. She is always willing to try new things, and her dream is to be more independent and find a real job in a shop. I'm happy to meet Marisela and Elena, and I can't wait to know more about them, so we'll be able to decide what we are going to do for the final project.

[Critique of 2/18/14](#)

<http://www.disabilityscoop.com/2013/03/11/governors-promote-employment/17467/>

My partner Marisela has a dream to find a real job. That's why I chose the article "Governors Promote Employment For People With Disabilities". The author of this article talks about Julie Williard, who was able to find a job at Walgreens, and she is also deaf. The facility at Walgreens is built with the needs of people with a range of disabilities. There are many touchscreens, images and symbols to illustrate function of every device. The nation's governors want to help people like Julie to find job. According to the NGA, the U.S. spends about \$300 billion annually to support unemployed workers with disabilities, but more than half of them would rather work and live a simple life if they could, instead of being unemployed. That's why governors try to provide different programs that help people find jobs and train them if they have any difficulties. Also, many states put in place different method of reviewing applications from people with disabilities that let them bypass the regular competitive hiring process, and instead, they get the opportunity to demonstrate their ability to do the job in a trial work period. Every year there are more and more employed adults with disabilities. And I hope that my partner Marisela will find a job very soon, as she always wanted.

[Critique of 3/4/14](#)

Students with disabilities in wheelchairs cannot conveniently access by elevator the 2nd floor of the Birnbaum Library at Pace Plaza. I always wonder if we can fly a man to the moon, why can't we put a wheelchair-accessible elevator everywhere it is needed. People with disabilities should not feel themselves limited. Pace University Library has so many interesting and useful books on the second floor, and if you do not have access to it, you cannot get a good grade for many courses because you always have to use reliable sources for your papers, not just Google and Wikipedia. Fortunately, you can easily find Pace librarians who are there to help you get any book you need, but sometimes you have to look through so many books to find what you need, and it would be much easier to do it yourself than ask for the librarians' help. So, I think that Pace University have to built a new wheelchair-accessible elevator or they should improve the one that they have, which is now used in emergency only. Or they should put all the book shelves downstairs and transfer the computer lab upstairs because student in wheelchairs can use computers in rooms W205, W206, W202. I hope that these changes are going to be made and all the students will have access to everything that is available at Pace University.

My Mid-Term Reflection Journal on [Book] Miracle Boy and on My Project

It has been about one and a half month since I first came to class working with the AHRC, and I can definitely say: "I am a different person". The most important thing I realized is that everybody is equal. It does not matter what sex, race or age you are, if you have a disability in any way, your marital status, pregnancy, your family status or family responsibility, the religious or political beliefs you might hold, any spent convictions you may have, your sexual orientation or gender history - everybody has the right to be treated fairly. During this semester I have heard many stories and have read many articles about people with cognitive, intellectual, or other disabilities. They want to live life no differently than anyone else. They want to be able to go shopping, go to the movies, go out to eat, work, and enjoy life, fully realizing that must be done within the boundaries of their limitations.

The real problem of disability is not the disability itself but what the members of the general public think about it. It is always hard for people with disabilities to find a job. Most employers are not willing to give them a chance. Employers often think that a disabled person won't be able to do the job as well as a non-disabled applicant. But they are just unable, not disabled. The thing is discrimination is hard to prove because the employer never responds or the prospect employer would state that they found somebody else more qualified even though the disabled person was the most qualified person that applied for the job at the time. In any case, the disabled person does not get the job while never knowing the real reason why he or she did not have a chance to try. That is why Mattlin always struggled to find a job, even after graduation from one of the best universities in the world - Harvard. He happened to be discriminated and humiliated by his potential employers: "But you would be here to help us, not for us to help you".

The book "Miracle Boy Grows Up: How the Disability Rights Revolution Saved My Sanity" by Ben Mattlin showed me that it is really important for people with disabilities to be treated equally. Mattlin was born with the rare degenerative condition, spinal muscular atrophy, a form of muscular dystrophy, robbing him of muscle strength. Since he was a little boy his parents tried to explain him that despite the fact he had a disability and he cannot stand or walk "there is nothing wrong with your head", which means that he should have a right to attend school and get a real job like anyone else. Throughout his entire life he only wanted to be equal and accepted. He was a normal person but he just happened to be in a wheelchair. Mattlin repeats how lucky he is, "I'm a survivor, the labors of my disability strengthen my character," and how he would not have survived in this complicated world without his wife's loving care, and the emotional support of his family.

The Miracle Boy story can be inspiring for all of us, especially for people with disabilities. And what I really want to do is to share this story with my partner Marisela. She cannot speak, and also she cannot hear. To express herself she uses American Sign Language, and for about a year ago she started using communication device. I am trying to do my best to improve Marisela's life through our project. There is nothing impossible. And I believe that one day her dream to have a family and get a real job would come true, like it happened to Mattlin. Marisela loves art and she is good at drawing. One of her Frida drawings was even sold for a little bit more than \$100. And that is something that she really likes to do. During our classes she spends most of the time sketching some images. "Choose something you like, and you will never have to work a day in your life." It is great that Marisela has a passion to draw. I want to encourage her to develop creative skills. Also, I want to help her explore the world. There are so many things she never tried. We are continuing to engage in Deaf Community of New York City: American Sign Language Classes, Ballet Classes for Deaf, different meetings, masses at St. Elizabeth Church, Theatres, Museum Programs. But even in one of the greatest city in the world like New York these opportunities are very limited. Fortunately, every year there are always more and more things available for people with any kind of disability.

The book "Miracle Boy Grows Up: How the Disability Rights Revolution Saved My Sanity" and my partner Marisela showed me that people with disabilities do not need sympathy or pity. They also don't need to be told that they are brave or courageous for living with a disability. Some young people with disabilities are brave, some are not, just like everyone else. People with disabilities do not need to be treated as children. They need opportunities to maximize their independence. They need positive encouragement to help them reset the vision and direction for their life!

[Critique of 3/25/14](#)

It always hurts me a lot when I hear any story about disabled people that are not appreciated enough by the society. Especially, when it comes to employment and sport. People have to judge each others in general. Weather you are disabled or not, it should be all about your talent and all the things you can do.

I am not a fan of baseball, but I have heard a lot about Jim Abbott. He was born without a right hand. Despite this fact, he played in Major League Baseball for about 10 years. I could not say that he was neglected or underestimated, but I am sure that he did not get as much admiration as he deserves. Everybody knows Babe Ruth, Willie Mays or Ty Cobb, but when it comes to Jim Abbott, half of the time people do not acknowledge him for his contributions and accomplishments in baseball. Fifteen years later after his retirement he is almost forgotten by many people. Fortunately, there are always people who remember and appreciate his talent. He won 87 games and had as much of an impact as any player who played the game, giving renewed hope to thousands with disabilities. Also, he always inspired people to achieve their goals in life and never give up. While I was doing my research on this topic I found an amazing quote by Jim Abbott: "There are millions of people out there ignoring disabilities and accomplishing incredible feats. I learned you can learn to do things differently, but do them just as well. I've learned that it's not the disability that defines you, it's how you deal with the challenges the disability presents you with. And I've learned that we have an obligation to the abilities we DO have, not the disability." I totally agree with him because if you have any type of disability it does not mean you cannot do things better than those who do not have it.

[Critique of 4/1/14](#)

People with disabilities become victims of crime at much higher rates than the rest of the population, and they are often targeted specifically because of their disabilities. Also, they are not always able to report crime less frequently because of their disability problems. Lack of knowledge on how to protect themselves make people with disabilities very vulnerable to become a victim. Sometimes they even might be unaware of how serious or dangerous the situation can be. That is why education and training is vital for individuals with any type of disabilities. They have to be prepared and acknowledged of anything that can happen to them. On of the best legislators of New York State is Andrew Cuomo. He created the Justice Center for the Protection of People with Special Needs, a state agency that provides standards and practices in the nation to protect the special needs community from abuse and neglect. He said: "People with disabilities have the right to receive services and supports in settings that do not segregate them from the community; it is a matter of civil rights." I really like what he is doing for the society of people with disabilities, their families and friends. And there is no doubt, that safety is the most important thing. We have to try to prevent all the possible crimes and ensure that anyone committing crimes is caught and penalized for their actions.

[Blog of 4/8/14](#)

Today we spend our time creating a movie for the final project. I put all the videos from different places and trimmed them in an interesting way. Marisela helped me to record the sound for our film. She was using her Assistive Communication Device to tell all the information, while I was recording, editing and putting

everything together. I think that iMovie is a great application. You can do so many things in there. It makes it easy to show the entire workflow with Marisela and save it for the future. That's what we did for the whole class except 15 minutes that we spend with the Film Making Team. We had an interview about our project, and after that they filmed us working in iMovie. Also, they asked me to send them some pictures made for this course. So, I hope that my project will be as good as the Film Making Team's.

[Critique of 4/8/14](#)

There are so many horrifying articles about individuals with disabilities that had been treated inappropriate. When I've read the story about Jerome Murdough's death, I was shocked that something like this can happen in today's world. He was just looking for a warm place to sleep when he went in an enclosed stairwell on the roof of a Harlem public housing project where he was arrested for trespassing. A week later, the mentally ill old man was found baked to death in a Rikers Island jail cell because of malfunctioning equipment. He was mentally ill, so he was locked in the mental-observation unit, which supposed to be checked every 15 minutes as part of suicide watch, but "Murdough was not discovered until four hours later, at about 2:30 a.m. on Feb. 15. He was slumped over in his bed and already dead." Also, the prison didn't tell his mother about his son's death until almost a month after. I think that Jerome Murdough's story is a genuine example of an apparent regression to the mentality evident from the period of Willowbrook, Staten Island. The Willowbrook State School was an asylum for mentally ill children. At its peak, the hospital had over 6000 residents and had many scandals. In 1965 Robert Kennedy toured the site and declared the conditions "living in filth and dirt, their clothing in rags, in rooms less comfortable and cheerful than the cages in which we put animals in a zoo". I think that we all pay enough taxes to make sure that the right people with specific skills are hired to take care of those who are not lucky enough to take care of themselves. We have to improve our city's justice at almost every level. This story also shows that there are many mental health problems among veterans, and whether they are receiving the proper care to prevent alcoholism, suicide, post-traumatic stress disorder, and other mental illnesses. Our government has to make sure that the facilities don't look like animal cages and everybody gets the attention that they deserve.

[Blog of 4/22/14](#)

Today we were working on our final project video and I realized that it is not easy to connect videos from different places all together so they look like a one piece and have smooth transitions. Marisela helped me to record sound using her communication device. Also, we decided to add short descriptive texts to our video clip because it would be very helpful for those who have hearing problems. Right after the class I went to AHRC with Marisela because I felt like I need more time to work on the project to finish it on time. I was happy to see that Marisela has so many friends there and everyone likes her. And I finally have seen her painting of Frida hanging on the AHRC walls.

[Critique of 4/29/14](#)

Mr. Herrera's story is really inspiring. He is deaf and does not speak, but still he is the most talkative person in the whole library where he works as a janitor. His coworker Yesenia Del Valle told that Mr. Herrera "can talk - for someone who doesn't speak, he never shuts up". But unfortunately, his story might not be the best inspiration for Marisela. She cannot read lips and write, as Mr. Herrera does. And when someone cannot understand him, he has a chance to write it down for him or her. Also, he became deaf at the age of 12, unlike Marisela who was born this way. Jaime Herrera's eagerness to communicate can definitely be inspiring for Marisela. He tries all the possible ways to be understood by other people. Marisela started using her communication device more often. So, I feel like this story would encourage her to use it even more frequently.

It is hard to believe, but today was the last meeting for the Spring 2014 CIS 102W class. We had the final presentations at the AHRC New York City. This event was really inspiring for all of us, and Julia kept saying: "If you can dream it, you can do it!" Our film making team had a little surprise for us, they created an amazing movie about our journey through this course: what we all did, how we did it, what kind of challenges we had and what we achieved. It is really great to see that we all did such an amazing job that seemed so difficult at the very beginning. This experience is something that we all going to remember all our lives. Later we had the Questions & Answers game. There were only three questions, and we had to write or draw our answers on the big piece of paper. The reason for this activity was to give a brief explanation of what this course is about for those who is going to take this course next semester. And I think it is all about Self-Advocacy, which is accepting yourself and finding your own way to do things. This course taught us all to speak up for others and ourselves, never give up and always believe in ourselves. At the end, all 23 students and 23 AHRC members got certificates of Service Learning Participation. I wish I could have a copy of my project, but unfortunately, it is not allowed and there was only one DVD with our movie for Marisela . Anyway I will never forget about this experience.

My Final Reflection Journal on My Project

This semester I had a chance to be a student of CIS 102W, which is a special course created by collaboration between Pace University and AHRC New York. It has been an amazing experience that formed a true notion of how to communicate and interact with people with disabilities. Before taking this course I never dealt with individuals with disabilities. It is not that I did not want to deal with them, I just had no idea how to do it. That is why I was a little bit afraid to first meet my partner Marisela ; I did not know what to expect. Thanks to the CIS 102W course I had a chance to spend this semester with this amazing girl and other members of the AHRC New York. Also, I found really helpful all the articles we had to read for this course, which made me familiar with different stories about people with disabilities not only in my class, but also around the world.

From the first day I met Marisela we really knew how to get along with each other easily. She is using communication device to express herself and I remember the first time she opened it to introduce herself to me. She was a little bit nervous, so was I, but in about ten minutes we started filling comfortable communicating with each other. Every time I met her we became closer and closer, and I was really happy the first time she hug me for no reason. That day I realized that this course was making a huge impact on me, leaving me with memories that will last a lifetime.

The technologies that we used were Assistive Communication Device "NOVA chat 5" and Ipad. It is really amazing how the Communication Device works; it gives deaf people a voice that they would otherwise not have. It was not easy for me at the very beginning to use it. I used to forget about the "clear" button and her device kept repeating previous sentences. Also, I did not know how to work with this device in "edit mode" to create new phrases and pages. But now I do know how to do basic things and it does not seem that difficult anymore. Talking about the iPad, both Marisela and I found it very user friendly. There are so many things you can do using it. The applications we used to work on the project were the Camera, Notes, Sketch Book, YouTube and mainly the iMovie. By the end of the semester we created an amazing video to share our experience with others. To make it more interesting we put a nice music as a background and added short descriptive texts to our film utilizing all the great features of the iMovie.

Our main goal was to explore the deaf community of New York City: American Sign Language Classes, Ballet Classes for Deaf, different meetings, masses at St. Elizabeth Church, Theatres, Museum Programs and all other things available for deaf people. But what was more important for me is to encourage Marisela to use her

communication device in everyday life. She has been using it for only a year, so she was not used to this device as much as to American Sign Language. Not everybody understands ASL, that is why I put all my efforts to make her take advantage of the communication device. During the semester she practiced using it every meeting we had while ordering food, asking for directions or just chatting with me.

I would like to thank Marisela for always being enthusiastic about our project, her mentor Elena for always accompanying us and helping with Sign Language, and of course Professor James Lawler and AHRC for creating this course and making it that interesting and unique. I'm so grateful to have chosen this class, and I will walk away from this course with so much insight into how I view people and life. It has made me more aware about persons with disabilities and how their lives are. Moreover, it makes me feel so great inside knowing that I have tried to improve someone's life by helping her share and open up to others. Hopefully there will be many other opportunities in the future for me to take part in an experience like this one.

My Certificate of Recognition of Service in the Semester

