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Silence isn't always golden

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Silence isn't always golden

Abstract

The idea of this project started around the year 2006. My passion for seeing a person acquire the ability to communicate has continued to grow over the years. After taking a class about assistive technology, so many doors of understanding opened for me as to how a person can communicate with an alternative/ augmentative communication device. I am extremely interested in learning more and finding out how I can help others begin to "have a voice".

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SILENCE ISN'T ALWAYS GOLDEN

By
Leandra Edwards

A Senior Thesis Submitted to the
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In Partial Fulfillment of the Requirements for Graduation
with Honors in Cognitive Impairment (Department of Special Education)

Approved at Ypsilanti, Michigan, on this date _____

Supervising Instructor (Print Name and have signed)

Honors Advisor (Print Name and have signed)

Department Head (Print Name and have signed)

Honors Director (Print Name and have signed)

Silence Isn't Always Golden

Leandra Edwards
Honors Senior Thesis
Dr. Ann Orr
3 June 2009

Special Thanks

I would like to give a special thanks to everyone that has helped me through this project and helped me complete this project.

To Dr. Ann Orr: Without you, this project would not have been possible. You have given me the opportunity to explore technology and broaden my horizons in the area of communication and disabilities. Thank you so much for all the hard work you have put into helping me with the many honors contract, fellowships, and now this senior thesis.

To the Cross family: Thank you so much for allowing me to come into your family and help me get a glimpse of what it is like to raise someone with a disability. Your family is my hero. I only pray the best for every single one of you. I hope that your family is truly blessed for all the times you have allowed me to work with Steven on different projects associated with my education.

To my mom: Thank you for standing by me this entire time. This project has been a challenge, but you have given me ideas on people and organizations to contact for funding. You have also pushed me to finish this project, even when there were the moments of failure. Thank you for being who you are. I love you.

Table of Contents

Introduction to Project.....	5
Journaling My Experiences.....	10
Description of Progress.....	21
Conclusion.....	27
References.....	30
Video (included with project)	

Introduction to Project

The Proposal

Communication is an essential part of every day life. It was Rollo May, an American existential psychologist, who once said, "Communication leads to community, that is, to understanding, intimacy, and mutual valuing." Without communication, society might not have been able to create all the innovations that have currently been produced.

Communication can be defined as "the imparting or interchange of thoughts, opinions, or information by speech, writing, or signs" (Dictionary.com). A change of ideas requires input between two or more people. A person is not able to get very far in life without the ability to share ideas. Communication plays a huge role in how successful people can become. One can learn to manipulate and expand their knowledge all through communication alone. For example, politicians can influence their audience to support their views. However, without eloquent communication politicians may not be able to grab the attention of their viewers.

Although communication is typically thought to consist of physically using the vocal chords, communication is not confined to speaking. Communication can include noises, gestures, facial expressions, signs, and even an augmentative/alternative communication (AAC) device. An AAC device is one that allows a person who does not have the ability to speak to communicate. AAC devices include no-tech, low-tech, and high-tech. An example of no-tech device is sign language and gestures. A type of low-tech AAC device is a board that stores recorded messages that are represented

by pictures, symbols, or words. The messages on the board can be retrieved by pushing a switch or button on the device. High-tech devices often incorporate synthesized speech and different types of access methods, such as switches or a joystick. By using alternatives for speaking—either no-tech, low-tech, or high-tech—it opens the doors for people to become active members of society.

However, for Steven Cross, the ability to communicate using his voice has been a challenge, but this could change if he was given the opportunity through alternatives. Steven was born in 1989 as a healthy baby boy; so, his family was not expecting any delays in development and skills. At five months old, Steven received a vaccine, which caused him to seize for approximately 75 minutes. After a visit to the emergency room, Steven seized a second time. As a result of the seizures, Steven's brain was damaged. His parents were heart broken when the doctors told them their son would never be "normal," and again when the doctors diagnosed him with cerebral palsy.

Over the last 19 years, the Cross family has learned to accept Steven's disabilities. His parents and older sisters treat him with the same respect that any person deserves. Steven has found ways of getting people's attention, but having the ability to communicate more fully would be a wonderful asset to his life. At the age of 12, Steven began training to learn to use a communication device, but the insurance company decided he

would never actually benefit from using the device. So, the training was discontinued. One might question the insurance company's true motive. Perhaps they did not want to have to provide funding for a costly AAC device.

Today, Steven attends Wing Lake Developmental Center, but the school is not willing to provide him with a communication device. Part of the problem is because the government only designates so much funding for technology. Although Steven's school does have low-tech devices in the room, the devices are not used often. Mr. and Mrs. Cross are Steven's biggest advocates, but during his Individualized Education Plan (governmental program to document what services he will be receiving from the school) meetings, the superintendent does not see the parents as being important. Mrs. Cross has even visited a lawyer. Unfortunately this lawyer is friends with the superintendent and is not willing to help advocate for Steven. Steven has not been able to increase his communications skills over the past few years. However, if he was given a simple device to use at home, it could greatly improve his participation at both home and school.

As a part of completing the requirements for the Honors College to graduate with honors in the special education program, I will introduce Steven to a communication board and train both him and his family how to use the device. I will research and apply for funding for a communication board and software for Steven. Once Steven and his family are trained on

the device, Steven will have the ability to talk with family and friends. He may even be able to learn how to read. The opportunities for Steven to excel, because of the device, would be endless. Sharon Schuster, President of the American Association of University Women, said, "When we have the courage to speak out—to break our silence—we inspire the rest of the 'moderates' in our communities to speak up and voice their views." With the ability to communicate, Steven would have greater opportunity to make a difference in the world.

Journaling My Experiences

Honors Senior Thesis in the Making

Introduction

The idea of this project started around the year 2006. My passion for seeing a person acquire the ability to communicate has continued to grow over the years. After taking a class about assistive technology, so many doors of understanding opened for me as to how a person can communicate with an alternative/augmentative communication device. I am extremely interested in learning more and finding out how I can help others begin to “have a voice”.

While working with Steven Cross as his part time aid in the summer of 2006, I sensed, through his eyes, the desire he has to communicate. The ability to communicate would give him so many more opportunities in life, and allow him and his family to truly understand one another. Before I even knew about AAC devices, I always wanted to find out a way to help the family. The Cross family does so much for other people; I wanted to find at least one way someone could give back to them.

After meeting Dr. Ann Orr (Professor in the Special Education Department at Eastern Michigan University) through the “Introduction to Assistive Technology” class for students studying to become special educators, I began to discuss with her my thoughts on this project becoming my senior thesis. During the course of the semester I completed a small research paper as an honors project that discussed funding for assistive technology. As the semester progressed, the concept for the senior thesis

continued to grow with the idea of my honors project becoming the base of the senior thesis project. It was obvious that funding the project would need to be done before the device could be purchased and given to the family.

After laying out the idea of the senior thesis project, I segmented the necessary actions into four phases:

1. Select an appropriate device that is easy to use for both Steven and his family.
2. Find funding for the device and any other needed materials.
3. Train Steven and his family on how to use the device and any other materials, possibly getting some pictures or video of the training sessions to record his progress.
4. Have Steven and his family begin to use the device without help.

April 2008

I found a device that I think could really benefit Steven, and the positive side is that it is not too costly. The device I would like to purchase is called the "Communication Builder" provided through Technology for Education, Inc. The "Communication Builder" is a low-tech AAC device that includes the following:

- Adjusts to the users developing skills

- Equipped with 5 easy to change frames, having the ability to refine communication choices as the person develops new skills.
- Record messages with the simplest push of a button.
- Light-weight, durable and easy to carry with a built in handle.
- Frames included are 1, 2, 4, 8 and 16-window options.
- Total recording time of 300 seconds.
 - 1 Window: 300 seconds
 - 2 Windows: 150 seconds
 - 4 Windows: 75 seconds
 - 8 Windows: 37 seconds
 - 16 Windows: 18 seconds

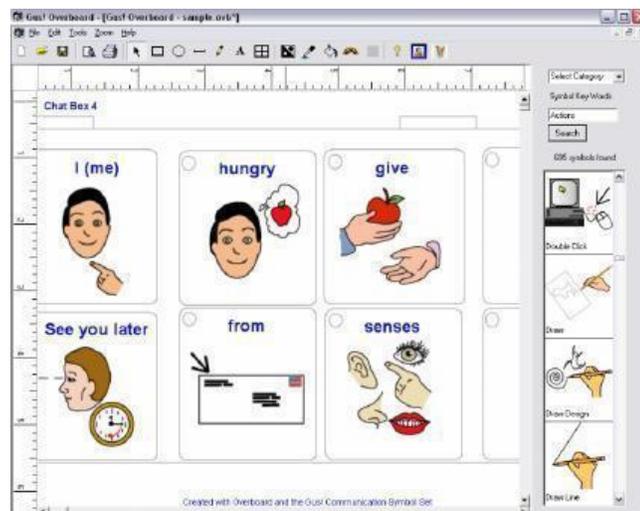
Along with the device, software is needed that allows for Steven to connect sound with pictures, letters, words, sentences, etc. The software that I am currently looking into is Boardmaker; however, I am still going to look at other options



Communication Builder

May 2008

I wrote an essay describing the project and the importance of communication. I will use this when contacting organizations about funding the project. I began researching different organizations and people I should contact about funding the equipment. I feel like this project is going well, time wise that is. If all goes as planned, I would hope to be finished around April or May of 2009. I am really excited to start delving into the heart of this project. I also decided that Overboard by *Gus Communications Inc.* is the best choice for software because it works similarly to Boardmaker but is almost half the price



Overboard

June 2008

I think I am going to take back the entire idea of the timeline. This project is going slower than molasses. Every organization I have contacted has said they are not interested because the funding would only help ONE individual. Many organizations are only willing to help other non-profit

organizations or groups of people because they want a tax write-off.

Following is a list of the all the organizations that have been contacted either through phone, e-mail, or mail:

- GiveTech
- Travis Roy Foundation
- Council for Exceptional Children (CEC)
- National Organization Center for Kids (NOCK)
- United Cerebral Palsy—Detroit Chapter
- Rotary Club—Ann Arbor Chapter
- Veterans of Foreign War—Michigan Chapter
- The Arc—Livingston County Chapter
- The Arc—Michigan Chapter
- Michigan TAM / Michigan CEC
- Michigan Jaycee
- 4MyChild

It really is sad that organizations are not willing to help. All it takes is one person to make a difference. It seems that more people are concerned about receiving a tax write-off than how the money could help someone get through life with much more ease. However, I have had some help from the organization 4MyChild. This organization does not actually handle anything with money. They would not be able to fund the equipment, but they are willing to work with me in finding some type of funding.

Oh, another positive thing I have found out this month is that the device and software could be purchased from the vendor, *Technology for Education*, for only \$336.20. This price includes shipping. Finding the communication board and software so reasonably priced should help with the whole funding issue. How hard can it be for organizations to donate \$336.20? Oh well, hopefully time will tell.

July 2008

I wrote a letter to the pastor of the church the Cross family attends asking for funding. I actually sent him two different letters over the four week period. It is already the end of the month, and I have not had any type of reply. Funding has probably been the hardest part of this project, and I honestly thought it would be the last thing I would have to worry about. July is almost over, and I still have not been able to purchase a device for Steven.

Not being able to purchase a device is upsetting. I feel as if I will not have all the time I need to complete the project within a year from now. Maybe Steven will surprise me and be able to understand how the communication device works much faster than I am expecting. Dr. Orr said I can borrow her device, in the meantime. Maybe starting in the fall semester, I will begin acclimating Steven and his family to the device.

4MyChild is still willing to help with finding funding. Unfortunately, we have not been able to get in touch with each other. Maybe through the month of August some type of contact will be established. This organization may be the one thing this project needs to get the ball rolling.

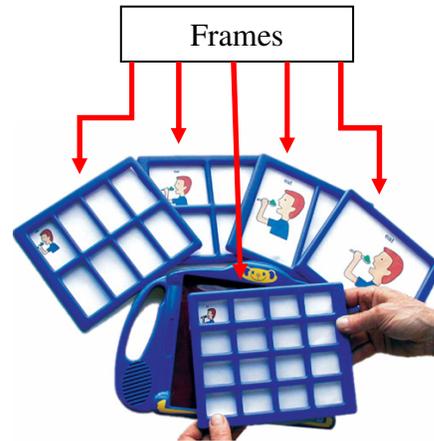
January 2009

Six months later and I have finally made some progress. Although funding is not 100% secured, I do know where the money is going to come from when purchasing the device. Being on the executive board of Student Council for Exceptional Children definitely has its advantages. The board has decided that whatever monies we make at the next fundraiser will be donated to my project. Some other exciting news is that the price went down for the device and software. It will now only cost \$310 with shipping. How wonderful is that?!

This month I applied for the senior thesis, and it was given the go-ahead. I am also beginning to work with Steven and his family. They are so excited to be involved in this experience and have such high-hopes for Steven. Since I haven't been able to purchase a device just yet, I am still borrowing Dr. Orr's. I have also downloaded a trial version of Boardmaker (Overboard doesn't offer a full version trial) to begin putting picture symbols together for Steven. I plan on working with three of the five frames. The frames are placed in the device to hold the picture symbols. See picture

below for a better illustration. I also figured out the size of the frames. Here are the approximate sizes for future reference:

Frames:	Sizes:
One	8.5" X 7"
Two	4.25" X 7"
Four	4.25 "X 3.5"
Eight	2.125" X 3.5"
Sixteen	2.125" X 1.75"



I thought it would be interesting to see all the people I had to go through in order to make this project happen. So, here is a list of every organization I have been in contact with regarding this project, to date:

Organization	Date	Response
GiveTech	May 2008	No
Travis Roy Foundation	May 2008	No
Council for Exceptional Children (CEC)	May 2008	No
National Organization Center for Kids (NOCK)	May 2008	No
United Cerebral Palsy—Detroit Chapter	May 2008	No
Rotary Club—Ann Arbor Chapter	May 2008	No
Veterans of Foreign War—Michigan Chapter	May 2008	No
The Arc—Livingston County Chapter	June 2008	No
The Arc—Michigan Chapter	June 2008	No
Michigan TAM / Michigan CEC	June 2008	No
Michigan Jaycee	June 2008	No

4MyChild	June 2008	N/A
Revival Outreach Center	July 2008	No
CEC—Eastern Michigan University Student Chapter	Oct. 2008	N/A

As this month is coming to an end, I have visited Steven and his family twice. It was exciting to find that Steven had used a similar device before, and he was roughly familiar with it. Also, he is used to working with picture symbols, which was a definite advantage. Device training is probably going to be the easiest part of this project. (See next section of this thesis for details on the training process) I have taken some video and pictures already, and I am also beginning to chart Steven’s progression. Once I purchase the device for the Cross family to keep, I will probably only have to visit them maybe two or three more times before they take over completely. It is exciting to see how this project is finally becoming reality, and that the end is almost here.

June 2009

I cannot believe how fast this year has gone. To date, I have purchased both the device and software. I ended up having to pull from my personal funds because the campus organization never followed through. During this month, I will officially give the Cross family the device to keep. I plan on training them for at least a couple months before I expect that they

will not need my help. Also, I was ultimately not able to purchase the device through *Technology for Education, Inc.* I bought the device through *Enabling Devices*, the original creator of the Communication Builder, and I bought the software directly through the main company, *Gus, Inc.* By going this route, the project was much more costly than I expected at a little over \$400. However, I am glad to have the device in my hands and proceed with the main part of this project: training and donating the device.

This project has been a long journey due to the struggle to find funding. I have decided to stop journaling my experiences at this point. What follows is an account of the device training procedure and a brief conclusion.

Description of Progress

Learning How to Use the Device

Date: January 8, 2009

Time: 7:00 PM to 8:30 PM

Description:

Today was the first meeting with the Cross family regarding this project. The family is extremely excited to begin seeing Steven using something simple as a form of communication. Talking with Mrs. Cross, I learned that Steven was, at one time, using something similar to the Communication Builder. However, that only lasted a short while. The insurance company decided that an augmentative/alternative communication device was not a necessity for Steven.

I briefly showed Mr. and Mrs. Cross how to operate the device. I explained to them that I would begin using the one with two frames and build up from there. I would start with simple "Yes"/"No" responses. I also had Mrs. Cross record her voice on the device, since it is familiar to Steven. At this point, Mr. and Mrs. Cross left the room, and I began to work with Steven.

Following suggestions from the article "The Child Hates Augmentative Communication and I've Tried Everything. 'The Quick and Easy Team to the Rescue!'" by Carolyn Rouse and Katera Murphy (speech pathologists), I started with something that Steven would enjoy: his collection of collectible cars. I began by asking Steven questions about his cars. I would then move his right hand, since he is right-handed, over the "Yes" and "No" while

saying the symbol. After, I would place his hand back in his lap and give him the opportunity to choose his answer. Most of the session consisted of routines like this. Every-so-often, Steven would decide to answer the question and make a response on the device. However, I was not sure if he was doing it to hear the response or to actually answer the question. Over time, I will be able to determine whether he is doing it to respond to the question or for simple entertainment. At the moment, I believe he is just trying to understand and get comfortable with how the device works.

January 15, 2009

Time: 7:00 PM to 8:00 PM

Description:

For today's meeting, it was just Steven and me. I also decided that I would video Steven using the device. I would use the video as a way to show a "before and after." I will plan on videoing him again near the end of this project to show his "speech" improvement with the device. Through this video and my journals, I hope to show how a low-tech device can improve the activities, big and small, in Steven's life.

Similar to last week, I focused on simple "Yes/No" tasks. My goal is to build him up to one of the larger frames (4 square, 8 square, or 16 square). Since I am still borrowing the device, I have not fully trained Mr. or Mrs. Cross on the device or software. Once I do have the permanent device and software in-hand, I plan to train Mrs. Cross (since she will most likely be the one doing the majority of the work putting together the symbols).

When I came to the Cross' house today, Steven was "playing" with his pens, pencils, and paintbrushes. I helped him use his paintbrush as a selection device to use the Communication Builder to respond to simple questions. Steven showed amazing improvement from last week. He is catching on pretty quickly as to how the device operates. I am excited to see what he can do once he has his own device that he will keep with him.

June 23, 2009

Time: 10:30 AM to 11:30 AM

Description:

I finally have both the permanent device and software. I planned to give the device to Steven, install the software on the family computer, and show Mrs. Cross how to use both the software and device. As soon as I walked in the door, I was greeted by Steven's home aide. The aide was extremely excited to start using the device in the mornings while getting Steven ready for the day. She immediately took the device and gave it to Steven. She allowed him to try pushing the different buttons.

While Steven was in the other room with the device, I was with Mrs. Cross trying to download Overboard software. However, we ran into a problem with how the license key is actually obtained. Fortunately, Overboard has a 30 day risk free trial. So, I used the trial to teach Mrs. Cross the simplicity of using Overboard and to show her how easy it is to create a new template. Together she and I created two templates that the family would be able to use with Steven's daily activities.

July 23, 2009

Time: 10:30 AM to 11:30 AM

Description:

It seemed as if it took forever to figure out how the license is obtained. However, before I could request the license key from the creators of the software, I needed to send them some information from the Cross' computer. So, I had to set up another meeting.

While I was at the Cross' house, I showed Mrs. Cross how to input the license key to get the full version of the software. Once I received the license key from the company, I would send it to Mrs. Cross for her to copy into the computer. Afterwards, Mrs. Cross informed me that Steven was using the device. She thought it was interesting, though, that he acted as if the device was a way of, as she described it, "insulting his intelligence" because he would never look at it when asked a question. At least he is using the device! That is an excellent sign of his progress on incorporating the device into his daily, in-home activities.

Conclusion

In the End

Completing this project has been one of the most difficult things I have ever done. It has been a long and complicated journey to get where I and the Cross family are today. I have also learned many new things regarding assistive technology and funding throughout this time. My hope is that this project can be a catalyst for showing organizations, companies, and lay persons how hard it can be to acquire a needed device for a person.

This project did not go as I had originally planned and has shown me how easily people can become frustrated with the system and give up. I have a new understanding regarding the challenge of obtaining help from organizations and other people. My eyes have been opened to see how people do not want to donate without a "kickback" or an underlying reward. I was shocked to discover that many organizations would not be willing to give even a small amount of money to help with funding the device and/or software because they would not be able to use the donation as a tax write-off.

If I could have done anything differently, I probably would have tried to work with other resources. As I have branched out my own involvement to other campus organizations this last semester, I realize there probably are people willing to help individuals without gaining something in return. However, it takes a lot of effort to find these groups and organizations that are willing to become involved in efforts such as this. Maybe, if I had the opportunity to do this over, I would actually hold a fundraiser to raise the

funds to pay for the equipment. I would love to, one day, start an organization that can help eligible individuals not associated with a group or organization or who are not able to receive funding from a governmental source. I would hate to see others face the same problems I have had with this project over the past year.

To date, Steven and his family are doing well. Steven had a medical complication and taking updated video of him using the device has been impossible, as of now. The video that is included with this project is a visual demonstration of how the device works and how Steven would use it in his daily activities. My end goal for this project is that people see that a dollar sign cannot be put in front of the basic human need to communicate. In America, freedom to speak is a part of the Constitution, and although people are sometimes silenced by disabilities, technology is available to allow them to exercise this right.

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