

Caring for the Non-Communicative

Communicating with People Living with Huntington's Disease

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Introduction

Six years ago, a woman opened up a speech about her illness with the following dedication: "Today I am going to be talking for all the people who can't talk for themselves." Now, she has become one of those people who cannot talk for themselves. Her Huntington's disease slowly robbed her of her ability to speak.

This woman is only one of the hundreds of souls who call Terence Cardinal Cooke Health Care Center (TCC) their home. These people include individuals with mid- to late-stage Huntington's Disease, advanced AIDS and HIV, and Alzheimer's and dementia. TCC contains units for people who require end-stage dialysis, sub-acute transitional care, or respiratory and tracheotomy care. TCC also houses a Specialty Hospital for pediatric residents with profound developmental disabilities and extraordinary medical needs. Many of the individuals living at TCC require around the clock care and assistance with activities of daily living. An interdisciplinary team, including medical and nursing staff, social workers, pastoral care, rehabilitation and speech therapists and more, collaborates to care for these souls.

I spent ten weeks at TCC this summer learning from the staff, residents and families on what it means to truly care. Caring, as my mentor Dr. Anthony Lechich puts it, has many

elements and adjectives that include intentionality, trust, devotion, patience, humility, and honesty. Above all, Dr. Lechich showed me how a good caregiver is someone who really *loves* the patient. My experiences at TCC have shown me that the ability to give good care to someone is not necessarily an inborn skill. At the core, good caregivers are individuals who nurture a bond founded on love with their patients.

It is not surprising that there are many barriers to providing good care. I imagine that as is true with many other skilled nursing facilities, there are challenges that arise from limited staff and resources and increased pressures for documentation. TCC also presents its own set of challenges from its unique patient populations. I was struck by one of TCC's barriers in particular: how can caregivers give the most independence and dignity and the highest quality of life to residents with an impaired ability to communicate? I chose to focus my internship on communication challenges in the Huntington's Disease unit because I was moved by my own difficulties of communicating with these residents.

An inability to effectively communicate is undeniably a major issue to be addressed. Communication is both a human need and a human right. Our capabilities of conveying our ideas, thoughts, and sentiments to another human being through highly sophisticated languages and non-verbal cues separate us from other living organisms. Our natural voices are like our fingerprints; they uniquely identify us. Communication allows us to express who we are to others, and in doing so, gives us dignity and empowers us. The loss of the ability to effectively communicate is a loss of something so important to the human experience. It is thus crucial for caregivers to find the best way for residents to participate in activities that require communication.

Communication Systems Affected by HD

Huntington's Disease (HD) devastates almost fifty lives at TCC. It is a neurodegenerative, genetic disorder. As an autosomal disease, a child with an HD-positive parent has a fifty percent chance of inheriting the disorder. HD is associated with an expanded repeating CAG triplet series in the huntingtin gene. This expanded gene results in the production of a protein with an abnormally long polyglutamine sequence. The defective huntingtin protein is somehow damaging to brain cells (Nance 6).

Individuals with HD experience a slow and terrible progression of motor, cognitive, and psychiatric decline. The symptoms of HD are essentially a triad of disorders. The movement disorder is characterized by chorea, involuntary dance-like movements, and the impairment of voluntary movements (Nance 39). The cognitive disorder includes a reduction of speed and flexibility in mental processing (Nance 51). The psychiatric disorder can be associated with depression, mania, obsessive compulsive disorder, various forms of psychosis, and behavioral changes (Nance 63).

Motor impairments disrupt an HD individual's ability to communicate. HD people may experience dysarthria, a motor speech deficit that results from impaired movement of the muscles required for speech production due to muscle weakness and incoordination (Hamilton 68). Apraxia, another motor speech deficit that occurs when an individual has difficulty planning and sequencing the muscle movements for speech, could further compromise communication (Hamilton 69). Abnormal body patterns that include continuous movements of the body may disrupt face-to-face interaction and confuse communication partners. Oculomotor problems limit

eye contact, and upper extremity impairments limit handwriting and computer access (Klasner 155).

Cognitive and emotional changes further compromise communication. The deterioration of executive functioning and working memory can affect linguistic skills. People living with HD may have difficulty with complex discourse. Word-finding abilities are affected. Their processing speed slows down, and they have difficulty initiating and maintaining conversation. They have difficulty learning new skills. Low frustration tolerance and increased irritability have been documented. Behavioral changes including social withdrawal and apathy can affect an individual's desire to communicate (Klasner 156).

The combination of motor, cognitive, and psychiatric impairments severely affect an HD individual's ability to communicate using typical methods of natural speech, handwriting and typing. The complex triad of disorders make it challenging for speech clinicians to successfully implement augmentative and alternative communication (AAC) interventions. Implementing AAC is further complicated by the unpredictable rate of progression and variable course of disease among HD individuals. No singular system will be optimal throughout the progression of an individual's disease, and each system must be tailored to that individual's symptoms.

Challenges aside, developing strategies to encourage participation in activities that require communication cannot be overlooked. Studies have reported that there may still be language comprehension in later stages of the disease when the ability to speak is significantly diminished (Paulsen 480). Thus, the inability to speak does not mean that an individual does not understand. Another study on HD reported that the median duration of the disease from a sample size of 2494 HD-positive patients was 21.4 years (Foroud 52). Continuously addressing and

managing communication issues is important to ensure this population is not left without a means of expression for such a long period of time.

The Role of the Speech and Language Pathologist

A speech and language pathologist (SLP) is integral to help HD individuals maintain as much independence in communication as possible. SLPs are trained to diagnose, assess, and treat various communication and swallowing disorders. They assist in developing techniques to help HD individuals compensate for communication and cognitive problems, and evaluate a person's ability to use AAC interventions that can supplement verbal communication.

The SLP team in the HD unit includes Mr. Peter Rahanis and New York University Steinhardt masters students. This team is supreme at helping HD residents speak. Although it is not always easy for HD people to use their natural voice, there are a variety of strategies that can help residents improve their intelligibility and articulateness. Some of these strategies include asking the resident to speak slower. Ask the resident to speak only one word. Encourage the resident to repeat or rephrase their answer. Tell the resident to over-articulate. Ask the resident to take a deep breath before speaking and speak loudly. Use simple yes or no questions one at a time. Eliminate surrounding distractions. Talk about something that the resident is knowledgeable about. If a resident is not participating, specifically ask that resident a question to help them engage.

The SLP team practices these strategies with residents in individual sessions and group sessions. In an individual consultation, a clinician and resident will converse about a familiar topic, while working on techniques to improve speech. For some sessions, the clinician will

focus on learning about the resident's personal life to construct a communication book. These communication books contain personal photographs, interests, and family information. These books are especially important because many individuals have difficulty initiating conversation and finding words, and they will decline to the point where natural speech is no longer possible. At these stages, the communication books let residents continue to share information about their lives with others, promoting social closeness and bringing happiness to the resident.

In group settings, the clinician plays a variety of interactive games such as jeopardy with the residents. The group speech therapy performs a dual function of helping individuals develop techniques to improve their verbal intelligibility and facilitating social ties among the residents. I have never seen the HD residents livelier than they are during group speech games. The residents who are able to participate come together and engage with each other. They bond over each other's interests, hobbies, and music with smiles on their faces.

Augmentative and Alternative Communication Device

Given the difficulties of verbal communication, it may be beneficial for a resident to use an AAC intervention as a supplement for communication. The TCC Huntington's unit recently acquired one high-tech AAC device called the Tobii-Dynavox I-15+, which I have been attempting to use with some of the residents. This device, although expensive, can be covered by Medicare most of the time. It has been designed to give its user increased communication ability and greater independence. It is a speech generating device (SGD). It can be controlled through gaze interaction using a built-in Tobii Eye Tracker or touch access using a capacitive touch screen. The device can be used in an upright and mounted position optimized for gaze

interaction, or in a horizontal orientation optimized for touch access. The device allows the user to generate computerized (synthesized) or digitized (recorded) speech for communication. The device uses a Microsoft Windows environment.

The Tobii-Dynavox I-Series+ is classified as a Class 1 Medical Device. The U.S. Food and Drug Administration classifies medical devices based on the risks associated with the device. Class 1 Medical Devices are determined to be low risk and therefore subject to the least regulatory controls.

The Tobii-Dynavox Compass Software is a flexible communication solution designed for individuals who are unable to use their natural voice to participate in daily activities. The software allows for the creation of customizable communication boards. These boards can contain a number of different buttons that can be programmed to carry out certain actions when the button is selected. For example, a button can be programmed to generate a sound or open a new page when it is selected. The buttons can be accessed through touch or eye tracking. With eye tracking, the button is chosen by looking at it for a certain amount of time that the user determines in the settings.

This AAC software does not need to be used on the Tobii-Dynavox I-Series devices, but it can also be used on an iPad. The main difference in using an iPad is that the individual needs to be able to use touch to select buttons as opposed to eye tracking.

Implementing this AAC device with the HD residents at TCC is experimental. At the risk of making a generalization, the HD population seems to be underserved when it comes to high-tech AAC devices especially compared to other neurodegenerative disease populations. The hesitation to use a high-tech device may come from the cognitive decline, chorea and the

necessity of training staff on using an AAC device. Because HD individuals have difficulty learning new skills, there may be doubt whether they would be able to learn how to use a high-tech AAC device. The standard therefore seems to be low-tech devices such as static communication boards that include alphabet boards for spelling and symbol based options that represent common items associated with activities of daily living (Burgess 75). While low-tech devices are more easily used by caregivers and may therefore be a more appropriate option, the question that I pose is whether HD individuals are capable of using a high-tech AAC device with electronic communication boards, and how it could impact their quality of life. Furthermore, with a new generation accustomed to using technology that experiences the devastating symptoms of HD, the hesitation that arises from the inability to learn new skills may not hold as much ground in the coming years.

I recognize the limits of my experiences as gauged through qualitative observation rather than formal testing and statistical analysis. In the following case studies and interviews, I attempt to describe a sampling of my experiences as well as the residents', families', and staff's experiences as candidly as possible. All resident and family names have been changed to respect privacy.

Selected Case Studies and Interviews

“Sally”

Sally is the woman who dedicated her speech on Huntington's Disease to those who couldn't talk. In this speech, she spoke about how she loves to work with people. Her former career as a pediatrician shows her passion for interacting with people. She describes, “Talking is

a problem. That was my first symptom. The inability to be heard. I went to speech therapists for about three years to learn how to speak clearly and to learn how to smile.” Out of the many symptoms of HD, the symptom that she spoke about the most was her impaired ability to talk. Unfortunately, after six years, her ability to talk has significantly declined. Her slurred, dysarthric speech is now very difficult to understand. She gets frustrated when people do not comprehend her. There have even been incidents when she pushed staff and yelled out. She curses when her words are not understood; ironically that is one of the only times her words are intelligible. It seems to me that her ability to communicate with others is very important to her sense of self.

Without using the AAC device, I am able to ask Sally yes or no questions. I will put my hand in front of her, and she will push my hand if she means yes. If she means no, she will not do anything.

When I first started using the device with Sally, I asked her a series of questions to assess her ability to use the device and follow my instructions. With the two-button Yes/No page, I asked her to look at ‘Yes,’ and then I asked her to look at ‘No’. I asked her if her name was ‘Sally,’ and then I asked her if her name was ‘Carman’. She was able to use both eye tracking and touch as access methods. Given ample time after I asked a question, she was able to respond to the questions correctly. Her delay in answering the questions could be explained by the delay in comprehension time or the delay in movements associated with HD.

She was able to tell me how she was feeling. The four-button page she used had four emotions: happy, excited, sad, and angry. I instructed her to select each button one at a time to make sure she could access each button and follow my instructions. Afterwards, I asked her how

she was feeling. She answered 'excited'. With the two-button Yes/No page, I asked her if she likes using the computer. She answered 'yes'.

The involuntary movements caused by HD limit the user's ability to use the device. For Sally, her answers were accurate up to four-button pages. Past four-buttons, she had difficulty focusing on a particular button. The number of options on a page must carefully consider an individual's movement disorder.

After we had used the device a couple of times together, I set up a blackjack game with her and the other two interns. Sally played with the assistance of one of the interns, Shannon. Shannon held her cards and helped her make a selection by letting her know how much her cards added up to and how much she needed to reach. The other intern Sophie played her own hand. I was the dealer and I played my own hand. When I asked Sally if she wanted another card, she was able to tell me 'Yes' or 'No' with the AAC device.

I believe that I can truly say that we all had a blast playing blackjack. Sally had a rare smile on her face while we were playing. After we finished playing a round, I always asked her if she wanted to play another round, and she always selected 'Yes'. When I presented her with a different page with options that included 'playing blackjack,' 'reading to me,' and 'nothing,' she selected 'playing blackjack'.

Sally is an example of someone who has been diagnosed with a mood disorder: in her case, major depressive disorder. While I am not a trained professional in mental health and I understand that HD causes changes to the brain that can affect mood, I feel that at least some part of her depression comes from her frustrating inability to be understood. In her speech six years ago, she emphasized how she lost the ability to be heard. Using the AAC device is a way to give

Sally back a literal voice that can be heard. However, it was not necessarily the physical AAC device that brought Sally joy, but rather the mere presence of someone who was actively making the effort to understand her.

Sally's joy is not something that I can quantify. However, having interacted with her in a variety of different ways that included reading to her, looking at family photos, and playing blackjack, I have seen the different ways that she reacted to these activities. Out of all of these activities, she always seemed to be most excited about blackjack. I can only conjecture about why she liked blackjack over the other activities, but I think part of the reason may be because she was actively participating and making choices rather than passively listening or observing. In playing blackjack, she is given a degree of independence and dignity that is not given to her when I only read to her or show her photos.

“Derek” and his wife “Gabby”

Derek is known as an anxious man with HD who frequently has breakdowns related to his depression. When he becomes agitated, he begins yelling and swearing in Greek and the only thing that can calm him down is giving him a religious plaque that he calmly holds to his forehead as if he is praying. He becomes agitated when staff encourages him to participate in 1:1 speech games, horticulture, and arts and crafts. He prefers passive, observational style activities.

Derek's wife, Gabby, says that she can understand Derek or at least anticipate his needs or feelings. She also says that Derek can understand everything. The Greek SLP Mr. Rahanis can sometimes understand Derek through gesture or gross approximation in his native Greek language. However, he is unable to express his needs to other staff. This is because Derek

attempts to speak in Greek, even though he knows English, and because of his dysarthric speech. I, myself, have not been able to understand Derek's speech.

With the help of Gabby, I worked with Derek on using the AAC device. Gabby was unsure how Derek would react to the device, but we decided to try. When I tried a two-button Yes/No page, Derek pushed the device away and did not follow any of my directions. Gabby told me that he was saying that he does not like it.

I brainstormed with Gabby about some of Derek's interests and came up with a list that included hunting, fishing, cats, and Greece. After organizing these interests into a four-button face and presenting the page to Derek, the response that I got was remarkably different. Instead of pushing the device away, he entirely focused on using the computer. He fixated on fishing and continuously pressed fishing with his finger, activating the computer generated voice that said "fishing".

Expanding on that encounter, I made a new six-button page all about fishing. The buttons included flounder, water, fishing, ice fishing, fish, and a boat. This time, he explored the whole page, but especially focused on the fish button the most. I recorded Gabby's voice, so that when he selected the fish button, he heard his wife speaking to him.

When his wife asked him to select a particular button, he sometimes responded correctly. For example, when his wife asked him to select the boat, he pressed the boat with his finger. However, most of the time, he did not follow his wife's instructions.

From then on, whenever I came back to visit him with the AAC device, he would get excited and reach out for the device to bring it closer to him. Gabby said that Derek told her he likes using the device very much.

Gabby mentioned how Derek used to love riding horses in Greece with his father. I made a 6-button page about horses, and he responded very well at first. However, after a couple of minutes, he seemed to be on the verge of a breakdown. His eyes were starting to water. I changed the page back to the one about fishing, and he calmed down and refocused on the fish.

Gabby spoke about how she becomes so happy when Derek is happy like this. Derek has had this disease for a long time, and it has been very difficult for her, especially when she used to take care of him by herself. She said that she liked using the device with him because it takes his mind away from what he is thinking and puts him somewhere else. He is happy using it, and he has a lot of good memories in the United States about fishing. She emphasized how it is the little things that she tries to do to make her husband happy because he needs it.

The use of the device could allow Derek to participate more actively in recreational and speech therapy than his current mode of passive participation. Staff could try to understand his needs better through the visual communication boards, thus transcending the language barrier. The device could also be used to calm Derek down during his depressive outbursts.

“Jeffrey”

Jeffrey is a verbal resident in the HD unit. I would describe Jeffrey as one of the more social residents. He is involved, upbeat, cooperative, and pleasant. He enjoys speaking to students, and he likes to show people his communication book. When I first met him, he showed me his communication book, page by page. I learned about his family, friends, career, favorite foods and favorite activities.

Although he is still able to speak, his speech has been declining over the past six months. I worked with Jeffrey on the AAC device as a step to help him maintain his ability to communicate and convey his preferences as his speech continues to decline.

Inspired by his communication book, I converted his page on his favorite music artists into the AAC software. He can now click into his own music library, and when he selects a button, the corresponding song will begin to play. He enjoyed using it so much that he requested that I add more songs, which I subsequently did. As his speech and fine motor skills further decline, this modified music library may allow him to maintain independence by picking a song of his choosing to listen to.

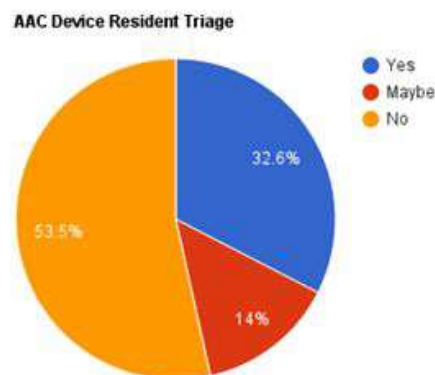
Working with Jeffrey showed me how advantageous it is to work with a resident with the device *before* the resident's speech becomes unintelligible. He can learn how to use the device before his ability to learn new skills declines too much. Because Jeffrey was still able to verbalize his preferences, I was able to get his thoughts on the device and software and even further personalize his pages. For example, I was able to record his voice on a page with pictures of his close family. When he does lose his ability to speak in the future, he will be able to hear his own voice saying the names of his loved ones rather than the computer generated voice. Hearing his own voice may also motivate him to independently initiate in conversation.

Speech and Language Pathology

Mr. Peter Rahanis is the expert speech and language pathologist for the TCC HD residents. As the SLP, he understands best what type of AAC is suitable for an individual and what access method (touch or eye tracking) is best. Out of 43 residents, he believes that about 14

of them would be appropriate candidates for the Tobii-Dynavox 15+. He was unsure whether 6 of them would be the right candidate for this program. He did not think that 23 of those 43 residents would be suited to use the AAC device.

Individuals may not be the right candidate for the program for a number of different reasons. Informally speaking, there are a number of different inclusion criteria and exclusion criteria to be considered. Most importantly, an individual has to be able to physically use the device, either through touch or eye tracking, and that individual has to be willing to use it. If an individual has difficulty with their vision, or if the person is too choreic, then that person may not be able to make selections. An individual's prior exposure to technology may be limited, and they may be unable to learn how to use a new device—this is why it is important to start using the device as early as possible. If someone has major psychiatric issues, then that person may not be willing to use it. For example, there is an individual so introverted to the point that I do not even know what she looks like. In my ten weeks at TCC, I have never seen her come out of her room. There are other individuals who can get agitated to the point of violence.



Neurology

Dr. Robert Fekete is an assistant professor of neurology at New York Medical College who does neurology consults in TCC's HD unit.

According to Dr. Fekete, people have different proportions of the triad of motor, cognitive, and psychiatric disorders. Each individual will present different challenges to using a high-tech AAC device such as the Tobii I-Series 15+.

HD slows saccade initiation and velocity. Before genetic tests for HD, physicians would look at a person's eyes to see if there was a slowing of eye movements. It is necessary that the individual has a saccade initiation fast enough to cooperate with answering questions.

Accessing a button through eye tracking requires an individual to look at a button without blinking for a set period of time, which can be complicated by facial chorea and head movements. Due to facial chorea, an individual may blink several times every second. Head movements can cause an individual to look away from the button which resets the timer to access a button. The settings on the device may need to be adjusted so that the individual needs to look at the button for some optimal time period before it is selected.

Chorea of the extremities makes pushing a button difficult, and it can be difficult to separate chorea from intentional movement.

Comparisons

I had the opportunity to learn about technology in the care of two other patient populations, people living with ALS and pediatric residents living with profound developmental

disabilities. In a rough, perhaps over-simplification, I think of the presence of technology in the three populations I saw as on a spectrum. The developmentally disabled children are the most limited in their use of technology at one end of this spectrum. People living with ALS have great capabilities of using computers at the other end of the spectrum. The HD population falls somewhere in the middle.

Amyotrophic Lateral Sclerosis

The Leonard Florence Center for Living is a one of a kind skilled nursing facility in Chelsea, Massachusetts. It is a permanent residence for individuals living with amyotrophic lateral sclerosis, also known as ALS or Lou Gehrig's disease. I had the pleasure of visiting this "ALS Heaven," as Dr. Lechich refers to it, to meet with resident SS.

Technology gave SS a degree of independence that was unable to be given to him by medicine. ALS is a neurodegenerative disease that affects nerve cells in the brain and spinal cord. Voluntary muscle action progressively declines to a point when individuals can no longer move, speak, or even breathe without artificial ventilation. The ALS unit at Leonard Florence is a fully automated facility. SS maintains independence in his living environment through an environmental control package installed at the facility. He can perform tasks such as typing, speaking, calling elevators, opening doors, turning on his TV, and moving his wheelchair through a computer and a sensor that tracks the slightest variation in his head movements.

A lot of effort was made to be able to do tasks such as open one's own door. The lengths that people have gone through to maintain as much independence as possible show me just how

important the ability to make choices is to a good life. Independence promotes happiness by making people feel like they are leading a life of their own. Independence is freeing.

Given that TCC is considering admitting people living with ALS, I think that the presence of technology can only continue to expand. Because ALS individuals do not experience cognitive decline nor chorea as in HD, the possibilities for AAC interventions are incredible. It is much easier for speech clinicians to implement AAC interventions to help them maintain communication independence. With only eye movements or head movements, people living with ALS can type using innovative software solutions. To give an example, SS is able to type using a software called Dasher by using his head as a mouse. The slightest movements of the eyes or head can give people living with ALS control over computers, providing them with complete access to the internet, email, games, and so forth.

Of course, Stephen Hawking is the perfect well-known example of someone who used technology to give him independence when his ALS debilitated him. He uses a program, sponsored by Intel, that has a software keyboard on a screen. A cursor scans across the keyboard and Hawking selects a character by moving his cheek to stop the cursor. The only way that he controls the computer is through that switch on his cheek. Furthermore, the program uses a word prediction algorithm, so he usually only types the first couple of characters before selecting the whole word. Using this program, he has the ability to control his entire computer (Hawking).

Terence Cardinal Cooke Specialty Children's Hospital

At the request of Dr. Deutsch, the medical director of the Specialty Children's Hospital, I spent some of my time setting up a different eye tracking computer for the residents. The

residents in the Specialty Hospital have profound intellectual disabilities and mental retardation. The residents that I worked with also had either spastic quadriplegia or spastic paraplegia. Eye tracking is therefore a more appropriate access method for an AAC device as opposed to touch.

Because of the extreme cognitive impairments of these residents, I used the AAC device for recreational purposes as opposed to communicative ones. For example, given two different buttons, individuals can look at whichever one they are more inclined to and it will activate that button. This means an individual can choose between clips like Barney or Winnie the Pooh. They can watch clips that family members recorded of themselves saying hello and how much they love them. This is a means of the residents getting acquainted with family members who may not always be able to visit from far away.

I worked with three residents with severe developmental disabilities on using the computer. Given that these residents are unable to communicate, I cannot say for certain whether they were intentionally activating certain buttons. I was not able to ask them questions or direct them to look at a particular button. My role was limited to programming the pages and positioning the device in front of them so that the device recognized their eyes. Then, when a resident looked at a picture for long enough, it would activate the button. For instance, if a resident looks at Barney for one second, the computer will begin to play a clip of Barney.

In order for the recreation department to continue working with the device with the residents, I wrote a quick start guide to programming the software of the device, included as Appendix C.

Connecting through Technology: Paradox?

Conventional wisdom has it that advanced computer technology makes our lives easier. For instance, the advent of phones has eliminated distance as a barrier to communication. Airplanes, cars, and trains have remarkably sped up transportation time. The convenience of computer technology seems to have improved our everyday interactions.

Nonetheless, there is a fear that technology will demolish the quality of human interactions. In this case, there is something eerie about a computer standing between two individuals having a conversation. It increases the space between communication partners. Family members of people living with HD have already expressed a concern that a lack of eye contact with them negatively affected communication (Hartelius 381). The introduction of an AAC device even further limits eye contact. Technology is dehumanizing in the sense that it reduces people's face-to-face interactions. Aldous Huxley said, "Technological progress has merely provided us with a more efficient means for going backwards." There may be something to be said about attempting to connect with people using technology as "backwards". One way of looking at this project is that I have been trying to gauge whether it is possible to connect with people using technology as a medium. However, is technology pulling me even farther away from the people I am trying to reach?

I cannot say the effect its usage would have on the individual's mental health, having never been in the position to use an AAC device myself. I can imagine that a person may feel that their communication abilities have been reduced to what seems to be a multiple-choice test. Speaking by means of selecting a button in a grid eliminates the creativity of the speaker. Hearing a computer generated voice rather than one's own voice feels foreign and disturbing.

I think that the device should be used in moderation, as with most things in life. I do not think it would be beneficial for any individual to be staring at this computer every waking second. Rather, I think it would be better to focus on using it when appropriate with an individual during one-on-one consultations or group activities as a tool to help someone initiate and participate in conversations in a different way. The idea for the AAC device is not to replace but rather to supplement human interactions.

Recommendations

At-Your-Service Volunteer Program

When I began my internship at TCC ten weeks ago, I was looking to get to know some of the residents. The other interns and I were paired up with all fully verbal, communicative residents. This was partly because there are more communicative residents than non-communicative ones, and because we were new and it is easier to get to know someone who clearly speaks.

However, I worry that too many volunteers provide companionship to only verbal residents, leaving the non-communicative residents without the same sort of companionship. There are non-communicative residents on the HD units who are able to comprehend at least some of what is going on around them, and assumptions cannot be made about their cognition. These non-communicative residents may struggle with initiating social contact. One on one volunteer services could help these residents feel more connected to others. I fear that too many non-communicative residents spend so much time in their own silence or the noises of the

television in the dining room. The communicative residents, on the other hand, are better able to participate in recreational activities and spend time with friends.

This is not to say that residents who can speak cannot benefit from having a volunteer spend time with them one on one. I have met many individuals who suffer from loneliness and depression, who, of course, would love to have someone to spend time with. Rather, what I am trying to convey is my hope that residents who have difficulty speaking are not neglected from volunteer services because of a belief that volunteers are unable to help them, or the notion that non-communicative residents cannot offer much to a volunteer.

I hope that my paper makes the point that there are many things to offer residents who are non-communicative. The AAC device that I used is only one means of reaching out to some of the less social residents who struggle with word-finding or initiating conversation. Not every resident is able to use the device--in fact, there was one resident who told me to "Go away" when I showed her the computer. For those who do like using the computer, it could provide another way for them to engage in social activities. The physical presence of a communication board in front of a resident could serve as a visual stimulus for someone to participate. Hearing their voice after pressing a button could be an auditory stimulus. The AAC device can be used for communication, such as with Sally and/or for recreational purposes, as in the case of Derek.

I would also encourage volunteers and speech students to use the AAC device when the family is present, as long as the family is open to it. The reason for this is twofold. First off, the family could help make personalized pages for a resident and encourage the resident to use the device. Secondly, I have encountered many family members who are troubled by their difficulties of communicating with their loved ones. It is upsetting when family cannot converse

together in the same way as they once did. Through students working directly with family members and residents, they could provide support to family and help them engage with their loved one in a new and different capacity. If family members want to use the software on their own and they own an iPad, students could also set up the pages for their use.

If the resident is unable to use the AAC device, another option is to speak to family and staff to find out more about the resident's interests and hobbies. This information can be used to find another way of engaging with a resident, whether in the form of reading to that resident, looking at pictures together, listening to music together, watching videos, etc.

My experiences working with the non-communicative have taught me much about the principles of palliative medicine. The aim of palliative medicine is to alleviate suffering and improve the quality of life of patients and their families in advanced illness. Historically, doctors are not interested in working with patients who cannot be cured. Working with residents who struggle communicating have taught me through experience how to treat someone with dignity, respect and love and how to practice non-abandonment.

Recreational Therapy

The recreational services at TCC are beyond excellent. The recreational therapist, Eileen, knows the residents incredibly well. She leads a wide variety of activities such as smoothie socials, trips around New York City, and games. Many of her games take a long time to set up because they are 1:1, meaning there needs to be one assistant for each participating resident. For example, in blackjack, there needs to be someone to hold the resident's cards for them and help a resident decide whether or not to get another card.

The integration of the AAC device into recreational games such as blackjack could provide another means for an individual to participate in an activity. One complication is that many HD individuals have a short attention span, especially in groups. It may therefore be difficult for an individual to focus on the computer to make selections. However, since many of the activities are already 1:1, the assistant or volunteer could help the resident communicate with the device as necessary. If the required communication boards are already set up, the helper would only need to turn on the computer, open the software, and navigate to the correct page.

Other uses for more coordinated and possibly verbal residents would be computer games. These games could help them exercise their cognitive skills. For example, luminosity is a web-based application with which individuals could train their brains as an enriching and engaging experience.

Nursing and Medical Staff Use

It is unfortunately not uncommon for nursing and medical staff to express difficulty communicating with many of the HD residents. It is an issue when staff cannot understand a resident because the residents cannot convey their preferences or feelings. A resident needs to be able to tell physicians and nurses about any pain or discomfort. Clinicians should be able to watch out for side effects of medications and changes in health. CNAs would like to be able to let residents choose what clothes they want to wear, what food they want to eat, where they want to sit, and so forth. It is basic human dignity to be able to express preferences in living and convey feelings of pain.

For a resident who is able to use it, the AAC device could be another means to convey these basic needs and preferences to staff. For example, there could be a 2-button page that says “Pain” or “No pain”. Another 2-button page may say “Bedroom” or “Dining room”. A 4-button page could have various colors so that someone can select what color shirt they want to wear today. Staff would need to be trained on using the device, and take the time to start the device and open the program. Because the device is so expensive, there also needs to be some chain of custody system in place to ensure that the device is not misplaced or stolen.

Conclusion

For good reason, TCC is renowned for its care of people living with Huntington’s Disease. The staff is dedicated, patient, respectful to the dignity of the residents, and knowledgeable about Huntington’s Disease. In particular, the speech therapy team does an incredible job with helping residents maintain independence in communication. I am grateful that I had the opportunity to explore the possibilities of using an AAC device with the HD population, and I am excited to see how the speech team, recreation, nursing and medical staff, and volunteers can keep expanding this work.

Influenced by my Gujarati culture, I grew up with a notion that families are supposed to take in the elderly into their homes. The old are venerated as the heads of the household. When I visit my grandparents in India, I bow down and touch their feet in respect. It, therefore, felt strange to me during my first few days where it seemed that the venerated aging people were being taken care of by random, busy staff. I learned however that TCC should be thought of as a home before a skilled nursing facility. The residents have an entire extended family of friends

and staff at TCC. I started off with my paper with a quotation from Sally's speech on her disease around when she first started living at TCC. There is something else that she said that stuck with me: "This is a new beginning for me." It is not about residents leaving behind their old lives, but rather starting a new life in a new home.

With this new life comes new challenges. These barriers should be addressed in a way to give residents the most independence and dignity possible. Overcoming difficulties with communication is not always easy, but I have learned that it is a challenge that is worth tackling for a better quality of life. The work that the speech team does is incredible, and I think that the lives of some of the residents can be even further improved by an increased technological presence. Of course, there are costs to any new technology, which may include more training and the physical expense of the device.

Ultimately, what matters most is that TCC keeps up the good work in making the active effort to understand this population. Costs of time, money, and effort are worth harboring if it makes residents happier. I guess I am just hoping that laughter really is the best medicine.

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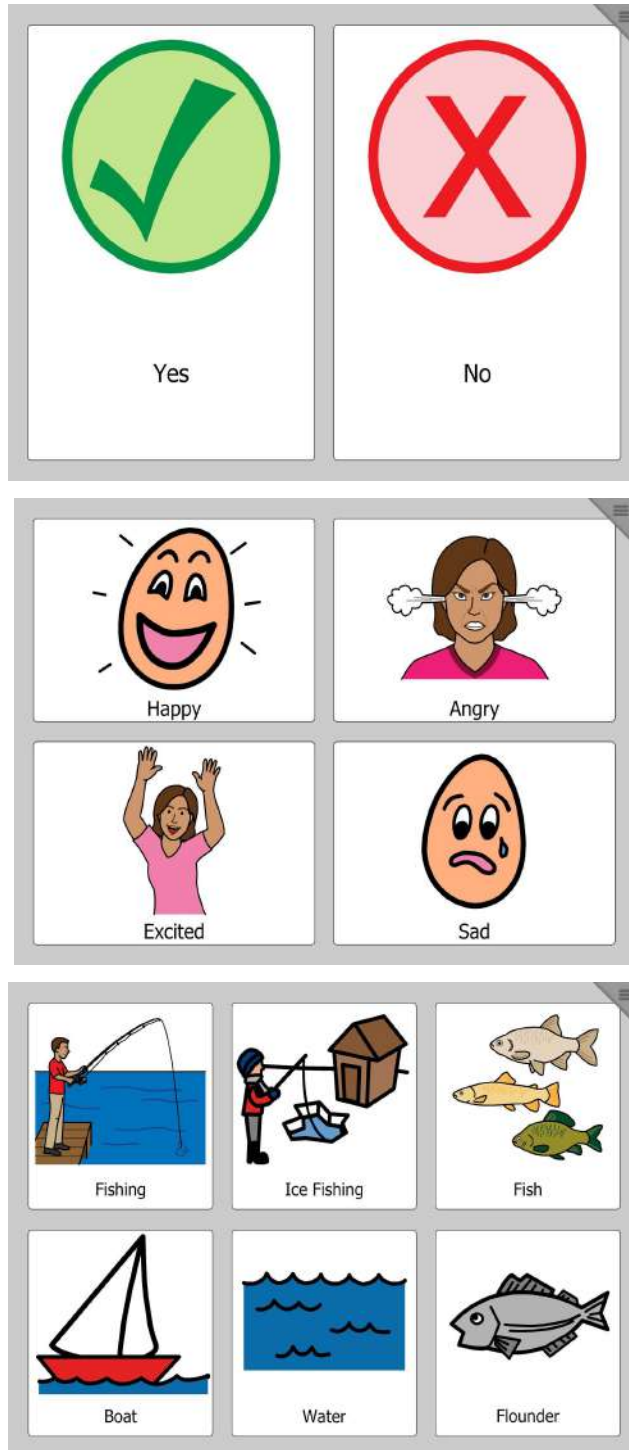
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Aug. 2016.

Appendix A: Sample Communication Boards



Appendix B: Tobii-Dynavox I-15+



Appendix C: Specialty Children's Hospital Recreation

Tobii Dynavox Vmax+ with EyeMax

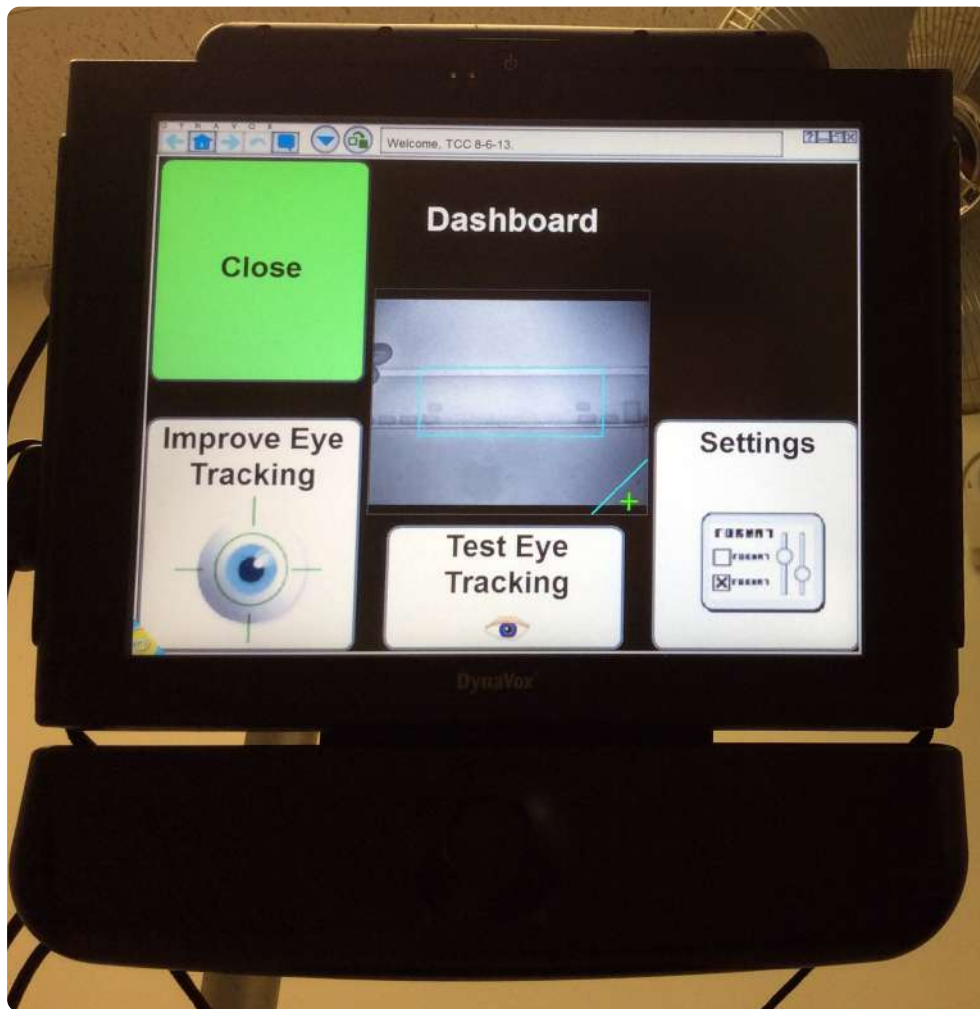
ABOUT THE DEVICE



This device is a Dynavox Vmax+ with an EyeMax eye-tracking accessory. The software is called *Series 5 Software*.

SERIES 5 SOFTWARE

Upon starting the computer, the software automatically opens and displays the *Dashboard* page. Alternatively, you can navigate to the desktop and double click on *Series 5 Software* to open the program.



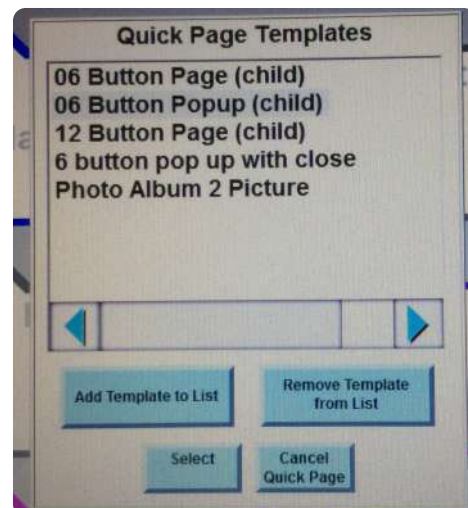
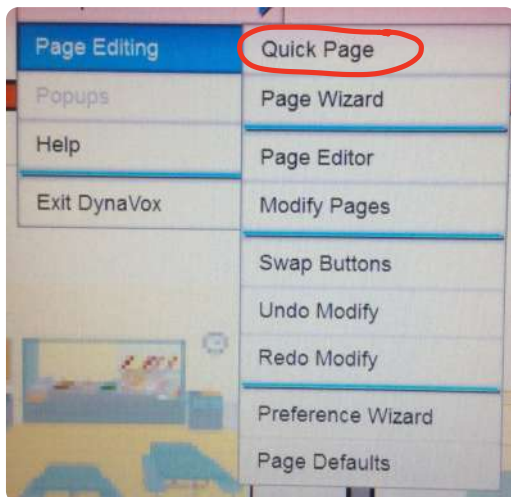
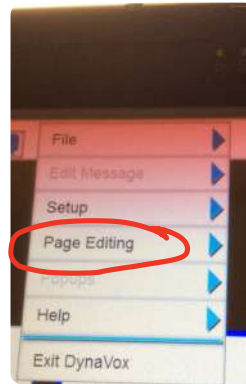
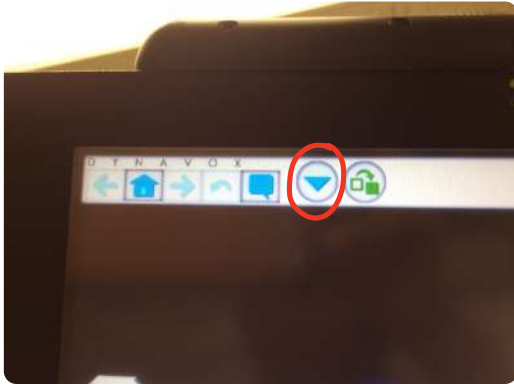
You can navigate to the *Dashboard* at any time by clicking the yellow eye in the bottom left corner of the page.

TO MAKE A NEW PAGE

Click the downward facing blue arrow on the top white bar. Select *Page Editing*. Select *Quick Page*. Select a template of your choosing.

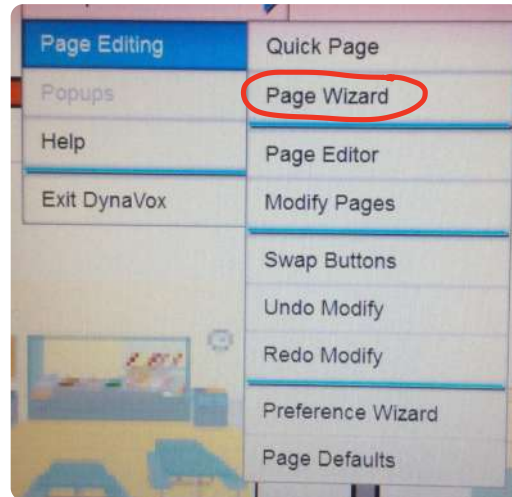
- If you select a popup, the new page will open on top of the page that it is linked to. If you select a page, the old page will close and the new page will open.
- If you select a popup with the option "close", then there will be a button "close" that will allow you to close the popup to see the page underneath. If you select a page or popup without the option "close", you can navigate back to the home page by clicking the house in the top left corner.

When you make a new page, remember what you name it. This will be important when you want to program a button to automatically open that page.



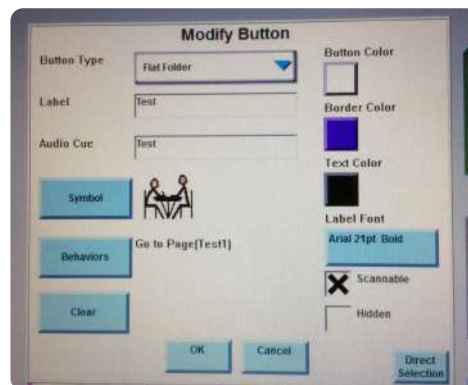
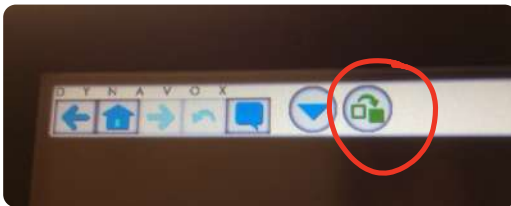
If you want to select a template that is different from the ones listed in *Quick Page Templates*, you can use the *Add Template to List* button to find a new template to use.

If you want to design your own template, then you click the downward facing blue arrow on the top white bar. Select *Page Editing*. Select *Page Wizard*. Page Wizard will take you through a series of steps that will allow you to customize the page to fit your specifications.



MODIFYING BUTTONS

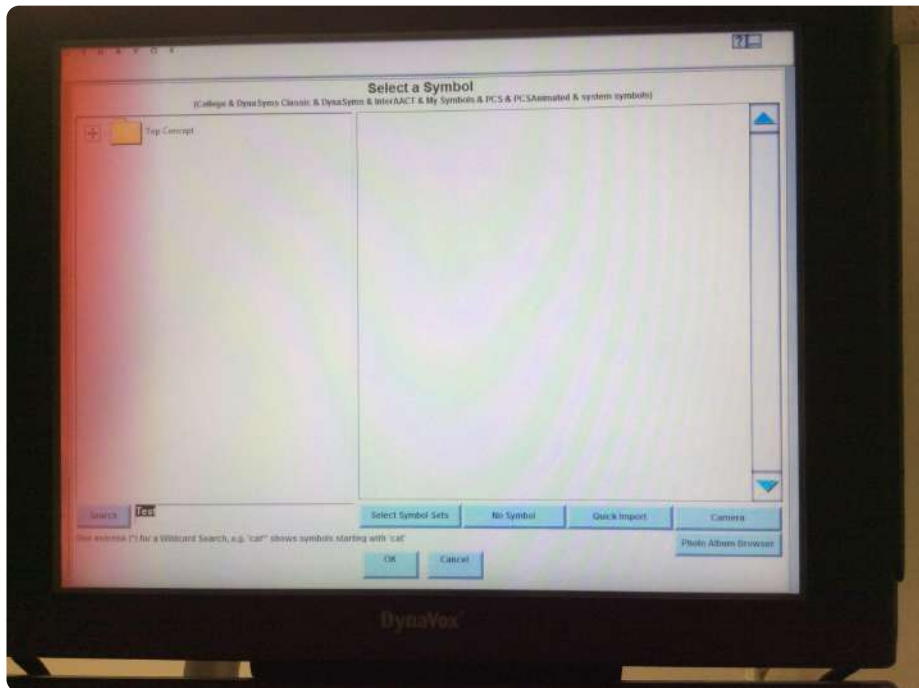
Click on the green button in the top white menu. Then, click on any button on the page. A *Modify Button* popup will open.



Button Type will let you change what the button looks like. The common types to select are "Rectangle" or "Flat Folder". Use the folder button if you have linked the button to open another page or popup. If the button is not linked to open another page, use the rectangle format. Be careful to not change the button type to something other than between rectangle, ellipse, folder, or flat folder after you have put in some behaviors because you may lose them. (See explanation of behaviors below)

Label is the writing that the button will display.

Symbol is the picture that the button will display. When you click on "Symbol", the following page will open:



You can search for a Symbol in the Dynavox's library in the bottom left corner. You can also use a picture that is saved on the computer's photo album. To save it in the photo album, use a USB flash drive with the photo and copy the photo into the "Photo Album" folder on the computer. Use the *Photo Album Browser* to select the photo.

Behaviors is where you can program a button to carry out an action. Useful behaviors to understand are "Speak Label", "Play a Sound", "Play a Video", "Go to Page", "Close Popup". These are saved in favorites for convenience. To add a behavior, click on the behavior you want and press the add button. The behaviors added to the button will appear in the right side of the screen. To remove a behavior, click on it on the right side and use the right side menu to delete.

- *Speak Label*
 - When the button is pressed, a computer generated voice will speak the label
- *Play a Sound*
 - When the button is pressed, a digitized (recorded) sound will play.
 - When you add the behavior, another popup will appear that will ask for the sound file. Click *Change Folder* and select *Show All Directories*. You will be able to use the file path to navigate to the sound file. Click the plus sign on the folders to expand them. Navigate to *Users* --> *Dynavox Users*
- *Play a Video*
 - When the button is pressed, a video will play
 - When you add the behavior, another popup will appear that will ask for the video file. Click *Change Folder* and select *Show All Directories*. You will be able to use the file path to navigate to the video file. Click the plus sign on the folders to expand them. Navigate to *Users*

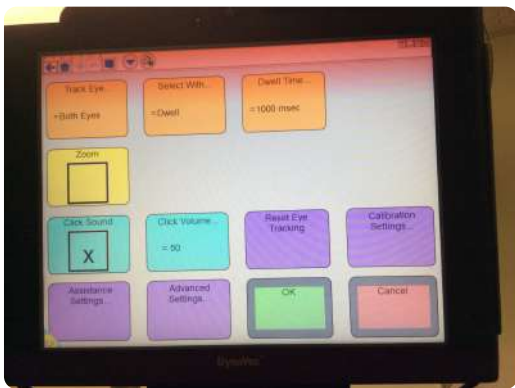
--> *Dynavox Users*

- *Go to Page*
 - Will open a page that you choose
 - If you are not sure where the page is saved, click on the "Top Level" folder and search for the page by its name.
- *Close Popup*
 - Will close the popup and display the page underneath

SETTING UP THE DEVICE WITH A PERSON

The first step is positioning the device to the person. Use the stand to place the computer in a comfortable position for the person. If it is not positioned the right way, the person will not be able to use eye tracking. Use the *Dashboard* camera to make sure that the eyes of the person are in view. When the person is looking at the device, there should be two green lights on the eye tracking accessory. If the screen is showing redness around the edges, it means that the device is not in the optimal position to recognize the eyes, or the person is not looking at the screen.

If possible, calibrate the device to the user. In the *Dashboard*, click *Settings*, and click *Reset Eye Tracking*. After the calibration, you can test how well it worked by an option that will appear on the screen.



Dashboard --> Settings