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Introduction

In this paper, we will discuss using alternatives to real-time speech. To do that, we first will need to discuss what real-time speech is and why someone would want to use a form of communication other then real-time speech. Included with this article is a matrix of different types of communication, which may be useful for people interested in what options exist. Finally, we will discuss prejudice and ignorance, as well as attitudinal issues.

What is Real-Time Speech?

"Real-time" is, basically, responding quickly to other people. An in-person conversation with someone has this quality, as does a computer chat session. Email or letters are not real-time, as they do not require immediate processing and responses.

Speech, in this context, means your natural voice.

So, real-time speech is the combination of the real-time element with speech. Most conversations between typical friends fall into this category.

In this paper, I am going to talk about communication that is either not real-time or not speech. Most of the things I talk about are either real-time or they are speech, but only some of them are both. Some autistics only have problems with one or the other, and for most autistics I have met that have problems with real-time speech, they have more severe problems with one aspect or the other. However, there are also autistics that have problems with both parts. Thus I will try to include different kinds of communication methods in this paper, some of which might not be suited for you but would be suitable for someone else.

Why Not Real-Time Speech?

Many autistics have problems with real-time speech, but one autistic's problem with realtime speech is not necessarily the same as another autistic's.

First, real-time speech places great demands upon working memory, the part of memory that holds things for extremely short periods of time. It is the part of memory which lets you remember what you were talking about when you started speaking a sentence. For autistics, this can be a major problem.

Secondly, real-time speech requires both yourself and your communication partner to understand a common language. Speech is not possible without a common language, so people who have trouble with language will also obviously have problems with speech.

It also requires the ability to respond quickly. In real-time speech, the listener expects a response shortly after asking a question or making a statement - few people are willing to wait 5 minutes for you to respond to a yes or no question.

There are other problems too - speech can also be physically painful for some people. It can also interrupt your thoughts if you cannot multitask well enough to both talk and disregard the sound of your voice at the same time.

There are many other neurological and physical problems, other then autism, which can make it difficult to talk. Obviously, if a person has problems with the physical aspect of speech, or if they have a neurological condition which makes speech difficult or impossible, then they are going to have a hard time with real-time speech.

Real-time speech also requires a high level of concentration and effort which can make it impossible for some people to focus on the reaction they are getting to their words. People who study communication say that these non-verbal reactions can often account for more communication then the words themselves. If someone could understand these non-verbal signals, but needs to focus all their energy on speech, then speech can really hinder communication.

Some autistics also have a hard time expressing emotional content or asking for help. Some autistics want to tell a parent or a spouse that they love them, that they are worried about something, or express a different emotion, but cannot do so with real-time speech. Emotional content or requests for help require emotional processing that makes the act of speech even more difficult - and these things become more difficult when speaking.

A Note about the Value of Real-Time Speech

It is important to remember that real-time speech is a valid form of communication and that this is not an all or nothing game. You can use real-time speech when it works for you, and use other forms of communication when it doesn't work for you.

It's not "faking" to find real-time speech to be good in one circumstance yet bad in another.

Types of Communication

Along with this article is a matrix that compares many different types of communication. Some of these forms of communication are language based, while others are not. Each has advantages and disadvantages. Some forms of communication are not suited for a given person, so as you look at the list realize that not every form of communication is expected to work for you.

Prejudice and Ignorance

Now we will talk about prejudice and ignorance. This is often the thing that scares people the most when they are considering using alternatives to real-time speech. Most of us have had bad experiences in the past when we have shown ourselves to be different, so we are hesitant to show differences. While I can't say anyone's experience will be good or bad, I can share some of my experiences as being someone who is obviously different.

Common Reactions by the General Public

By far the most common reaction to me using pre-composed notes or a synthesizer is that I'm deaf. I've had people respond in sign language, talk much louder then necessary, exaggerate their lip movements, and other stereotypical responses to deaf people. This is so common that I handle it by using a preprogrammed message on my synthesizer: "I can hear fine."

Most people do not seem to make assumptions about the intelligence of someone using alternative forms of communication, provided that the person otherwise looks normal and uses a means of communication that obviously requires literacy. On the other hand, though, some people do make negative assumptions if the non-speaking person is using a wheelchair or symbolic/picture communication systems.

A lot of people are very curious about technological devices used in the place of real-time speech. If you choose to use one, you can expect a lot of comments and questions about it.

For the most part, people do not actively discriminate against people using alternatives to real-time speech. Sometimes they unknowingly erect barriers, but like almost all disability discrimination, it is very rare for someone to purposefully try to keep people from being included. Typically the barriers are based in assumption and tradition that the person does not want to change, rather then something intended to harm others.

And, finally, most people simply do not make a big deal about alternatives to real-time speech - other then being very curious.

Less Common Reactions by the General Public

Some other reactions may occur for people using alternative means of communication. These reactions are far less frequent then the common reactions described previously, but they can still exist.

As previously mentioned, if you use other assistive technology, like a wheelchair, or look obviously disabled, people sometimes will make assumptions about your intelligence.

Another possible reaction is that the person using alternatives to speech is being disruptive. This is most common in places where other people have the option of

whispering or talking at a lower volume but someone using a speech device does not have that luxury.

Some people will respond to a non-speaking person by using "baby-talk" and similar condescension. Unfortunately these people don't typically respond well to correction - most of the time they actually see themselves as nice people who care about others.

Once someone starts to use a communication method that allows them to say more and have more influence upon their environment, some will feel that the communicator has become an asshole. Where the person may have been passive with situations that were unpleasant, now they may have a way to express their discontent. People, especially human services and educational staff, often see this apparent change in personality as negative, as the communicator is quite possibly making more requests and expressing more needs.

And, finally, one reaction I've had at work from some people is a push to have more "face time". The reasoning is that email and other communication that are not real-time encourage misunderstandings that could be easily reconciled with a rapid back-and-forth in-person communication session. Typically a little explanation on my part helps, but some managers seemingly lack the empathy to understand that some people do not communicate best in-person.

Reactions by Professionals

The reactions medical, educational, and human services professionals give is varied. Many are understanding and cope well with a person using non-traditional communication methods. However, not all are understanding.

The assumption in most professional's minds regarding communication is that speech is the "best" form of communication, and should be the communication used if it looks to them like the person can use it. So, people with decent vocabularies and reasonable pronunciation will be expected to use their natural voice. It's also assumed that alternatives to real-time speech don't need to be examined for this group, because they would see little benefit.

Sometimes the act of not using real-time speech will actually be seen as a psychiatric condition separate from autism. This of course is a misunderstanding of autism, as communication differences are clearly part of autism. But sometimes it is seen as attention-seeking or bipolar, especially if the person does use a natural voice for real-time communication some of the time.

With children and others who are developing language, once speech begins to develop, the assumption is that alternatives to real-time speech can be discouraged and more time can be spent on speech, since speech is "obviously", to the professional, better. This is often true even if the communicator is unable to express himself as well with speech as he can with alternatives.

Another problem is that professionals often assume IQ, "functioning level", and other measurable factors are relevant in determining who may be helped by finding alternatives to real-time speech. This goes both ways - some people assume someone would never be able to use non-speech alternatives simply because they have too low of a functioning level or IQ, while others assume that a person would be best able to use speech over any alternatives since they have a high IQ or functioning level.

And, finally, professionals often address alternatives to speech prior to addressing alternatives to real-time communication. For people who have trouble with the real-time communication component, professionals are often unsure of how to help the person - and often are not even able to fully identify this problem.

Reactions from Other Autistics

Autistic people also have different reactions then the other groups. I believe autistics differ from neurotypicals in their reactions mainly because we often understand that communication differences exist and think about our own differences much more then neurotypicals think about different ways of communicating.

One thing that a lot of autistics say, because of some books that had incorrect information, is that someone has selective or elective mutism. Often, they will distinguish between the two, although the professional criteria are the same - both selective mutism and elective mutism refer to the same condition. When used to refer to autistics who sometimes do not speak, the terms selective or elective mutism are almost always incorrect. Unfortunately there is not a cute name for the differences in communication in most autistics who speak only some of the time.

Most autistics do not have a problem with someone using alternative means of communication, provided the autistic hasn't been taught that speech is to be valued above all other means of communication. My autistic friends barely even give notice to my use of alternative means of communication.

However, autistics may be much more curious about alternative means of communication. The reason is often simple - they see a form of communication that may be helpful to themselves. In addition, many autistics perseverate on autism and neurological differences, so an obvious expression of a neurological difference may elicit interest from other them. Of course some people don't want the added interest - many autistic people dislike being the center of attention!

Autistic people with Central Auditory Processing Disorder (CAPD) may have a very difficult time understanding synthetic voices. They may ask for things to be repeated and you may find it is easiest to use writing or to let the other person simply read what you are writing, rather then hearing it.

Finally, autistics in particular often have trouble with the turn-taking that is required when communicating with people using real-time methods other then speech. Part of the reason is that we often have poor working memories, and if we don't express a thought when we have it, we'll lose track of that thought. Unfortunately, that also causes the person who is using different means of communication to be interrupted and possibly never able to complete an entire thought. My friends who know me well have learned strategies for this, but unfamiliar autistics usually have not.

Difficulties of using Alternative Means of Communication

Engaging in group conversations, outside of computer chat, can be very difficult without a natural voice. Typically, in a group, eye contact and vocal sound is how you indicate you want to speak. Someone using a silent means of communication and who doesn't make eye contact may not have either option. Even someone with a speech synthesizer may have trouble, as the timing will never be exact enough to speak at the exact right moment necessary to indicate intent to communicate. There are solutions, but nearly all of them involve one or more other group participants expressly acknowledging your turn to communicate, possibly through use of alternative signals or asking you if you have anything to say.

Most of the language based alternatives, other then sign language, are very difficult to use while standing or walking. They often require a flat surface to type or write upon.

It is also difficult to get a job without using speech at the interview. Communication ability is highly valued by most employers, so anything that makes it look like an interviewee will have trouble with this will make it hard for the person to get past the interview. It is possible to overcome this, but this societal barrier has a very deep foundation and is unlikely to go away anytime soon. It's very important for people who don't speak to find ways of demonstrating that the employer is still getting good value for their money, even if you don't communicate the same way or as quickly. Often this means that the person will have to be more qualified in other areas then someone who speaks normally would have to be.

Alternative means of communication are typically much slower then natural speech. I am a very fast typist, able to type over 100 words per minute. That means that, assuming I can maintain that typing speed while writing new thoughts, which I cannot, I am able to communicate at approximately one third the speed of a native speaker who can communicate at 200 words per minute. Because I have to first type the utterance, at half the speed of a native speaker, and then wait for my device to speak it, at the same speed as a native speaker, it takes me three times as long. Most people using speech synthesizers, myself included, average much slower speeds then this even. Unfortunately people in general are not very patient and are not always willing to wait for a complete thought. This is one of the reasons finding solutions which are not real-time may be helpful.

Finally, using communication that is not real-time can make misunderstandings more common. Nearly everyone knows of an email that was misinterpreted and resulted in a lot of problems between people until the miscommunication was resolved. With realtime communication, it's easy to correct a miscommunication early in the thought. Without that ability, the miscommunication often is more troublesome and harder to fix.

Personal Attitudes

While I've had problems with other people's attitudes towards me, the most harmful attitudes have been my own.

A lot of these attitudes mirror those of someone who just recently realized they are autistic. A lot of it has to do with the reality of your existence not fitting the image that society expects, and not yet having the confidence to dismiss society's expectation.

I sometimes think I'm faking my communication differences or that I'm communicating differently for attention. After all, society doesn't have a good category for people like me, so it makes me think that perhaps society is right and I am wrong. Logically though, I realize that no one who didn't have problems with real-time speech would want to find an alternative to it. Real-time speech, for people who can access it reliably, is usually the easiest way to have control over your environment. Anyone who challenges that norm may have trouble as a result, and there are easier ways to get attention then that! For someone who needs the alternatives to speech, this is liberating, and the feeling is actually very different from the feeling of being the center of attention.

Thinking that there are people who really need alternatives to speech and that I am not one of them is another common thought I have. Of course the reality is simpler then this, as anyone that needs an alternative to speech should have one. Degree of disability is really irrelevant. But the thought still plagues me sometimes.

And, finally, I've been told my whole life, by parents, professionals, employers, teachers, and others that speech is the best form of communication. I've been told that speech is something I should spend significant effort to perfect and that it will get easier with practice. Of course 27 years have proven this isn't the case, but it's hard to go against nearly everyone that has been an authority figure in your past.

The thing to realize here is that if alternatives to real-time speech help you communicate, then you should use them and try not to worry about whether or not you are doing it for evil reasons. That's much easier said then done though, and is probably the biggest challenge someone who wants to look at alternatives will face.

Conclusion

The most important point in this paper is that it's okay to not communicate normally. You need the set of communication methods that best enable you to have control over your own life. For many people, that's primarily real-time speech. Even for many autistics, it's primarily real-time speech. That's okay too. But for people where real-time speech is not the best way to communicate in a given situation, alternatives can and should be used. Fighting to get access to these alternatives may take work, but it is worth it.

Internet Resources

Information about this paper and the corresponding presentation, including the slides, handouts, and additional resources are available at <u>http://www.geocities.com/growingjoel/autreat05.html</u>

Communication Boards

- An example for law enforcement use: <u>http://www.dol.net/~srz/</u>
- Example for sexual health and abuse communication: http://www.aacsafeguarding.ca/vocabulary-com_displays.htm
- Good source of symbols for communication boards: <u>http://www.symbols.net/</u>

Facilitated Communication (FC)

- Breaking the Barriers: <u>http://www.breaking-the-barriers.org/stories.htm</u>
- Facilitated Communication Institute (FCI): <u>http://soeweb.syr.edu/thefci/</u>

General Resources

• Augmentative Communication On-Line User's Group (ACOLUG) [Note that most users are either professionals, parents, or individuals with Cerebral Palsy]: http://disabilities.temple.edu/programs/assistive/acolug/tacolug.html

TTY and Relay Services

- AT&T Internet Relay Services: <u>http://www.relaycall.com/national/index.html</u>
- State of Wyoming Equipment Distribution Program (an example of a government program to help people get TTYs): http://www.wyomingworkforce.org/programs/vr/wrs_equip.asp
- TTY Etiquette: http://wally.rit.edu/depts/ref/research/deaf/ttyuse.html
- U.S. FCC Consumer Guide: <u>http://www.fcc.gov/cgb/dro/trs/con_trs.html</u>

Voice Output Communication Aids (portable synthesizers) Manufacturers

- RJ Cooper: <u>http://www.rjcooper.com/auggie/index.html</u>
- Prentke Romich Company (PRC): <u>http://www.prentrom.com/</u>
- Zygo USA: <u>http://www.zygo-usa.com/</u>