

Assistive Technology Outcomes and Benefits
 Volume 11, Summer 2017, pp. 58-65
 Copyright ATIA 2017 ISSN 1938-7261
 Available online: www.atia.org/atob

Communication and Developing Relationships for People Who Use Augmentative and Alternative Communication

Chris Klein
BeCome AAC

Abstract

Building meaningful relationships is one of the most important things a person can do in his or her lifetime. It also is one of the most difficult things a person can do. Communication is a necessity to build relationships, so a person with a communication disability has a very difficult time building relationships. There are various publications that are calling for relationship building in the field of augmentative and alternative communication (AAC). As a person who has used AAC for over 36 years, I have experienced this first hand and feel this is a discussion that gets forgotten about all too often. It also is a discussion led by clinicians, professors, and manufacturers. This is why I feel it is important to give my perspective on this topic.

Keywords: consumer perspective, AAC, communication, building relationships

Introduction

Today in augmentative and alternative communication (AAC), we see folks with a wide range of communication disabilities. Some, like me, mostly have physical limitations. Many have cognitive issues as well. People with autistic spectrum disorders may not understand that interpersonal communication can be one of the most enriching

aspects of life. Nevertheless, many people that use AAC are not different from the rest of society. They want to build and maintain relationships. However, lack of communication often times becomes a major barrier to building relationships. We are living in a fast-paced society where people seem to have little time to stop and have a genuine conversation. These conversations still happen on occasion, but it takes effort to get people to stop and truly engage in a conversation. I have seen people say hello to somebody and walk away before even getting a response from the person they just said hello to. People seem to want the person to respond that instant, so that they can go on their way. This is why often times people with communication disabilities have a difficult time getting into a conversation. When a person can't effectively communicate, he or she has limited opportunities to interact with others.

Differing Communication Goals

Participation in school often becomes the focus of the teacher, family, and speech-language pathologist. Participation in class by answering specific questions like "What do we call the process of cell division?" (Mitosis) can be part of academic life for an augmented communicator. However, answering such questions regularly puts a burden on teachers, therapists, and family members to

supply such “homework words” on a weekly or even daily basis. Such activity also tends to replace learning how to communicate as an interesting person with one’s classmates, family, and friends.

In my experience, social isolation is a common factor for people who use augmentative and alternative communication. People who use AAC tend to have limited access to common, everyday language, which prevents them from building relationships. It isn’t enough to give a person an AAC device if it is pre-programmed with phrases and sentences. As I have discussed among my peers, we want to have the ability to say anything we want to say as quickly as possible. When we are able to share anything, we are able to share the intimate struggles that are going on in our lives. Sharing these struggles and consoling one another is how long lasting relationships are built. This is why it is so important an AAC device gives them the proper access to everyday language. People who use AAC need access to at least 150 core words, so that they can start to learn how to develop sentences.

A primary responsibility of a speech-language pathologist working with a person with a communication disability is to advocate for and promote the use of AAC systems that allow the person to communicate to their best of their abilities. However, the question then becomes, “Where do we go from here?” We have so many different influences that decide this direction that we lose sight of what is important to the person who is going to be using the AAC device.

This is where the influences or decisions become the dictator. They become the end goal and all of a sudden communication becomes something different. It doesn’t become about his or her language abilities; it becomes about meeting the educational standards or simply using important features of the device.

But, are we expecting people with communication disabilities to grow their language skills? Are we expecting them to be able to build relationships?

Parents, teachers, and speech-language pathologists are faced with these two questions. However, the educational standards usually take precedence over any other skills. By doing this, we aren’t giving the student the tools to communicate effectively enough to build on their language skills.

I acknowledge some people with a complex communication disability have a language barrier that also hampers their language development. This can make assessing their language skills very difficult. However, if a speech-language pathologist doesn’t give them access to everyday language on their device, assessing their language skill is more difficult.

I am speaking from personal experience because I was born with cerebral palsy and I have a complex communication disability. I remember how frustrating it was trying to express myself without being able to just say the words I wanted to say. I felt like I was trapped inside myself, and this feeling is overwhelming. I understood everything that was happening around me, but I couldn’t show anybody because I didn’t have access to everyday language.

Framework for Considering Goals and Improving Communication

The question becomes “What are the tools of communication?” Janice Light defines adequacy of communication as an adequate level of communication skill to function within a certain environment. She states it does not imply a total mastery of the art of communication (Light, 1989). I believe this is a good definition of adequate communication. Light gives us four competencies underlying this definition of adequate communication. These four competencies are linguistic, operational, social, and strategic. She breaks down these into two sections. The first section is labeled as the knowledge and skill in tool use, which includes the linguistic and operational competencies. The second section is labeled by Light as the functional knowledge and judgment in interaction, which includes the social and strategic components. Let’s take a look at each of these

competencies.

Linguistic Competence

The linguistic competency, in my opinion as an AAC user, is crucial in developing progress in communication. If you don't have simultaneous access to a broad range of core words, you aren't going to be able to communicate effectively or develop adequate language. One of the most important things to a person who uses AAC is to communicate to the best of their abilities. We need this linguistic component to be there on whatever device he or she decides to use.

Janice Light breaks the linguistic component down into two sections. A person with AAC has to have mastery of their native language. A person using AAC also has to develop a way to progress through the linguistic code found in his or her AAC device. The central tool in achieving these four competencies, for the AAC user, is automatic processing in the micro-skills (reading, writing, listening, and speaking) of language mastery. Mastering language can be viewed as automatic processing concerning what you want to say, having motor plans well mapped out for accessing your communication aid, and strong familiarity with core vocabulary, core syntax, core morphology, and core pragmatics. In practice, mastery of these skills can translate into an increased rate of communication, which is critical to successful communication and relationship building.

Communication rate became an important aspect of my life at a very young age. It was frustrating for me trying to play a guessing game with my family. Every time I wanted or needed something, the guessing game began. At times, I became so frustrated that I would curl up in a ball and cry. Nobody could understand me, even after I tried to point and gesture to the object that I wanted or needed. For myself, it was very frustrating, yet it was even more frustrating for my communication partner. They didn't know what I needed or wanted, so they were equally as frustrated. This is where my speech-

language pathologist gave us a picture board to solve the problem of communication. It had pictures of the bathroom, a mom, a dad, a way to say I love you, I want a drink, and those types of things. It did solve a little of the frustration, but I was a child who wanted to say more than that. I had other things that I wanted to say and I couldn't do it with a picture board.

Communication with a picture board and gestures wasn't enough for me, but how would they ever know that. I couldn't exactly tell them what was happening in my mind, so I tried to communicate with what I had and what I knew. It was at six years old that I received my first augmentative communication device. It was a word-based system, which had four levels of words on it. Also, on the fourth level of it, it had three rows of phonetic letters. You could sound out any word that you wanted to say. The system here allowed me to say anything that I wanted to say.

Operational Competence

I was sent home with that device on a Friday, and by Friday night, I was already talking in complete sentences with it. My speech-language pathologist gave me words for the first time in my life, and I could finally tell my older brothers and sisters to leave me alone. I could say what I wanted to say for the first time in my life, and that is why I used it quickly.

Communication devices have been known to use pre-programmed sentences and words that are nouns more. In my experience, many people believe people who use AAC need to answer a question in class, order food, tell somebody what they need, and those types of things. I don't believe they are looking at the bigger picture. A communication device has the opportunity to give a person a chance to develop language skills. By being able to develop language skills, it gives the person a chance to build relationships. In order for that communication device to do that, it has to give the person the chance to say anything he wants to say.

The idea of a communication device is to have conversations with people. In order to have conversations with people, the person needs access to everyday language on his or her device. This allows the person to learn language, while the person is learning how to communicate. It allows the person to go through the stages of language development, which allows them to build upon their vocabulary. Yet, the most important aspect is it allows the person to build and develop the long lasting relationships that we all desire.

The device that my speech-language pathologist gave me had everyday language on it. I was able to say anything that I wanted to say. I could tell my brothers and sisters to leave me alone for the first time. My teachers were able to see me build sentences, which showed them that they weren't challenging me enough. They were able to correct my grammar and syntax, which allowed me to grow in my language skills.

This helped everybody to assess my language skills. I was put in special education, but once I was able to express myself properly, they were able to see that I needed to be challenged. I was put in the regular classroom starting in third grade.

The teachers taught me like all of their other students, giving me a chance to answer their descriptive questions about a subject. We had a word of the day contest, which we would have to define. Whoever defined it correctly first received a prize for that day. This was to help build onto our ever-expanding vocabulary, but also help us build our language skills by having us describe the word, instead of just naming it. This was the key to my success because if I didn't have the same opportunities to learn, I was going to be far behind my classmates.

I don't remember ever programming homework words into my device. My teachers asked me descriptive questions, such as "What is Photosynthesis?" I was able to answer, "It is the process of how plants use the sun and light to make food." I was learning about what photosynthesis

was, but I learned how to describe it with everyday language.

It is important to build onto a person's vocabulary with these educational vocabulary words. However, we don't have to program these words into their device. A person can describe these words by using everyday language. This is better for him or her because the parent, teacher, or student aide can correct syntax and grammar. This is how the person is going to build on his or her language skills and thus, become a more effective and efficient communicator.

Social Competence

While the educational side of things is important to concentrate on, the social aspect of life is just as important. If you think about it, we are designed to be social. It is in our nature, so it is just as important we give people with complex communication disabilities the same opportunities.

People who use AAC often don't get to interact socially, so using an AAC device feels like homework to many of them. This is why it is so important we give people with AAC an opportunity to interact socially. If we are going to have success with people who use AAC, we need to create opportunities for them to interact with people without making it seem like work.

It begins with the family unit. This is where we get a lot of our interaction, so we need to have activities set up so that the person who uses AAC is included in the activities. These social interactions will develop their language skills because it will help develop what they have been learning to do in school and therapy. The family unit can help correct syntax and grammar, all while having fun together. It is going to help them get mastery of everyday vocabulary.

This also is where a person learns social skills. A person needs to be able to learn how to listen, take turns, and reply properly within a social setting.

They can have achieved all of the linguistic and operational components, but if a person with a complex communication disability can't use them in a social setting, the communication goal won't be achieved (Light & McNaughton, 2014). If you are socially isolated, you aren't going to learn how to use these vital tools. It isn't only language that builds relationships; it's learning how to properly interact with others and respond appropriately. The family unit is a great place to start learning about these social skills.

Strategic Competence

The strategic competence involves the use of AAC devices throughout a variety of settings and for a range of purposes. Light has expanded the definition of adequacy of communication to include motivation of the person, attitude of a person and his or her support team, confidence of a person, and the resilience of a person (Light & McNaughton, 2014). If an individual isn't motivated to communicate, it isn't going to happen. If the family, teachers, and other professionals aren't willing to embrace AAC, the individual isn't going to want to use it for communication. Failure to be supportive and create motivation will affect their confidence and resilience to use AAC. This is logical, and yet we're still wondering how to get individuals to embrace AAC and become efficient communicators.

My family embraced my communication device, so we came up with our own games to play with it. We played a lot of Uno, Monopoly, and other board games. I had to say things like pick up that card, or move my guy over there, and so on. However, I learned how to talk during games too. I learned how to take turns, listen to them, ask questions, and even trash talk during the game we were playing.

I had a one-on-one aide through lunch for third and fourth grade. My one-on-one aide would write all of my tests, and also help me with the personal care stuff. After lunch, students would help me complete the rest of the day's schoolwork. They would take turns helping me, which made them more

comfortable interacting with me. These interactions soon developed into friendships. I would have friends of mine volunteering to do recess with me, which was either playing a game inside the classroom or playing soccer on another area of the school's playground. These social interactions were so important to my development that we fought to keep me in the same school district for my middle school years. I believe without this social interaction in these early years, I wouldn't have been as equipped as I was when I went to college. I believe my social development started this early, which we need to recognize, too!

While language skills are taught and learned at the educational level, they are mostly learned when we play and are social with our peers. It is difficult learning language without a communication disability. It is even more difficult when you are learning how to use an AAC device as well. This is why we need to incorporate social activities when a person is learning how to use an AAC device.

This is why I am encouraging clinicians to make learning AAC less about work, and more about fun. Learning language skills isn't supposed to be easy, but it also isn't supposed to be a grind. You're supposed to have fun as you are developing language, and in my experience this fun part is getting left out.

New Opportunities for AAC Users

The implication of social media has changed the landscape of options of socialization for people with complex communication disabilities. In order to use social media effectively, an individual needs to have advanced use of functional linguistic skills, as well as advanced use of operational skills (Light, McNaughton, 2014). Social media can be a great tool for somebody using AAC, but they need to know how to read and they need to know how to gather and post meaningful pictures.

In some ways, social media has taken down the social barriers for a person who uses AAC. They can

interact with people on Facebook, Twitter, Instagram, etc. without having the stigma of having their communication partner waiting for the response. Social media does have some advantages and I would argue that social media is a great way to keep in touch with people you already have relationships with, but it isn't a place to build long lasting relationships. In my experience, long lasting relationships are built with face-to-face conversations. This is where an individual learns those sociolinguistic skills that are needed to build those long-lasting relationships.

As I have traveled around to different places, events, and conferences, I have noticed that many professionals working in AAC are focusing on meeting the educational standards. It's the logical thing to work on and I would say it is the easiest thing to work on. However, teaching people how to communicate socially has been overlooked. We don't know how to teach this and thus we work on the things that we know how to do best. However, by doing that, we are limiting the person. The goal of AAC should be to say anything that you want to say. It isn't about telling a person what you need and/or want. It's about becoming an effective communicator, so you can build relationships. Building relationships helps you to network, which helps you become anything that you want to become.

This is why we need to change our approach regarding AAC. We need to make it more socially oriented because that is how most people learn to build on their language skills. There is one activity that I wish I would have had myself growing up. I wish I would have had a mentor to talk with and to ask questions to. I believe a mentor and mentee relationship would be beneficial to everybody involved. It would give the mentee an opportunity to ask questions to somebody that has been there already. This would be an important connection because the mentor could help the mentee with different types of issues. Plus, the mentor could help guide them through different scenarios they are going to go through. This is why I have started a mentor program.

BeCOME: AAC- Building Connections with Others through Mentoring & Education about AAC

BeCOME: AAC is committed to assisting persons with speech disabilities to live in fulfilling ways. We believe that the cornerstone to a full life is derived from the ability (1) to participate in meaningful relationships with others and (2) engage in everyday social interactions as a fully ratified participant. In order to address this primary objective, BeCOME: AAC is focused on providing tools and services to people who use AAC in order to enable and enhance communication leading to social integration and community building. Specifically, BeCOME: AAC will develop and distribute educational materials, facilitate mentoring relationships, and provide resources to support life transitions for people who use AAC, all with the specific purpose of relationship and community building.

BeCOME: AAC wants to help every community develop a social group that would get together and do fun activities together on a weekly or monthly basis. These activities would be social activities, which would allow people who use AAC the opportunity to interact with other people. We want to have activities that allow the person not only to be social, but also help them give something back to the community.

Mentors

This is where BeCOME: AAC feels having a mentor who uses AAC is very helpful. Our goal is to match up people who are successful using AAC with beginners using AAC, so that they can have a mentor who knows what they are going through. The mentor can help the person learn how to take turns, listen, etc. These are all important skills to learn, and these skills can be learned in the context of a social interactive activity.

Mentors set up a time to meet with their mentee one-to-one. This is where they can work on actively listening to each other and taking turns responding to each other. Children and adults who are first

learning how to use an AAC device don't have many opportunities to get into a one on one conversation. When this doesn't happen, they have a difficult time learning how to take turns listening, and taking turns responding to one another. In this setting, the mentor and mentee can talk about something that interests the mentee, which is going to help them learn how to take turns. As this is happening, they are still developing their language skills while being more motivated to talk. This begins to help develop their confidence, which will make them more resilient.

Group Activities

A mentor also could set up a group activity. This activity should make the group be social, so that they have to interact with one another. As this activity is going on, each mentor can observe a mentee interacting with other people. The mentor can work on social interactions within the group setting.

One activity could be having a group of people go to an animal shelter, and help the shelter by interacting with the puppies and kittens. As they are learning to play with the puppies, telling them to sit down, come here, lie down, stop it, etc., they are doing it in a social setting. They would have to work as a team, which would make them socialize with each other, as they are helping train the puppies. This would allow the group of people to interact with one another, but also it would give them a sense of purpose. They would be helping the community out by coming and giving an hour to play with animals.

It is a great thing to have a buddy to communicate with. Actually, sometimes a buddy can get more out of the person, so this is an activity that is very useful. This will help promote language, which will help her or him develop more tools for life.

You can organize a support group. You can bring together a bunch of people who use AAC, so that they can support one another. This would be another way to do a group activity together. The group can

pick an activity they would like to do together, and go do it. They could practice using their core vocabulary together, which would help them enhance their language skills.

Setting the Stage for Future Opportunities

These relationships that are being developed are so important, not only for their language skills, but also for their life and leadership skills. Networking is a vital aspect in getting employment and being put into a leadership role. Without the ability to network, a person will have a difficult time finding a role in leadership. This is why building relationships with co-workers and committee members is so vital. They need to have those connections because without them it is going to be difficult for them to learn how to be a leader. It is going to be difficult for them to find a leadership role without a relationship with a committee member or somebody already in a leadership role.

In my experience, leadership skills are hard to achieve for many augmentative communicators in general. Everything that has been discussed up to this point would be very helpful in developing leadership skills. It would be an appropriate task for a camp or a support group to appoint officers of the group. Each officer would have the opportunity to plan an activity for the group, which would be voted on by everybody in the group. It would give everybody a taste of what it is like to be a leader, which would help them develop another skill.

The fact is we need more people who use AAC to become leaders. I don't believe our voice is heard enough, so we need to rectify that problem. Manufacturers, speech-language pathologists, and others in this industry need to understand what we desire. The thing that some AAC users, such as myself, desire the most is the ability to access common everyday language, so that we can develop other skills. By giving us the opportunity to develop our automaticity using core vocabulary, automaticity in using core syntax, automaticity in core morphology, and automaticity in core pragmatics, you are giving

us a chance to contribute to society.

All these activities are great to promote and I believe every activity will help the individual develop language, which would lead to developing leadership skills and building relationships. The goal in doing this is to stop the social isolation many people with AAC experience. Everybody needs to feel like they are a part of something, especially a part of a community. People who use AAC are needing and wanting that as well.

It starts by giving them access to everyday language. When they have access to everyday language, they can learn how to build sentences. Those sentences can lead into developing relationships. When a person can build relationships, they can accomplish any goal they set.

Declarations

This content is solely the responsibility of the author and does not necessarily represent the official views of ATIA. No financial relationships were disclosed by the author of this paper. The author disclosed a non-financial relationship with USAAC.

References

- Light, J. (1989). Toward a definition of communicative competence for individuals using augmentative and alternative communication systems. *Augmentative and Alternative Communication*, 5(2), 137-144. DOI: 10.1080/07434618912331275126
- Light, J. & McNaughton, D. (2014). Communicative competence for individuals who require augmentative and alternative communication: A new definition for a new era of communication? *Augmentative and Alternative Communication*, 30(1), 1-18. DOI: 10.3109/07434618.2014.885080